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November 4, 2015

Roy Ritzmann, PhD Chair, Faculty Senate c/o Rebecca Weiss, Secretary of the University Faculty Adelbert Hall 7001

Dear Dr. Ritzmann:

As noted in the accompanying memo from Dr. Bill Schilling, Chair of the School of Medicine's Faculty Council, the Faculty Council has recommended approval of a Master of Arts in Bioethics and a Master of Science in Genetic Counseling Dual Degree Program.

This program will establish a comprehensive curriculum integrating foundational principles of genetics and ethics through the collaborative efforts between two nationally renowned programs. The departments and faculty have experience with the management and coordination necessary for successful dual degree programs.

The proposal approval process is outlined in Dr. Schilling's memo. An ad hoc Committee was convened to review this new program and after revisions, the program was approved by the Faculty Council.

I concur with the Faculty of Medicine and recommend approval of this dual degree program.

Please submit the proposed dual degree program to the appropriate committees for their review at their earliest opportunity. I would be pleased to answer any questions that might arise during the review process.

Thank you.

Sincerely,

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Pamela B. Davis, MD, PhD

c: Dr. Bill Schilling, Chair, Faculty Council Nicole Deming, Assistant Dean for Faculty Affairs and Human Resources, SOM

enclosures



SCHOOL OF MEDICINE

CASE WESTERN RESERVE UNIVERSITY

## Proposal for a Dual Degree between Bioethics (MA) and the Genetic Counseling Training Program (MS)

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

### A. Brief Summary

We are proposing the creation of a Dual Degree between the Masters in Bioethics and Genetic Counseling Programs that will establish a comprehensive curriculum integrating foundational principles of genetics and ethics,. The goal of this program would be to train Genetic Counselors who could also apply Bioethics into their clinical practice and/or research.

B. Rationale for a Joint Degree and a New Course in Bioethics and Genetic Counseling 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. Moreover, the integration of 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. Nevertheless, there is currently only one academic program in the U.S. that fully integrates training in Genetic Counseling and Bioethics in a dual degree program.

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. For many years faculty from both programs have taught in each other's courses, been mentors to each other's students, and collaborated in grants and other scholarly activities. In addition, we have had one graduate from our Bioethics Master's Program accepted to the Genetic Counseling Training Program. A number of Genetic Counseling students have chosen to do their thesis/capstone research project on an ethics related topic. However, even with the increasing relevance of Bioethics to the Genetic Counseling curriculum, and strong interest among student from both programs, there is no formal collaborative training program. We are proposing a dual degree program between the MA program in Bioethics and the MS in Genetic Counseling.

While genetic counseling programs all provide some ethics training to their students, the ethics curricula tend to focus on ethical issues that arise in practice and professional life. The dual degree program however, will allow students to pursue a broader exploration into bioethics scholarship, develop methodological empirical ethics skills, and deeply explore topics of genetics and health systems, genomics research, and public health genomics. The dual degree program will allow 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. Graduates will be more prepared to participate in the ongoing national dialogue about the ethical, legal, and social implications of advances in genomic technology. Additionally, many genetic counselors are becoming more involved in research within their home institutions and with other counselors nationwide. This research frequently focuses on patient uptake and perceptions of new genetic testing technology, patient preferences regarding 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. A Dual Degree in Genetic Counseling and Bioethics would enhance a graduate's ability to engage in these issues and increase the value and skill set they bring to the research team.

The MS GC Degree is a "terminal" degree in the sense that persons with the degree will be able to pursue a variety of career paths. The MA in bioethics is not traditionally a "terminal degree" in that it enhances careers in other fields – e.g. law, medicine, nursing, public health or in this case, genetic counseling. Thus, the dual bioethics-genetic counseling degree would fuel careers in every aspect of genetics, genomics and health, clinical genetics, and health policy.

