

**Department of Genetics & Genome Sciences
Case Western Reserve University**

**GENETIC COUNSELING TRAINING
PROGRAM**

GRADUATE STUDENT HANDBOOK

2018 - 2020

WELCOME TO THE GENETIC COUNSELING TRAINING PROGRAM IN THE DEPARTMENT OF GENETICS & GENOME SCIENCES AT CASE WESTERN RESERVE UNIVERSITY! This handbook is designed to provide you with general information about the program with emphasis on the clinical training you will receive. It also contains helpful general information about the Department and Case Western Reserve University (CWRU). Please feel free to expand and add information to it as you proceed through your program. Let us know if you think of ways this reference can be improved. **KEEP IT HANDY - YOU WILL USE IT REPEATEDLY OVER THE NEXT TWO YEARS!** Meanwhile

WE ARE EXCITED THAT YOU ARE HERE AND LOOK FORWARD TO WORKING WITH YOU!!!!!!!!!!!!!!

“**GENETIC COUNSELING** is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates:

- Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence.
- Education about inheritance, testing, management, prevention, resources and research.
- Counseling to promote informed choices and adaptation to the risk or condition.

National Society of Genetic Counselors, 2005

Responsibilities of genetic counselors are defined by the NSGC Scope of Practice and include:

- To provide expertise in clinic genetics
- To counsel and communicate with patients on matters of clinical genetics
- To provide genetic counseling services in accordance with professional ethics and values

Please refer to the NSGC Scope of Practice publication in the Additional Materials section at the back of your Handbook for details regarding specific responsibilities in the areas of Clinical Genetics, Counseling and Communication, and Professional Ethics and Values.

Mission & Guiding Principles of the Genetic Counseling Training Program

The mission of the Genetic Counseling Training Program is to prepare students for the ongoing practice of genetic counseling in the rapidly changing healthcare environment of the 21st century. The curriculum has been developed in a framework that is based on the following principles:

1. The core concepts of genetics, genomics, genetic counseling, and health and disease prevention are fully integrated into the curriculum.
2. Graduate education in genetic counseling is experiential and emphasizes the skills for scholarship, critical thinking and lifelong learning.
3. Educational methods are chosen to stimulate an active interchange of ideas among students and faculty.
4. Students and faculty are mutually respectful partners in learning.
5. Students are immersed in a graduate school educational environment characterized by flexibility and high expectations for independent study and self-directed learning.
6. Students acquire a core set of competencies in the knowledge, mastery of clinical skills and attitudes that are pre-requisite to genetic counseling education.
7. The genetic counseling program fosters the development of professional skills to provide students with the tools to become knowledgeable, competent and caring genetic counselors and emphasize personal growth including:
 - Humanism, compassion, integrity, and respect for others; based on the characteristics of an empathetic genetic counselor
 - A sense of duty and accountability to patients, colleagues, society, and the genetic counseling profession
 - High standards of ethical behavior which includes maintaining appropriate professional boundaries
 - Self-awareness of one's own knowledge, skill, and emotional limitations that leads to appropriate help seeking behaviors
 - Trustworthiness that makes colleagues feel secure when one is responsible for the care of patients

OVERVIEW

During the two years you will spend as a graduate student in the Department of Genetics & Genome Sciences, you will learn the principles of genetic counseling, human and medical genetics and genomics and their application to clinical genetics health care. Ultimately, you will acquire the knowledge and clinical skills to function as a competent, effective and caring genetic counselor in a wide range of settings and roles. The curriculum of the program has been designed to provide you with in-depth knowledge regarding principles of human and medical genetics and genomics, the psychosocial

impact of genetic risks and disorders, and the research process in genetic counseling. You will obtain basic content through course work and learn to apply the information through clinical rotations and your research project. In addition, you will gain experience through attendance and presentations in conferences, seminars, and journal club. All of these activities will enable the student to meet the practice-based competencies as outlined by the Accreditation Council for Genetic Counseling (ACGC).

REQUIREMENTS FOR THE MASTER OF SCIENCE DEGREE (PLAN B)

The Department of Genetics & Genomic Sciences offers a Master of Science degree in Genetics/Genetic Counseling. There are 40 semester hours required for completion of the genetic counseling training program: 21 are didactic courses; 11 are clinical rotations and 8 hours are devoted to research.

Course Requirements

Students **MUST** receive a grade of B or better throughout the Program. Each course in the Program has specific requirements and evaluation processes. If any one course grade is below a B (C or less constitutes a failing grade), the student will be required to demonstrate his or her mastery of the material (for example, retaking the course and earning at least a B or other remediation) as decided by Dr. Matthews and the course faculty in order to successfully complete the program. Additionally, each student must demonstrate appropriate development of clinical skills and competencies during rotations. Successful completion of **EACH** clinical rotation is required. Drs. Matthews and Darrah and Ms. Merrill will closely monitor student progress. If there is a concern regarding academic performance, they will work with the student and faculty to remedy such difficulties on a case by case basis. Tutoring is available.

Comprehensive Examination (PLAN B)

To meet the requirements under Plan B of the School for Graduate Studies, there is a comprehensive examination given in the beginning of spring semester of the second year for all students. There are both written and oral sections to the exam.

Written: The written section is a multiple choice and short answer examination that covers the didactic courses and clinical genetic counseling material covered during the genetic counseling program and is taken by all second year students who have performed satisfactorily in all aspects of the program. Portions of the examination are patterned after the certification examination given by the American Board of Genetic Counseling, but there is no intent to “teach to the board exam”.

Oral: The oral section is given shortly after the written examination. This portion of the Comprehensive Exam allows students to expand on their knowledge base of human and medical genetics and genetic counseling. The oral exam committee is composed of the Program Director and Assistant Director and one or two additional faculty. Students are given genetic counseling scenarios to discuss, asked general

knowledge questions in any area of the curriculum as well as to clarify answers given in the written examination.

Requirements: Students must pass both sections of the examination in order to meet graduation requirements by the Program. Students are expected to pass the written examination at the 70%ile. The student's oral exam committee comes to a consensus regarding a student's performance on the oral examination and decides if the student has passed this section of the comprehensive examination.

If a student fails one or both sections of the examination, the examination committee will provide avenues for the student to rectify the deficiency, such as having the student take another written examination or repeating the oral section. Committee members may also decide that additional course or clinical work is necessary in order to meet the requirements of the Program. If a student is unable to pass the comprehensive examination either written, oral or both following remediation, the student will be asked to withdraw from the Program.

Clinical Practicum

Students must satisfactorily complete all rotations of clinical practicum. Rotations include the following areas: General Genetics (pediatric and adult patients), Specialty Clinics, Prenatal Genetics Clinic, and Hereditary Cancer Clinic. Clinical rotations are held at four sites: Center for Human Genetics at University Hospitals Cleveland Medical Center (UHCMC), MetroHealth Medical Center, Genomic Medicine Institute at the Cleveland Clinic and the Genetics Center, Akron Children's Hospital. In addition to the above rotations, students will have opportunity to choose an elective rotation which may include additional exposure in a specific area such as ophthalmologic genetic counseling or an opportunity to work with genetic counselors in areas such as industry or commercial companies. Finally, each student will rotate through the Cytogenetics and Diagnostic Molecular Genetics Laboratory at UHCMC. Clinical rotations begin during summer between first and second year and continue through second year. Students are formally evaluated twice during each rotation. The evaluations are based on a student's ability to demonstrate mastery of the ACGC practice-based competencies.

Research Project

The program requires a research project for the completion of the program. This scholarly project may be literature based research, a clinical or counseling project or laboratory based and should relate to some aspect of genetic counseling. Dr. Matthews will advise students regarding appropriate topics and projects. During fall semester of the first year, students meet on a regular basis with Drs. Matthews and Darrah to discuss the research process, potential topics and faculty research interests. They will assist each student in identifying an appropriate thesis advisor and other faculty members from the Department of Genetics & Genome Sciences or affiliated institutions to compose the student's research committee. The committee is charged with assisting the student in defining the area of research and carrying out the project.

Together, the student and the committee will determine the research schedule. Students begin to garner ideas considering possible projects during the first semester of the first year and begin to write their proposals during the spring semester. During spring semester of the first year, students register for 2 credit hours of GENE 601 Research in Genetics and meet weekly for the Genetic Counseling Research Seminar to discuss elements of the research process in more detail. A major component of the seminar is to prepare a research proposal, thus hopefully students will be able develop their projects during this time and obtain guidance and feedback from course faculty. The written proposal is expected to be completed and students have met with or set up meetings with their committee members no later than the end of spring semester. Failure to have drafted a proposal to submit to the thesis committee will result in receiving a “No Pass” grade for GENE 601.

Students are encouraged to meet with their research committee members early on to discuss the purpose of the study and specific aims of the project. Once students have incorporated the committee’s recommendations, they will set up a date for the committee to meet for a proposal presentation and circulate the written proposal to their committee members. During the initial proposal committee meeting, students formally present their research proposal to their committee members and work with the research committee to finalize the project. Students whose projects involve human subjects must submit their proposals to Case Western Reserve University Institutional Review Board (Case IRB), University Hospitals Cleveland Medical Center’s Institutional Review Board (UH IRB) and/or to other institutional IRBs as appropriate as soon as their committee approves the project. During the summer semester, students continue to work on their chosen projects. Students meet periodically with their committee for ongoing guidance and recommendations. As students near completion of their projects, they will schedule an oral defense with their research committee. The committee then makes the decision as to whether or not the student has successfully passed the oral defense. The final research project will be submitted to the committee in manuscript format suitable to submit for consideration for publication.

All students will present their work formally to the department faculty, staff and students at the annual departmental retreat as well as at the Research Showcase at the end of the 2nd year. More information about the research process can be found later in the Handbook.

Maximum Time Allowed

All the requirements for the master’s degree must be completed within five consecutive calendar years. While students usually complete the didactic and clinical course work within five semesters of the program, additional time may be necessary to finish a research project, which could in turn, extend the time that a student remains in the program. It is anticipated however, that the majority of students will be able to finish within two academic years.

ORGANIZATIONAL STRUCTURE

Department of Genetics & Genome Sciences

Anthony Wynshaw-Boris, MD, PhD	Professor & Chair	368-0581	ajw168@case.edu
Michelle Yanick	Dept Manager	368-8539	mxy36@case.edu
Clarice Young	Secretary	368-3431	cdy5@case.edu
Elizabeth Janniello	Admin Assistant	368-1891	exj103@case.edu

Genetic Counseling Training Program

Anne L. Matthews, RN, PhD	Director	368-1821	alm14@case.edu
Rebecca M. Darrah, PhD	Associate Director	368-4911	rjm11@case.edu
Michelle Merrill, MS, LCGC	Clinical Training Director	844-7234	michelle.merrill@uhhospitals.org
Anna Mitchell, MD, PhD	Medical Director	844-3936	anna.mitchell@case.edu
Clarice Young	Program Assistant	368-3431	cdy5@case.edu
Elizabeth Janniello	Admin Assistant	368-1891	exj103@case.edu

Center for Human Genetics

Anna Mitchell, MD, PhD	Medical Director	983-0845	anna.mitchell@case.edu
Aditi Parikh, MD	Faculty	844-6024	aditi.parikh@uhhospitals.org
Laura Konczal, MD	Faculty	844-7638	laura.konczal@uhhospitals.org
Lori Schillaci, MD	Faculty	844-7208	lori-anne.schillaci@uhhospitals.org
Suzanne DeBrosse, MD	Faculty	844-7942	suzanne.debrosse@uhhospitals.org
Jirair (Jerry) Bedoyan, MD, PhD	Faculty	844-6023	jirair.bedoyan@uhhospitals.org
Carlos Gallego, MD	Faculty	983-0032	carlos.gallego@uhhospitals.org
Cindy Medves	Adm Asst	844-7236	Cynthia.Medves@uhhospitals.org

Genetic Counselors

Leslie Cohen, MS, LGC	Faculty	844-7213	leslie.cohen@uhhospitals.org
Lauren Bokovitz, MS, LGC	Faculty	844-8431	lauren.bokovitz@uhhospitals.org
Kimberly Wallis, MS, LGC	Faculty	983-0844	kimberly.wallis@uhhospitals.org
Sarah Grimes-Hodges, MS, LGC	Faculty	844-7225	sarah.grimes@uhhospitals.org
Joanna Horn, MS, LGC	Faculty	844-7215	joanna.horn@uhhospitals.org
Michelle Merrill, MS, LGC	Faculty	844-7234	michelle.merrill@uhhospitals.org
Larisa Rippel, MS, LGC	Faculty	844-7235	larisa.rippel@UHhospitals.org
Christine Shuss, MS, LGC	Faculty	286-9677	christine.shuss@uhhospitals.org

Center for Human Genetics Laboratory Walker Bldg 10524 Euclid Ave 6th floor

Thomas Pryor, PhD	Director, Molecular Genetics	
Shashirekha Shetty, PhD	Director, Cytogenetics	Shashirekha.Shetty@UHhospitals.org
Sarah Aufmuth, MS, LGC	Lab counselor	Sarah.aufmuth@uhhospitals.org
CHG Laboratory 983-1134		

Residents/Fellows

Kate Dempsey, MD	CHG Genetics resident	Residents Office 844-7221
------------------	--------------------------	---------------------------

Edwin Ferren “Clay”MD	Genetics resident
Vincent Cruz, MD	Genetics resident
Suha Bachir, MD	Genetics resident
Tin-Yun Tang, MD	Genetics resident
Deepika Burkardt, DO “Dee”	Genetics resident

Additional Associated Facilities

MetroHealth Medical Center

Rocio Moran, MD	Geneticist, Director	216-778-4444 rmoran@metrohealth.org
Jacqueline Scott, MS, LGC	Genetic Counselor	jscott@metrohealth.org
Elizabeth Hogan, MS, LGC	Genetic Counselor	ehogan@metrohealth.org
Monica Nardini, MS, LGC	Genetic Counselor	mnardini@metrohealth.org
Amy Pizzino, MS, LGC	Genetic Counselor	apizzino@metrohealth.org

Akron Children’s Hospital Medical Center

Carrie Costin, MD	Geneticist	330-543-8792
Catherine Ward-Melver	Geneticist	
Joleen Viront, MS, LGC	Genetic Counselor	jviront@chmca.org
Connie Motter, MS, LGC	Genetic Counselor	cmotter@chmca.org
Susan Woods, MS, LGC	Genetic Counselor	swoods1@chmca.org
Amanda Saler Archbold, MS, LGC	Genetic Counselor	asaler@chmca.org
Marcie Parker, MS, LGC	Genetic Counselor	mparker@chmca.org
Jennifer Stein, MS, LGC	Genetic Counselor	jstein@chmca.org
Katie Krepkovich, MS, LGC	Genetic Counselor	kkrepkovich@chmca.org

Genomic Medicine Institute/Cleveland Clinic Foundation

Charis Eng, MD, PhD	Chairman and Director	216-445-7862 engc@ccf.org
Angelika Erwin, MD, PhD	Geneticist	
Vickie Zurcher, MD	Geneticist	
Marvin Natowicz, MD, PhD	Geneticist	
Amy G. Shealy, MS, LGC	Genetic Counselor	shealya@ccf.org
Diane Stanley-Clements, MS, LGC	Genetic Counselor	clemend@ccf.org
Marissa Coleridge, MS, LGC	Genetic Counselor	smithm31@ccf.org
Brandie Leach, MS, LGC	Genetic Counselor	leachb@ccf.org
Shreya Malhotra	Genetic Counselor	malhotr@ccf.org
Jessica Marquard, MS, LGC	Genetic Counselor	molinej@ccf.org
Ryan Noss, MS, LGC	Genetic Counselor	nossr@ccf.org
Christina Rigelsky, MS, LGC	Genetic Counselor	rigelsc@ccf.org
Allison Schreiber MS, LGC	Genetic Counselor	schreia@ccf.org
Brittany Psensky, MS, LGC	Genetic Counselor	psenskb@ccf.org
Lauren Palange, MS,	Genetic Counselor	palangl@ccf.org
Meghan Marino, MS, LGC (C. Eye)	Genetic Counselor	marinom2@ccf.org
Jacqueline Riley, MS, LGC (Lab)	Genetic Counselor	rileyj2@ccf.org
Chris Wensel, MS, LGC (lab)	Genetic Counselor	
Sarah Harter, MS, LGC (lab)	Genetic Counselor	

CONFERENCES AND CLINICAL ROUNDS

REQUIRED

CLINIC CONFERENCE:

4:00 p.m. Tuesdays Center for Human Genetics (CHG)

Selected patients seen during the preceding week, or patients scheduled to be seen during the upcoming week, are presented to the clinical genetics team for comments and suggestions regarding diagnosis and management. Abnormal laboratory results are also discussed. Students rotating through the CHG are required to present their assigned patients at this conference.

GENETIC COUNSELING JOURNAL CLUB:

~ 2 – 3 times per month (usually Mondays – 5:00 p.m.)

Students and faculty review and discuss recent journal articles relevant to genetic counseling. Students will have an opportunity to learn to critically review and critique the literature. Each student will be assigned a specific date on which to present an article or articles of their choosing for the group to discuss.

CLINICAL GENETICS ROUNDS:

2:00 p.m. Fridays BRB 8th floor

Clinical Genetics Rounds are presented by the genetics faculty, genetic counselors, residents and fellows or invited speakers from both within and without CWRU and UH. Topics relevant to the practice of clinical genetics and genetic counseling are presented. Presentations may be case based, review of current knowledge regarding a particular topic or a researcher's current endeavors. Once a quarter, the conference is held jointly with the Department of Bioethics & the Center for Genetic Research Ethics and Law to discuss social, ethical and legal issues regarding genetics and genomics topics.

PROFESSIONAL ISSUES SEMINAR – 2ND YEAR

~ 2 x monthly (TBD – usually 4:00 p.m.)

The second year professional issues seminar is an opportunity for students to discuss professional issues as they prepare to graduate at the end of their 2nd year. The intent of the seminar is to a forum to discuss pertinent and timely topics regarding professional practice. The seminar covers such topics as an overview of the professional societies (NSGC, ABGC, ACGC, AGCPD, ABMG, ACMG, ASHG), billing & reimbursement for genetic services, writing effective resumes, tips on interviewing and negotiating for genetic

counseling positions, developing effective talks & slide presentations, examining non-traditional roles in genetic counseling, aspects of clinical supervision and preparing for their first genetic counseling position.

REQUIRED CONFERENCES & SEMINARS DURING ROTATIONS

During clinical rotations students are required to attend a number of clinical conferences and seminars as part of the requirements for successful completion of the rotation. During orientation to each rotation, student responsibilities and expectations regarding these seminars and conferences will be outlined. Some examples include:

ROTATIONS AT CENTER FOR HUMAN GENETICS (CHG): FETAL BOARDS

This monthly conference is directed toward genetics topics of interest to the obstetricians and neonatologists. Genetic counseling students will attend this conference when appropriate as directed by the supervising genetic counselor during their prenatal diagnosis rotation. They are invited to attend during the rest of their program as time permits.

MULTI-DISCIPLINARY BREAST CANCER CONFERENCE & GI TUMOR BOARD

Newly diagnosed and follow-up patients with breast cancer and other hereditary type cancers are presented for consensus of treatment care paths. Medical specialty groups attending include Genetics, Surgery, Oncology, Radiation Oncology, Pathology and Clinical trials. Genetic counseling students will be required to attend this conference during their Cancer genetics rotation.

CHG CYTOGENETICS/DNA DIAGNOSTIC LAB CONFERENCE:

Discussion of a topic related to the clinical labs by a faculty member, student or guest. Genetic counseling students will be required to attend this conference during their laboratory rotation. The rotating student will also present a topic of their choosing during this conference.

METROHEALTH MEDICAL CENTER

In addition to attending the weekly Genetics Case Conference, students attend one lecture/educational session per week at MetroHealth depending on their rotation emphasis – cancer, prenatal. Students attend Pediatric Morning Report, Pediatric lectures, Cancer Genetics lectures, Neurology lecture series, OB grand rounds, OB clinical conference, Breast tumor board and GI tumor board.

GENOMIC MEDICINE INSTITUTE – CLEVELAND CLINIC

Students attend Case Review Conference and Grand Rounds as well as attending at least one other multidisciplinary meeting during General Genetics rotation. During the Cancer Genetics rotation students attend Family Review conference & CC Breast tumor conf.

ADDITIONAL DEPARTMENT SEMINARS – OPTIONAL

STUDENT/POSTDOC RESEARCH SEMINAR:

11 a.m. Mondays BRB Lecture Hall 105

Graduate students, postdoctoral research students and clinical fellows present their research to the rest of the department. Genetic counseling students are encouraged to attend to support their fellow doctoral students and to be informed of the newest areas of research happening in the department.

DEPARTMENTAL RESEARCH SEMINAR:

11 a.m. Wednesdays BRB Lecture Hall 105

Faculty from within and outside the institution discuss their research. This is an opportunity to hear highly accomplished researchers discuss state of the art genetic research in a wide range of areas. Dr. Matthews will inform students of invited speakers which she feels would be of particular interest to genetic counselors and students.

BIOETHICS AND CGREAL SEMINARS:

Varies

The Department of Bioethics and The Center for Genetic Research Ethics and Law (CGREAL) hold a number of “conversations”/seminars during the academic year that relate to ethical issues in genetics and genomics. These are presented by faculty, students and invited outside speakers. CGREAL’s major area of research and interests are to address some of the most pressing ethical, legal and social questions raised by recent advances in genetic and genomic research. Dr. Matthews will inform students of invited speakers which she feels would be of particular interest to genetic counseling students.

SUPPLEMENTARY REQUIRED ACTIVITIES

CLINICAL OBSERVATION EXPERIENCE:

First year, first and second semester

Starting in first semester and continuing throughout the second semester of the first year, each student will have an opportunity to observe cases in prenatal genetics, general genetics (pediatrics & adult genetics) and cancer genetics in at least two of the three affiliated institutions on Cleveland. Students will observe cases at the Center for Human Genetics at University Hospitals Case Medical Center in the General Genetics Clinic, Cancer Genetics Clinic, Prenatal Diagnosis Clinic and/or any of the Specialty Clinics; Prenatal Genetics and Cancer Genetics at Genetic Services at MetroHealth Medical Center and/or General Genetics and Cancer Genetics at the Center for Personalize Genetic Healthcare in the Genomic Medicine Institute at the Cleveland Clinic. Each rotation block is approximately six weeks; students will be provided with their individual observation schedule early in the first semester. Each student will observe at least one case per week during the semester with a minimum of 4 cases per clinical area (prenatal, cancer, general genetics and specialty clinics). Each week, students will select one or two cases and obtain approval of the genetic counselor to attend the session. They will prepare for the case by reviewing the patient chart as well as reading appropriate literature to familiarize themselves with the diagnosis, etc. Students may be asked by the genetic counselor to participate in the counseling session such as collecting history information or taking the family pedigree.

Additionally, each rotation site may have other requirements for the student to successfully complete during the observational experiences such as writing clinic notes, patient letters, researching and presenting on a specific topic, and/or attending procedures (CVS, amniocentesis, etc).

Students will provide written feedback of each case observed during the semester to the Program Director. Discussion time regarding these experiences will be provided during GENE 528 Principles and Practice of Genetic Counseling and GENE 529 Psychosocial Issues in Genetic Counseling. In addition, students will prepare a counseling outline for specific assigned role play cases. Specific guidelines for developing these counseling outlines will be discussed during the early part of fall semester.

GENETIC COUNSELING RESEARCH SEMINAR:

First year – Fall Semester TBD

The Genetic Counseling Research Seminar provides students an opportunity to discuss the research process, to explore potential research projects to begin developing a research proposal. Starting in fall of the first year, topics will provide an overview of different research approaches including quantitative, qualitative and mixed research approaches, as well as identifying projects, discussing initial time lines and inviting faculty to present their

research interests. It is anticipated that students will identify an area of interest and research question by the end of the first semester. The seminar continues through spring semester (GENE 601) as students discuss their potential research questions and specific aims, critiquing the literature, human subjects' protection (IRBs) and statistical approaches to develop their proposals.

***MEDICAL GENETICS, TERMINOLOGY & ANATOMY REVIEW:**

First year, during first week of fall semester - Dr. Matthews

This required one-week intensive at the beginning of fall semester is devoted to reviewing fundamental concepts in medical genetics. The review includes patterns of inheritance, complex traits, non-Mendelian patterns of inheritance and genetic testing. An introduction and review of common medical terminology and a brief overview of the physical examination process using a systems approach is also covered.

***HUMAN DEVELOPMENT OVERVIEW:**

First year, during first week of spring semester - Dr. Matthews

This required one-week seminar is an overview of normal individual development through the life cycle that complements and expands material from GENE 528 – Principles and Practice of Genetic Counseling. It provides a review of basic developmental tasks for each life stage in the context of physical, psychological, familial, and sociocultural factors.

***TEACHING/PUBLIC PRESENTATIONS: variable**

Students have the opportunity to formally present topics of interest during clinical rotations and at the CHG Clinical Genetics Rounds throughout their training. Students may also have the opportunity to gain experience in presenting information regarding genetic counseling, the career of genetic counseling or some aspect of clinical genetics to lay, student and/or professional audiences outside of the department. As requests are received by the Department of Genetics & Genome Sciences/Center for Human Genetics, students will be asked to present. Under the guidance of the Program Director and genetic counselors, the student will have an opportunity to prepare and give such a talk. As the number of requests for such talks is variable, students may or may not have this experience. All students also participate in DNA Day and provide lectures and demonstrations at high schools in the Cleveland area.

Students also do presentations as part of the requirements of a number of courses. This allows students to present on a number of topics to their classmates and the faculty. All second year students prepare posters of their research projects for the poster presentations which are held at the annual departmental retreat in spring semester. And finally, all students present their research projects to the department at the end of the 2nd year as part of the Research Showcase.

COURSES AND CREDITS

FIRST YEAR

All first year students in the genetic counseling tract are expected to complete the required courses of the first year of the program for a total of 19 credits, receiving a minimum of a B grade. Students will also participate in other activities such as clinical conferences, departmental seminars, Journal Club, etc. Students will begin to identify suitable projects for consideration for research projects. It is expected that the research proposal will be presented during spring semester.

