

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

**GENETIC COUNSELING TRAINING  
PROGRAM**

**GRADUATE STUDENT HANDBOOK**

**2020 - 2022**

**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 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 the Co-Directors 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. The Co-Directors 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 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.

**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 Co-Directors 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 with a score of at least 70%. 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 required 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, and 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 advanced rotation in areas such as metabolism, cardiomyopathies, or in-patient consults. In addition electives may include an opportunity to work with genetic counselors in areas such as industry or commercial companies. Finally, each student will have the opportunity for a laboratory experience. Currently the students rotate at the Cleveland Clinic Pathology and Laboratory Medicine Institute. 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 completion of a research project. This scholarly project may be a clinical or counseling project, a project designed for professional issues in the genetic counseling field, or a laboratory based project, and should relate to some aspect of genetic counseling. During fall semester of the first year, students meet on a regular basis with Drs. Goldenberg 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 toward the end of first semester and through the spring semester (registering for 1 credit of GENE 601). 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 it is expected that students will schedule meetings with their committee members during the spring, and defend their proposals approximately May/June of the first year. 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 2<sup>nd</sup> 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.

## **Remediation Plan:**

Should a student's performance in any of the following areas be deemed insufficient, a formal remediation plan will be initiated as described below.

### Academics:

Students are expected to achieve a grade of B or better in every academic course. If a student receives a grade of C or lower in any course, the student will be placed on academic probation by the University, and a remediation plan will be initiated. This plan will be formalized by the Co-Directors on an individualized basis, and may include tutoring (from either the Co-Directors, or other course instructors), retaking all or portions of a class again, retaking exams, or being required to do extra coursework as needed. In addition, if any score on an individual exam or assignment is below a C, the Co-Directors will meet with the student to discuss his/her approach to learning and reviewing the material, understanding of the concepts, and plans for improvement of academic performance.

### Clinical Rotations:

If it is determined by a rotation supervisor that a student is not progressing at the desired rate in a clinical rotation, one or both of the Co-Directors and the Assistant Program Director of Clinical Supervision will meet with the student along with the rotation supervisor to determine an intervention strategy. The student's specific area of weakness (counseling skills, genetic knowledge, time management, etc) will guide the development of the remediation plan. Interventions may include role-playing sessions, choosing specific patients to help the student focus on a challenging area, helping a student review coursework or attend additional review lectures if needed, or reducing the number of managed cases per week. If extra clinical time is needed, this will be built into the final semester of the program, prior to graduation, or in some cases a delay of graduation to August in order to accommodate additional clinical rotations will be discussed.

### Thesis Project:

The student is required to have several meetings with his/her thesis committee during the development and execution of the thesis project. If at any time the thesis committee has concerns regarding the progress of the project, the committee will discuss ways to remedy the situation. If the progress is lacking due to the student not putting forth the appropriate effort, then a timeline for completion of the project and graduation may need to be adjusted, which may include delaying graduation until August. Occasionally through no fault of the student the project will encounter unforeseen delays and challenges. If this is the case, the committee will discuss other options for completion including focusing on a portion of the project, altering some aspect of data collection, or significantly limiting the scope. The student's research committee will make these decisions with input from the Co-Directors.

## 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
John Kaufman	Admin Assistant	368-3433	jak251@case.edu

### Genetic Counseling Training Program

Anne L. Matthews, RN, PhD	Director	368-1821	alm14@case.edu
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Aaron Goldenberg, PhD, MPH	Research Director		ajg10@case.edu
Anna Mitchell, MD, PhD	Medical Director	844-3936	anna.mitchell@case.edu
Clarice Young	Program Assistant	368-3431	cdy5@case.edu
John Kaufman	Admin Assistant	368-3433	jak251@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
Suzanne DeBrosse, MD	Faculty	844-7942	suzanne.debrosse@uhhospitals.org
Jirair (Jerry) Bedoyan, MD, PhD	Faculty	844-6023	jirair.bedoyan@uhhospitals.org