Year 01 FALL

GENE 524: Advanced Medical Genetics: Molecular & Cytogenetics (2 credits) **Matthews, Darrah and Mitchell**

Molecular aspects of gene structure; mechanisms, detection and effects of mutations; imprinting; triplet repeat disorders; X-chromosome inactivation; mitochondrial disorders; animal models for genetic disease and gene therapy are covered. Fundamental principles regarding clinical cytogenetics including discussion of autosomal numerical and structural abnormalities; sex chromosome abnormalities; mosaicism; uniparental disomy; contiguous gene deletions and current laboratory approaches will also be covered.

GENE 526: Advanced Medical Genetics: Quantitative Genetics & Genomics **Darrah and Mitchell** (2 credits)

The purpose of this course is twofold: first, to provide a foundation in quantitative genetics and second, to focus on genomic approaches and technologies which have greatly expanded our understanding of not only rare genetic disorders but common ones as well. The course covers concepts related to risk assessment and calculation and its application to medical genetics. Principles and application of Hardy Weinberg equilibrium as a means of estimating disease incidence and carrier frequency, and apply Bayes' Theorem as a mechanism to refine risk assessment based on data specific to the patient will also be addressed. The second area of focus is on understanding the clinical implications of the interpretation of next generation sequencing results, identify limitations of genomic technologies, and practice curation / annotation and interpretation of genomic testing results. In addition, resources and bioinformatics tools including national databases and clinical labs to aid in the interpretation of genomic test results including variants of uncertain significance are discussed.

GENE 528: Principles and Practices of Genetic Counseling (3 credits) **Matthews and faculty**

Fundamental principles needed for the practicing genetic counselor. Topics include skills in obtaining histories (prenatal, perinatal, medical, developmental, psychosocial and family); pedigree construction and analysis, physical growth and development; the genetic evaluation; the physical examination and laboratory analyses; prenatal issues, prenatal screening and diagnosis; and teratogenicity.

SASS 477: Direct Practice Generalist – Methods & Skills (3 credits)
Faculty at MSASS

The course introduces major social work theories (i.e., systems-based, cognitive-behavioral, and relationship-based intervention approaches utilized in social work [and genetic counseling] practice with individuals and families. The course is structured to include lecture, discussion and experiential laboratory learning. Interviewing skills for beginning practitioners relevant to work with individuals and families will be a major focus of work both in lectures and during the skills lab incorporating engagement, assessment, goal-setting/treatment planning, intervention and evaluation, termination and follow-up.

Embryology (certificate)

This online course (taught by embryologist Dr. DJ Lowrie), is sponsored by the Genetic Counseling Program at the University of Cincinnati and provides the student with an understanding of normal human development/embryology and the processes by which developmental anomalies occur. The course is divided equally into basic embryology and clinical application presentations. Each lecture is presented using a combined audio/video format and detailed PowerPoint slides. There are self-assessment activities and a final examination. Students will have access to the course starting in June, prior to classes beginning in August and will be required to complete the online course by the end of November of the first year. All students who successfully pass the course will receive a certificate of completion. The fee for the course will be paid for by the Department of Genetics & Genome Sciences.

Research Seminar (0 credits)
Matthews & Darrah

This required seminar begins in early fall of first year. The purpose of the fall seminar meetings is for students to have an opportunity to begin exploring the research process and to discuss potential research projects. Discussion will begin regarding quantitative, qualitative and mixed research approaches, approaches to identifying projects and presentations from faculty about their research interests. Discussion also includes identifying research questions and writing specific aims for projects. Initial discussion of the research process timeline will also be included. Students are asked to draft a research question and aims to submit at the beginning of spring semester.

Year 01 SPRING

GENE 525: Advanced Medical Genetics: Clinical Genetics (2 credits)
Matthews and faculty

Fundamental principles regarding congenital malformations, dysmorphology and syndromes. Discussion of a number of genetic disorders from a systems approach: CNS malformations, neurodegenerative disorders, craniofacial disorders, skeletal dysplasias, connective tissue disorders, cardiovascular disorders, etc. Discussions also include diagnosis, etiology, genetics, prognosis and management. Students begin to develop a

knowledge base from which to develop differential diagnoses, syndrome recognition and diagnostic approaches along with specific information needed for providing appropriate genetic counseling.

GENE 529: Psychosocial Aspects of Genetic Counseling (3 credits)
Matthews and faculty

Fundamental principles regarding the psychosocial aspect of birth defects and genetic disease, its psychological and social impact on the individual and family are presented. Topics include the genetic counseling interview process, issues regarding pregnancy, chronicity, death and loss. The impact of cultural issues are addressed. Resources for families are also explored. Basic interviewing and genetic counseling skills are practiced through role plays and actual interviewing situations.

GENE 531: Clinical Cancer Genetics (2 credits)
Merrill, Matthews and faculty

This required seminar during spring semester discusses basic concepts in cancer epidemiology, principles of cancer genetics, inherited cancer syndromes, cytogenetics of cancers, pedigree analysis for familial cancer risk, approaches to differential diagnosis, risk assessment, genetic testing, screening and management of patients with familial or inherited cancer disorders and psychosocial issues.

GENE 601 Genetic Counseling Research Seminar (2 credit)
Cohen and Matthews

This required research seminar is a continuation of the fall research seminar. The major focus of the spring semester will be to provide guidance regarding the development of a research proposal. Discussion continues regarding quantitative, qualitative and mixed research approaches except now in the context of specific research projects. Students will identify their specific research question and specific aims, discuss issues regarding review of the literature, develop the appropriate research design (study population, data collection, data analysis) to answer the research question, discuss the required format of the proposal, human subjects' protection (IRBs) issues and the proposal defense. The end product of the seminar will be a written research project proposal.

SECOND YEAR

Second year students will complete the remainder of course work, an additional 5 semester hours. Students will also register for research hours during the second year, 5 hours over two semesters. Additionally, they will register for 11 credit hours of clinical practicum – 3 hours in summer semester, 4 hours in fall semester and 4 hours in spring semester. During January, second year students will sit for the Comprehensive Examination (written and oral).

Year 02 SUMMER

GENE 532 Clinical Rotation II (3 credits)
Matthews and faculty

Year 02 FALL

GENE 527: Advanced Medical Genetics: Biochemical Genetics (2 credits)
Bedoyan and faculty
Fundamental principles of metabolism including amino acid disorders; organic acid disorders; carbohydrate disorders; peroxisomal disorders; mitochondrial disorders are discussed. Major metabolic disorders are covered in regard to their phenotypes, genetic testing, differentials and treatment. Discussion of screening principles and newborn screening as well as therapy for metabolic diseases is included.

GENE 532 Clinical Rotations III (4 credits)
Matthews and faculty

GENE 601: Research in Genetics (3 credits)
Matthews and faculty

Year 02 SPRING

BETH 412: Ethical Issues in Genetics & Genomics (3 credits)
Goldenberg and Matthews
Ethical, legal and professional issues inherent in medical genetics, genomics and genetic counseling are addressed including predictive genomic screening and testing, prenatal diagnosis, genetic privacy, implications for incidental findings, human genetic variation research, health disparities, research ethics and legal issues. Basic bioethical principles as they relate to genetic issues such as confidentiality, privacy, discrimination, autonomy and informed consent will also be discussed.

GENE 532 Clinical Rotations IV **Matthews and faculty** (4 credits)

GENE 601: Research in Genetics **Matthews and faculty** (2 credits)

YEAR 01 - FALL

Gene 524	Advanced Medical Genetics: Molecular & Cytogenetics	2
Gene 526	Advanced Medical Genetics: Quantitative Genetics & Genomics	2
Gene 528	Principles & Practices of Genetic Counseling	3
SASS 477	Direct Practice Generalist – Methods & Skills	3

Embryology Online course - summer prior to Year 1 Certificate
Total = 10

SPRING

Gene 529	Psychosocial Issues in Genetic Counseling	3
Gene 525	Advanced Medical Genetics: Clinical	2
GENE 531	Clinical Cancer Genetics	2
Gene 601	Genetic Counseling Research Seminar	2

Total = 9

YEAR 02 - SUMMER

Gene 532	Clinical Rotation	3
----------	-------------------	---

Total = 3

FALL

Gene 527	Advanced Medical Genetics: Metabolism (biochem)	2
Gene 532	Clinical Rotations	4
Gene 601	Research	3

Total = 9

SPRING

BETH 412	Ethical Issues in Genetics & Genomics	3
Gene 532	Clinical Rotations	4
Gene 601	Research	2

Total = 9

Total credit hours = 40

**CASE WESTERN RESERVE UNIVERSITY
GENETIC COUNSELING PROGRAM RESEARCH PROJECT**

GOALS:

The goals of the research experience are to:

1. Familiarize the student with the literature in genetics, genetic counseling and related disciplines
2. Enable the student to critically review and synthesize relevant literature
3. Help the student formulate research questions
4. Acquaint the student with the research methods that can be used to address these questions
5. Expose the student to other aspects of conducting research such as the IRB approval process
6. Give the student practice in collecting, analyzing and presenting research data
7. Develop scientific writing skills
8. Improve organization and time-management skills

PROCESS:

1. Begins when students arrive. Students are encouraged to think about ideas that would lead to a research project. Students will meet for the Research Seminar with Drs. Matthews and Darrah during fall semester to begin discussions regarding the research process. We will begin to explore different research approaches and ways to identify developing a research question and study purpose.
2. Keep a list of topics that pique your interest. Venues that may offer possible research topics and questions include:
 - Genetics PhD Student Seminar – hear about what the PhD and post-doc students are doing from the lab perspective
 - Case Conference and Clinical Rounds – hear about cases and research going on from the clinical side
 - Journal Club – students present and critique articles in the literature; discuss other questions that could be asked regarding the topic
 - Lectures and class discussions
 - Browsing through relevant journals
 - Literature reviewed for class assignments or projects
 - Reviewing abstracts from the NSGC Annual Education Conference (found in selected issues of the Journal of Genetic Counseling)

- Meeting with faculty with whom you might like to work with. Some of the faculty come to describe the type of research they do or ideas they have for projects during the Research Seminar time.
3. Students are encouraged to talk to faculty about their research – their ideas for being involved. Do this in late fall/early spring semester – Dec/Jan
 4. Students make appointments with Dr. Matthews and/or Darrah to meet individually to discuss their ideas – hash out what might and might not work; what faculty might be helpful, doing a quantitative vs qualitative study; clinical vs lab, etc. By the beginning of spring semester 1st year students will have drafted a study question/purpose and specific aims (Discussed at round table sessions in GENE 601, spring semester).
 5. Once a question is identified – students, in consultation with Drs. Matthews, Darrah and Cohen, begin to form their research committees (minimum 3 faculty members) by asking faculty if they are willing to sit on their committees. This occurs during spring semester as part of GENE 601 – Research Seminar.
 6. During spring semester, students will draft a timeline for their specific projects to ensure projects are completed in a timely manner.
 7. The chair of the committee will depend on topic and area of research. EX: If the study is a lab project – then the PI of the lab is the appropriate committee chair.
 8. The written proposal will be in written in a specific format (below). Each specific section of the research proposal will be discussed during the Research Seminar.
 Research proposal format:
 1. Introduction – short overview of area of research
 2. Purpose & Specific Aims – purpose &/or research question, hypotheses, etc
 3. Background and Significance – literature review; significance for genetic counseling
 4. Preliminary data – usually this section is not included since the student would not be expected to have any preliminary data – unless data is available from lab or PI
 5. Research design and Methods – design of study, how it will be conducted, instruments used, projected analysis of data
 8. Students are encouraged to convene their committees during the development of their proposals to receive guidance and recommendations regarding their initial drafts.
 9. A draft of the written proposal must be completed by the end of spring semester. Each student will schedule a proposal defense for the end of spring semester (~May or June). The proposal is submitted to the student’s committee members at least one week ahead of the date set for the proposal defense.

Proposal Defense

1. The committee meets with the student. There is an initial executive session in which the committee members discuss the proposal while the student is not present in the room. The committee then asks the student to rejoin them.
2. The student will make a brief presentation (~15 minutes) about the project and then there is open discussion and questions by committee members
3. During this meeting, faculty will provide guidance and recommendations to the student regarding the research question, the specific aims of the project, significance and background of the literature, previous work in the area and the chosen methodology for achieving the research aims.
4. The committee then goes into executive session and a decision is made as to whether or not student needs to have an additional meeting in ~ 1-2 month's time to discuss changes, etc.
9. Proposals drafts not submitted to committee members by the end of summer semester of 1st year will result in a grade of "Not Passing" for GENE 601.

Following study approval

1. Once the research committee has approved the project's aims, research design and methodology, the student prepares an IRB proposal, if appropriate, under the direction of the Program Director or committee chair.
2. Following IRB approval, the student carries out the project with data collection, data analysis and writing a draft of the manuscript.
3. The Program or PI is responsible for costs associated with the project.

Follow-up committee meetings

1. Students are expected to meet with their PI as often as necessary. It is the student's responsibility to keep their committee chair up-to-date on all aspects of the project.
2. At a minimum, students should convene a committee meeting in early to mid-fall semester and again in early spring semester to update the committee on progress of the project and to receive additional suggestions and recommendations from committee members. The student may request additional meetings as needed.

Committee defense

1. Once data collection is complete, analysis done – the student gives a rough draft(s) of the manuscript to the PI/committee chair and other appropriate committee members to critique and edit. On approval of the committee chair, the student may schedule the committee defense – committee members receive a final draft of the manuscript a minimum of 10 days prior to committee defense.
2. Committee Defense – the student will schedule a 2 hour session with their research committee members to defend the project. The format is similar to the proposal defense with executive sessions before and after a short presentation by the student and committee member questions regarding the research. Following this defense, the research committee will make a recommendation regarding manuscript preparation and if the student has met the objectives of the research project.

Research Presentations

1. All 2nd year students are required to present their research projects as posters at the annual departmental retreat, usually the beginning of May.
2. At the end of spring semester of the 2nd year, all graduating students present their research projects at the Genetic Counseling Program Research Showcase. Students give a short presentation of their projects and then discuss those projects with members of the department faculty, staff and students individually.

NOTE: Perhaps one of the most difficult aspects of the research process is selecting a time that all of your committee members are available to meet - faculty schedules fill very quickly and far in advance. The student must take the initiative to schedule committee meetings, which often means contacting faculty 2-3 months in advance.

Additional Expectation:

1. All students submit abstracts to NSGC, ACMG or ASHG (where ever appropriate) for platform or poster presentation at the next year's meetings.

The CREC Program and Research Education

All genetic counseling students are **required** to take the on-line Case Western Reserve University's Continuing Research Education Credit (CREC) Program which "provides investigators documented training in the protection of human subjects in research" (CREC

website – below). **This training must be completed by the end of fall semester of first year.** The program outlines the ethical principles of human subjects research and prepares the researcher, in this case the student, to “protect the rights, dignity, welfare and privacy of human research participants” (UHCMC IRB website – below).

The main page for Case research programs can be found at: <http://ora.ra.cwru.edu/research/orc/> or you can go directly to the Continuing Research Education Credit Program (CREC) link - http://ora.ra.cwru.edu/research/orc/crec/CREC_Pg1.cfm

On this page you will find a link for the Collaborative Institutional Training Initiative (CITI) - this is the program used to become certified re: human subjects research in order to conduct your research projects. Obviously, if you elect to do a lab based study - you do not need to have this type of certification, but we require all students to complete the course regardless of the type of project you elect to carry out.

Information about University Hospitals Case Medical Center Institutional Review Board can be found at:

<http://www.uhhospitals.org/Research/InstitutionalReviewBoard/PoliciesandProcedures.aspx>

GRADUATES THESES PROJECTS GENETIC COUNSELING TRAINING PROGRAM

Year of Graduation

2000

Jeanne W Brunger	“Parental Attitudes toward Genetic Testing for Children Who Are Hard-of-hearing or Deaf”
Rebecca J Marsick	“The Relationship between Cystic Fibrosis Pulmonary Phenotype and IL-10 and TNF- α Promoter Polymorphisms
Shannon M McGuire	“Phenotype/Karyotype Correlations and Definition of a Critical Region in Duplication 9p Syndrome”
Ann Weiss	“Investigation of NAT2 Polymorphisms Associated with Increased Risk for Colon Neoplasia”

2001

Rhonda Nation Dugan	“Genetic Counselor’s Experience with the Conflict between Patients’ Right to Confidentiality and the Duty to Warn at-risk Relatives”
Erica Burner	“Attitudes and Feelings of Siblings Towards Having a Brother or Sister with Prader-Willi Syndrome”

2002

- Joanna L Bohl "Attitudes and Perceptions of the Public Toward DNA Sampling for Research"
- Cheryl Turansky Hess. "Genetic Conditions During Adolescence: Knowledge Levels and Communication Patterns of Parents and Teens"
- Arlene B. Ilagan "Defining the Role of Genetic Counseling in Reproductive Medicine"
- Michelle Merrill "An Examination of the Impact of Genetic Discrimination on Genetic Testing and Medical Management Decisions among Persons at Risk for Hereditary Breast and Ovarian Cancer"
- Susan L. Thompson "Phenotype/Karyotype Correlation in Inv Dup(15) Marker Chromosomes: Update and Review of the Literature"

2003

- Sarah J Grimes "Explorations of the Neurobehavioral Aspects of Marfan Syndrome"
- Elizabeth Regier "Attitudes toward Genetic Testing and Genetic Research in an African American Population"
- Stavit Biton "Molecular and Phenotypic Characterization of 9p23-p24.3 deletions"

2004

- Elyce Carson "A Description of Current Prenatal Genetic Counseling Practice with Regards to Sonographic Markers for Down Syndrome in the Second Trimester of Pregnancy"
- Devon Lamb "An investigation of current parent experiences with the Ohio Newborn Screening Program since the implementation of the Supplemental Newborn Screening Program"
- Azita Sadeghpour "Ashkenazi Jewish Community-Based Genetic Education and Counseling for Hereditary Cancer: Coping Styles, Psychological Distress, Discrimination Concerns and Satisfaction"
- Mary Topping "A description of current genetic screening practices of donor gamete programs in the United States including the utilization of guidelines and recommendations published by the American Society of Reproductive Medicine (ASRM)"
- Heidi Vance "Further Characterization and Phenotype/Karyotype Correlations in the 9p Syndrome"

2005

Erin Fink

“Family Medical History and Genetic Research”

Stacey Fiorillo

“Utilization of Genetic Testing for Carrier Status in the Ashkenazi Jewish Population of Cleveland”

June Malkiewicz

“Practices of Genetic Counselors and Obstetricians in the Counseling of Women Diagnosed with a Fetal Anomaly”

2006

Ryan Bisson

“Correlation of Second-Trimester Ultrasound and Biochemical Markers When Screening for Down Syndrome”

Cassandra Gulden

“Folate Pathway Polymorphisms and Colorectal Neoplasia Risk”

Diana Katz

“Genetic Screening of Egg Donors for In-vitro Fertilization”

Bronson Riley

“Polymorphisms in the Transforming Growth Factor Beta1 Gene and their Association with CF Pulmonary Disease”

2007

Jennifer Glass

“Current Pediatricians’ Practices Regarding Testing for Metabolic Disorders among Internationally Adopted Patients”.

Elizabeth Lindsey

“Attitudes of Adults with Osteogenesis Imperfecta Towards Pre-Implantation Genetic Diagnosis”

Nichole Morman

“Pregnant Women’s Preferences Regarding First Trimester Screening for Down Syndrome”.

Kristan Moxley

“Impact of Carrier Screening on Pregnant Women’s Knowledge of Sickle Cell Anemia”

2008

Megan Doerr

“A systematic review of ENDRA polymorphisms and disease HGE/GA”

Vandana Sharma

“Parental Experience with Ohio’s Cystic Fibrosis Newborn Screening Program”

2009

Pinchia Huang

“Implications of False-Positive Trisomies 18 or 21 Test Results in Predicating Adverse Pregnancy Outcomes”

Corissa Manou	“Evaluation of an Alternative Method of Providing Written Information to Individuals Attending Genetic Counseling for Hereditary Breast and Ovarian Cancer”
Willonnie Mendonca	“Impact of Characteristic Behaviors of Patients with Prader Willi Syndrome on Caregiver Self-esteem, Mental Health and Family Functioning”
Marissa Smith	“Genetic Counselors’ Views and Current Practice with Regard to the Use of Array-CGH for Prenatal Diagnosis”
2010	
Sarah Bragg	“Correlation of Poor Growth and Decreased Liver Fatty Acid Synthesis in Cystic Fibrosis Conditional Knockout Mice”
Karen Buser	“Parental perceptions of the benefits and risks associated with newborn screening for Duchenne Muscular Dystrophy”
Hannah Colabrese	“Impact of Cleft Lip with or without Cleft Palate on Parental Knowledge of Risk and Opinions of Genetic Testing”
Meghan Marino	“Genetic Disorders Misdiagnosed as Multiple Sclerosis: A Systematic Review of the Literature”
2011	
Elizabeth Hogan	“Impact of genetics professionals’ involvement in the care of individuals with cystic fibrosis in regard to genetics knowledge and reproductive decision making”
Amy Linn	“Evaluation of the validity and utility of direct-to-consumer genetic testing for the autoimmune diseases: systemic lupus erythematosus”
2012	
Brittney Knyszek	“ Impact of Visual Aids on Prenatal Genetic Counseling Session Patient Outcomes”
Brittany Psensky	“Factors impacting attendance of patients with hypertrophic cardiomyopathy for cardiovascular genetic counseling”
Christine Shuss	“Student perceptions of genetic counselor supervision in the clinical setting”
Krista Sondergaard	“Non-vascular Ehlers-Danlos syndrome and pregnancy complications”

2013

- Erika Holt “Impact of Disease Severity on Quality of Life for Parents of Patients with Hemophilia”
- Theodora Jacobson “Health, Social and Daily Living Skills: An Assessment of Adults with Down Syndrome”
- Agnes Machaj “Breast Cancer in PHTS: Can a Predictive Fingerprint be Identified?”
- Monica Nardini “Genomic Counseling in the Newborn Period: Are Genetic Counselors Ready?”

2014

- Evelyn Crawford “Efficacy of Genetic Testing in Cases of Ambiguous Genitalia Detected on Prenatal Ultrasound”
- Jeannie Klavarian “Low Adiposity in Cystic Fibrosis Mice”
- Andrea Lutter “The Impact of Rosa’s Law on Describing Persons with Intellectual Disability”
- Rebekah Moore “Provision of Genetic Services: Is It Time to Embrace Social Media”
- Danielle Mouhlas “Parental Experiences with Whole Exome Sequencing”
- Rebecca Nelson “Growth Deficiency in Cystic Fibrosis is Observable at Birth & Predictive of Early Pulmonary Function”

2015

- Lauren Bokovitz “Impact of Cystic Fibrosis on Women’s Reproductive Decision-Making”.
- Lauren Maline “Non-invasive prenatal testing: Its influence on pregnancies established through in vitro fertilization”.
- Carolyn Piccinin “Fundamental Philosophies and Professional Demands: Exploring Evidence of Genetic Counseling Models of Practice”.
- Adriane Shorkey “Anxiety in Women Undergoing Noninvasive Prenatal Testing”.
- Kristin Zajo “Knowledge and Patient Satisfaction following genetic counseling for inherited retinal dystrophies”

2016

- Jenny Frey “Two polymorphisms and their association with Cystic Fibrosis pulmonary disease severity”.
- Jenna Huey “Analyzing lincRNAs as a possible mechanism of trastuzumab resistance and target for dual therapy in HER2+ breast cancer.”
- Hannah Mianzo “The role of the circadian rhythm in cystic fibrosis”.
- Hailey Pinz "Psychosocial Aspects of Prenatal Genetic Counseling (PAPGC) questionnaire: Development of a screening tool for use in prenatal genetic counseling".
- Leah Rogers “The patient’s prospective: Is there a role for religious/spiritual assessment in genetic counseling?”
- Elana Wishnefsky “The Impact of hyperphagia and food restriction on siblings of individuals with Prader-Willi syndrome”.

2017

- Megan Cermak "The Patient Experience of a Moderate-risk Breast/Ovarian Cancer Susceptibility Gene Mutation“
- Sarah Harter “Down Syndrome Information Acts: Knowledge, Opinions, and Practices of Medical Professionals“
- Megan Horn* “Patient Perspective of the Informed Consent Process for Noninvasive Prenatal Screening.”
- Jennifer Preslar “Generating a Cellular Model for Evaluation of Pyruvate Dehydrogenase Complex Deficiency”
- Nive Rajakumar* “Factors Influencing Cultural Competency in Genetic Counselors”
- Allison Thomsen “Practices in Synagogues Regarding Jewish Genetic Disease Education”.

* Dual degree student – MS Genetic Counseling / MA Bioethics

2018

Katie Clayback	"Is Less Really More? The influence of Demographic Factors on Multi-gene Panel Testing Choice for Inherited Breast Cancer Syndromes."
Stephanie Gerber	"Assessing the Effects of Renin Angiotensin System Drugs on Lung Function in Patients with Cystic Fibrosis."
Morgan Hnatiuk	"The Current State of Genetic Counseling Assistants."
Annelise Page*	"Lived Experiences of Individuals with Cystic Fibrosis on CFTR Modulators"
Ali Robzen	"Evaluating Patient Satisfaction with Genetic Counseling Sessions: What is the Impact of Genetic Counseling Trainees?"
Amy Siemon	"Progress of Newborn Screening Educational Materials"

* Dual degree student – MS Genetic Counseling / MA Bioethics

CLINICAL ROTATIONS

Description

Students must satisfactorily complete all rotations of clinical practicum. Rotations include the following areas: General Genetics (pediatric and adult patients), Specialty Clinics, Prenatal Genetics Clinic, and Hereditary Cancer Clinic. Clinical rotations are held at four sites: Center for Human Genetics at University Hospitals Case Medical Center, MetroHealth Medical Center, Genomic Medicine Institute at the Cleveland Clinic and the Genetics Center, Akron Children's Hospital. Additionally, each student will rotate through the Cytogenetics and Diagnostic Molecular Genetics Laboratory at UHCMC. The first rotations occur in the summer between first and second year. There is a 6-week rotation held at Genetic Services, Akron Children's Medical Center as well as a 3-week rotation in the CHG Laboratory. The remaining 3 rotations are scheduled in 10-week blocks (fall, winter and spring) during the second year of the program. The rotations are:

Akron Genetics: General Genetics, Prenatal, Cancer (6 weeks)

Clinical Cytogenetics/Molecular Laboratory Rotation (3 weeks)

MetroHealth Medical Center: Prenatal Genetics and/or Cancer Genetics

Center for Human Genetics: Prenatal Genetics, General Genetics* and/or Cancer Genetics

Center for Personalized Medicine, Cleveland Clinic: General Genetics* and/or Cancer Genetics

*General Genetics includes Pediatrics, Adults, Metabolic & Specialty Clinics

The specific rotational schedule for each student will be assigned by Dr. Matthews, Darrah and Michelle Merrill during the spring semester of the first year.