### Genetic Counselors

Sarah Aufmuth, MS, LGC	Faculty	844-0343	Sarah.aufmuth@uhhospitals.org
Lauren Bokovitz, MS, LGC	Faculty	844-8431	lauren.bokovitz@uhhospitals.org
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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 6<sup>th</sup> floor

Thomas Prior, PhD	Director, Molecular Genetics	thomas.prior@uhhospitals.org
Shashirekha Shetty, PhD	Director, Cytogenetics	shashirekha.shetty@UHhospitals.org

### Residents/Fellows

	CHG	Residents Office 844-7221
Vincent Cruz, MD	Genetics resident	
Suha Bachir, MD	Genetics resident	
Tin-Yun Tang, MD	Genetics resident	
Lauren Pronmen, MD	Genetics resident	
Demitrios Dedousis, MD	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, Director	330-543-8792
Catherine Ward-Melver	Geneticist	
Joleen Viront, MS, LGC	Genetic Counselor	jviront@akronchildrens.org
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Katie Krepkovich, MS, LGC	Genetic Counselor	kkrepkovich@akronchildrens.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	
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Chris Wensel, MS, LGC (lab)	Genetic Counselor	wenselc@ccf.org
Sarah Arneson, MS, LGC (lab)	Genetic Counselor	harters@ccf.org

## 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 (Thursdays – 4:00 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 Rainbow Babies Auditorium**

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 – 2<sup>ND</sup> YEAR**

**~ 2 x monthly (Thursdays 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 2<sup>nd</sup> 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.

### **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. The Co-Directors will inform students of invited speakers which they feel 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. The Co-Directors and Dr. Goldenberg will inform students of invited speakers which they feel 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 in Cleveland. Students will observe cases at the Center for Human Genetics at University Hospitals Cleveland 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 Prenatal Diagnosis Clinic, General Genetics, Prenatal Genetics, and Cancer Genetics at the Center for Personalized Genetic Healthcare in the Genomic Medicine Institute at the Cleveland Clinic. Each rotation block is approximately six-seven 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 Co-Directors. 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.

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

#### **First year, during first week of fall semester – Ms. Merrill**

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 – Ms. Merrill**

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 Co-Directors 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 2<sup>nd</sup> 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) **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) **Merrill 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 508: Individual Theory and Practice**  
**Faculty at MSASS**

(2 credits)

This course focuses on theory and practice with individuals. The overarching goal of ITP is to develop culturally competent social work generalist practitioners who are armed with the knowledge and skills necessary to practice ethically with individuals in diverse social work practice settings. This course is structured to include pre-recorded lecture to be viewed before class, and discussion and experiential laboratory learning in a 1.5 hour face-to-face session. In addition to watching the pre-recorded lectures, there is also considerable preparation time required before each class session. The lab portion provides the opportunity for students to practice skills and receive constructive feedback from the instructor and peers.

**GENE 601 Research Seminar**  
**Darrah & Goldenberg**

(1 credit)

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.

**Collaborative Practice I**  
**University Faculty and others**

(0 credit)

This new year-long course will include curriculum that focuses on community-based projects and includes classroom instruction and simulation which supports the students' work. This course will include entry-level health professions students and other interested students. Students will learn how to work in interprofessional teams by completing community-based projects, with didactic coursework and leadership mentoring throughout. Genetic counseling students will participate in this course alongside students from dental medicine, nursing, medicine, psychology, physician assistance and social work, among other disciplines.

**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 September of the first year at the latest. 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.

**Year 01      SPRING**

**GENE 525: Advanced Medical Genetics: Clinical Genetics** (2 credits)  
**Merrill 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)  
**Merrill 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 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 credits)  
**Goldenberg and Darrah**

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)  
**Merrill and faculty**

### **Year 02 FALL**

**GENE 527: Advanced Medical Genetics: Biochemical Genetics** (2 credits)  
**Merrill 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)  
**Merrill and faculty**

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

### **Year 02 SPRING**

**BETH 412: Ethical Issues in Genetics & Genomics** (3 credits)  
**Goldenberg**

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** (4 credits)  
**Merrill and faculty**

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

**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
Gene 601	Research Seminar	1
SASS 508	Individual Theory and Practice	2
	Collaborative Practice I	0
Embryology	Online course - summer prior to Year 1	Certificate
		<b>Total = 10</b>

**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
	Collaborative Practice I	0
		<b>Total = 9</b>

**YEAR 02****SUMMER**

Gene 532	Clinical Rotation	3
		<b>Total = 3</b>

**FALL**

Gene 527	Advanced Medical Genetics: Metabolism (biochem)	2
Gene 532	Clinical Rotations	4
Gene 601	Research	3
		<b>Total = 9</b>

**SPRING**

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

**Total credit hours = 40****Total = 9**

**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. Darrah and Goldenberg during fall semester to begin discussions regarding the research process. We will begin to explore different research approaches and ways to develop 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.
  4. During the Research Seminar we will 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 1<sup>st</sup> 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. Darrah and Goldenberg, begin to form their research committees (minimum 3 faculty members) by asking faculty if they are willing to sit on their committees. This occurs in early 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. Specific Aims Page – 1 page detailing the purpose &/or research question, hypotheses, and aims of the project
    2. Background and Significance – brief overview of the literature; pertinent research done in the area, gaps in the knowledge that lead to your proposed project
    3. Innovation – how the study findings may add to the genetic counseling body of literature, and how this project differs from other similar projects you may be inspired by.
    4. Approach – the study design and Methods – design of study, how it will be conducted, how participants will be recruited, inclusion/exclusion criteria, instruments used, projected analysis of data
  8. Students are required 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 the student needs to have an additional meeting in ~ 1-2 month's time to discuss changes, etc.
5. Proposals not submitted to committee members by the end of summer semester of 1<sup>st</sup> 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 Co-Directors 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 Committee Chair 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, and 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 7 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 2<sup>nd</sup> 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 2<sup>nd</sup> 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](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- $\alpha$ 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”
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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”
<b>2005</b>	
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”
<b>2006</b>	
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”
<b>2007</b>	
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”
<b>2008</b>	
Megan Doerr	“A systematic review of ENDRA polymorphisms and disease HGE/GA”
Vandana Sharma	“Parental Experience with Ohio’s Cystic Fibrosis Newborn Screening Program”
<b>2009</b>	
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”
Willonie 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”
<b>2010</b>	
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”
<b>2011</b>	
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”
<b>2012</b>	
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”
<b>2013</b>	
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?”
<b>2014</b>	
Evelyn Crawford	“Efficacy of Genetic Testing in Cases of Ambiguous Genitalia Detected on Prenatal Ultrasound”
Jeannie Klavonian	“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”
<b>2015</b>	
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”
<b>2016</b>	
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”.
<b>2017</b>	
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

**2019**

Alex Bakos Hansley	"Kleefstra Syndrome: Its Impact on Parents"
Emily Creque	"“On the fringe:” clinical application of less commonly used ultrasound markers for Down syndrome"
Molly Ford	"The meaning of preparation: Parental experiences following the prenatal diagnosis of aneuploidy"
Sharisse Jimenez*	"Spanish-Speaking Patients’ Perspectives on Interpersonal Relationship, Communication, and the Decision-Making Process in Genetic Counseling Sessions"
Caroline Linke	"Influences on uptake: carrier versus aneuploidy screening"
Cortlandt Martin	"Factors Influencing Compliance with National Comprehensive Cancer Network (NCCN) Guidelines following Positive test result for a Pathogenic Gene mutation"
Kristy Nguyen	"Functional Studies of Variants of Unknown Significance in GSD 1a"
Maddie Williamson	"Challenging the Huntington Disease Paradigm: Evaluation of Psychosocial Issues in Persons at-risk for Genetic Prion Disease"