Each clinical rotation will provide students with opportunities to have first-hand experience with individuals and families affected by a broad range of genetic disorders. The intent of each rotation is to expose students to the natural history and management of common genetic conditions and birth defects and to the relevant psychosocial issues involved in each case. During these clinical experiences students will be required to observe and practice a range of genetic counseling functions, including preparing for cases; obtaining medical and family histories; determining risks; performing psychosocial assessments; communicating information about disease characteristics, inheritance, and natural history; providing

anticipatory guidance and supportive counseling; identifying and using medical and community resources; communicating information to other health care professionals; and case management and follow-up.

Each student, over the period of 3 semesters, will be able to complete a Logbook of Supervised Cases and other materials documenting their clinical training. These materials become a permanent part of the student's portfolio and will be collected by Dr. Matthews at the end of each clinical rotation. In each clinical setting, the student will have direct supervision by a certified genetic counselor and/or medical geneticist. During the laboratory rotation, the student will be under the supervision of the laboratory genetic counselors and directors of the laboratories. The student must register for a total of 11 credit hours of Gene 532 (3 credit hours in summer; 4 hours in fall and 4 credit hours for the final spring semester) for a total of 36 clinical rotation weeks (average of 900 hours of clinical practicum and an additional 120 hours laboratory experience).

Grading

Grading is on a Pass/Fail basis. Successful completion of **EACH** clinical rotation is required to graduate from the program. Specific requirements for successful achievement in clinical rotations are those listed in the Handbook under each clinical rotation and outlined by your clinical supervisors during each rotation. These include, but are not limited to, preparing for a minimum of 3 cases per week (chart review, literature search on appropriate topics pertaining to each case, obtaining additional information – lab data, hospital records, etc), and meeting with the supervising counselor prior to each case (at a time agreed upon by the student and the counselor) to discuss counseling issues and strategies. In addition, the student will prepare a pre-case counseling outline and write-up. The pre-case write-up will be the basis for case review and discussion with the supervising counselor. The pre-case must be completed and reviewed (see individual clinical rotation requirements) prior to seeing the patient in order for the student to actually see the case.

Following each case, clinic notes, letters, post case write-ups and other additional information requested must be submitted in a timely manner (see specific clinical rotation information). Failure to meet expected deadlines more than 3 times for case write-ups, letters, etc, will result in a failing grade for the rotation and the student will either need to repeat the rotation or be asked to withdraw from the program. In the event that a student does not perform satisfactorily and meet the requirements of the practice-based competencies, the student will meet with the supervising genetic counselor(s), the clinical coordinator and the Program Director to decide how deficiencies will be rectified. This may be, but is not limited to, doing additional clinical work which in turn may prolong the student's program.

Practicum Objectives

The clinical practicum supports the development of practice-based competencies as outlined by the Accreditation Counsel for Genetic Counseling and represents practice areas that define activities of a genetic counselor. These competencies fall into the following domains: 1) Genetics expertise and analysis; 2) Interpersonal, psychosocial and counseling skills; 3) Education; and 4) Professional Development & practice. During each rotation, students will

be assessed on skills necessary for achievement of each competency as outlined in specific objectives (see attached ACGC Practice-Based Competencies for Genetic Counselors).

LOGBOOKS

Each student will keep a logbook of **ALL** patients he/she sees **including all observations**. This log should include all information needed to satisfy documentation of the student's role in each case as well as detailed notes on the cases and counseling strategies. The logbook should reflect the depth and breathe of the student's clinical experience. A program **logbook** form will be provided to you electronically before starting clinical rotations (see example and instructions in the Additional Materials section of the Handbook). Logbooks will be reviewed by the Program Director at the end of each clinical rotation. Additionally, all student cases will be reviewed and must be completed to the satisfaction of the supervising genetic counselors, and program leadership prior to the student leaving the program. Patient identifiers (such as patient hospital number) must never be used on the logbook. The student will assign a unique identifier for each case seen.

Specific expectations during each rotation for each clinical site will be given to the student prior to starting the rotation. In addition to the pre and post case write-ups for each case, the student will provide the supervisor for each case a copy of the **Patient Encounter form** (see example and instructions). Elements of the counseling session (management/counseling roles) are listed and will be checked off during and after the session as appropriate. After the case is finalized, the student will have the supervisor review the form and sign and date it. A copy of the student's post-case write-up (the student's self-evaluation of the session) needs to accompany the completed Patient Encounter form. These forms **MUST** be given to the Program Director (electronically) to be maintained in the student's permanent file at the end of each rotation.

You will have an exit interview with Dr. Matthews to review your logbooks and other materials before leaving CWRU.

Finally, prior to starting each rotation, each student will identify specific goals that the student wishes to accomplish during that rotation. Students will continue to add and build upon the list of goals at the beginning of each new rotation and will review them with the supervising counselor(s) at the beginning and end of a rotation. It is anticipated that by the end of the Program, the students will have achieved the goals that they set for themselves.

CLINICAL ROTATION SITES

Center for Human Genetics University Hospitals Case Medical Center

The Center for Human Genetics is located at 1500 Lakeside. Patients are also seen at a number of satellite clinics throughout northeast Ohio such as UH Landerbrook Health Center, UH Chagrin Highlands Health Center, UH Ahuja Medical Center, UH Mentor Health

Center and UH Westlake Health Center. The Center's vision is to achieve excellence in three areas of human medical genetics: patient care, research and education. By combining these three areas, the Center provides unique opportunities for research collaboration and excellent education of residents, fellows and graduate students. The Center for Human Genetic Laboratory is located in the W.O. Walker Building.

The Center for Human Genetics is under the direction of Dr. Wynshaw-Boris. The Center's Medical Director is Anna Mitchell, MD, PhD. There are seven board certified clinical geneticists including two who are board certified in biochemical genetic, one in clinical molecular genetics and one in cytogenetics, nine board certified genetic counselors, two board certified genetic counselors in the CHG laboratory, a nutritionist, as well as laboratory technologists / technicians and support staff members. Additionally, there are two board certified OB clinical geneticists whose primary appointments are in the Department of OB/GYN and who oversee care of high risk prenatal patients.

The CHG laboratory provides state-of-the-art clinical cytogenetic, molecular and prenatal services for screening, diagnosis and monitoring. The clinical and molecular cytogenetics laboratory performs chromosome analysis on a variety of specimens including blood, bone marrow and various tissues including skin biopsies and tumor samples. The molecular diagnostic testing laboratory performs DNA-based testing such as next generation sequencing for many disorders including cystic fibrosis, hereditary hemochromatosis, uniparental disomy and hearing loss. In addition, the lab provides engraftment monitoring for patients who have undergone bone marrow transplantation. The prenatal laboratory offers both first trimester screening and 2nd trimester screening for maternal serum samples.

The Center also has very active specialty clinics for cancer genetics, craniofacial disorders and metabolic disorders (including abnormal newborn screens). The cancer genetics program was the first in Ohio. The cystic fibrosis newborn screening program is the only program of its kind in the Cleveland metropolitan area.

The metabolic service participates as one of eight Urea Cycle Disorders (UCD) centers in the United States. As part of the UCD center, they are actively enrolling subjects into the Longitudinal Study of Urea Cycle Disorders. In addition, the Center houses the Mount Sinai Center for Jewish Genetic Diseases, which is the only center of its kind in Northeast Ohio.

Genetics Center Children's Hospital Medical Center

The Genetic Center at Akron Children's Hospital helps individuals and families understand the role of genetics in their lives as it relates to their health. The Center has two geneticists and seven genetic counselors. The center provides counseling in the areas of pediatric genetics, adult genetics, cancer genetics, preconception and prenatal services and a number of specialty clinics.

The Fetal Treatment Center of Northeast Ohio is a comprehensive center providing expertise in all facets of preconception care, prenatal diagnosis, reproductive genetics and prenatal treatment for the mother carrying a fetus with a potential or confirmed genetic condition or

birth defect. Established in 2002, it is based at the Genetic Center at Akron Children's Hospital, with additional offices at both Akron City Hospital and Akron General.

Genetics Division MetroHealth Medical Center

The Genetics Division, under the direction of Dr. Rocio Moran, provides outpatient and inpatient consultation services for adult, prenatal and pediatric patients at MetroHealth Medical Center and at several outreach locations: the Cleveland Clinic, Fairview Hospital, the Elyria City, Medina County and Richland County Health Departments. The division has four certified genetic counselors.

Specialty areas include cranial facial, hearing loss, neuromuscular, cancer, Huntington disease and fetal alcohol clinics.

In addition to genetic services, the Perinatal Center of Northeast Ohio at MetroHealth provides comprehensive maternal fetal medicine evaluations for high risk pregnancies which include Level II ultrasounds, amniocentesis, and chorionic villus sampling. The staff includes a board certified clinical obstetric geneticist and several board certified and board eligible Maternal Fetal Medicine specialists.

Genomic Medicine Institute & Center for Personalized Genetic Healthcare at CCF

In 2005, Dr. Charis Eng came to the Cleveland Clinic and launched the Genomic Medicine Institute (GMI). GMI serves as the expert base for investigation and practice of genomic medicine by being a single platform for research, clinical care and outreach/education ultimately directed at genomic-based personalized genetic healthcare. The clinical branch of the GMI is the Center for Personalized Genetic Healthcare (CPGH), which is staffed by five geneticists and twelve genetic counselors. There are also board certified genetic counselors providing services in the Department of Ophthalmology at the Cole Eye Institute and the Molecular laboratory.

The CPGH Program provides care in all areas of medical genetics including cancer genetics, general genetics and prenatal genetics. Cancer genetic research is a major focus.

ETC. ETC. ETC.

University Academic Calendar & Holidays

Graduate students in the Department of Genetics & Genome Sciences are officially registered for the entire year and as such are expected to dedicate full time to course work, clinical training and research. Graduate students in the professional schools are subject to the University Graduate School Calendar (not the Undergraduate Calendar), which specifies the holidays they may observe each year. Thus, graduate students in the Genetic Counseling Training Program are expected to be present throughout the entire semester, regardless of whether or not classes, etc, are in session. Official holidays include Labor Day, 2 days at Thanksgiving, 2 weeks for Winter break (Christmas & New Year's), Martin Luther King Day, 1 week spring break in March and July 4th. Vacation times will be planned and discussed with the appropriate clinical faculty or supervising genetic counselors, etc. Final approval must be given by Dr. Matthews.

Attendance

Students are expected to attend all required conferences, classes and clinical assignments. Attendance is required whether or not the student is actively involved in a rotation, even when the rotation is off campus. If the student is ill or must miss a conference, class or clinical assignment, the student must contact the appropriate supervising genetic counselor, professor or Dr. Matthews to notify them that they are ill. During clinical rotations, if a student misses more than 6 days during the rotation, the student will be expected to repeat that rotation in order to receive a passing grade. If the student misses a significant portion of required attendance at clinical conferences or classes, the student may be asked to extend their program to make up deficiencies.

Graduate Student Stipends

The Genetic Counseling Training Program is supported by departmental funds. For the class of 2018-2020, each student will receive a stipend of \$5,000.00 per year for a total of \$10,000.00. Students will receive a monthly stipend check on the last day of each month starting on September 30th during the first year (a 10 month period) and continuing through May of Year 02 which begins July 1 (an 11 month period). In addition to the stipend, the

Department also covers the Technology fee of \$426 per year (which is subtracted from the tuition bill each semester), the \$495 registration fee for the on-line embryology course, expenses associated with research projects and \$1000.00 to attend the NSGC meeting in fall of 2nd year.

Financial Aid

Each student is responsible for obtaining his or her own financial aid. The Office of University Financial Aid should be able to assist you. The telephone number is (216) 368-4530. Financial arrangements should be made by the time the student registers for each semester. Tuition for the 2018-19 academic year is \$1,882.00 per semester hour. Fall and spring semester tuition bills are sent directly to the student. Summer tuition must be paid “up front” at the time of registration (the University does not mail out tuition bills – they collect at the time you register for classes – which is 3 credit hours in summer).

Other expenses include the CWRU Medical Plan fee which is automatically billed at the beginning of both fall and spring semesters (spring semester covers summer). The cost is \$1,087 per semester. Students who have alternate medical insurance may waive the CWRU Medical Plan fee each semester by completing a waiver form, which is available at the University Health Service (368-2450). There is an Activity fee of \$18 per semester. Finally, there is a fee for membership to One to One Health Fitness Club on campus – fall = \$119 and spring = \$148 (includes summer). You are automatically enrolled in One to One and are billed accordingly unless you opt-out of the program.

Students may work part time as long as it does not interfere with program requirements including didactic coursework and class times, clinical rotation responsibilities and thesis work. Students may contact the Office of Student Employment which assists students seeking part-time employment on and off campus during the academic year and summer term.

Student Office

The genetic counseling students have assigned office space in the Department of Genetics & Genome Sciences on the 6th floor of the Biomedical Research Building. There is an open cubical area (the “Cube”) where five computers are available. The computers are connected to CWRUnet, which allows students to access the Internet as well as email. Each student at CWRU receives free access to email services through Case gmail. You will receive an ID number and directions for accessing the Internet from home after you receive your official acceptance by the School of Graduate Studies. Moreover, the campus is wireless, so students should be able to access the Internet from anywhere on campus if their laptops have wireless capability.

Reference texts as well as copies of two journals are kept in either the Cube or in room 632. Most of the texts are Dr. Matthews’ personal copies, but they are there for your benefit. They **MUST** be left available in the office and **must NOT** be removed.

The telephone is available for local use ONLY. Please do not give out the Department of Genetics & Genome Sciences phone number for personnel messages unless it is for an emergency.

Mailboxes

Students will each have their own mailbox in the cubical area in which Dr. Matthews and faculty will be able to leave materials and messages for each student. In addition, students have an assigned mailbox on the 6th floor BRB (west administrative area). Please check this daily for messages, or other related program activities. Announcements and activities in the Department are usually posted by the elevators and on bulletin boards on both the 6th and 7th floors.

Libraries – Case and Student Office

Students have access to all of the libraries on the Case campus. The majority of journals and texts that will most likely be useful to genetic counseling students can be found in either the Health Sciences Library or Allen Medical Library. Additionally many journal subscriptions are available to Case students on line. You are free to use Dr. Matthews' personnel subscription copies (the Journal of Genetic Counseling issues from 1/2004-12/2005 are on-line only as are any issues after 2015). Dr. Matthews' Genetics in Medicine Journal are also in the student office.

Student Office Space at Rotation Sites

Office space (cubicle area or other arrangement) has been made available to students when they are involved in clinical rotations at the various institutions. Each genetics center will provide students with access to patient records and materials including computer access to on-line databases as appropriate. In order to remain HIPAA compliant, **absolutely NO PATIENT RECORDS ARE TO BE REMOVED FROM ANY GENETICS CENTER – NOR MAY ANY PATIENT DATA BE COPIED AND TAKEN OUT OF THE FACILITY.** Office space at the various institutions is not large. Please do NOT use hallways or secretaries' office areas as gathering or meeting places. Students should **NEVER** telephone patients or do telephoning of patient related matters from any area other than those that have been designated by your supervisors. NO personal calls should be made or received at your rotation site unless there is an emergency.

Library

Students may use the Center for Human Genetics Library at any time. Books, journals and reprints may NOT be removed, but copies may be made at the Center. Other facilities will let you know what reference materials you have access to during your rotations.

Confidentiality Agreements and HIPAA Training

Students must sign Confidentiality Agreements with the various institutions prior to participating in any clinical activities including observations and clinic conferences. This is to preserve patient confidentiality. Due to regulations under HIPAA (Health Insurance Portability and Accountability Act) – guidelines regarding maintaining patient confidentiality have been instituted. In this regard, students may **NOT** copy and maintain any patient records including the pedigree. All pre-case and post-case write-ups must have patient names, etc blacked out.

Clinical Rotations at the Center for Human Genetics, Akron, Metro and GMI

Students will be oriented to each of these institutions by the supervising genetic counselors at the time of their rotations. Institutional services, expectations, roles and responsibilities will be addressed in detail at that time.

Dress

Appropriate attire and demeanor is expected when seeing patients or when otherwise engaging in professional activities at all clinical rotation sites. Students should wear their CWRU/UHC nametag at all times when involved in any patient situation. Check with the clinic you are assigned to regarding dress codes. Some facilities are stricter than others. In general, blouse and skirt or coat and tie, dress or pantsuit is appropriate attire when seeing families in the clinic area. NOTE: Blue jeans, shorts, t-shirts or tank tops, very short skirts or tops that are low cut or do not cover the abdomen, heavy boots or shoes, sneakers, etc., are not appropriate clothing for the clinical areas. Body piercing and tattoos cannot be visible to patients. Additionally, if you are seeing patients on consults and will be in the patient areas, you should be dressed as if you were seeing patients. Chewing gum, eating or drinking when seeing patients is unprofessional and should never be done. Dress in the department is casual and you may wear jeans and other casual clothing. However, some items should never be worn such as very short shorts, revealing clothes (see-through blouses, tube tops, etc) or dress that is provocative in nature.

Textbooks

We have tried to keep highly recommended texts to a minimum. I would, however, highly suggest that you purchase or have available the following texts (have put approximate prices from Amazon.com for a new copy here but double check and you certainly may find them cheaper) – all of these texts are used in the courses you'll be taking.

HIGHLY RECOMMEND:

1. Wendy Uhlmann , Jane Schuette and Beverly Yashar. A Guide to Genetic Counseling. 2nd ed. John Wiley & Sons, New York, 2009. \$92

2. Patricia McCarthy-Veach, Bonnie LeRoy, and Dianne Bartels Facilitating the Genetic Counseling Process: A Practice Manual. 2nd ed. Spring, New York, 2018. \$130

OR

3. Bonnie LeRoy, Patricia McCarthy-Veach, and Dianne Bartels. Genetic Counseling Practice: advanced concepts and skills. Process: A Practice Manual. Wiley-Blackwell, New York, 2010. \$92

4. Kenneth Jones, editor. Smith's Recognizable Patterns of Human Malformations. 7th ed. W.B. Saunders Company, Philadelphia, 2013. \$82

5. Nussbaum RL,, McInnes RR and Willard HF. Thompson & Thompson Genetics in Medicine 8th edition, W.B. Saunders, 2015. \$52

Other medical genetics texts:

1. Jorde LB, Carey JC and Bamshad MJ. Medical Genetics. 4th ed. Mosby Elsevier, Philadelphia, 2010.

2. Korf BR and Irons MB. Human Genetics and Genomics, 4th ed. Wiley-Blackwell, 2013.

6. Mathiesen A & Roy K, editors. Foundations of Perinatal Genetic Counseling. Oxford University Press, 2018 \$130

7. MacFarlane IM, McCarthy Veach P, LeRoy BS. Genetic Counseling Research: A Practical Guide. Oxford University Press, 2014. \$44

8. Katherine Schneider. Counseling about Cancer: Strategies for Genetic Counseling. 3rd ed. Wiley-Liss, 2011 \$70

The following are also excellent references (all available in student office as well):

1. Gardner RJ, Sutherland GR and Shaffer L. Chromosome Abnormalities and Genetic Counseling. 4th ed. Oxford University Press, 2011.

2. Strachan T, Goodship J, Chinnery P. Genetics and Genomics in Medicine. Garland Science, 2014.

3. William Reardon. The Bedside Dysmorphologist. Oxford University Press, New York, 2007.

4. Greenwood Genetic Center. Genetic Counseling Aids. 6th ed. Order directly from Greenwood Center Genetics. (2013

5. Medical dictionary – any good medical dictionary is fine. Example: Stedman's Medical Dictionary, 28th ed. Williams & Wilkins, 2005.
6. Creswell, JW. Research Design: Qualitative, Quantitative, and Mixed Methods Approaches. 3rd ed. Sage Publications, Inc. 2008.
7. J Fernandes, JM Saudubray and G van den Berghe, editors. Inborn Metabolic Diseases. 4th ed, Springer, New York, 2004
9. Bennett, Robin. The Practical Guide to the Genetic Family History. 2nd ed. Wiley-Blackwell, 2010.
10. Cassidy, Suzanne and Allanson, Judith. Management of Genetic Syndromes. 3rd ed. Wiley-Liss, 2010
11. Love, Susan Dr. Susan Love's Breast Book. 5th ed. Merloyd Lawrence Books, 2010. (Good for cancer course)
12. Gersen, SL and Keagle MB. Principles of Clinical Cytogenetics. 3rd ed. Springer Press, 2013.
13. Young, Ian D. Introduction to Risk Calculation in Genetic Counseling. 3rd ed, Oxford University Press, 2006

All of the above texts will be available to you at the office. You will have assigned readings from Uhlmann and McCarthy-Veach/ LeRoy for the genetic counseling courses during first and second semesters, and in spring semester we will use *Genetic Counseling Research*, by MacFarlane et al. The visual aids flip chart book is very helpful for role plays in these courses as well. Nussbaum et al., *Genetics in Medicine* is the medical genetics text most people use here - it is used in a number of courses – GENE 524, 525, and 526.

There are copies of most of the textbooks in the student office. Books needed for courses outside of Genetics will be assigned by the professor for those courses (SASS 477).

Academic Integrity

The importance of academic integrity cannot be over-emphasized. Throughout the course of their professional careers, genetic counselors are expected to maintain academic integrity. The School for Graduate Studies has prepared a detailed document about Case's academic integrity policy. It is the responsibility of each incoming student to read this document, available at this URL: <http://case.edu/gradstudies/current/policies.html>.

University policy states, in part, "All forms of academic dishonesty including cheating, plagiarism, misrepresentation, and obstruction are violations of academic integrity

standards.” Anything you write, whether it is for a course, clinical rotation or thesis document, must be entirely in your own words. Students who copy the words of others are engaging in plagiarism, which is a form of academic dishonesty which can lead to loss of credit or dismissal from the program. Whether intentionally or unintentionally, making extensive use of sources without acknowledging them (including the internet) are all interpreted as acts of plagiarism. Quotations, paraphrases and borrowed information must be properly referenced.

Advising

The student’s major advisor for the Program will be Dr. Matthews, the Program Director. Dr. Matthews is available to assist students with all aspects of the Program as well as personal issues if the student so desires. Dr. Becky Darrah, Associate Director, and Michelle Merrill, Clinical Training Director, are also available as well as all of the genetic counselors who are very willing to assist students.

During clinical rotations, the supervising genetic counselor of that rotation should be the student’s first choice for a resource person. However, a student may also wish to discuss counseling styles, strategies, etc., with Michelle, Becky or other counselors to get a broader perspective. If a counselor feels that information brought to their attention by the student should be shared with the Program Director, the counselor will inform the student of such.

Other

Please address faculty formally as Dr. unless they instruct you that you may do otherwise. In the clinical setting when seeing patients, **ALWAYS** address the faculty member as Dr. Also, be sure to ask the counselors how they would like to be addressed in a professional setting – many counselors do not use a nickname when seeing patients.

Background Checks

Students are required to have criminal background check as they enter the program. Case Protective Services will do this for a fee of \$65 (cash only). This fee covers both the electronic National Webcheck (FBI) and the electronic Ohio Webcheck (BCI) fingerprinting. Results are sent directly to the student as well as to the program director. A positive response on the background check will not automatically preclude admission, however, such findings will be reviewed by the Genetics Department Graduate Program committee who will make a recommendation regarding acceptance into the genetic counseling program.

CWRU PD currently does this by appointment only, on Tuesday mornings or Thursday afternoons (dates/times subject to change) at the main campus police department, 1689 E. 115th

Street. Contact the department at 216-368-5993 or email Sargent Daniel J. Schemmel at djs49@case.edu to schedule an appointment.

Please note that results of any of the criminal background checks may be shared with any of the affiliated hospitals at their request. Students may also need to undergo additional background checks according to policies of affiliated hospitals as well.

TB Testing/Immunizations

TB testing/Immunization Records: Students are required to have an annual TB (Tuberculin) test as well as to submit documentation of current immunization records. TB screening is available at University Health Service, 2145 Adelbert Road, on any weekday but Thursday, and is available at no cost. It does not require an appointment. For hours and other information, call 216-368-2450 or go to: <https://students.case.edu/wellness/info/newstudents/>

All students are required to log in to myhealthconnect.case.edu and to fill out the Health History, Immunization History and to acknowledge the privacy policy, whether or not they plan on using University Health Service for their medical needs.

In addition to filling out the online forms, students in the Case School of Medicine – the Genetic Counseling Program follows the School of Medicine requirements - are required to submit supporting documentation for their Immunization History so the information can be validated to satisfy clinical requirements of your program.

Supporting documentation should be directly uploaded using the 'Add immunization record...' button located near the bottom of the online Immunization form. If you are not able to directly upload the documents, we are able to accept the records by postal mail or FAX.

Graduation time

Believe it or not, there will come a day when you will graduate and become our colleagues. The School for Graduate Studies (<http://gradstudies.case.edu/>) has information about important dates and deadlines for submitting graduation information. Also, when the time comes – there are a few things that you will need to do when you leave CWRU.

Exit Interview & Forwarding Information: You will need to provide us with your contact information following graduation. You will have an exit interview with Drs. Matthews and Darrah to review the program, key elements that were helpful, what could be changed, any other suggestions.

Keys and ID Badges: UH ID badge & key must be returned to the **Center for Human Genetics** – Cindy Medves, administrative assistant at the CHG. Metro, CC and Akron will inform you about when you need to turn in your IDs following your rotations.

CAMPUS RESOURCES

The Case campus has a number of resources available to graduate students. Information about resources can be found at the Case website: <http://www.cwru.edu>. In particular, graduate students have access to:

Student Health Insurance

Information about the CWRU student health insurance plans can be found at the website below. All students must have health insurance unless they have health insurance through their family, in which case, they may request a waiver of health care.

https://www.aetnastudenthealth.com/stu_conn/student_connection.aspx?groupID=474889

University Health and Counseling Services), is a division of Student Affairs. Health Services is staffed by several professionals including physicians, nurse practitioners, psychologists, psychiatrists, social workers, and registered nurses. A number of the physicians are affiliated with University Hospitals of Cleveland and with the CWRU School of Medicine. Call 216-368-2450 for an appointment.

Counseling Services offers help to students who experience a variety of difficult personal and interpersonal challenges. Graduate school can be very demanding and adjusting to these challenges is not always easy. The UCS office is staffed with psychologists, psychiatrists, social workers, counselors, and doctoral-level counseling trainees. We recommend that students feel free to utilize these services at any time. Call 216-368-5872 for an appointment. UCS also has walk-in hours and emergency assistance. Please refer to the Counseling Services website for additional information <https://students.case.edu/departments/wellness/>

Case Western Reserve University Police Department:

Non-emergency phone number = **216-368-3300**; Emergency-only number = **216-368-3333**

THE UNIVERSITY, UNIVERSITY CIRCLE and CLEVELAND

Case Western Reserve University (CWRU) is a private nondenominational institution. It was established in 1967 by the joining of Western Reserve University (founded in 1826) and its neighboring institution, Case Institute of Technology (founded in 1880). CWRU is located four miles east of downtown Cleveland in University Circle, one of the largest cultural and educational centers in the nation. Over thirty educational, scientific, medical, cultural, social service and religious institutions are located here. The Cleveland Museum of Art, the Museum of Natural History, the Museum of Modern Art, the Historical Museum, the Botanical Gardens, The Cleveland Institute of Music, the Cleveland Institute of Art, and Severance Hall, home of the world famous Cleveland Orchestra, are located adjacent to the University campus within the 500 acre University Circle community. The University also maintains an active program of theater, films and music at nominal cost to students. Athletic

facilities at the University are excellent and there are active intramural programs in various sports.

Cleveland is a cosmopolitan community of 2 million people richly endowed with a wide range of cultural and recreational opportunities, including an extensive park system. Cleveland is home of professional sports teams in baseball, football, basketball, hockey and soccer. Lake Erie and the camping, sailing, and skiing areas of Ohio, western Pennsylvania and western New York are readily accessible.

HOUSING

Most graduate students live off campus in one of the pleasant residential neighborhoods within walking or biking distance of the University. There is a variety of very reasonably priced housing available in these areas. Information about off-campus housing can be obtained from: Off Campus Housing at (216) 368-3780 or the CWRU housing website <http://housing.cwru.edu>.

SOURCES OF ADDITIONAL INFORMATION

Graduate Student Handbook: contains a description of the General Academic Rules and Policies governing Graduate Students as set forth by the University and Graduate School.

<http://www.cwru.edu>

Case Student Handbook: University 401: contains lots of information about life as a graduate student – understanding academic resources; living off campus – tips from graduate students about where to live, etc; being involved in campus life; healthcare options for graduate students, finances, etc.

<http://studentaffairs.case.edu/handbook/university401/>

The Department of Genetics & Genome Sciences: <http://genetics.cwru.edu>

MASTER OF SCIENCE IN GENETIC COUNSELING & MASTER OF ARTS IN BIOETHICS Dual Degree Program

Dual Degree Program Directors: Anne Matthews, PhD & Aaron Goldenberg, PhD

If you are interested, the Departments of Genetics & Genome Sciences and Bioethics offer a dual degree program between the Masters in Genetic Counseling and the Masters in Bioethics Programs. It dual degree program provides a comprehensive curriculum integrating foundational principles of genetics and ethics. The goal of the program is to train Genetic Counselors who wish to able to apply additional Bioethics expertise into their

clinical practice and/or research.

Advances in next generation sequencing technologies, such as whole exome and whole genome sequencing and multiplex testing, have the potential to spur better integration of genetics and genomics into patient care. However, appropriate utilization of these technologies will require the capacity to manage, interpret, and communicate very large amounts of personal genetic information. The integration of such genomic technology into clinical and research settings raises a number of ethical issues related to privacy of genomic data, the impact of genomic information on families, and utility of genomic information. Additionally, there are a number of important questions regarding equity and access to these new technologies among underserved or uninsured families. This raises questions about the potential negative impact that differential access to these technologies may have on health disparities. Addressing these issues requires comprehensive education and counseling for patients and families going through various forms of genetic screening. Genetic Counselors will need to not only interpret the genetic/genomic findings themselves, but to contextualize those findings within the broader social and ethical impact of these technologies.

We are very fortunate at Case to have prominent Masters Programs in both Genetic Counseling and Bioethics. The collaborative nature between the two programs is well established. While the Genetic Counseling Program provides some ethics training, the dual degree program allows students to pursue a broader exploration into bioethics scholarship, development of methodological empirical ethics skills, and deeply explore topics of genetics and health systems, genomics research, and public health genomics. The dual degree program allows graduates to engage in both contemplative analysis and application of knowledge in the counseling of patients, for example, deciding whether to pursue genomic screening with a trained eye for the personal and ethical implications of the results. The dual degree program should allow graduates to be more prepared to participate in the ongoing national dialogue about the ethical, legal, and social implications of advances in genomic technology as well as research within their home institutions and with other counselors nationwide regarding issues of new genomic testing technology, concerns about genetic services, and issues related to genetic discrimination, privacy, and the return of genetic and genomic results. All of these topic areas raise unique ethical, legal, and social implications. Thus, the dual bioethics-genetic counseling degree should fuel careers in every aspect of genetics, genomics and health, clinical genetics, and health policy.

Currently, we have had two students graduate from the dual degree; one student entering her 3rd year and one student entering her 2nd year.

If you are interested in hearing more about this program, please let Drs. Matthews and Goldenberg know. We would be happy to discuss it with you (and our graduates and students are happy to discuss this with you as well).

**Master of Science in Genetic Counseling & Master of Arts
in Bioethics Dual Degree Curriculum**

Total Credit Hours = 62

	FALL			SPRING			
	Course #	Name	Credit Hrs	Course #	Name	Credit Hrs	
YEAR 1	GENE 524	AMG: Cyto/Molecular Genetics	2	GENE 529	Psychosocial Genetic Counseling	3	
	GENE 526	AMG: Quant/Genomics	2	GENE 525	AMG: Clinical Genetics	2	
	GENE 528	Principles Genetic Counseling	3	GENE 531	Clinical Cancer Genetics	2	
	SASS 477	Practice Foundation Methods & Skills	3	GENE 601	Research – Seminar	2	
			Total Credit Hours = 10				Total Credit Hours = 9
YEAR 2	GENE 532	Clinical Practicum	4	GENE 532	Clinical Practicum	4	
	GENE 527	AMG: Metabolism	2	BETH 412	Ethical Issues Genetics / Genomics	3	
	2BETH 401	Foundations in Bioethics I	6	BETH 402	Foundations in Bioethics II	6	
			Total Credit Hours = 12				Total Credit Hours = 13
YEAR 3	GENE 601	Research	3				
	BETH 405	Clinical Ethics Rotation I & II	3				
	BETH	Elective	3				
	BETH	Elective	3				
			Total Credit Hours = 12				

TEACHING FACULTY

The following is a list of some of the faculty from the Department of Genetics & Genome Sciences, the Center for Human Genetics at University Hospitals Case Medical Center, MetroHealth Medical Center, Akron Children's Hospital and the Genomic Medicine Institute at the Cleveland Clinic who will have the majority of involvement with students in the Genetic Counseling Training Program. Other faculty in the Department may also be involved, particularly if a student's research interests are compatible with the specific faculty's research interests.

PROGRAM LEADERSHIP

Anne Matthews, R.N., Ph.D., LGC, FACMG is **Professor of Genetics & Genome Sciences and Director of Genetic Counseling Training Program**. Dr. Matthews, who was director of the Graduate Program in Genetic Counseling at the University of Colorado Health Sciences Center, Denver, Colorado for 8 years, was specifically recruited to develop, administer and teach in the Program. Dr. Matthews received her diploma in nursing from the Massachusetts General Hospital School of Nursing in 1968 and her baccalaureate degree in 1971 from McGill University. In 1973, she received a master's degree and completed her doctorate in genetics and nursing in 1984 from the University of Colorado Health Sciences Center (UCHSC). Dr. Matthews has had extensive experience in genetic counseling, first as Coordinator of the Regional Genetic Counseling Clinic for Colorado and Wyoming and later as a nurse geneticist with Genetic Services and the Maternal-Fetal Surgery and Medicine Program at UCHSC. She was an Assistant Professor on the faculties of the Schools of Medicine and Nursing at UCHSC. In 1996, she joined the Department of Genetics and Genome Sciences at Case Western Reserve University. Dr. Matthews is board certified by the American Board of Medical Genetics and the American Board of Genetic Counseling. She is a past President of the Association of Genetic Counseling Program Directors. She is also an advisory board member for the Genetic Counseling Program at Stanford University. She is a member of the National Society of Genetic Counselors, and a founding fellow of the American College of Medical Genetics. She is a past editor of the Journal in Genetic Counseling and past president of the International Society of Nurses in Genetics. Her areas of clinical interest and research include curriculum development and graduate education in genetic counseling as well as issues arising from the numerous and complex ethical, social legal and educational issues faced by genetic counselors.

Rebecca Darrah, MA, MS, PhD, LGC is the **Associate Director of the Genetic Counseling Program**. She is an Assistant Professor in the Francis Payne Bolton School of Nursing and in the Department of Genetics & Genome Sciences. Dr. Darrah received her master's degree in biomedical ethics from Case Western Reserve University in 1998, her master's degree in genetic counseling from Case Western Reserve University in 2000, and PhD in genetics in 2010. Dr. Darrah, who is board certified by the American Board of Genetic Counseling, coordinates the clinical rotations for the Genetic Counseling Program and works closely with students, the Program and clinical supervisors at the Program's affiliated institutions. Dr. Darrah teaches in a number of

courses in the Program and is a chair or member of a number of student research committees. Dr. Darrah's research is focused on modifier genes involved in cystic fibrosis and pulmonary disease.

Michelle Merrill, MS, LCGC who is a board certified and licensed genetic counselor, is the **Director of Clinical Training for the Genetic Counseling Training Program** and a clinical instructor in the Department of Genetic & Genome Sciences. Michelle is also a senior genetic counseling supervisor in the Center for Human Genetics at University Hospitals Cleveland Medical Center. She joined UH in January 2012 and brings with her over 15 years of clinical experience counseling patients and their families at risk for hereditary cancer. Michelle earned her master's degree in genetic counseling in 2002 from Case Western Reserve University. She worked at MetroHealth Medical Center until 2012 and founded their Hereditary Cancer Clinic. At MetroHealth, Michelle also directed the clinical rotation experience for genetic counseling students, residents, and fellows during their time seeing patients in Clinical Genetics. She was a member of the Breast Cancer Leadership Committee and the Palliative Care team. In addition, she participated in clinical research involving the utilization of cancer genetic testing services among patients diagnosed with breast cancer. In 2012, Michelle came to University Hospitals where she has continued counseling patients and families at risk for hereditary cancer, and supervising clinical rotation experiences in the Cancer Genetics Clinic for genetic counseling students, residents and fellows. Michelle has participated in the initiative to bring Telemedicine genetic counseling services for inherited cancer risk assessment at University Hospitals, and has piloted genetic counselor billing.

Michelle became Director of Clinical Training in the Genetic Counseling Training Program in 2018. In addition to her activities as Clinical Training Director, she helped develop and has been the course director for the Clinical Cancer Genetics course; is a member of the Admissions Committee and sits on a number of student research committees and oral examination committees.

Anna Mitchell, MD, PhD - Clinical Supervisor and Faculty
Associate Professor, Department of Genetics & Genome Sciences; Medical Director, Center for Human Genetics, UHCMC

Dr. Mitchell joined the Department of Genetics & Genome Sciences and the Center for Human Genetics in 2005. Dr. Mitchell received her MD degree and her PhD in Human Genetics from the University of Michigan. She completed a residency in Pediatrics and a fellowship in Medical Genetics at the University of Washington. Dr. Mitchell's research interests have been primarily in the area of connective tissue disorders. She is board certified by the American Board of Pediatrics and the American Board of Medical Genetics in Clinical Genetics. Dr. Mitchell became the Medical Director of the Genetic counseling Training Program in 2018. She supervises counseling students in Cancer Genetics, General Genetics and Marfan Clinic. She teaches in *GENE 525 AMG: Clinical*, *GENE 524 AMG: Cytogenetics* and co-directs *GENE 526 AMG: Molecular and Quantitative Genetics* as well as sitting on a number of research committees.

Department of Genetics & Genome Sciences

Anthony Wynshaw-Boris, MD, PhD. Professor and Chairman

Tony Wynshaw-Boris received his MD/PhD degrees from Case Western Reserve University School of Medicine. His PhD was under the direction of Richard Hanson, PhD, where he elucidated the sequences within the PEPCK promoter required for activation by cAMP and glucocorticoids. He did his residency in Pediatrics at Rainbow Babies and Children's Hospital, followed by a medical genetics fellowship at Boston Children's Hospital. While in Boston, he did a postdoctoral fellowship at Harvard Medical School under the direction of Philip Leder, MD, where he studied mouse models of developmental disorders. In 1994, Dr. Wynshaw-Boris set up an independent laboratory at the National Human Genome Research Institute of the NIH, where he initiated a program using mouse models to study human genetic diseases, with a focus on neurogenetic diseases. In 1999, he moved to UCSD School of Medicine, where he became Professor of Pediatrics and Medicine, as well as Chief of the Division of Medical Genetics in the Department of Pediatrics. In 2007, he moved to UCSF School of Medicine, where he was the Charles J. Epstein Professor of Human Genetics and Pediatrics, and the Chief of the Division of Medical Genetics in the Department of Pediatrics. In June 2013, he returned to Cleveland to become the Chair of the Department of Genetics and Genome Sciences.

Department of Bioethics

Aaron Goldenberg, PhD, MPH is an Associate Professor in the Department of Bioethics and Genetics & Genome Sciences at Case Western Reserve University School of Medicine and **Co-Director of the Genetic Counseling & Bioethics dual degree program**. He is also the Director of Research for the Bioethics Department as well as the Associate Director of the Center for Genetic Research Ethics and Law, a NIH Center of Excellence in Ethical, Legal, and Social Implications Research for the National Human Genome Research Institute. He earned his PhD in Bioethics at Case Western Reserve University. Since joining the faculty at Case Western Reserve University, Dr. Goldenberg's work has focused on the ethical, legal, and social implications of genetics and genomics in clinical and public health settings. His research program has been grounded by a number of major project areas, including: 1) ethical implications of expanding newborn screening programs; 2) storage and use of perinatal and pediatric biological specimens for future research; 3) implications of genetics and gene-environment interactions for racial/ethnic minorities and other communities experiencing health disparities. Dr. Goldenberg is currently the Co-PI of a project funded by the Health Resources and Services Administration (HRSA) to explore the ethical and programmatic challenges of integrating genomic technology into Newborn Screening Programs. He is also the Principal Investigator on a project funded by the NIH National Human Genome Research Institute to examine parental attitudes regarding the research use of biospecimens collected from newborns. He is also leading a project to assess how

genomic advances may impact medically-underserved communities, and how clinicians and public health agencies could better assess biological and social determinants to account for gene-environment interactions. In addition to these scholarly initiatives, Dr. Goldenberg Director for Ethics, Policy and Practice for the National Newborn Screening Clearinghouse, also known as Baby's First Test. He is a member of the Ethics and Legal Workgroup for the Newborn Screening Translational Research Network and the Legal and Legislative Workgroup for the American Public Health Laboratory Association. He is a member of the Pediatric Task Team for the Global Alliance for Genomics and Health.

See Dept website for information about other faculty members in the department.

Department of Genetics & Genome Sciences and Center for Human Genetics (CHG) University Hospitals Case Medical Center (UHCMC)

**Sarah Authmuth, MS, CGC - Clinical Supervisor and Faculty
Clinical Instructor, Department of Genetics & Genome Sciences; CHG, UHCMC**

Sarah is a licensed board certified genetic counselor in the Center for Human Genetics. She works as a laboratory genetic counselor, primarily doing maternal serum screening. She also works as a research coordinator within the CHG on several studies involving patients with pyruvate dehydrogenase complex deficiency and other mitochondrial disorders. Sarah graduated from the University of Cincinnati's Genetic Counselor Training Program in the spring of 2013. Prior to her position at UHCMC, Sarah worked as a prenatal genetic counselor at ProMedica Toledo Hospital. Sarah was very involved in the perinatal bereavement/palliative care teams and the CARE support group. Sarah helps to coordinate the lab rotation and supervises students during this rotation.

**Jirair Bedoyan, MD, PhD – Clinical Supervisor and Faculty
Clinical Assistant Professor, Department of Pediatrics; CHG, UHCMC**

Dr. Bedoyan joined the Center for Human Genetics in 2012. He is board certified by the American Board of Medical Genetics in clinical genetics. Dr. Bedoyan's research interests include advanced Genomic Technologies, Autism Spectrum Disorders, Biochemical Genetics, Clinical Genetics, Human Genomic disorders, Inborn Errors of Metabolism, and Molecular Genetics of Neurodevelopmental disorders.

**Lauren Bokovitz, MS, LCGC – Clinical Supervisor and Faculty
Clinical Instructor, Department of Genetics & Genome Sciences; CHG, UHCMC**

Lauren is a licensed certified genetic counselor who joined the CHG in August 2017. Lauren received both her undergraduate degree and master's degree in genetic counseling from Case Western Reserve University. Lauren was a cancer genetic counselor at West

Clinic in Memphis TN before joining the CHG. Her area of expertise is in cancer genetics.

Leslie Cohen, MS, PhD, CGC - Clinical Supervisor and Faculty

Clinical Instructor, Department of Genetics & Genome Sciences; CHG, UHCMC

Leslie Cohen, a licensed certified genetic counselor, has been an invaluable addition to the Program. Ms. Cohen received her master's degree in genetic counseling from Northwestern University in 1993 and her PhD from Cleveland State University in Urban Education. Prior to coming to the Center for Human Genetics in 2003, her previous work included genetic counseling at Christ Hospital and Medical Center in Oak Lawn Illinois as well as initiating genetic counseling services in the Chicago Department of Public Health Clinic at the University of Illinois. She also provided clinical supervision to genetic counseling students from Northwestern University. Ms. Cohen is board certified by the American Board of Genetic Counseling and has served on the ABGC Board of Directors. She has been an active member of the National Society of Genetic Counselors and was presented with the 2002 NSGC Region IV Leadership. Ms. Cohen chairs the NSGC subcommittee on Billing and Reimbursement and co-chaired the Ohio licensure initiative. Ms. Cohen is a senior genetic associate in the Center for Human Genetics. Her major efforts for the Program include clinical supervision in prenatal diagnosis, teaching in *GENE 525, AMG: Clinical Genetics, GENE 528, Principles of Genetic Counseling, GENE 529, Psychosocial Issues in Genetic Counseling and the Research Seminar*. Ms Cohen sits on thesis committees, on oral comprehensive exam committees and has sat on the Program's admissions committee. Ms. Cohen is a member of the Program's Advisory Board.

Jane Corteville, MD – Clinical Supervisor and Faculty

Director, MacDonald Imaging Center, UHCMC; Assistant Professor, Department of Reproductive Biology, UHCMC

Dr. Corteville received her MD degree from Washington University and completed her residency and fellowship in Maternal Fetal Medicine from Barnes-Jewish Hospital in St. Louis, MO. She also completed a fellowship in medical genetics at St Louis Children's Hospital in St Louis. Dr. Corteville is board certified in Obstetrics and Gynecology as well as Medical Genetics (ABMG). Dr. Corteville's special interests are in the diagnosis and treatment of fetal malformations, obstetric ultrasound and prenatal genetics. She supervises students in the prenatal clinic and lectures in *GENE 528 Principles of Genetic Counseling*.

Kimberly Wallis, MS, CGC – Clinical Supervisor and Faculty

Clinical Instructor, Department of Genetics & Genome Sciences; CHG, UHCMC

Kim Dessoify is a licensed board certified genetic counselor in the Center for Human Genetics. She sees patients primarily in the general and metabolic clinics. She also works as a research coordinator within the CHG on several studies involving patients with genetic conditions, including a longitudinal study of urea cycle disorders and a clinical trial for treatment of hyperammonemia in patients with urea cycle disorders. Kim graduated from the Genetic Counselor Training Program at the University of Wisconsin-Madison in May 2013. Prior to entering graduate school, she spent a summer at the

National Institutes of Health working with genetic counselors on a research project involving families with hereditary breast and ovarian cancer, and she volunteered at Appalachian Behavioral Healthcare during her undergraduate years at Ohio University. Kim coordinates the General Genetics clinical rotation and supervises students during this rotation.

Mitchell Drumm, PhD. - Faculty

Professor of Pediatrics & Genetics & Genome Sciences and Vice Chair for Research of Pediatrics

Dr. Drumm received his B.S. in 1983 from the Ohio State University and his Ph.D. from the University of Michigan in 1990, where he worked with Francis Collins, M.D., Ph.D., on identification of the gene causing cystic fibrosis. He was recently honored with one of the Cystic Fibrosis (CF) Foundation's highest distinctions – the Paul di Sant'Agneses Distinguished Scientific Achievement Award. He joined the faculty at CWRU in 1992. He heads an extensive research program in cystic fibrosis. Dr. Drumm lectures in *GENE 526 Advanced Medical Genetics: Molecular/Quantitative Genetics* has provided his expertise by sitting on several theses committees.

Sarah Hodges, MS, CGC – Clinical Supervisor and Faculty

Clinical Instructor, Department of Genetics & Genome Sciences; CHG, UHCMC

Sarah Hodges is a licensed board certified genetic counselor and senior genetic counselor in the Center for Human Genetics primarily with the Hereditary Cancer Genetics Clinic and Marfan Clinic. Ms. Hodges graduated from Case Western Reserve University with her master's degree in genetic counseling in 2003. Prior to undertaking her graduate studies, she was a research assistant for the "Stress and Immunity Breast Cancer Project" in Columbus Ohio conducting psychological assessments with breast cancer patients. She was also a research assistant in the Department of Genetics & Genome Sciences at CWRU for the "Clinical Genetics in Primary Practice" project. In addition to clinical supervision of students, Ms. Hodges does role playing and lecturing in *GENE 529, Psychosocial Issues in Genetic Counseling* as well as teaching *GENE 531 Clinical Cancer Genetics*.

Joanna Horn, MS, CGC - Clinical Supervisor and Faculty

Clinical Instructor, Department of Genetics & Genome Sciences; CHG, UHCMC

Joanna Horn is a licensed board certified genetic counselor in the Center for Human Genetics. She sees patients in the general, metabolic, and cancer clinics. She also works part-time as a research coordinator within the CHG on a study involving individuals with Prader Willi syndrome. Joanna graduated from the Genetic Counseling Training Program at Case Western in 2002. Before coming to UH in 2014, she worked as a genetic counselor in an academic cancer center, a researcher in a lab, and as a genetic counselor/prenatal services coordinator in an academic medical center. Joanna is a clinical supervisor for the general/metabolic and cancer rotations.

Dr. Laura Konczal, MD - Clinical Supervisor and Faculty

Instructor, Department of Genetics & Genome Sciences; CHG, UHCMC

Dr. Konczal is a board certified pediatrician and ABMG clinical geneticist. Dr. Konczal earned her M.D. degree from Boonshoft School of Medicine Wright State University in Dayton, Ohio. After completing residency and fellowship at Nationwide Children's Hospital/ The Ohio State University in Columbus, Ohio, she joined the Center for Human Genetics as a faculty member in Clinical Genetics and completed a concurrent fellowship in Medical Biochemical Genetics in 2009. Her clinical/research focus is on metabolic disorders and craniofacial syndromes.

Noam Lazebnik, MD Clinical Supervisor and Faculty

Associate Professor, Department of Genetics & Genome Sciences; Center for Human Genetics, UHCMC

Dr. Lazebnik is an associate professor in the Department of Obstetrics and Gynecology at CWRU. Dr. Lazebnik did his medical training and residency at Sackler School of Medicine in Tel Aviv, Israel. He completed fellowships in maternal fetal medicine at MetroHealth Medical Center and genetics at the University of Pittsburgh. He is board certified in clinical genetics by the American Board of Medical Genetics. Dr. Lazebnik supervises students in the prenatal diagnosis clinic and has sat on thesis committees.

Aditi Parikh, MD - Clinical Supervisor and Faculty

Instructor, Department of Genetics & Genome Sciences; CHG, UHCMC

Dr. Parikh joined the Department of Genetics & Genome Sciences and the Center for Human Genetics 2007. Dr. Parikh received her MD degree from Case Western Reserve University. She completed a residency in Pediatrics at Mercy Hospital of Pittsburgh and a fellowship in Medical Genetics at University Hospitals Case Medical Center. She is board certified by the American Board of Pediatrics and the American Board of Medical Genetics in Clinical Genetics. She supervises counseling students in General Genetics and Prenatal Genetics as well as sitting on thesis committees.