\*Dual degree student – MS Genetic Counseling / MA Bioethics

**2020**

Paul Crawford	“Thoracic aortic aneurysms and dissections: Clinical and genetic findings of individuals pursuing gene panel testing”
Zoey Freedman	“The potential incorporation of pharmacogenetic testing into genetic counseling practice”
Hannah Garn	“Genetic counselors’ practices and perceptions when counseling Native clients” General/Pediatric Genetics
Joseph Liu	“Impact of ancestry-related limitations on informed consent and pre-test genetic counseling”
Emma Lynch	“Barriers and facilitators to undergoing genetic testing: A study of women with ovarian, fallopian tube or primary peritoneal cancers”.
Hannah Sigurdson	“Are genetic counseling graduate students prepared to counseling on health insurance coverage and costs of genetic testing with patients?”
Emma Stocker	“Frequency of embryos appropriate for transfer following preimplantation genetic testing for monogenic disease”
Tim Trobenter	“Non-thoracic aneurysms and genotype-phenotype correlations in molecularly confirmed Marfan syndrome”.

## CLINICAL ROTATIONS

### Description

Students must satisfactorily complete all rotations of clinical practicum. Rotations include the following areas: General Genetics (pediatric and adult patients, including 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, 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 Cleveland Clinic Pathology and Laboratory Medicine Institute. 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.

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 2-week rotation at the CC Pathology & Laboratory Medicine Institute. The remaining 4 rotations are scheduled in 8-week blocks (fall 1, fall 2, spring 1 and spring 2) during the second year of the program. The rotations are:

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

CC Pathology & Laboratory Medicine Institute Rotation (2 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

Elective rotations: Industry: Myriad, Invitae, Cooper Genomics, GeneDx and the DDC clinic. Other potential areas for rotations: Telemedicine cancer - UH/CCF joint rotation; Fetal care – UH; Inpatient consults – UH; Metabolism – UH; Clinical trials/clinical research – UH; Ophthalmology – CCF; Cardiomyopathy- CCF or UH

\*Elective rotation opportunities are variable from year to year. This represents an example of what might be available.

The specific rotational schedule for each student will be assigned by the Co-Directors and Clinical Coordinator 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 the Co-Directors 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 900-1000 hours of clinical practicum and an additional 70-80 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 3-4 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 Co-Directors 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 Co-Directors 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 Co-Directors (electronically) to be maintained in the student's permanent file at the end of each rotation.

You will have an exit interview with the Co-Directors 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 Minhoff Health Center, UH Ahuja Medical Center, UH Mentor Health Center, UH St John Medical Center, UH Midtown, 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 and seven board certified genetic counselors. In addition, there is 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 2<sup>nd</sup> 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 twenty 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 (including the Genetic Counseling Training Program) 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, Memorial Day 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 the Co-Directors.

### **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 one of the Co-Directors 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 2019-2021, 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 30<sup>th</sup> 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 2<sup>nd</sup> 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 2020-21 academic year is \$1,997.00 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 \$1,165 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 \$19 per semester. Finally, there is a fee for membership to One to One Health Fitness Club on campus – fall = \$126 and spring = \$157 (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 are two open cubical areas (the “Cube”), one on the west side and one on the east side where you have desk space and there are four computers available at each Cube space. 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. The first year students utilize the west side Cube (next to the 632 classroom).

### **Mailboxes**

Students will each have their own mailbox in the cubical area in which 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 the Allen Medical Library. Additionally many journal subscriptions are available to Case students on line.

## **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 CPM/CC**

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. We 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. 2<sup>nd</sup> ed. John Wiley & Sons, New York, 2009.
2. Patricia McCarthy-Veach, Bonnie LeRoy, and Dianne Bartels Facilitating the Genetic Counseling Process: A Practice Manual. 2<sup>nd</sup> ed. Spring, New York, 2018.

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.
4. Kenneth Jones, editor. Smith's Recognizable Patterns of Human Malformations. 7<sup>th</sup> ed. W.B. Saunders Company, Philadelphia, 2013.
5. Nussbaum RL,, McInnes RR and Willard HF. Thompson & Thompson Genetics in Medicine 8<sup>th</sup> edition, W.B. Saunders, 2015.