Larisa Rippel, MS, CGC – Clinical Supervisor and Faculty

Clinical Instructor, Department of Genetics & Genome Sciences; CHG, UHCMC

Larisa Rippel is a licensed board certified genetic counselor, who graduated from the University of North Carolina at Greensboro Genetic Counseling Training Program. Her clinical interests include prenatal genetic counseling as well as expanding the role of the genetic counselor in Hematology Clinics. She has also actively been involved in organizing the State of Ohio Annual Genetic Counselors Meeting since 2007. Ms. Rippel provides clinical supervision of students during both their prenatal and general genetics rotations. She also lectures for *GENE 525 Clinical Genetics*, sits on the Admissions Committee and is involved in research committees.

Christine Shuss, MS CGC – Clinical Supervisor and Faculty

Clinical Instructor, Department of Genetics & Genome Sciences; CHG, UHCMC

Christine Shuss, a licensed board certified genetic counselor, joined the CHG in fall 2017. Christine received her undergraduate degree from Wittenberg University and her

MS in Genetic Counseling from CWRU. Christine provided genetic counseling services at Nationwide Children's Hospital in Columbus for five years before joining the faculty at CHG.

Faculty at the Genetics Center at MetroHealth Medical Center:

Rocio Moran, MD– Clinical Supervisor

Dr. Moran is the Medical Director of the Division of Genetics in the Department of Pediatrics at MetroHealth Medical Center. Dr. Moran received her MD degree from Case Western Reserve University School of Medicine and did her fellowship in Pediatrics and Medical Genetics at University Hospitals Case Medical Center. Dr. Moran is a clinical geneticist interested in the identification, treatment and natural history of connective tissue disease, cardiovascular genetics and general genetics, specifically in patients with mental retardation, developmental delay and dysmorphism. Dr. Moran is boarded in Pediatrics and Medical Genetics. She provides clinical supervision during general genetics rotations.

Elizabeth Hogan, MS, CGC – Clinical Supervisor

Ms. Hogan provides genetic counseling for cancer genetics clinic, prenatal genetics clinical and general genetics. She received her undergraduate degree in biology from the University of Arizona and her master's degree in Genetic Counseling from Case Western Reserve University. Ms. Hogan supervises students in cancer genetics and prenatal genetics. She lectures in *GENE 531 Clinical Cancer Genetics*.

Monica Nardini, MS, CGC – Clinical Supervisor

Ms. Nardini is a licensed genetic counselor at Metrohealth Medical Center and supervises students in prenatal and general genetics. She received her BS in Biology from John Carroll University in 2010, a MA in Bioethics from Case Western Reserve University in 2011, and a MS in genetic counseling from Case Western Reserve University in 2013. Prior to joining Metro, Monica provided genetic counseling services in general genetics (pediatrics and adult) and cancer genetics at the Cleveland Clinic.

Jacqueline Scott, MS, CGC – Clinical Supervisor

Mrs. Scott provides genetic counseling at MetroHealth Medical Center in the prenatal genetics and general genetics clinics. She received her undergraduate degree in biology from the University of Dayton and her master's degree in Genetic Counseling from the University of Cincinnati. Ms. Scott supervises students in prenatal genetics and general genetics. She also sits on oral comprehensive examination committees.

Amy Pizzino, MS, CGC – Clinical Supervisor

Ms. Pizzino, who did her undergraduate degree at the Ohio State University and her MS in Genetic Counseling at Case Western Reserve University, is a licensed certified genetic counselor at Genetic Services, MetroHealth Medical Center in Cleveland OH. Prior to joining MetroHealth in fall 2017, Ms. Pizzino was the genetic counselor for the White Matter Disease Program at Children's National Health System. She also worked at

Kennedy Krieger Institute as a genetic counselor and study coordinator in the endocrinology department. Amy also was a research assistant at NIH providing data analysis, DNA extraction, and management of sample storage in the lab as well as assisting with the validation of the Surgeon General's tool, My Family Health Portrait.

Faculty at the Division of Medical Genetics at Akron Children's Medical Center:

Katie Krepkovich, MS, CCG – Clinical Supervisor

Ms. Krdpkovich is a licensed genetic counselor who provides genetic counseling and coordination of patient care in the Maternal Fetal Medicine program at Akron Children's Hospital.

Connie Motter, MS, CGC– Clinical Supervisor

Ms. Motter received her graduate degree in Genetic Counseling from the University of Cincinnati in 1987. Ms. Motter became board certified in genetic counseling in September 1990. Since 1987, she has been working as a genetic counselor at Akron Children's Hospital. Ms. Motter does mostly prenatal counseling, but also works in the cystic fibrosis and myelodysplasia clinics. Besides counseling services, she is involved in community education and serves on two folic acid committees; one at the Ohio Department of Health and one for the National Society of Genetic Counselors. Ms. Motter is a clinical supervisor for the Program.

Marcie Parker, MS, CGC - Clinical Supervisor

Amanda Saler Archbold, MS, CGC– Clinical Supervisor

Ms. Archbold is a genetic counselor at Akron Children's Hospital. Ms. Archbold graduated with her master's degree in genetic counseling from the University of Michigan in 2001 and is board certified by the American Board of Genetic Counseling. Ms. Archbold has been an active member of the NSGC's Region IV. She provides clinical supervision to students.

Jennifer Stein, MS, CGC– Clinical Supervisor

Ms. Stein is a genetic counselor at Akron Children's Hospital who received her master's degree in genetic counseling from Sarah Lawrence College. Ms Stein was a genetic counselor at the Cleveland Clinic before coming to join the counseling staff at ACMC. She supervises students in all areas during their rotations.

Catherine Ward-Melver, MD– Clinical Supervisor

Dr. Ward-Melver is a board certified pediatrician and clinical geneticist (ABMG) who received her medical school training at the University of Texas Medical Branch in Galveston, TX. She did her residency in pediatrics at the Medical College of Virginia before completing a fellowship in clinical genetics at the University of Texas Health Science Center, Houston, TX. Dr. Ward-Melver provides clinical supervision of students during their Akron rotation.

Susan Woods, MS. CGC– Clinical Supervisor

Ms. Woods is a genetic counselor at Akron Children's Hospital in Akron Ohio. Ms. Woods received her master's degree in medical genetics from the University of Wisconsin in Madison in 1997. She was certified by the American Board of Medical Genetics in 1990 and is a charter member of the American Board of Genetic Counseling. Since joining the Division of Medical Genetics at Akron Children's in 1987, Ms. Woods has been involved in prenatal, pediatric and adult genetic services. She has facilitated bringing genetic services to those with or at-risk for HD to northeastern Ohio. She is also involved in a number of specialty clinics including outreach, CF and skeletal dysplasias. Ms. Woods is a clinical supervisor in Akron and serves on the Advisory Board to the Program.

Joleen Viront, MS, CGC– Clinical Supervisor

Ms. Viront received her master's degree in Human Genetics from University of Michigan in 1990. Ms. Viront has been a genetic counselor at Akron Children's Hospital in Akron Ohio for ten years. Prior to that she started a genetic counseling program at the Toledo Hospital and worked at University Hospitals Case Medical Center. Ms. Viront wears a number of different hats; however her primary interest is prenatal genetics. She also works with several specialty clinics, primarily CF and craniofacial. She is a clinical supervisor for the Program.

Faculty at the Center for Personalized Genetic Healthcare, Genomic Medicine Institute at the Cleveland Clinic:

Charis Eng, MD, PhD, FACP – Clinical Supervisor and Faculty Professor & Vice Chair, Department of Genetics & Genome Sciences; Director, Genomic Medicine Institute, CC

Dr. Eng is the Sondra J and Stephen R Hardis Chair of Cancer Genomic Medicine and Chair and Director of the Genomic Medicine Institute at the Cleveland Clinic. She is the founding Director of the Center for Personalized Genetic Healthcare and founding director of the cancer genomic medicine clinical fellowship training program. She is also Professor of Molecular Medicine at the Lerner College of Medicine. She is also the ACS Clinical Research Professor. Dr. Eng received both her MD and PhD degrees from the University of Chicago. Dr. Eng specialized in internal medicine at Beth Israel Hospital, Boston and trained in medical oncology at Harvard's Dana-Farber Cancer Institute. She was formally trained in clinical cancer genetics at the University of Cambridge, UK, and in laboratory-based human cancer genetics at the University of Cambridge. She is boarded by the American Board of Internal Medicine in internal medicine and medical oncology. Prior to coming to the Cleveland Clinic, Dr. Eng was Klotz Professor, director of the Clinical Cancer Genetics program and the director of the Division of Human Genetics in the Department of Internal Medicine at The Ohio State University. Dr. Eng's clinical and research interests include cancer genomic medicine, clinical cancer genetics, cancer genetic risk assessment and management and personalized healthcare.

Diane Stanley Clements, MS, CGC – Clinical Supervisor

Ms. Clements is a genetic counselor at the Cleveland Clinic Center for Personalized Genetic Healthcare. She received her BA in Psychology from Miami University in Ohio in 1983 and her MS in genetic counseling from the University of Pittsburgh in 1986. Her areas of interest are prenatal genetics, screening and diagnosis, pediatric genetics, community and K-12 education. Ms. Clements is certified by the American Board of Genetic Counseling and the American Board of Medical Genetics. Ms. Clements provides clinical supervision in general genetics.

Brandie Heald Leach, MS, CGC– Clinical Supervisor

Ms. Heald is a genetic counselor at the Cleveland Clinic Center for Personalized Genetic Healthcare. She has a BA from Case Western Reserve University and her MS in genetic counseling from the University of Cincinnati. Ms. Leach is certified by the American Board of Genetic Counseling. Brandie’s specialty areas include cancer genetics and hereditary colorectal cancer syndromes. Her research interests include familial Barrett’s esophageal and esophageal adenocarcinoma and hamartomatous polyposis syndromes. Ms. Leach supervises students during their cancer rotations and will be involved in teaching in the Cancer Genetics Seminar.

Jessica Marquar, MS, CGC– Clinical Supervisor

Ms. Moline is a genetic counselor at the Cleveland Clinic Center for Personalized Genetic Healthcare. She received her BS in Biology from the University of Iowa in 2004 and her MS in Human Genetics from the University of Michigan in 2008. She began working at the Cleveland Clinic in June of 2008. She received certification by the American Board of Genetic Counseling in 2009. Her areas of interest include cancer genetics, endocrine neoplasia syndromes, and gynecologic cancers. She coordinates the SDH Study for Hereditary Paraganglioma under P.I. Charis Eng, MD, PhD. Ms. Moline supervises students in the cancer genetics clinical rotation at the Cleveland Clinic and is a member of the Advisory Board.

Ryan Noss, MS, CGC – Clinical Supervisor

Mr. Noss is a genetic counselor at the Cleveland Clinic Center for Personalized Genetic Healthcare. He received his BS in Microbiology as well as a minor in Psychology from The Ohio State University in 2006. In 2010, Ryan obtained his master’s degree in genetic counseling from the University of North Carolina at Greensboro. His areas of interest include pediatrics, adult, and cancer genetics. He staffs the Cleveland Clinic’s Multidisciplinary Myelomeningiocele Clinic as well as helps facilitate the incorporation of whole exome sequencing into clinical practice.

Brittany Psensky, MS, CGC – Clinical Supervisor

Ms. Psensky is a genetic counselor in the Center for Personalized Genetic Healthcare at the Cleveland Clinic. Brittany received her BS in Biology and Chemistry from Lock Haven University in 2009 and MS in Genetic Counseling from Case Western Reserve University in 2012. She specializes in cardiovascular genetics, with an interest in cardiomyopathies and connective tissue disorders.

Christina Rigelsky, MS, CGC– Clinical Supervisor

Ms. Rigelsky is a genetic counselor in the Cleveland Clinic Center for Personalized Genetic Healthcare. Following a BS from the University of Toledo, she received her master's degree in genetic counseling from the University of North Carolina at Greensboro. She is certified by the American Board of Genetic Counseling. Ms. Rigelsky's clinical interests include pediatric and adult genetics, specializing in cardiovascular genetics, Marfan syndrome, Loeys Dietz syndrome, Ehlers Danlos syndrome, cardiomyopathies and hereditary arrhythmias. She is also interested in community and professional education. Ms. Rigelsky supervises students during their general genetics rotations.

Allison Schreiber, MS, CGC– Clinical Supervisor

Ms. Schreiber is a genetic counselor in the Cleveland Clinic Center for Personalized Genetic Healthcare. After receiving a BA from Wittenburg University she received her MS degree in genetic counseling at Virginia Commonwealth University. She is certified by the American Board of Genetic Counseling. Areas of clinical interest include pediatric genetics, adult genetics, neurofibromatosis, and hearing loss. Ms. Schreiber supervises students during their general genetics rotations.

Amy Shealy, MS, CGC– Clinical Supervisor

Ms. Shealy is a genetic counselor in the Cleveland Clinic Center for Personalized Genetic Healthcare. Amy received her BS degree from John Carroll University and her master's degree in genetic counseling from the University of South Carolina. She is certified by the American Board of Genetic Counseling. Amy is interested in pediatric genetics, preconception genetic counseling and Tuberous Sclerosis Complex. Other interests include community and professional education. Ms. Shealy coordinates and supervises the general genetics rotation.

Marissa Smith Coleridge, MS, CGC– Clinical Supervisor

Ms. Coleridge is a genetic counselor at the Cleveland Clinic Center for Personalized Genetic Healthcare. She received her BS in Biology from Ohio University in 2002, a master's degree in Cell and Molecular Biology from West Virginia University in 2007 and her master's degree in genetic counseling from Case Western Reserve University in 2009. Her areas of interest include prenatal and cancer genetics. She coordinates the Risk Factor Analysis of Hereditary Breast and Ovarian Cancer study under P.I. Charis Eng, MD, PhD.

Vickie Zurcher, MD, FAAP, FACMG– Clinical Supervisor

Dr. Zurcher is a medical geneticist in the Cleveland Clinic Center for Personalized Genetic Healthcare. She received her medical degree from the University of Cincinnati College of Medicine and completed a pediatric residency at Children's Memorial Hospital in Chicago and a clinical genetics fellowship at University Hospitals Case Medical Center. Dr. Zurcher is interested in chromosomal abnormalities, congenital malformations, dysmorphic syndromes, neurofibromatosis and preconceptional and prenatal risk assessment and counseling.

Additional faculty and supervisors at GMI;

Meghan Marino, MS, CGC Ms. Marino is a genetic counselor at the Cleveland Clinic Cole Eye Institute. She received her BS in Biology from Walsh University in 2008 and her master's degree in genetic counseling from Case Western Reserve University in 2011. She specializes in ophthalmic genetics with a focus on hereditary retinal diseases. She coordinates the Molecular Genetics of Eye Diseases study and the ProgSTAR: Natural History of Stargardt Disease study under P.I. Elias Traboulsi, MD. She is also the genetic coordinator for the ophthalmic research department and the national retina donor coordinator for the Foundation Fighting Blindness Rare Eye Donor Program.

Jacquelyn Riley, MS, CGC

Ms. Riley is a genetic counselor at the Cleveland Clinic Pathology and Laboratory Medicine Institute. She received her BS in Biochemistry and her MS in Medical Genetics from University of Wisconsin-Madison. From 2001 to 2008 she worked for Spectrum Health in Grand Rapids and Kalamazoo, Michigan, where she specialized in prenatal genetic counseling and worked in the adult general genetics clinic. She has been in a laboratory genetic counseling position since June 2011 and has developed interests in appropriate genetic test utilization and the variety of important roles that genetic counselors can play in clinical laboratories.

Support Staff

Clarice Young and Elizabeth (Lizzie) Janniello are the Program administrative assistant.

Michelle Yanick is Director of Administration and Finance, Department of Genetics & Genome Sciences.

PROFESSIONAL ORGANIZATIONS

1. **NATIONAL SOCIETY OF GENETIC COUNSELORS:** The National Society of Genetic Counselors (NSGC) was organized in 1979 for the purpose of providing a network of communication between practicing genetic counselors. The Society holds annual education meetings at the national and regional levels (which you are eligible to receive a reduced registration rate as a NSGC student member), publishes a quarterly journal, *The Journal of Genetic Counseling*, and a quarterly newsletter, *Perspectives* (also part of membership). NSGC addresses issues pertinent to genetics and genetic counselors. A job hotline is available to members. There is a one time application fee of \$15. Students receive a reduced membership fee (currently \$100.00). NSGC now offers a *New Member Special Rate* that is valid starting July 1 of the first year of membership through December 31 of the next year, making the initial dues payment valid for up to 18 months, dependent on the join date of new member. For students this is 125.00. *Information and an application can be found at www.nsgc.org*

2. **NSGC CODE OF ETHICS:** The NSGC Code of Ethics was established to affirm the ethical responsibilities of genetic counselors and “provide them with guidance in their relationships with self, clients, colleagues, and society”. Please review the Code of Ethics that follows. During your course of study, you will have numerous occasions to call upon the Code for discussion and guidance.

3. **AMERICAN BOARD OF GENETIC COUNSELING / CERTIFICATION:** The mission of ABGC is to establish the standards of competence for clinical practice and advance the role of Genetic Counselors in healthcare through accreditation of graduate programs in genetic counseling and certification and recertification of genetic counseling professionals.

It is expected that upon completion of the Program, students will be eligible for certification as a genetic counselor. Certification is awarded by the American Board of Genetic Counseling through a written examination given yearly. To be eligible to sit for the ABGC genetic counseling examination, the student must show documentation of graduating from an accredited genetic counseling program and have 50 documented logbook cases.

As students begin their clinical rotations, we will discuss in-depth the guidelines and specific requirements for log book cases.

4. ACCREDITATION COUNCIL FOR GENETIC COUNSELING

The Accreditation Council for Genetic Counseling (ALGC) is the accrediting body for educational training programs granting master's degrees or higher in genetic counseling. ALGC's purpose is to provide leadership by protecting the interest of the students, public and the integrity of the genetic counseling profession through: 1) establishing standards for graduate level genetic counseling education; 2) evaluating educational programs to ensure compliance with those standards; and 3) accrediting genetic counseling training programs that meet the accreditation standards established by the Accreditation Council for Genetic Counseling

5. AMERICAN SOCIETY OF HUMAN GENETICS: The ASHG was organized in 1948 to encourage research in human genetics and to bring into closer association investigators from Canada, Mexico and the United States. The Society publishes the American Journal of Human Genetics and holds an annual educational meeting every fall.

Active membership is open to any resident of Canada, Mexico or the United States who is interested in human genetics research. Annual dues for students are \$60 with the Journal and \$20 without the Journal. Applications may be found in the back of the Journal.

6. AMERICAN COLLEGE OF MEDICAL GENETICS: The ACMG is the professional organization of medical and laboratory geneticists, similar in scope to the NSGC. Genetic counselors are associate members. The ACMG holds its annual education meeting in the spring of each year. The College publishes Genetics in Medicine.

ADDITIONAL MATERIALS

1. CLINICAL MATERIALS
 - a. Logbook and Patient Encounter Instructions and Forms
 - b. Mid-Rotation Evaluation form
 - c. Final Clinical Rotation Evaluation form
2. ALGC PRACTICE-BASED COMPETENCIES for GENETIC COUNSELORS
3. GENETIC COUNSELING SCOPE OF PRACTICE
4. CODE OF ETHICS - NATIONAL SOCIETY OF GENETIC COUNSELORS
5. CWRU & CLEVELAND OVERVIEW – go to <http://case.edu/about/cleveland> or case.edu/campuslife etc for information about Case and Cleveland
6. CALENDARS
7. FUN STUFF ABOUT CLEVELAND AND AREA

GENETIC COUNSELING TRAINING PROGRAM
DEPARTMENT OF GENETICS

LOGBOOK and CASE ENCOUNTER FORMS

Our goal for all clinical experiences and rotations is that students learn the skills and specific concepts necessary to become competent and effective genetic counselors. As outlined previously in your handbook, there are six rotation experiences including a three-week cytogenetic and molecular genetics laboratory experience; a six-week clinical experience at Genetic Services at Akron Children's Medical Center in Akron Ohio and three ten-week clinical rotations in Cleveland held at three institutions: the Center for Human Genetics Case Medical Center, the Genomic Medicine Institute at the Cleveland Clinic, and Genetic Services, MetroHealth Medical Center.

During your clinical rotations (including observations of counseling sessions) you will need to document your patient involvement in order to demonstrate that you have had a breadth and depth of counseling experiences. All cases that you see, whether as an observation or a case that meets criteria to count toward a required logbook of 60 core cases must be maintained in an electronic **Logbook** database (see attached logbook database). These will be reviewed by the Program Director at the end of each rotation.

In addition to logbook entries students, along with their supervisor for the case, will be required to complete a **Patient Encounter form** (PE form) (see attached). The student should print this form and make copies as needed. The student should fill out the top part of the form, then give the form to the supervising genetic counselor of the case for the counselor to use during and / or after the case. If students complete additional roles such as writing the clinic note/family letter, they may check off the "Follow-Up" box. It will be the student's responsibility to see that each Patient Encounter form is signed and dated by the supervisor before leaving the rotation. The mid-rotation and / or final evaluation meeting is a good time to check that all of your supervisors have signed off and dated each patient encounter form. You should make a copy of the form and leave it with the rotation supervisor (s); and you must turn in a copy of each signed form to the Program Director.

To reflect the ABGC practice analysis survey of genetic counselors roles in prenatal, cancer, pediatrics and adult genetics – please provide the **type of counseling case** at the top of the Patient Encounter form (write out) and on the Logbook form (for Logbook – use the letters A- E)

- A. Preconception counseling
- B. Prenatal counseling (age, abnormal US or serum screening, maternal disease, teratogen, etc)
- C. Pediatric genetics (general, disease-specific, dysmorphic evaluation)
- D. Adult genetics (cardiovascular, neurogenetics, individuals affected with genetic conditions, etc)
- E. Cancer genetics (personal hx, family hx, risk assessment, genetic testing, etc)

Note: If multiple family members are evaluated and / or counseled - these sessions may only count as one (1) case.

To be considered a "core case", the clinical interaction must occur face-to-face and active student participation in at least 1 role in each of the 3 categories of Fundamental Counseling Roles (Management, Education, and Counseling) must be documented.

To reflect the **Management/Education/Counseling Roles** listed on both the Logbook and the Patient Encounter form, use the following guideline:

a. **Management Roles:**

- **Case preparation** involves reviewing all relevant information about the client and the indication for genetic counseling prior to the session.
- **Collection/documentation of medical, developmental and/or pregnancy history** implies the eliciting of pertinent medical information including pregnancy, development and medical histories and environmental exposures.
- **Collection/documentation of family history/pedigree** involves the eliciting of information for and construction of a complete pedigree.
- **Risk assessment** involves pedigree analysis and evaluation of medical and laboratory data to determine recurrence/occurrence risks.
- **Evaluation/coordination of genetic testing** includes determining the appropriate genetic test(s), evaluating laboratories, and/or coordinating the testing.
- **Clinical documentation (clinic notes, letters)** implies writing clinic notes or letters about the appointment
- **Other follow-up (calls, referrals)** includes but not limited to conducting further literature review, maintaining contact with the family to address any additional concerns, or identification of other health care professionals or resources for patient care.

b. **Education Roles**

- **Inheritance pattern** involves educating patients about modes of inheritance.
- **Risk counseling** involves educating patients about their personal and/or familial risks
- **Diagnosis/prognosis/natural history** includes conveying genetic, medical, and technical information about the diagnosis, etiology, natural history and prognosis of genetic conditions and/or birth defects.
- **Medical management/prevention/treatment** includes discussing current medical management, prevention, and treatment of genetic conditions and/or birth defects.
- **Genetic and/or prenatal testing options and possible results/benefits/limitations** includes explaining the technical and medical aspects of diagnostic and screening methods and reproductive options, including associated risks, benefits, and limitations.
- **Results disclosure** involves interpreting the results and discussing them with the patient; can include the development of teaching aids and the provision of educational materials
- **Research options /consenting** involves discussion about research opportunities and/or consenting the patient for the study.

c. **Counseling Roles**

- **Establishing rapport/contracting** refers to initiating the genetic counseling session, eliciting client concerns and expectations and establishing the agenda.
- **Psychosocial assessment** includes eliciting and evaluating social and psychological histories and assessing clients' psychosocial needs.
- **Psychosocial support/counseling** involves providing short term, client-centered counseling, psychosocial support, and anticipatory guidance to the family as well as addressing client concerns.
- **Resource identification/referral** includes helping the client identify local, regional and national support groups and resources in the community.
- **Case processing/self-assessment/self-reflection:** involves critical thinking about the session; what was done successfully as well as areas to improve.

**Case Western Reserve University
Genetic Counseling Logbook of Supervised Clinical Experience**

Student Name:

Rotation Focus:

Clinical training site:

Date:

Entry #	Date (mo/yr)	Case #	Patient Type A-E	Management/Education/Counseling Roles																Diagnosis	Clinical Supervisor (Initials)	Core Case					
				Check all roles performed for each case																							
				1. Case Preparation	2. Collect/document med, develop, +/-or pregnancy history	3. Collect/document fam hx/pedigree	4. Risk assessment	5. Evaluation/coordination genetic testing	6. Clinical documentation - notes / letters	7. Other follow-up (calls, referrals)	8. Inheritance pattern	9. Risk counseling	10. Diagnosis/prognosis/natural HX	11. Medical management / prevention/TX	12. Genetic +/-or prenatal testing options , results, benefits, limitations	13. Results disclosure	14. Research options/consenting	15. Establishing rapport/contracting	16. Psychosocial assessment	17. Psychosocial support/counseling	18. Resource identification/referral	19. Case processing/self-assessment					
01																											
02																											
03																											
04																											
05																											
06																											
07																											
08																											
09																											
10																											
11																											
12																											
13																											
14																											

Genetic Counseling Encounter Form

Student _____ **Supervisor** _____ **Clinic** _____

Date _____ **Case #** _____ **Patient Type (A-E)** _____

Diagnosis _____

E = Excellent S = Satisfactory NI = Needs improvement N/A = Not applicable to case
 U = Unsatisfactory; role not attempted in case but should have been

Note: Logbook cases must include one role from each category in order to “count” towards a Core Case

	E	S	NI	N/A	U
MANAGEMENT ROLES					
Case preparation					
Collection/documentation of medical, developmental, and/or pregnancy history					
Collection/documentation of family history/pedigree					
Risk assessment					
Evaluation/coordination of genetic testing					
Clinical documentation (notes, letters)					
Other follow-up (calls, referrals)					
EDUCATION ROLES					
Inheritance pattern					
Risk counseling					
Diagnosis/prognosis/natural history					
Medical management/prevention/treatment					
Genetic and/or prenatal testing options and possible results/benefits/limitations					
Results disclosure					
Research options/consenting					
COUNSELING ROLES					
Establishing rapport/contracting					
Psychosocial assessment					
Psychosocial support/counseling					
Resource identification/referral					
Case processing/self-assessment/self-reflection					

Supervisor’s Overall Comments:

 Supervisor’s Signature

GENETIC COUNSELING TRAINING PROGRAM

POST-CASE SELF ASSESSMENT

(this should be attached to every encounter form for each patient you counseled):

Your Name: _____

Patient ID: _____

Date seen: _____

What do you think went well during this session? Please provide specific examples.