Other medical genetics texts:

1. Jorde LB, Carey JC and Bamshad MJ. Medical Genetics. 4<sup>th</sup> ed. Mosby Elsevier, Philadelphia, 2010.
2. Korf BR and Irons MB. Human Genetics and Genomics, 4<sup>th</sup> ed. Wiley-Blackwell, 2013.
6. Mathiesen A & Roy K, editors. Foundations of Perinatal Genetic Counseling. Oxford University Press, 2018
7. MacFarlane IM, McCarthy Veach P, LeRoy BS. Genetic Counseling Research: A Practical Guide. Oxford University Press, 2014.
8. Katherine Schneider. Counseling about Cancer: Strategies for Genetic Counseling. 3<sup>rd</sup> ed. Wiley-Liss, 2011

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. 5<sup>th</sup> ed. Oxford University Press, 2018.
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. 6<sup>th</sup> ed. 2013. Order directly from Greenwood Center Genetics.
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. 3<sup>rd</sup> ed. Sage Publications, Inc. 2008.
7. J Fernandes, JM Saudubray and G van den Berghe, editors. Inborn Metabolic Diseases. 4<sup>th</sup> ed, Springer, New York, 2004
8. Bennett, Robin. The Practical Guide to the Genetic Family History. 2<sup>nd</sup> ed. Wiley-Blackwell, 2010.
9. Cassidy, Suzanne and Allanson, Judith. Management of Genetic Syndromes. 3<sup>rd</sup> ed. Wiley-Liss, 2010

10. Love, Susan Dr. Susan Love's Breast Book. 5<sup>th</sup> ed. Merloyd Lawrence Books, 2010. (Good for cancer course)
11. Gersen, SL and Keagle MB. Principles of Clinical Cytogenetics. 3<sup>rd</sup> ed. Springer Press, 2013.
12. Young, Ian D. Introduction to Risk Calculation in Genetic Counseling. 3<sup>rd</sup> ed, Oxford University Press, 2006

Most of the above texts are available to you in the BRB library, 632. 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.

Books needed for courses outside of Genetics will be assigned by the professor for those courses.

### **Disability Accommodations**

In accordance with federal law, if you have a documented disability, you may be eligible to request accommodations from Disability Resources. In order to be considered for accommodations you must first register with the Disability Resources office. Please contact their office to register at 216.368.5230 or get more information on how to begin the process. Please keep in mind that accommodations are not retroactive.

### **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/about-the-school/policies-procedures/>. Any violation of the University's Code of Ethics will not be tolerated. 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 Michelle Merrill and Becky Darrah, the Program Co-Directors. Dr. Matthews will be available for the fall semester as well. The leadership team is available to assist students with all aspects of the Program as well as personal issues if the student so desires. In addition, the supervising genetic counselors are very willing to assist students, and the second year students often serve as a welcome resource as well.

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 Co-Directors, 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 \$70 (credit card 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. 115<sup>th</sup> Street. Contact the department at 216-368-5993 or email Sargent Daniel J. Schemmel at [djs49@case.edu](mailto: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](http://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 the Co-Directors 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** – to the 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](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/>

### School for Graduate Studies

The School for Graduate Studies main website is found at <https://case.edu/gradstudies/>. There is information for new students as well as current students. Under Current Students you will find resources for the “Program Plan of Study”, “Dates and Deadlines”, the CWRU Bulletin and the Graduate Student Newsletter”. In addition, major policies and procedures of the Graduate School are listed on their website at <https://case.edu/gradstudies/about-the-school>. The website lists a number of areas germane to graduate students. Those most pertinent to master’s students, and thus, students in the Genetic Counseling Training program include Academic Integrity Standards, Graduate Student Grievance Procedures and Graduate Student Holiday, Vacation and Leave policies.

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>

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>.

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

*Dual Degree Program Directors: Rebecca Darrah, 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.

We have now had four students graduate from the dual degree and have one 2<sup>nd</sup> year student entering her 2<sup>rd</sup> year.

If you are interested in hearing more about this program, please let Drs. Darrah 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).

Per one of our graduates:

I just wanted to send an e-mail with a couple of examples of how wonderful the MS/MA dual degree can be post-graduation if you would like to share with any students who may be interested in enrolling.

I attended an ethics meeting at my hospital as an observer to see if I would be interested in joining the board. The committee members were immediately impressed by my MA (we don't have a sole ethicist on the team) and encouraged me to immediately join. They also requested that I give a presentation about ethics and genetics at the next meeting! Another time I found the dual degree helpful was within my own GC department. We are actually designing our own informed consent for genetic testing. Writing an informed consent was an assignment that I had with Patty in research ethics! I explained the importance of the main elements of informed consent to the team, ethical concerns I had about the context in which it was being used, and re-wrote a lot of the form to try to get it down to a 6th grade reading level. My fellow GCs were very appreciative of the explanation and edits.

The dual degree was a wonderful experience and is so useful in practice! I hope more students continue to join.  
Sincerely, Annelise Page Graduate 2018

**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	2	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				

## **PROGRAM LEADERSHIP**

**Rebecca Darrah, MA, MS, PhD, LGC** is the **Co-Director of the Genetic Counseling Program**. She is an Associate Professor 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, 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** is the Co-Director for the Genetic Counseling Training Program. Michelle is a board certified and licensed genetic counselor and an Instructor in the Department of Genetic & Genome Sciences. Michelle has previously served as the Associate Director of Genetic Counseling for the Center for Human Genetics at University Hospitals Cleveland Medical Center, and as the Director of Clinical Training with the Genetic Counseling Training Program. 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.

**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 is 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.

**Anne Matthews, R.N., Ph.D., LGC, FACMGG is Professor of Genetics & Genome Sciences and Director of Genetic Counseling Training Program (retiring).** 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 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.

**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.

**Support Staff**

**Clarice Young and John Kauffman** are the Program administrative assistants.

**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](http://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. ACGC PRACTICE-BASED COMPETENCIES for GENETIC COUNSELORS
3. GENETIC COUNSELING SCOPE OF PRACTICE
4. CODE OF ETHICS & EXPLANATION - NATIONAL SOCIETY OF GENETIC COUNSELORS
5. CWRU & CLEVELAND OVERVIEW – go to <http://case.edu/about/cleveland> or [case.edu/campuslife](http://case.edu/campuslife) etc for information about Case and Cleveland
6. FUN STUFF ABOUT CLEVELAND AND AREA
7. COMBINED GC PROGRAMS SUMMER READING LIST

## 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 two-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 four eight-week clinical rotations, one of which is an elective rotation. The institutions in Cleveland where students rotate include: the Center for Human Genetics at University Hospitals Cleveland Medical Center, the Genomic Medicine Institute at the Cleveland Clinic, and Genetic Services, MetroHealth Medical Center. Electives may be on-site or remote.

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 each 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. At the end of each rotation, you will need to upload each Encounter form (along with your self-reflection form for each case) and email mail it to the Program Director who will keep them in your student file.

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.

**GENETIC COUNSELING TRAINING PROGRAM**

**STUDENT:** \_\_\_\_\_ **DATE:** \_\_\_\_\_  
**ROTATION SITE:** \_\_\_\_\_

**CLINICAL OBSERVATION FORM**

1. Demographics: who attended visit? Describe patient/client (gender, age, ethnicity, general appearance, etc); What professionals saw the client (MD, counselor, etc)
  
2. Contracting and client expectations: what was the indication for referral; did you feel client/family understood the reason for the visit? What was the emotional demeanor at the start of the session (upset, anxious, not interested, etc)?
  
3. Did the client/family have an opportunity to “tell their story”? what were the major concerns?
  
4. What histories were obtained & by whom? Was a risk assessment made (what was it?
  
5. What information was given to the client/family: etiology, incidence, etc; clinical features; natural history, testing options; surveillance, management, treatment options; support groups; other resources; what about follow-up – communicating results, etc?

6. What was the client's/family's response to the information given? What do you think the level of intellectual understanding was?

7. Counseling process:

Evaluate the helping relationship the genetic counselor formed. What did s/he do to establish such a relationship? Provide a brief statement(s) to illustrate the skill(s).

What types of communication did you observe (questioning, silence, rephrasing, etc). What was the counselor's role in the session?

What goals did the genetic counselor seem to have for this session?

What could the genetic counselor have done differently, if anything, or if you were to provide feedback to the counselor, what suggestions would you give?