Describe your perception of your interactions with the patient:

Developing rapport:

The patient's understanding of the information you presented:

Your feelings about the patient:

Your feelings about your performance during the session:

Describe any aspects of the session that you think did not go well during the session.

Provide suggestions for improving this aspect of your performance in subsequent sessions.

Comments:

5. Follow-up:

(needs improvement) (appropriate for level of training)

Comments:

6. Attendance/Promptness:

(needs improvement) (appropriate for level of training)

Comments:

7. Initiative:

(needs improvement) (appropriate for level of training)

Comments:

**CASE WESTERN RESERVE UNIVERSITY - DEPARTMENT OF GENETICS
GENETIC COUNSELING TRAINING PROGRAM**

CLINICAL ROTATION EVALUATION

STUDENT NAME: _____
 DATES OF ROTATION: _____
 ROTATION SUPERVISOR: _____

CLINICAL SITE: _____
 ROTATION FOCUS: _____

MANAGEMENT ROLES	Exceeds expectations for level of training	Meets expectations for level of training	Needs Improvement	N/A	Comments
1. Case preparation: reviews all relevant information about the client and the indication for genetic counseling prior to the session.					
2. Collection/documentation of medical, developmental and/or pregnancy history: elicits pertinent medical information including pregnancy, development and medical histories and environmental exposures.					
3. Collection/documentation of family history/pedigree: elicits information for and construction of a complete pedigree.					
4. Risk assessment: analyzes pedigree and evaluates medical and laboratory data to determine recurrence/occurrence risks.					
5. Evaluation/coordination of genetic testing: determines the appropriate genetic test(s), evaluates laboratories, and/or coordinates the testing.					
6. Clinical documentation (clinic notes, letters): writes clinic notes or letters about the appointment					
7. Other follow-up (calls, referrals): conducts further literature review, maintaining contact with the family to address any additional concerns, or identification of other health care professionals or resources for patient care.					

EDUCATION ROLES	Exceeds expectations for level of training	Meets expectations for level of training	Needs Improvement	N/A	Comments
1. Inheritance pattern: educates patients about modes of inheritance.					
2. Risk counseling: educates patients about their personal and/or familial risks					
3. Diagnosis/prognosis/natural history: conveys genetic, medical, and technical information about the diagnosis, etiology, natural history and prognosis of genetic conditions and/or birth defects.					
4. Medical management/prevention/treatment discusses current medical management, prevention, and treatment of genetic conditions and/or birth defects.					
5. Genetic and/or prenatal testing options and possible results/benefits/limitations: explains the technical and medical aspects of diagnostic and screening methods and reproductive options, including associated risks, benefits, and limitations					
6. Results disclosure: interprets the results and discusses them with the patient; can include the development of teaching aids and the provision of educational materials					
7. Research options /consenting: discussion about research opportunities and/or consenting the patient for the study.					

COUNSELING ROLES	Exceeds expectations for level of training	Meets expectations for level of training	Needs Improvement	N/A	Comments
1. Establishing rapport/contracting: initiates the genetic counseling session, elicits client concerns and expectations and establishes the agenda.					
2. Psychosocial assessment: elicits and evaluates social and psychological histories and assesses clients' psychosocial needs.					
3. Psychosocial support/counseling: provides short term, client-centered counseling, psychosocial support, and anticipatory guidance to the family as well as addressing client concerns.					
4. Resource identification/referral: helps the client identify local, regional and national support groups and resources in the community.					
5. Case processing/self-assessment/self-reflection: critically thinks about the session; what was done successfully as well as areas to improve.					

PROFESSIONAL SKILLS	Exceeds expectations for level of training	Meets expectations for level of training	Needs Improvement	N/A	Comments
1. Initiative: Takes initiative					
2. Organization: Is organized; uses time wisely					
3. Task completion: Completes assigned tasks accurately and in timely manner					
4. Dependability					
5. Professional conduct: Maintains a professional manner with patients, supervisors, staff					
6. Responsibility: Assumes responsibility for his/her actions					
7. Functions as a team member					

8. Accepts values, lifestyles & cultures of others; nonjudgemental					
9. Flexibility: Shows flexibility in counseling					
10. Openness to critique: Accepts directions, criticism					
11. Self-reflection: Seeks feedback; integrates critique into practice					

OVERALL PERFORMANCE AND COMMENTS – REVIEW OF GOALS:

Supervisor's Signature: _____
Date: _____

Grade for Rotation: _____

STUDENT COMMENTS:

Student Signature: _____
Date: _____

**CASE WESTERN RESERVE UNIVERSITY - DEPARTMENT OF GENETICS
GENETIC COUNSELING TRAINING PROGRAM**

CLINICAL ROTATION EVALUATION

STUDENT NAME: _____
DATES OF ROTATION: _____
SUPERVISOR: _____

CLINICAL SITE: _____
ROTATION FOCUS: _____

SUMMARY OF CASES

	Observed	Managed
Prenatal		
Cancer		
General		
Inpatient Consults		
Specialty Clinics (list)		

STUDENT COMMENTS:

Student Signature: _____

Date: _____

Rotation Supervisor's Signature: _____

Date: _____

**CASE WESTERN RESERVE UNIVERSITY
DEPARTMENT OF GENETICS & GENOME SCIENCES**

GENETIC COUNSELING TRAINING PROGRAM

CLINICAL ROTATION STATISTICS

STUDENT NAME: _____

DATES: YR 1: October _____ **to May** _____

DATES: YR 2: May _____ **to May** _____

SUMMARY OF CASES	Observed		Managed	TOTAL
	YR 1	YR 2		
Prenatal				
Cancer				
General				
Pediatric cases				
Adult cases				

ACGC

Accreditation Council
for Genetic Counseling

Practice-Based Competencies for Genetic Counselors

© 2014

ACGC

Accreditation Council for Genetic Counseling

PO Box 15632, Lenexa, KS 66285

913-895-4629

www.gceducation.org

Practice-Based Competencies for Genetic Counselors

This document defines and describes the twenty two practice-based competencies that an entry-level provider must demonstrate to successfully practice as a genetic counselor. It provides guidance for the training of genetic counselors and an assessment for maintenance of competency of practicing genetic counselors. The didactic and experiential components of a genetic counseling training curriculum and maintenance of competency for providers must support the development of competencies categorized in the following domains: **(I) Genetics Expertise and Analysis; (II) Interpersonal, Psychosocial and Counseling Skills; (III) Education; and (IV) Professional Development & Practice.** These domains describe the minimal skill set of a genetic counselor, which should be applied across practice settings. Some competencies may be relevant to more than one domain. *Italicized words are defined in the glossary.*

Domain I: Genetics Expertise and Analysis

1. Demonstrate and utilize a depth and breadth of understanding and knowledge of *genetics* and *genomics* core concepts and principles.
2. Integrate knowledge of psychosocial aspects of conditions with a genetic component to promote *client* well-being.
3. Construct relevant, targeted and comprehensive personal and family histories and pedigrees.
4. Identify, assess, facilitate, and integrate genetic testing options in genetic counseling practice.
5. Assess individuals' and their relatives' *probability of conditions with a genetic component* or carrier status based on their pedigree, test result(s), and other pertinent information.
6. Demonstrate the skills necessary to successfully manage a genetic counseling case.
7. Critically assess genetic/genomic, medical and social science literature and information.

Domain II: Interpersonal, Psychosocial and Counseling Skills

8. Establish a mutually agreed upon genetic counseling agenda with the client.
9. Employ active listening and interviewing skills to identify, assess, and empathically respond to stated and emerging concerns.
10. Use a range of genetic counseling skills and models to facilitate informed decision-making and adaptation to genetic risks or conditions.
11. Promote client-centered, informed, non-coercive and value-based decision-making.

12. Understand how to adapt genetic counseling skills for varied service delivery models.

13. Apply genetic counseling skills in a culturally responsive and respectful manner to all clients.

Domain III: Education

14. Effectively educate clients about a wide range of genetics and genomics information based on their needs, their characteristics and the circumstances of the encounter.

15. Write concise and understandable clinical and scientific information for audiences of varying educational backgrounds.

16. Effectively give a presentation on genetics, genomics and genetic counseling issues.

Domain IV: Professional Development & Practice

17. Act in accordance with the ethical, legal and philosophical principles and values of the genetic counseling profession and the policies of one's institution or organization.

18. Demonstrate understanding of the research process.

19. Advocate for individuals, families, *communities* and the genetic counseling profession.

20. Demonstrate a self-reflective, evidenced-based and current approach to genetic counseling practice.

21. Understand the methods, roles and responsibilities of the process of clinical supervision of trainees.

22. Establish and maintain professional *interdisciplinary relationships* in both team and one-on-one settings, and recognize one's role in the larger healthcare system.

Appendix: Samples of Activities and Skills that may assist in Meeting Practice-Based Competencies

These samples may assist in curriculum planning, development, implementation and program and counselor evaluation. They are not intended to be exhaustive nor mandatory, as competencies can be achieved in multiple ways.

Domain I: Genetics Expertise and Analysis

1. Demonstrate and utilize a depth and breadth of understanding and knowledge of *genetics* and *genomics* core concepts and principles.

- a) Demonstrate knowledge of principles of human, medical, and public health genetics and genomics and their related sciences. These include:
 - Mendelian and non-Mendelian inheritance
 - Population and quantitative genetics
 - Human variation and disease susceptibility
 - *Family history* and *pedigree* analysis
 - Normal/abnormal physical & psychological development
 - Human reproduction
 - Prenatal genetics
 - Pediatric genetics
 - Adult genetics
 - Personalized genomic medicine
 - Cytogenetics
 - Biochemical genetics
 - Molecular genetics
 - Embryology/Teratology/Developmental genetics
 - Cancer genetics
 - Cardiovascular genetics
 - Neurogenetics
 - Pharmacogenetics
 - Psychiatric genetics
- b) Apply knowledge of genetic principles and understand how they contribute to etiology, clinical features and disease expression, natural history, differential diagnoses, genetic testing and test report interpretation, pathophysiology, recurrence risk, management and prevention, and *population screening*.

2. Integrate knowledge of psychosocial aspects of conditions with a genetic component to promote *client* well-being.

- a) Demonstrate an understanding of psychosocial, ethical, and legal issues related to genetic counseling encounters.

- b) Describe common emotional and/or behavioral responses that may commonly occur in the genetic counseling context.
- c) Recognize the importance of understanding the lived experiences of people with various genetic/genomic conditions.
- d) Evaluate the potential impact of psychosocial issues on client decision-making and adherence to medical management.

3. Construct relevant, targeted and comprehensive personal and family histories and pedigrees.

- a) Demonstrate proficiency in the use of pedigree symbols, standard notation, and nomenclature.
- b) Utilize interviewing skills to elicit a family history and pursue a relevant path of inquiry.
- c) Use active listening skills to formulate structured questions for the individual case depending on the reason for taking the family history and/or potential diagnoses.
- d) Elicit and assess pertinent information relating to medical, developmental, pregnancy and psychosocial histories.
- e) Extract pertinent information from available medical records.

4. Identify, assess, facilitate, and integrate genetic testing options in genetic counseling practice.

- a) Investigate the availability, analytic validity, clinical validity, and clinical utility of screening, diagnostic and predictive genetic/genomic tests.
- b) Evaluate and assess laboratories and select the most appropriate laboratory and test based on the clinical situation.
- c) Identify and discuss the potential benefits, risks, limitations and costs of genetic testing.

Practice-Based Competencies for Genetic Counselors

- d) Coordinate and facilitate the ordering of appropriate genetic testing for the client.
- e) Interpret the clinical implications of genetic test reports.
- f) Recognize and differentiate specific considerations relevant to genetic versus genomic and clinical versus research testing in terms of the informed consent process, results disclosure, institutional review board (IRB) guidelines, and clinical decision-making.

5. Assess individuals' and their relatives' probability of conditions with a genetic component or carrier status based on their pedigree, test result(s), and other pertinent information.

- a) Assess probability of conditions with a genetic component or carrier status using relevant knowledge and data based on pedigree analysis, inheritance patterns, genetic epidemiology, quantitative genetics principles, and mathematical calculations.
- b) Incorporate the results of screening, diagnostic and predictive genetic/genomic tests to provide accurate risk assessment for clients.
- c) Evaluate familial implications of genetic/genomic test results.
- d) Identify and integrate relevant information about environmental and lifestyle factors into the risk assessment.

6. Demonstrate the skills necessary to successfully manage a genetic counseling case.

- a) Develop and execute a *case management* plan that includes case preparation and follow-up.

- b) Assess and modify the case management plan as needed to incorporate changes in management and surveillance recommendations.
- c) Document and present the genetic counseling encounter information clearly and concisely, orally and in writing, in a manner that is understandable to the audience and in accordance with professional and institutional guidelines and standards.
- d) Identify and introduce research options when indicated and requested in compliance with applicable privacy, human subjects, regional and institutional standards.
- e) Identify, access and present information to clients on local, regional, national and international resources, services and support.

7. Critically assess genetic/genomic, medical and social science literature and information.

- a) Plan and execute a thorough search and review of the literature.
- b) Evaluate and critique scientific papers and identify appropriate conclusions by applying knowledge of relevant *research methodologies* and statistical analyses.
- c) Synthesize information obtained from a literature review to utilize in genetic counseling encounters.
- d) Incorporate medical and scientific literature into evidenced-based practice recognizing that there are limitations and gaps in knowledge and data.

Domain II: Interpersonal, Psychosocial and Counseling Skills

8. Establish a mutually agreed upon genetic counseling agenda with the client.

- a) Describe the genetic counseling process to clients.
- b) Elicit client expectations, perceptions, knowledge, and concerns regarding the genetic counseling encounter and the reason for referral or contact.

- c) Apply client expectations, perceptions, knowledge and concerns towards the development of a mutually agreed upon agenda.
- d) Modify the genetic counseling agenda, as appropriate by continually *contracting* to address emerging concerns.

9. Employ active listening and interviewing skills to identify, assess, and empathically respond to stated and emerging concerns.

- a) Elicit and evaluate client emotions, individual and family experiences, beliefs, behaviors, values, coping mechanisms and adaptive capabilities.
- b) Engage in relationship-building with the client by establishing rapport, employing active listening skills and demonstrating empathy.
- c) Assess and respond to client emotional and behavioral cues, expressed both verbally and non-verbally, including emotions affecting understanding, retention, perception, and decision-making.

10. Use a range of genetic counseling skills and models to facilitate informed decision-making and adaptation to genetic risks or conditions.

- a) Demonstrate knowledge of psychological defenses, family dynamics, family systems theory, coping models, the grief process, and reactions to illness.
- b) Utilize a range of basic counseling skills, such as open-ended questions, reflection, and normalization.
- c) Employ a variety of advanced genetic counseling skills, such as anticipatory guidance and in-depth exploration of client responses to risks and options.
- d) Assess clients' psychosocial needs, and evaluate the need for intervention and referral.
- e) Apply evidence-based models to guide genetic counseling practice, such as short-term *client-centered* counseling, grief counseling and crisis counseling.
- f) Develop an appropriate follow-up plan to address psychosocial concerns that have emerged in the encounter, including referrals for psychological services when indicated.

11. Promote client-centered, informed, non-coercive and value-based decision-making.

- a) Recognize one's own values and biases as they relate to genetic counseling.
- b) Actively facilitate client decision-making that is consistent with the client's values.

- c) Recognize and respond to client-counselor relationship dynamics, such as transference and countertransference, which may affect the genetic counseling interaction.
- d) Describe the continuum of non-directiveness to directiveness, and effectively utilize an appropriate degree of guidance for specific genetic counseling encounters.
- e) Maintain professional boundaries by ensuring directive statements, self-disclosure, and self-involving responses are in the best interest of the client.

12. Understand how to adapt genetic counseling skills for varied service delivery models.

- a) Tailor communication to a range of service delivery models to meet the needs of various audiences.
- b) Compare strengths and limitations of different service delivery models given the genetic counseling indication.
- c) Describe the benefits and limitations of *distance encounters*.
- d) Tailor genetic counseling to a range of service delivery models using relevant verbal and non-verbal forms of communication.
- e) Recognize psychosocial concerns unique to distance genetic counseling encounters.

13. Apply genetic counseling skills in a culturally responsive and respectful manner to all clients.

- a) Describe how aspects of culture including language, ethnicity, life-style, socioeconomic status, disability, sexuality, age and gender affect the genetic counseling encounter.
- b) Assess and respond to client cultural beliefs relevant to the genetic counseling encounter.
- c) Utilize multicultural genetic counseling resources to plan and tailor genetic counseling agendas, and assess and counsel clients.
- d) Identify how the genetic counselor's personal cultural characteristics and biases may impact encounters and use this knowledge to maintain effective client-focused services.

Domain III: Education

14. Effectively educate clients about a wide range of genetics and genomics information based on their needs, their characteristics and the circumstances of the encounter.

- a) Identify factors that affect the learning process such as intellectual ability, emotional state, socioeconomic factors, physical abilities, religious and cultural beliefs, motivation, language and educational background.
- b) Recognize and apply risk communication principles and theory to maximize client understanding.
- c) Communicate relevant genetic and genomic information to help clients understand and adapt to conditions or the risk of conditions and to engage in informed decision-making.
- d) Utilize a range of tools to enhance the learning encounter such as handouts, visual aids, and other educational technologies.
- e) Communicate both orally and in writing using a style and method that is clear and unambiguous.
- f) Present balanced descriptions of lived experiences of people with various conditions.
- g) Explain and address client concerns regarding genetic privacy and related protections.
- h) Employ strategies for successful communication when working with interpreters.

15. Write concise and understandable clinical and scientific information for audiences of varying educational backgrounds.

- a) Develop written educational materials tailored to the intended audience.
- b) Recognize the professional and legal importance of medical documentation and confidentiality.
- c) Assess the challenges faced by clients with low literacy and modify the presentation of information to reduce the literacy burden.

16. Effectively give a presentation on genetics, genomics and genetic counseling issues.

- a) Assess and determine the educational goals and learning objectives based on the needs and characteristics of the audience.
- b) Develop an educational method or approach that best facilitates the educational goals of the presentation and considers the characteristics of the audience.
- c) Present using a delivery style that results in effective communication to the intended audience that is clear and unambiguous.
- d) Assess one's own teaching style and use feedback and other outcome data to refine future educational encounters.

Domain IV: Professional Development & Practice

17. Act in accordance with the ethical, legal and philosophical principles and values of the genetic counseling profession and the policies of one's institution or organization.

- a) Follow the guidance of the National Society of Genetic Counselors Code of Ethics.
- b) Recognize and respond to ethical and moral dilemmas arising in genetic counseling practice and seek outside consultation when needed.
- c) Identify and utilize factors that promote client autonomy.
- d) Ascertain and comply with current professional credentialing requirements, at the institutional, state, regional and national level.

- e) Recognize and acknowledge situations that may result in a real or perceived conflict of interest.

18. Demonstrate understanding of the research process.

- a) Articulate the value of research to enhance the practice of genetic counseling.
- b) Demonstrate an ability to formulate a research question.
- c) Recognize the various roles a genetic counselor can play on a research team and identify opportunities to participate in and/or lead research studies.
- d) Identify available research-related resources.

- e) Apply knowledge of research methodology and *study design* to critically evaluate research outcomes.
- f) Apply knowledge of research methodology and study designs to educate clients about research studies relevant to them/their family.
- g) Describe the importance of human subjects' protection and the role of the Institutional Review Board (IRB) process.

19. Advocate for individuals, families, communities and the genetic counseling profession.

- a) Recognize the potential tension between the values of clients, families, communities and the genetic counseling profession.
- b) Support client and community interests in accessing, or declining, social and health services and clinical research.
- c) Identify genetic professional organizations and describe opportunities for participation and leadership.
- d) Employ strategies that to increase/promote access to genetic counseling services.

20. Demonstrate a self-reflective, evidenced-based and current approach to genetic counseling practice.

- a) Display initiative for lifelong learning.
- b) Recognize one's limitations and capabilities in the context of genetic counseling practice.
- c) Seek feedback and respond appropriately to performance critique.
- d) Demonstrate a scholarly approach to genetic counseling, including using available evidence-based principles in the preparation and execution of a genetic counseling encounter.
- e) Identify appropriate individual and/or group opportunities for ongoing personal supervision and mentorship.
- f) Accept responsibility for one's physical and emotional health as it impacts on professional performance.
- g) Recognize and respect professional boundaries between clients, colleagues, and supervisors.

21. Understand the methods, roles and responsibilities of the process of clinical supervision of trainees.

- a) Engage in active reflection of one's own clinical supervision experiences.
- b) Identify resources to acquire skills to appropriately supervise trainees.
- c) Demonstrate understanding of the dynamics and responsibilities of the supervisor/supervisee relationship.

22. Establish and maintain professional *inter-disciplinary relationships* in both team and one-on-one settings, and recognize one's role in the larger healthcare system.

- a) Distinguish the genetic counseling *scope of practice* in relation to the roles of other health professionals.
- b) Develop positive relationships with professionals across different disciplines.
- c) Demonstrate familiarity with the *health care system* as it relates to genetic counseling practice including relevant privacy regulations, referral and payment systems.
- d) Demonstrate effective interaction with other professionals within the healthcare infrastructure to promote appropriate and equitable delivery of genetic services.
- e) Assist non-genetic healthcare providers in utilizing genetic information to improve patient care in a cost-effective manner.
- f) Promote responsible use of genetic/genomic technologies and information to enhance the health of individuals, communities, and the public.

Glossary

Case management: The planning and coordination of health care services appropriate to achieve a desired medical and/or psychological outcome. In the context of genetic counseling, case management requires the evaluation of a medical condition and/or risk of a medical condition in the client or family, evaluating psychological needs, developing and implementing a plan of care, coordinating medical resources and advocating for the client, communicating healthcare needs to the individual, monitoring an individual's progress and promoting client-centered decision making and cost-effective care.

Client centered: A non-directive form of talk therapy that was developed by Carl Rogers during the 1940's and 1950's. The goal of client-centered counseling is to provide clients with an opportunity to realize how their attitudes, feelings and behavior are being negatively affected and to make an effort to find their true positive potential. The counselor is expected to employ genuineness, empathy, and unconditional positive regard, with the aim of clients finding their own. (This is also known as person-centered or Rogerian therapy.)

Client: Anyone seeking the expertise of a genetic counselor. Clients include anyone seeking the expertise of a genetic counselor such as individuals seeking personal health information, risk assessment, genetic counseling, testing and case management; health care professionals; research subjects; and the public.

Contracting: The two-way communication process between the genetic counselor and the patient/client which aims to clarify both parties' expectations and goals for the session.

Distance Encounters: At present, and even more so in the future, clinical genetic services will be provided to patients/clients by providers who are not physically in the same location as the patient/client. These encounters can be called Distance Encounters, even if the provider and patient are not physically located at great distances from each other. Ways in which this care can be provided include interactive two-way video sessions in real time; asynchronous virtual consultations by store-and-forward digital transmission of patient images, data, and

clinical questions from the patient/client's healthcare provider to the genetic services provider; telephone consultation between genetic provider and patient/client; and perhaps additional forms of interaction between providers and patients/clients unimagined at present.

Family history: The systematic research and narrative of past and current events relating to a specific family that often include medical and social information.

Genetics: The branch of biologic science which investigates and describes the molecular structure and function of genes, how gene function produces effects in the organism (phenotype), how genes are transmitted from parent to offspring, and the distribution of gene variations in populations.

Genetic counseling: The process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. Genetic counselors work in various settings and provide services to diverse clients.

Genomics: The branch of biology which studies the aggregate of genes in an organism. The main difference between genomics and genetics is that genetics generally studies the structure, variation, function, and expression of single genes, whereas genomics studies the large number of genes in an organism and their interrelationship.

Health care system: The organization of people, institutions, and resources to deliver health care services to meet the health needs of target populations. The laws, regulations and policies governing healthcare systems differ depending on the country, state/province, and institution.

Interdisciplinary relationships: Connections and interactions among members of a team of health care staff from different areas of practice.

Pedigree: A diagram of family relationships that uses symbols to represent people and lines to represent relationships. These diagrams make it easier to visualize relationships within families, particularly large extended families.

Population screening: Testing of individuals in an identified, asymptomatic, target population who may be at risk for a particular disease or may be at risk to have a child with a particular disease. Population screening may allow for the provision of information important for decision-making, early diagnosis, and improved treatment or disease prevention.

Probability of conditions with a genetic component: The chance, typically expressed as a fraction or a percentage, for an individual or a specific population to experience a condition that has a genetic component. This terminology is used intentionally rather than “genetic risk” because the concept of “risk” is not synonymous with “probability.” The origin of a probability can come from principles of Mendelian inheritance or from epidemiology. The probability of genetic disease is differentiated from risk of genetic disease in that probability conveys the numerical estimate for an individual patient or a specific population while risk includes additional elements including the burden of disease.

Population Genetics: The study of allele frequency distribution and change under evolutionary processes, and includes concepts such as the Hardy-Weinberg principle and the study of quantitative genetic traits.

Research methodologies: The process to define the activity (how, when, where, etc.) of gathering data.

Scope of practice: Genetic Counselors work as members of a health care team in a medical genetics program or other specialty/subspecialty; including oncology, neurology, cardiology, obstetrics and gynecology, among others. They are uniquely trained to provide information, counseling and support to individuals and families whose members have genetic disorders or who may be at risk for these conditions. The genetic counseling scope of practice is carried out through collaborative

relationships with clinical geneticists and other physicians, as well as other allied healthcare professionals such as nurses, physicians and social workers.

Study design: The formulation of trials and experiments in medical and epidemiological research. Study designs can be qualitative, quantitative, descriptive (e.g., case report, case series, survey), analytic-observational (e.g., cross sectional, case-control, cohort), and/or analytic-experimental (randomized controlled trials).

Accreditation Council for Genetic Counseling

PO Box 15632, Lenexa, KS 66285

913-895-4629

www.gceducation.org

National Society of Genetic Counselors Code of Ethics

The National Society of Genetic Counselors

Received: 19 September 2017 / Accepted: 4 October 2017 / Published online: 27 October 2017
© National Society of Genetic Counselors, Inc. 2017

Abstract This document is the revised Code of Ethics of the National Society of Genetic Counselors (NSGC) that was adopted in April 2017 after majority vote of the full membership of the NSGC. The explication of the revisions is published in this volume of the Journal of Genetic Counseling. This is the fourth revision to the Code of Ethics since its original adoption in 1992.

Keywords Code of ethics · Genetic counseling · National Society of genetic counselors

NSGC Code of Ethics

A Code of Ethics is a document which attempts to clarify and guide the conduct of a professional so that the goals and values of the profession might best be served.

Preamble

Genetic counselors are health professionals with specialized education, training, and experience in medical genetics and counseling. The National Society of Genetic Counselors (NSGC) is the leading voice, authority and advocate for the genetic counseling profession. Through this code of ethics, the NSGC affirms the ethical responsibilities of its members.

✉ The National Society of Genetic Counselors
nsgc@nsgc.org

¹ The NSGC Executive office, 330 North Wabash Avenue, Suite 2000, Chicago, IL 60611, USA

NSGC members are expected to be aware of the ethical implications of their professional actions and work to uphold and adhere to the guidelines and principles set forth in this code.

Introduction

A code of ethics is a document that attempts to clarify and guide the conduct of a professional so that the goals and values of the profession are best served. The NSGC Code of Ethics is based upon the distinct relationships genetic counselors have with 1) themselves, 2) their clients, 3) their colleagues, and 4) society. Each section of this code begins with an explanation of the relevant relationship, along with the key values and characteristics of that relationship. These values are drawn from the ethical principles of autonomy, beneficence, nonmaleficence and justice, and they include the professional principles of fidelity, veracity, integrity, dignity and accountability.

No set of guidelines can provide all the assistance needed in every situation, especially when different values appear to conflict. In certain areas, some ambiguity remains, allowing for the judgement of the genetic counselor(s) involved to determine how best to respond to difficult situations.

Section I: Genetic Counselors Themselves

Genetic counselors value professionalism, competence, integrity, objectivity, veracity, dignity, accountability and self-respect in themselves as well as in each other. Therefore, genetic counselors work to:

1. Seek out and acquire balanced, accurate and relevant information required for a given situation.

2. Continue their education and training to keep abreast of relevant guidelines, regulations, position statements, and standards of genetic counseling practice.
3. Work within their scope of professional practice and recognize the limits of their own knowledge, expertise, and competence.
4. Accurately represent their experience, competence, and credentials, including academic degrees, certification, licensure, and relevant training.
5. Identify and adhere to institutional and professional conflict of interest guidelines and develop mechanisms for avoiding or managing real or perceived conflict of interest when it arises
6. Acknowledge and disclose to relevant parties the circumstances that may interfere with or influence professional judgment or objectivity, or may otherwise result in a real or perceived conflict of interest.
7. Assure that institutional or professional privilege is not used for personal gain.
8. Be responsible for their own physical and emotional health as it impacts their professional judgment and performance, including seeking professional support, as needed.

Section II: Genetic Counselors and their Clients

The counselor-client relationship is based on values of care and respect for the client's autonomy, individuality, welfare, and freedom in clinical and research interactions. Therefore, genetic counselors work to:

1. Provide genetic counseling services to their clients within their scope of practice regardless of personal interests or biases, and refer clients, as needed, to appropriately qualified professionals.
2. Clarify and define their professional role(s) and relationships with clients, disclose any real or perceived conflict of interest, and provide an accurate description of their services.
3. Provide genetic counseling services to their clients regardless of their clients' abilities, age, culture, religion, ethnicity, language, sexual orientation and gender identity.
4. Enable their clients to make informed decisions, free of coercion, by providing or illuminating the necessary facts, and clarifying the alternatives and anticipated consequences.
5. Respect their clients' beliefs, inclinations, circumstances, feelings, family relationships, sexual orientation, religion, gender identity, and cultural traditions.
6. Refer clients to an alternate genetic counselor or other qualified professional when situations arise in which a genetic counselor's personal values, attitudes and beliefs may impede his or her ability to counsel a client.

7. Maintain the privacy and security of their client's confidential information and individually identifiable health information, unless released by the client or disclosure is required by law.
8. Avoid the exploitation of their clients for personal, professional, or institutional advantage, profit or interest.

Section III: Genetic Counselors and their Colleagues

The genetic counselors' professional relationships with other genetic counselors, trainees, employees, employers and other professionals are based on mutual respect, caring, collaboration, fidelity, veracity and support. Therefore, genetic counselors work to:

1. Share their knowledge and provide mentorship and guidance for the professional development of other genetic counselors, employees, trainees and colleagues.
2. Respect and value the knowledge, perspectives, contributions, and areas of competence of colleagues, trainees and other professionals.
3. Encourage ethical behavior of colleagues.
4. Assure that individuals under their supervision undertake responsibilities that are commensurate with their knowledge, experience and training.
5. Maintain appropriate boundaries to avoid exploitation in their relationships with trainees, employees, employers and colleagues.
6. Take responsibility and credit only for work they have actually performed and to which they have contributed
7. Appropriately acknowledge the work and contributions of others.
8. Make employers aware of genetic counselors' ethical obligations as set forth in the NSGC Code of Ethics.

Section IV: Genetic Counselors and Society

The relationships of genetic counselors with society include interest and participation in activities that have the purpose of promoting the well-being of society and access to genetic services and health care. These relationships are based on the principles of veracity, objectivity and integrity. Therefore, genetic counselors, individually or through their professional organizations, work to:

1. Promote policies that aim to prevent genetic discrimination and oppose the use of genetic information as a basis for discrimination.

2. Serve as a source of reliable information and expert opinion on genetic counseling to employers, policymakers, payers, and public officials. When speaking publically on such matters, a genetic counselor should be careful to separate their personal statements and opinions made as private individuals from statements made on behalf of their employers or professional societies.
3. Participate in educating the public about the development and application of technological and scientific advances in genetics and the potential societal impact of these advances.
4. Promote policies that assure ethically responsible research in the context of genetics.
5. Adhere to applicable laws and regulations. However, when such laws are in conflict with the principles of the profession, genetic counselors work toward change that will benefit the public interest.

National Society of Genetic Counselors Code of Ethics: Explication of 2017 Revisions

Leigha Senter¹ · Robin L. Bennett² · Anne C. Madeo³ · Sarah Noblin⁴ · Kelly E. Ormond⁵ · Kami Wolfe Schneider⁶ · Kelli Swan⁷ · Alice Virani⁸ ·
The National Society of Genetic Counselors Code of Ethics Review Task Force
(COERTF)

Received: 7 August 2017 / Accepted: 4 October 2017 / Published online: 27 October 2017
© National Society of Genetic Counselors, Inc. 2017

Abstract The Code of Ethics (COE) of the National Society of Genetic Counselors (NSGC) was adopted in 1992 and was later revised and adopted in 2006. In 2016, the NSGC Code of Ethics Review Task Force (COERTF) was convened to review the COE. The COERTF reviewed ethical codes written by other professional organizations and suggested changes that would better reflect the current and evolving nature of the genetic counseling profession. The COERTF received input from the society's legal counsel, Board of Directors, and members-at-large. A revised COE was proposed to the membership and approved and adopted in April 2017. The revisions and rationale for each are presented.

Keywords Genetic counseling · Ethics · Ethical principles · Genetics

Introduction

The National Society of Genetic Counselors' (NSGC) Code of Ethics (COE) was adopted in 1992 (Benkendorf et al. 1992). In 2004, legal counsel proposed a revision, at which time a COE working group was convened to conduct an in-depth review of ethical codes from other professional organizations to search for themes that were not already represented in the NSGC COE. Based on their review, another set of revisions was proposed, feedback was received from the NSGC membership, legal counsel, and the NSGC Board of Directors. The second revision was approved by majority vote of the membership and adopted in 2006 (Bennett et al. 2006).

Given that ten years had passed since the last revision of the COE and in response to the American Board of Genetic Counseling (ABGC) Exam Eligibility Task Force's request to review and revise or reaffirm the NSGC COE, the NSGC COE Review Task Force (COERTF) was convened in 2016. The ABGC Exam Eligibility Task Force proposed the use of the NSGC COE as the definition of ethical practice in fulfillment of the Institute for Credentialing Excellence criteria for certification. For this reason, and to maintain the relevancy of the COE for the NSGC membership, periodic review is critical. The COERTF reviewed the COE as outlined in the Methods section. Proposed changes then were approved by the NSGC Board of Directors. Both the NSGC membership and the NSGC Conflict of Interest Task Force provided feedback on the proposed changes, which were incorporated into the final document. The final version of the COE was approved by membership vote and adopted in April 2017.

✉ Leigha Senter
leigha.senter@osumc.edu

¹ Department of Internal Medicine, Division of Human Genetics, The Ohio State University, 2012 Kenny Road, Columbus, OH 43221, USA

² Department of Medicine, Division of Medical Genetics, University of Washington, Seattle, WA, USA

³ Genetic Counselor Service, Integrated Oncology and Genetics Division, ARUP Laboratories, Salt Lake City, UT, USA

⁴ Department of Obstetrics, Gynecology and Reproductive Sciences, McGovern Medical School, UTHealth, Houston, TX, USA

⁵ Department of Genetics and Stanford Center for Biomedical Ethics, Stanford University, Stanford, CA, USA

⁶ Section of Hematology, Oncology, and Bone Marrow Transplantation, University of Colorado Anschutz Medical Campus, Children's Hospital Colorado, Aurora, CO, USA

⁷ Myriad Genetics, Inc., Salt Lake City, UT, USA

⁸ Department of Medical Genetics, University of British Columbia, Vancouver, BC, Canada

Here, we explain the process of review and revisions to the current COE.

Methods

Composition of the NSGC Code of Ethics Review Task Force

The COERTF was appointed by the NSGC BOD and chaired by Leigha Senter and included Robin Bennett, a representative from the 2004 COE Work Group; Kelli Swan, past Chair of the NSGC Ethics Advisory Group and recipient of a Master of Arts in Medical Humanities and Bioethics; Sarah Noblin, NSGC Board member and ABGC Exam Eligibility Task Force member; Anne Madeo, ABGC board member; Kelly Ormond and Alice Virani, both of whom have formal ethics training; and NSGC member at large Kami Wolfe Schneider. NSGC executive office staff and attorney also reviewed and provided feedback on proposed revisions. The composition of the COERTF was aligned with prior recommendations (Bennett et al. 2006).

The Process for Review and Revisions

The COERTF used a similar process to the 2004 COE Work Group in reviewing the COE. First, codes of ethics or professional conduct from 9 other health care professional organizations were reviewed (Table 1). All COERTF members reviewed the COE in its entirety, and each section of the COE was assigned to a pair of COERTF members for in depth analysis. The COERTF reviewed the COE with respect to

changes in the genetic counseling profession that have occurred since the last set of revisions was adopted. Careful attention was paid to situations faced by genetic counselors of all specialties and in different practice settings, including those based in industry, and in light of new technologies and modes of communication (e.g. telemedicine and the impact of social media on genetic counseling practice). In general, the COERTF felt that the COE was a strong and concise document that has served the NSGC membership well over many years.

The COERTF proposed changes that were brought to the NSGC membership for feedback from January 4, 2017 until January 25, 2017. Communication occurred via Membership eBlast and was promoted through the NSGC Member News section of the NSGC website (www.nsgc.org). The revised COE was approved by majority vote of the NSGC membership in April 24, 2017 after a 3-week voting period.

Explication of Revisions to the Code of Ethics of the NSGC

The revised NSGC COE is published in this issue of the *Journal of Genetic Counseling*. The following sections explain each 2017 revision to the NSGC COE. The COE is written in *italics* with explanations provided after each section.

Preamble

Genetic counselors are health professionals with specialized education, training, and experience in medical genetics and counseling. The National Society of Genetic Counselors

Table 1 Codes of ethics and/or professional conduct reviewed by COETF

Organization	Title	URL
Australasian Society of Genetic Counsellors	Code of Ethics	https://www.hgsa.org.au/documents/item/22
Genetic Counsellor Registration Board	Code of Conduct	http://www.gcrb.org.uk/media/6374/gcrb-code-of-conduct.pdf
American Counseling Association	Code of Ethics	http://www.counseling.org/docs/ethics/2014-aca-code-of-ethics.pdf?sfvrsn=4
Association of Genetic Nurses and Counsellors	Code of Ethics	http://www.agnc.org.uk/about-us/code-of-ethics/
European Board of Medical Genetics	Code of Professional Practice for Genetic Counsellors in Europe	https://www.eshg.org/fileadmin/GCGN_Downloads/EBMG_CodeofprofessionalpracticeforgeniccounsellorsinEurope.pdf
Canadian Association of Genetic Counsellors	Code of Ethics	https://www.cagc-accg.ca/doc/code%20of%20ethics%20e-070628.pdf
American Psychological Association	Ethical Principles of Psychologists and Code of Conduct	http://www.apa.org/ethics/code/
Coalition of National Health Education Organizations	Code of Ethics for the Health Education Profession	http://cnheo.org/ethics.html
Association of American Educators	Code of Ethics for Educators	https://www.aateachers.org/images/pdfs/aaecodeofethicsforeducators.pdf

(NSGC) is the leading voice, authority and advocate for the genetic counseling profession. Through this code of ethics, the NSGC affirms the ethical responsibilities of its members. NSGC members are expected to be aware of the ethical implications of their professional actions and work to uphold and adhere to the guidelines and principles set forth in this code.

Introduction

A code of ethics is a document that attempts to clarify and guide the conduct of a professional so that the goals and values of the profession are best served. The NSGC Code of Ethics is based upon the distinct relationships genetic counselors have with 1) themselves, 2) their clients, 3) their colleagues, and 4) society. Each section of this code begins with an explanation of the relevant relationship, along with the key values and characteristics of that relationship. These values are drawn from the ethical principles of autonomy, beneficence, nonmaleficence and justice, and they include the professional principles of fidelity, veracity, integrity, dignity and accountability.

No set of guidelines can provide all the assistance needed in every situation, especially when different values appear to conflict. In certain areas, some ambiguity remains, allowing for the judgement of the genetic counselor(s) involved to determine how best to respond to difficult situations.

Revisions to Preamble and Introduction

- Revisions were made to reduce redundancy but contextual meaning was generally not changed.
- The professional ethics principles of fidelity, veracity, integrity, dignity, and accountability were added to the code to better recognize and highlight the importance of professional ethics values, as well as already included traditional bioethical principles, in such a code. These principles are first mentioned in the introduction and included throughout the Code.

Section I: Genetic Counselors Themselves

Genetic counselors value professionalism, competence, integrity, objectivity, veracity, dignity, accountability and self-respect in themselves as well as in each other. Therefore, genetic counselors work to:

1. Seek out and acquire balanced, accurate and relevant information required for a given situation.
2. Continue their education and training to keep abreast of relevant guidelines, regulations, position statements, and standards of genetic counseling practice.
3. Work within their scope of professional practice and recognize the limits of their own knowledge, expertise, and competence.
4. Accurately represent their experience, competence, and credentials, including academic degrees, certification, licensure, and relevant training.
5. Identify and adhere to institutional and professional conflict of interest guidelines and develop mechanisms for avoiding or managing real or perceived conflict of interest when it arises.
6. Acknowledge and disclose to relevant parties the circumstances that may interfere with or influence professional judgment or objectivity, or may otherwise result in a real or perceived conflict of interest.
7. Assure that institutional or professional privilege is not used for personal gain.
8. Be responsible for their own physical and emotional health as it impacts their professional judgment and performance, including seeking professional support, as needed.

Revisions to Section I

The first section of the COE highlights the responsibility that genetic counselors have to themselves. It clearly states what qualities genetic counselors value in themselves and in each other. In the opening statement the values of professionalism, competency, integrity, objectivity, veracity, dignity, accountability, and self-respect are identified. Professionalism and accountability were added to this section to both recognize and highlight the importance of professional ethics, as well as emphasize the importance of accountability, particularly in light of the changes made to this section (described below) in relation to recognizing and managing conflicts of interest.

One new statement was added to Section I (number 7), and the original statements 2 and 3 were combined. Wording changes were made to all statements, as described below:

- Statement I.1 was expanded to include the words “balanced” and “accurate” to add more specificity to what should be considered relevant information.
- Statement I.2 now combines the previous statements 1.2 and 1.3 as both sought to address continued training. The previous version only referenced “standards of practice” and the current version elaborates to include guidelines, regulations and position statements.
- Statement I.3 was revised to include reference to the NSGC Genetic Counselor Scope of Practice, which was developed in 2007 (<http://www.nsgc.org/p/cm/ld/fid=18>).
- Statement I.4 is an amended version of the previous statement 1.5, and now includes certification and licensure as relevant indicators of expertise.

- Statement I.5 is an amended version of the previous statement 1.6. It has been amended to include the addition of a genetic counselors' responsibility to follow their organization(s) and institution(s) conflict of interest guidelines.
- Statement I.6 is an amended version of the previous statement 1.7. It has been amended to recognize that conflicts of interest cannot always be avoided. In situations in which they cannot be avoided, they should be acknowledged and managed appropriately.
- Statement I.7 is a new statement to elaborate upon the concept of conflicts of interest, emphasizing that any such privileges arising from institutional or professional association should not be used for personal gain. This statement was added to highlight the potential overlap between professional and personal roles.
- Statement I.8 was amended to include a responsibility of genetic counselors to seek professional support, where necessary, to address physical or emotional health issues. This addition is in keeping with other COEs from other health professionals.

Section II: Genetic Counselors and Their Clients

The counselor-client relationship is based on values of care and respect for the client's autonomy, individuality, welfare, and freedom in clinical and research interactions. Therefore, genetic counselors work to:

1. Provide genetic counseling services to their clients within their scope of practice regardless of personal interests or biases, and refer clients, as needed, to appropriately qualified professionals.
2. Clarify and define their professional role(s) and relationships with clients, disclose any real or perceived conflict of interest, and provide an accurate description of their services.
3. Provide genetic counseling services to their clients regardless of their clients' abilities, age, culture, religion, ethnicity, language, sexual orientation and gender identity.
4. Enable their clients to make informed decisions, free of coercion, by providing or illuminating the necessary facts, and clarifying the alternatives and anticipated consequences.
5. Respect their clients' beliefs, inclinations, circumstances, feelings, family relationships, sexual orientation, religion, gender identity, and cultural traditions.
6. Refer clients to an alternate genetic counselor or other qualified professional when situations arise in which a genetic counselor's personal values, attitudes and beliefs may impede his or her ability to counsel a client.
7. Maintain the privacy and security of their client's confidential information and individually identifiable health

information, unless released by the client or disclosure is required by law.

8. Avoid the exploitation of their clients for personal, professional, or institutional advantage, profit or interest.

Revisions to Section II

The second section of the NSGC COE describes the relationship that genetic counselors have with their clients. The COERTF debated at-length the appropriateness of including different client-types in this section given the varied nature of these relationships for genetic counselors in current practice. The COERTF concluded that it was important to maintain this section to address genetic counselor interactions with clinical and research clients and thus, this was defined in the introductory sentence as a "counselor-client" relationship with values of care and respect to the client's autonomy, individuality, welfare, and freedom in clinical and research interactions.

One guideline was added (number 3) to this section, and seven guidelines were revised to add clarity to previous statements and minimize ambiguous or lofty statements. Detailed changes are as follows:

- Statement II.1 was revised to clarify that services to clients should be provided within genetic counselors' scope of practice, and to add the expectation of referral to other providers for unmet needs.
- Statement II.2 was revised to include disclosure of real or perceived conflict of interest.
- Statement II.3 was added to specify factors of abilities, age, religion, ethnicity, language, sexual orientation, and gender identity for which the services to clients should be provided without discrimination.
- Statement II.5 was revised to include sexual orientation, religion, and gender identity.
- Statement II.6 was revised to distinguish this statement from statement II.1 and clearly specify the appropriate action when the personal values of the genetic counselor impede his or her ability to counsel a client.
- Statement II.7 was revised to better reflect the laws already in place regarding identifiable health information and its confidentiality.
- Statement II.8 was revised to include avoidance of exploitation for professional and institutional advantage.

Section III: Genetic Counselors and Their Colleagues The genetic counselors' professional relationships with other genetic counselors, trainees, employees, employers and other professionals are based on mutual respect, caring, collaboration, fidelity, veracity and support. Therefore, genetic counselors work to:

1. Share their knowledge and provide mentorship and guidance for the professional development of other genetic counselors, employees, trainees and colleagues.
2. Respect and value the knowledge, perspectives, contributions, and areas of competence of colleagues, trainees and other professionals.
3. Encourage ethical behavior of colleagues.
4. Assure that individuals under their supervision undertake responsibilities that are commensurate with their knowledge, experience and training.
5. Maintain appropriate boundaries to avoid exploitation in their relationships with trainees, employees, employers and colleagues.
6. Take responsibility and credit only for work they have actually performed and to which they have contributed.
7. Appropriately acknowledge the work and contributions of others.
8. Make employers aware of genetic counselors' ethical obligations as set forth in the NSGC Code of Ethics.

Revisions to Section III

This version of the COE maintains the importance of genetic counselors' relationships, and to reflect the broader workplaces and roles of genetic counselors, has added "employers, employees and other professionals" to reflect interactions with colleagues that do not necessarily fall into the healthcare category. The term "students" was changed to "trainees" to reflect the broad range of individuals with whom genetic counselors interact, but who may not be "students" per se. These changes were made in the introduction for this section and in several statements (III-1, III-2, and III-5) described below.

- Statement III.2 was edited to remove "highest quality of service" as it is difficult to define.
- Statements III.6 and III.7 were added because statements of this nature are included in many other professional codes of ethics, and reflect the desire to collaborate in a truthful manner with colleagues and peers, and is especially relevant in an academic or research setting.
- Statement III.8 was added in light of the addition of employers to this section of the COE. This was done in order to clarify the importance of transparency with our employers regarding our professional COE, of which they may not otherwise be aware.

Section IV: Genetic Counselors and Society

The relationships of genetic counselors with society include interest and participation in activities that have the purpose of promoting the well-being of society and access to genetic

services and health care. These relationships are based on the principles of veracity, objectivity and integrity. Therefore, genetic counselors, individually or through their professional organizations, work to:

1. Promote policies that aim to prevent genetic discrimination and oppose the use of genetic information as a basis for discrimination.
2. Serve as a source of reliable information and expert opinion on genetic counseling to employers, policymakers, payers, and public officials. When speaking publicly on such matters, a genetic counselor should be careful to separate their personal statements and opinions made as private individuals from statements made on behalf of their employers or professional societies.
3. Participate in educating the public about the development and application of technological and scientific advances in genetics and the potential societal impact of these advances.
4. Promote policies that assure ethically responsible research in the context of genetics.
5. Adhere to applicable laws and regulations. However, when such laws are in conflict with the principles of the profession, genetic counselors work toward change that will benefit the public interest.

Revisions to Section IV

The relationships of genetic counselors with society include interest and participation in activities that have the purpose of promoting the well-being of society and access to genetic services and health care. This section addresses the ethical responsibilities that genetic counselors have in this regard. The introductory paragraph was revised to add the more specific phrase "access to genetic services" in addition to the broader "access to health care." This paragraph was also revised to reflect the overall addition of principles (veracity, objectivity and integrity) across the revised COE.

In the revisions of Section IV, two statements were removed (IV-1, IV-4) and the list was reorganized. Each of these changes is described below.

- Statement IV.I from the previous version of the COE, which stated "keep abreast of societal developments that may endanger the physical and psychological health of individuals," was removed. After discussion, the COERTF agreed that the scope of this statement was not specific to genetics and society, and that such a broad statement could be outside the scope of practice of a genetic counselor. Similarly, the previous statement IV.4 which stated "participate in activities necessary to bring about socially responsible change," was removed. This

statement was not sufficiently specific to genetics and its essence is captured in the remaining statements encouraging genetic counselors to promote the well-being of society and access to genetic services.

- Statement IV.1 is now a combination of the previous version's IV.2 and IV.3 because they complement each other in protecting an individual's genetic information and discouraging genetic discrimination.
- Statement IV.2 refers to being a reliable source of information and expert in "genetic counseling." Based on review of other health professions' codes of ethics and member feedback, the COERTF considered the phrases "on human genetics" or "on genetics" instead of "on genetic counseling." After much discussion, it was agreed that "on genetic counseling" was most appropriate to maintain genetic counselors' scope of expertise. Employers and payers were added to this statement with the current revisions to reflect the increasing number of situations where a genetic counselor may be called upon to provide expertise. Additionally, the following was added: "When speaking publically on such matters, a genetic counselor should be careful to separate their personal statements and opinions made as private individuals from statements made on behalf of their employers or professional societies." The new COE attempts to reflect the current landscape of media and the many possible outlets available to genetic counselors to express their opinions while expecting that genetic counselors will maintain a professional boundary between personal and professional statements.
- Statement IV.3 reflects revisions made to the previous statement IV.6 to narrow the focus of the statement and make it specific to genetics rather than applicable to "technological and scientific advances" in general.
- Statement IV.4 reflects revisions made to the previous statement IV.7 to narrow the focus of the statement and make it specific to genetics, similar to above.

- Statement IV.5 reflects revisions made to the previous IV. 8. The word "applicable" was added to limit the laws and regulations with which genetic counselors would be expected to be familiar within their professional settings.

Discussion

Future Revisions to the NSGC COE: Recommendations for the Review Process

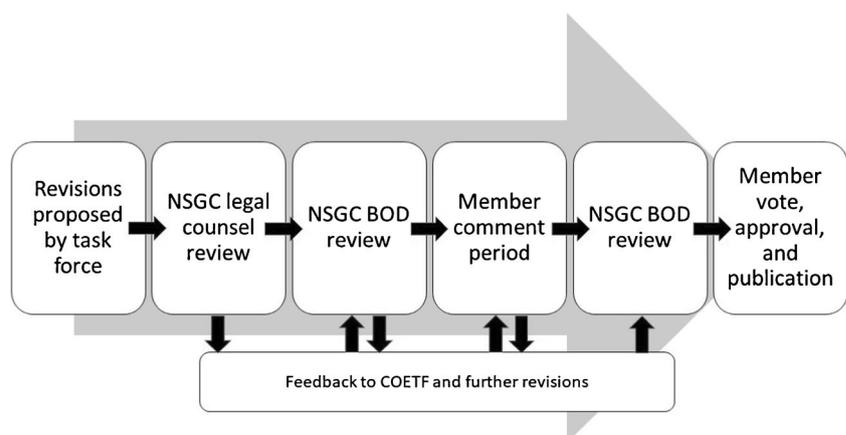
Bennett et al. (2006) made recommendations for the continued review of the NSGC COE. We agree with these recommendations and have reiterated them here. Given the substantial number of revisions made to this COE, review and revision or reaffirmation of the COE should be conducted on an interval shorter than every 10 years. The previous COE work group suggested a 5-year interval between reviews, and we agree with this approach. Special care was taken to make statements specific yet broadly applicable, which should lend to longevity of the relevance of the COE, but documentation of review is essential to maintain the integrity of the COE. We recommend that documentation of review become an NSGC policy.

Composition of Revision Task Force

A task force should be appointed by the NSGC President. We recommend that representation include, but not be limited to:

- one individual from each of the past COE revision groups (if available);
- the current Chair(s) of the NSGC Ethics Subcommittee;
- at least one NSGC member at large, not previously involved in drafting or revising the COE, and not serving on the Ethics Subcommittee;

Fig. 1 Revision approval process



- a member with relevant leadership experience within the ABGC;
- a member with relevant leadership experience within the Association of Genetic Counseling Program Directors
- a member with relevant leadership experience within the Accreditation Council for Genetic Counselors
- a representative from the current NSGC Board of Directors (BOD).

Timeline

COE should undergo review with the possibility of revision at least every 5 years from the date of the previous revision, or sooner if there is a need based on membership request, legal counsel, or substantial changes in genetic counseling practice. Resources should be allocated to the task force so that their work can be completed in a timely fashion (e.g., budget for conference calls, working meetings, executive office staffing, etc.).

Basis for Revision

The task force should consider changes to the COE based on recognition of changes to the field of genetic counseling since the last revision, and based on their review of codes of ethics and professional conduct for other professional organizations with similar interests or goals (e.g., counseling, social work, healthcare education, etc.). All revisions should carefully maintain the original framework and philosophy of the COE, as initially adopted.

Approval Process

All proposed revisions should be sent to the NSGC legal counsel, and to the BOD for review. After their review, comments should be solicited from the membership. After adequate time has been provided for comment and feedback, the revisions should be submitted to the membership for majority vote (Fig. 1).

Summary

The NSGC COE was revised July 2016–April 2017 through the work of the COERTF appointed by the NSGC leadership,

with considerable input from the NSGC general membership. These revisions were adopted after majority vote of the NSGC membership in April 2017. The core principles, structure and conciseness of the original 1992 COE has served the development and expansion of the genetic counseling profession well. Continued revisions to the COE at regular intervals will be necessary as the landscape of genetic counseling continues to shift and expand in exciting and unanticipated directions.

Acknowledgements We would like to acknowledge Judith Benkendorf, a member of the original COE author group, who provided input to the COERTF and actively solicited feedback from the original COE author group.

Funding The work represented in this manuscript was unfunded.

Compliance with Ethical Standards

Conflict of Interest

Leigha Senter has served as paid consultant for AstraZeneca, Clovis Oncology, and MyGeneCounsel.

Robin Bennett has received royalties from John Wiley and Sons, Inc.

Ann C. Madeo declares that she has no conflict of interest.

Sarah Noblin declares that she has no conflict of interest.

Kelly E. Ormond declares that she has no conflict of interest.

Kami Wolfe Schneider declares that she has no conflict of interest.

Kelli Swan is currently an employee of Myriad genetics and owns stock from Myriad genetics.

Alice Virani declares that she has no conflict of interest.

Human Studies and Informed Consent The work submitted in this manuscript did not involve human subjects.

Ethical Approval The work submitted in this manuscript was not subject to institutional approvals.

Animal Studies There were no animal studies involved in this publication.

References

- Benkendorf, J. L., Callanan, N. P., Grobstein, R., et al. (1992). An explication of the national society of genetic counselors (NSGC) code of ethics. *Journal of Genetic Counseling*, 1, 31.
- Bennett, R. L., Callanan, N., Gordon, E., et al. (2006). Code of ethics of the national society of genetic counselors: explication of revisions. *Journal of Genetic Counseling*, 15, 313.

Genetic Counselors' Scope of Practice

This "Genetic Counselors Scope of Practice" statement outlines the responsibilities of individuals engaged in the practice of genetic counseling. Genetic counselors are health professionals with specialized education, training and experience in medical genetics and counseling who help people understand and adapt to the implications of genetic contributions to disease.¹ Genetic counselors interact with clients and other healthcare professionals in a variety of clinical and non-clinical settings, including, but not limited to, university-based medical centers, private hospitals, private practice, and industry settings. The instruction in clinical genetics, counseling, and communication skills required to carry out the professional responsibilities described in this statement is provided in graduate training programs accredited by the American Board of Genetic Counseling (ABGC)² or the equivalent, as well as through professional experience and continuing education courses.

The responsibilities of a genetic counselor are threefold: (i) to provide expertise in clinical genetics; (ii) to counsel and communicate with patients on matters of clinical genetics; and (iii) to provide genetic counseling services in accordance with professional ethics and values. Specifically:

Section I: Clinical Genetics

1. Explain the nature of genetics evaluation to clients. Obtain and review medical and family histories, based on the referral indication, and document the family history using standard pedigree nomenclature.
2. Identify additional client and family medical information relevant to risk assessment and consideration of differential diagnoses, and assist in obtaining such information.
3. Research and summarize pertinent data from the published literature, databases, and other professional resources, as necessary for each client.
4. Synthesize client and family medical information and data obtained from additional research as the basis for risk assessment, differential diagnosis, genetic testing options, reproductive options, follow-up recommendations, and case management.
5. Assess the risk of occurrence or recurrence of a genetic condition or birth defect, using a variety of techniques, including knowledge of inheritance patterns, epidemiologic data, quantitative genetics principles, statistical models, and evaluation of clinical information, as applicable.

6. Explain to clients, verbally and/or in writing, medical information regarding the diagnosis or potential occurrence of a genetic condition or birth defect, including etiology, natural history, inheritance, disease management and potential treatment options.
7. Discuss available options and delineate the risks, benefits and limitations of appropriate tests and clinical assessments. Order tests and perform clinical assessments in accordance with local, state and federal regulations.
8. Document case information clearly and concisely in the medical record and in correspondence to referring physicians, and discuss case information with other members of the healthcare team, as necessary.
9. Assist clients in evaluating the risks, benefits and limitations of participation in research, and facilitate the informed consent process.
10. Identify and access local, regional, and national resources such as support groups and ancillary services; discuss the availability of such resources with clients; and provide referrals, as necessary.
11. Plan, organize and conduct public and professional education programs on medical genetics, patient care and genetic counseling issues.

Section II: Counseling and Communication

1. Develop a genetic counseling agenda with the client or clients that includes identification and negotiation of client/counselor priorities and expectations.
2. Identify individual client and family experiences, behaviors, emotions, perceptions, values, and cultural and religious beliefs in order to facilitate individualized decision making and coping.
3. Assess client understanding and response to medical information and its implications, and educate client appropriately.
4. Utilize appropriate interviewing techniques and empathic listening to establish rapport, identify major concerns and engage clients in an exploration of their responses to the implications of the findings, genetic risks, and available options/interventions.
5. Identify the client's psychological needs, stressors and sources of emotional and psychological support in order to determine appropriate interventions and/or referrals.

6. Promote client-specific decision making in an unbiased non-coercive manner that respects the client's culture, language, traditions, lifestyle, religious beliefs and values.
7. Use knowledge of psychological structure to apply client-centered techniques and family systems theory to facilitate adjustment to the occurrence or risk of occurrence of a congenital or genetic disorder.

Section III: Professional Ethics and Values

1. Recognize and respond to ethical and moral dilemmas arising in practice, identify factors that promote or hinder client autonomy, and understand issues surrounding privacy, informed consent, confidentiality, real or potential discrimination and potential conflicts of interest.
2. Advocate for clients, which includes understanding client needs and perceptions, representing their interests in accessing services, and eliciting responses from the medical and social service systems as well as the community at large.
3. Recognize personal limitations in knowledge and/or capabilities and seek consultation or appropriately refer clients to other providers.
4. Maintain professional growth, which includes acquiring relevant information required for a given situation, keeping abreast of current standards of practice as well as societal developments, and seeking out or establishing mechanisms for peer support.
5. Respect a client's right to confidentiality, being mindful of local, state and federal regulations governing release of personal health information.

This Scope of Practice statement was approved in June 2007 by the National Society of Genetic Counselors (NSGC) - the leading voice, advocate and authority for the genetic counseling profession. It is not intended to replace the judgment of an individual genetic counselor with respect to particular clients or special clinical situations and cannot be considered inclusive of all practices or exclusive of other practices reasonably directed at obtaining the same results. In addition, the practice of genetic counseling is subject to regulation by federal, state and local governments. In a subject jurisdiction, any such regulations will take precedence over this statement. NSGC expressly disclaims any warranties or guarantees, express or implied, and shall not be liable for damages of any kind, in connection with the information set forth in this Scope of Practice statement or for reliance on its contents.

Genetic counseling is a dynamic profession, which undergoes rapid change with the discovery of new genetic information and the development of new genetic tests and treatment options. Thus, NSGC will periodically review and, where appropriate, revise this statement as necessary for consistency with current practice information.

References:

1. NSGC Definition of Genetic Counseling. Journal of Genetic Counseling April 2006; 77-82
2. American board of Genetic Counseling website; www.abgc.net

For additional information, please contact the National Society of Genetic Counselors.

Five Year Academic Calendar (2017 – 2022)

FALL	2017-2018	2018-2019	2019-2020	2020-2021	2021-2022
Registration (and Drop/Add) Begin (UG)	Apr 10	Apr 9	Apr 8	Apr 6	Apr 5
Classes Begin	Aug 28	Aug 27	Aug 26	Aug 24	Aug 23
Late Registration Fee (\$25) Begins	Aug 29	Aug 28	Aug 27	Aug 25	Aug 24
Labor Day Holiday	Sep 4	Sep 3	Sep 2	Sep 7	Sep 6
Late Registration and Drop/Add End	Sep 8	Sep 7	Sep 6	Sep 4	Sep 3
Deadline Credit/Audit (UG)	Sep 8	Sep 7	Sep 6	Sep 4	Sep 3
Fall Break	Oct 23/24	Oct 22/23	Oct 21/22	Oct 19/20	Oct 18/19
Mid-Semester Grades Due (UG)	Oct 23	Oct 22	Oct 21	Oct 19	Oct 18
Deadline for removal of prev. term "I" grades (UG)	Nov 10	Nov 9	Nov 8	Nov 6	Nov 5
Deadline Credit/Audit (G)	Nov 10	Nov 9	Nov 8	Nov 6	Nov 5
Deadline for Class Withdrawal and P/NP (upperclass UG)	Nov 10	Nov 9	Nov 8	Nov 6	Nov 5
Registration for Spring Begins (UG)	Nov 13	Nov 12	Nov 11	Nov 9	Nov 8
Thanksgiving Holidays	Nov 23/24	Nov 22/23	Nov 28/29	Nov 26/27	Nov 25/26
Deadline for Class Withdrawal and P/NP (first year UG)	Dec 8	Dec 7	Dec 6	Dec 4	Dec 3
Deadline for removal of prev. term "I" grades (G)	Dec 8	Dec 7	Dec 6	Dec 4	Dec 3
Last Day of Class	Dec 8	Dec 7	Dec 6	Dec 4	Dec 3
Reading Days	Dec 11, 15	Dec 10, 14	Dec 9, 13	Dec 7, 11	Dec 6, 10
Final Exams Begin	Dec 12	Dec 11	Dec 10	Dec 8	Dec 7
Final Exams End	Dec 20	Dec 19	Dec 18	Dec 16	Dec 15
Final Grades Due by 11:00 am	Dec 22	Dec 21	Dec 20	Dec 18	Dec 17
Fall Awarding of Degrees	Jan 19 (2018)	Jan 18 (2019)	Jan 17 (2020)	Jan 15 (2021)	Jan 14 (2022)
SPRING	2018	2019	2020	2021	2022
Registration (and Drop/Add) Begin (UG)	Nov 13 (2017)	Nov 12 (2018)	Nov 11 (2019)	Nov 9 (2020)	Nov 8 (2021)
Martin Luther King Jr. Holiday	Jan 15	Jan 21	Jan 20	Jan 18	Jan 17
Classes Begin	Jan 16	Jan 14	Jan 13	Jan 11	Jan 10
Late Registration Fee (\$25) Begins	Jan 17	Jan 15	Jan 14	Jan 12	Jan 11
Late Registration and Drop/Add End	Jan 26	Jan 25	Jan 24	Jan 22	Jan 21
Deadline Credit/Audit (UG)	Jan 26	Jan 25	Jan 24	Jan 22	Jan 21
Mid-Semester Grades Due (UG)	Mar 12	Mar 11	Mar 9	Mar 8	Mar 7
Spring Break	Mar 12-16	Mar 11-15	Mar 9-13	Mar 8-12	Mar 7-11
Deadline for removal of prev. term "I" grades(UG)	Mar 30	Mar 29	Mar 27	Mar 26	Mar 25
Deadline Credit/Audit (G)	Mar 30	Mar 29	Mar 27	Mar 26	Mar 25
Deadline for Class Withdrawal and P/NP (upperclass UG)	Mar 30	Mar 29	Mar 27	Mar 26	Mar 25
Open registration for Summer Begins (UG)	Apr 2	Apr 1	Mar 30	Mar 29	Mar 28
Open registration for Fall Begins (UG)	Apr 9	Apr 8	Apr 6	Apr 5	Apr 4
Deadline for Class Withdrawal and P/NP (first year UG)	Apr 30	Apr 29	Apr 27	Apr 26	Apr 25
Deadline for removal of prev. term "I" grades(G)	Apr 30	Apr 29	Apr 27	Apr 26	Apr 25
Last Day of Class	Apr 30	Apr 29	Apr 27	Apr 26	Apr 25
Reading Days	May 1/2	Apr 30/May 1	Apr 28/29	Apr 27/28	Apr 26/27
Final Exams Begin	May 3	May 2	Apr 30	Apr 29	Apr 28
Final Exams End	May 10	May 9	May 7	May 6	May 5
Final Grades Due by 11:00 am	May 12	May 11	May 9	May 8	May 7
University Commencement	May 20	May 19	May 17	May 16	May 15
SUMMER	2018	2019	2020	2021	2022
Classes Begin	Jun 4	Jun 3	Jun 1	Jun 1	Jun 6
Independence Day Holiday	Jul 4	Jul 4	Jul 3	Jul 5	Jul 4
Classes End	Jul 30	Jul 29	Jul 27	Jul 27	Aug 1
Final Grades Due 12:00 noon	Aug 1	Jul 31	Jul 29	Jul 29	Aug 3
Summer Awarding of Degrees	Aug 17	Aug 16	Aug 14	Aug 13	Aug 19

Some People Don't Know These Things Came From Cleveland

The history of Cleveland is marked by great people, brilliant minds and genius inventions. Many innovations in science, art, industry and countless other fields can trace their lineage to the Forest City. These Cleveland inventions just go to show how much our city has changed the world for the better.

1. Superman

Move over, Metropolis. The creators of the world's first and greatest superhero, Jerry Siegel and Joe Shuster, were high schoolers in Cleveland when they first came up with the idea for their caped creation in 1933. Given just how popular superheroes are today, the landscape of modern entertainment truly owes a great debt to Cleveland.

2. Golf balls

While golf has been around for centuries, it wasn't until Cleveland inventor Coburn Haskell created the modern rubber-cored dimpled ball that golf as we know it today came to be.

3. Electric streetcar

Charles Brush debuted the very first electric rail streetcar in the Forest City, forever changing public transportation in major cities. The magic of a streetcar ride is still a special feeling today, made even more amazing by the fact that this phenomenon was born in Cleveland.

4. Shopping mall

Built in 1890, the Cleveland Arcade was the first indoor shopping complex in America. The iconic skylight was a remarkable feat of engineering, and you can still take in all its beauty by visiting today.

5. Lifesavers

These uniquely shaped mints were created after a Cleveland confectioner named Clarence Crane used a pharmacist's pill-making press to design a minty candy he could sell in the summer months. The iconic life preserver-inspired design came from his experiences watching ships come in and out of Lake Erie.

6. Electric traffic light

While this wasn't the first attempt at a street traffic control mechanism, Cleveland installed the first electric light that soon became the global standard for traffic regulation.

7. Street lights

Do you like being able to see the road when you're driving at night? You can thank Charles Brush for his foresight in creating arced street lights.

8. Gas masks

Invented in 1916, the modern gas mask came just in time for the chemical weapons use that was rampant in the early days of World War I. All sides of the conflict borrowed the technology Cleveland inventor Garrett A. Morgan originally designed to rescue trapped miners.

9. Medical scanning technology

A physicist at the Case School of Applied Science at Cleveland's Case Western University named Dayton C. Miller was the first to invent a full-body scanning machine, the technology driving everything from MRIs to CAT scans today.

10. Cars

While Detroit is widely considered by many to be the heart of the American car industry, most don't realize that the very first gas-powered automobile was manufactured by Ohio City's own John W. Lambert, making Cleveland the first true home of the car.

11. Quaker Oats Cereal

Quaker Square in Akron is where all the magic started. Oatmeal and breakfast cereals! The complex is now owned by the University of Akron, which turned it into dorms and offices.

12. Air traffic control tower

Cleveland's airport opened the first radio-equipped control room in the US in 1930.

13. Phrase: Rock 'n' Roll

Cleveland disc jockey Alan Freed has long garnered credit for coining the term Rock 'n' Roll.

14. Speed of light

Began with an experiment by 2 CWRU professors, Albert Michelson and Edward Morley in 1887.

15. Saran Wrap

Developed by a Dow Chemical Co employee and CWRU graduate Charles Strosacker

16. Automatic coffee maker

Developed and manufactured by Vincent Marotta, founder of Mr. Coffee, Inc

17. Ready-mixed paint

Developed by Henry Sherwin, founder of Sherwin-Williams Paint Company

The most striking Northeast Ohio inventions of the last 30 years

By AMY ANN STOESSEL

An endless number of inventions and innovations have originated from Northeast Ohio minds, institutions and companies over the past 30 years. Some are life-changing. Some are helpful and handy. And some, quite frankly, are just goofy. Historically, the region has been a hotbed for all types of innovation — Thomas A. Edison even got his start as a young inventor just west of the area in his birthplace of Milan, Ohio. Today, the region continues to be a strong contributor to the research, development and commercialization of new concepts. Here are just some of the bright ideas to come out of the region over the past 30 years. Feel free to add to the list with what you think are the greatest and brightest concepts to be delivered from the area.

Healthy dose of innovation

- Case Western Reserve University in 1987 developed a test for infants that made it possible to identify mental retardation within a year after birth.
- The same institution also can be credited with the first artificial human chromosomes in 1997, opening the door to more detailed study of human genetics and potentially offering a new approach to gene therapy and the treatment of a broad range of genetic diseases.
- The NeuRx Diaphragm Pacing System, a pacemaker developed as a result of research at Case Western Reserve and University Hospitals, allows spinal cord injury patients to breathe without using a ventilator. It first was implanted in the late actor Christopher Reeve in 2003.
- The first near-total face transplant in the United States was performed in 2008 at the Cleveland Clinic. A surgical team used a face from a cadaver and put it on a woman who had experienced major trauma that left her without the ability to eat and breathe on her own. The patient had no nose and was missing some bone support.
- Cleveland Clinic cardiothoracic surgeon Dr. Delos M. Cosgrove, who now is the institution's CEO, in the 1980s developed a computerized device that monitors a patient's condition and automatically administers drugs according to need. In 1991, he pioneered aortic valvuloplasty, a procedure that allows surgeons to repair diseased heart valves.
- In 1992, Cleveland Clinic neurosurgeon Gene H. Barnett and researcher Donald W. Kormos developed the sonic wand, an imaging technique that allows brain surgeons to pinpoint lesions.
- Cleveland Clinic otolaryngologist Dr. Marshall Strome performed the first successful total larynx transplant in 1998.
- Cleveland Clinic physicians Inderbir Gill and Craig D. Zippe in 2000 pioneered a minimally invasive technique to remove the prostate. The procedure, a laparoscopic radical prostatectomy, is designed to decrease recovery time and pain in men who must have cancerous prostates removed.
- Cleveland Clinic Dr. Peter Koltai in 2002 developed a new procedure to remove tonsils. This new technique shaves away a portion of the tonsils rather than completely cutting them out.

Getting some bounce

- Due to the presence of such industry powerhouses as B.F. Goodrich, Goodyear and Firestone, Akron has been called “the rubber capital of the world.” Today, the city is home to 400 polymer-related companies and the University of Akron's College of Polymer Science and Polymer Engineering. In just one example of the continued innovation coming out of the sector, Akron-based Goodyear recently received acclaim for its Fuel Max tire from *Popular Science* magazine, which dubbed the fuel-efficient tire as one of the top 10 automotive innovations of 2009.

Crystal clear

- Kent State University, its Liquid Crystal Institute and university spinoff companies have been on the leading edge of development and research involving liquid crystals. While liquid crystals and their uses have far-reaching implications and a variety of commercial and industrial purposes, they can have fun — yet, practical — uses too. Just look at the recently released Boogie Board: Liquid crystal technology developed in Northeast Ohio is used in the high-tech message pad. Users can write or draw pictures on the plastic liquid crystal display of the \$30 product, then erase them by touching a button.
- A transparent, optical film invented by Dr. Frank Harris, a University of Akron distinguished professor emeritus of polymer science, and Dr. Stephen Cheng, dean of the UA College of Polymer Science and Polymer Engineering, last year topped \$1 billion in sales, according to the university's web site. The pair's 1989 development of soluble polyimides, when converted to film, enabled large LCD screens (think big-screen TV) to be viewed from all angles for the first time.

Invention powerhouses

- Joseph Kennedy, a distinguished professor of polymer science and chemistry at the University of Akron, received his 100th patent in 2009. Among his inventions are a copolymer and thermoplastic elastomer that serves as the basis for a polymer coating on Boston Scientific Corp.'s Taxus cardiovascular stents, which keep coronary arteries open. The polymer coating allows the stents to time-release drugs into the body that will allow blood to flow through the coronary artery, Dr. Kennedy said in a 2009 Crain's article. The stent has been implanted in more than 5 million people worldwide.
- John Nottingham and John Spirk, both graduates of the Cleveland Institute of Art, opened their own design business in 1972. Today, Nottingham-Spirk Design Associates has more than 480 issued and commercialized patents. One of the designs that helped launch the company was a football-shaped toy chest for The Little Tikes Co. Other designs attributed to Messrs. Nottingham and Spirk include the Crest SpinBrush, Swiffer SweeperVac, Dawn Power Dish Brush and the Huffy Green Machine.

Strange, but true

- Northeast Ohio inventor Wally Berry is the person behind the Siphon Flush, a floating siphon on the end of a collapsible rubber hose that is attached to the hole in the toilet where the flapper

is normally attached. Unless the toilet is flushed — in this case, by beginning the siphoning action with a downward push from the handle to collapse the rubber hose — it is a closed system that cannot leak.

- Local entrepreneurs Richard G. Brindisi and Gregory Vittardi can be credited with the SmartShopper, a handheld, voice-recognition gadget for dictating shopping and errand lists.
- Northeast Ohio entrepreneur Aaron LeMieux was an engineering student at the University of Toledo when he came up with the idea for the nPower personal energy generator. Mr. LeMieux was backpacking along the Appalachian Trail in 1996, when he put his mind to work to figure out how to convert the kinetic energy in the motion of his backpack into electrical energy.

Hall of famers

Northeast Ohio not only is home to inventors and institutions that make the world a better place, but it also pays homage to them at the National Inventors Hall of Fame in Akron. In fact, Akron itself has even been called the “city of invention” — not a surprise, considering the innovations linked to the city. According to the city of Akron web site, Akron is home to:

- The first breakfast cereal, now Quaker Oats;
- Processed cereals developed by Akron's Ferdinand Schumacher, the “oatmeal king;”
- Ice cream cones, hamburgers and caramel corn snacks, invented in Akron by Charles E. Menches; and
- The first artificial fish bait, made by Pfleuger Fishing Tackle Co. As for the hall of fame itself, the obvious candidates such as Alexander Graham Bell are included, but more obscure — but definitely no less important — contributions are recognized. Robert Adler, for example, who invented the television remote control, gets his rightful place in history as a member of the hall of fame. (Unfortunately, Northeast Ohio can't take credit for this stroke of genius — Mr. Adler actually hailed from Vienna, Austria.)