#### **C. Institutional Partners**

This project would be developed within the contexts of two primary institutional and programmatic partners:

#### 1. The Masters in Bioethics Program, Department of Bioethics (Plan B)

The Department of Bioethics Master of Arts program in Bioethics emphasizes the multi- and interdisciplinary nature of the field. The master's degree programs reflect our values: to provide excellent education in bioethics to students and professionals in the School of Medicine and throughout the University; contribute outstanding research and scholarship to the world literature in bioethics; provide local, regional, and national service to health professionals, policy makers, and the public; and to promote international bioethical dialogue through research collaborations, training programs, and institutional partnerships. The program has an excellent track record of training students in Bioethics. Since its inception the program has graduated over 185 students. Many of these students have gone on to PhD programs, medical school, law school, or work in the areas of bioethics research, research oversight, or clinical ethics. Moreover, the Department of Bioethics has a very strong track record regarding dual degree programs and currently offers programs in Medicine, Law, Public Health, Nursing, Social Work, and Genetics. The stand-alone Bioethics MA is 27 credits and includes a Final Project/Paper that allows the student to engage in an in-depth exploration of a bioethics topic of their choosing.

# **2.** The Genetic Counseling Training Program, Department of Genetics and Genome Sciences (Plan B)

The Genetic Counseling Training Program, leading to a Master of Science degree in Genetics, is a two-year academic program comprised of course work, laboratory exposure, extensive clinical training and research experience. The overall objective of the Program is to prepare students with the appropriate knowledge and experiences to function as genetic counselors in a wide range of settings and roles. The Program is accredited by the Accreditation Council for Genetic Counseling and graduates are eligible to sit for the national certification examination

administered by the American Board of Genetic Counseling (ABGC). The Program strives to train students who can interface between patients, clinicians and molecular and human geneticists. The stand-alone Genetic Counseling degree is 40 credits and includes both a written and oral comprehensive exam given in their second year and the completion of a research project. The Program has had an excellent track record: approximately 50-60 applications are received each year; since 2000, 60 students have graduated; there has been a 98% pass rate on the ABGC certification examination; and 90+% are employed as genetic counselors throughout the US and Canada.

# **D.** Dual Degree Program Leadership and Anticipated Participation

The dual Degree in Genetic Counseling and Bioethics will be co-directed by Dr. Anne Matthews, Professor of Genetics and Genome Sciences and Dr. Aaron Goldenberg, Associate Professor of Bioethics. It will utilize the expertise of other genetics and bioethics faculty. We anticipate that we will <u>accept up to two</u> students each year for the Genetic Counseling/Bioethics Dual Degree Program (currently the Genetic Counseling Training Program can accommodate six students). In the future, we may be able to accommodate more students depending on the size of the genetic counseling program (the Genetic Counseling Program is planning on expanding their program to eight students per year within the next two years) and available faculty.

# **E. Dual Degree Requirements**

The curriculum for the Dual Genetic Counseling/Bioethics Degree will consist of 59 credit hours to be completed in 2.5 years (Option 2) *See Appendix A*. This program will allow an enrolled student to finish the program in 5 full time semesters. Students enrolled in the dual degree program will spend their first year taking courses entirely within the Genetic Counseling Program and then will spread out their Bioethics coursework over the next 1.5 years.

The reduction in total credit hours is accounted for through the counting of the BETH 412: Ethical Issues in Genetics and Genomics course (3 credits) and GENE 601 Research Hours (6 credits) towards both degrees. Both of these elements will be key elements of the dual degree program:

#### 1. Core Genomics and Ethics Course

One of the centerpieces of the Joint Degree between Bioethics and the Genetic Counseling Program is the new core course on the Ethical, Legal, and Social issues associated with advancements in Genetics and Genomics. For many years the Department of Bioethics had a Course on Ethical Issues in Genetics (BETH 412). However, with the departure of the course director in 2009, the course had not been taught in over 4 years. With recent advances in genomic technology and the integration of genetics into clinical care, we believed it was vital that the University offer a new course on the Ethical Implications of these advances.

BETH 412, Ethical Issues in Genetics and Genomics, is designed as an interactive seminar with the goal of exposing graduate students to the ethical, legal, and social implications of advances in genomics and genetics. The Course is designed to utilize multimedia, peer led discussions, and presentations from local/national experts. The curriculum focuses on two major areas; *1*) *Genomics in Research Settings and 2*) *Genomics* 

*in Clinical Settings*. Topics for the course include the predictive genomic screening, prenatal diagnosis, genetic privacy, implications for incidental findings, human genetic variation research and health disparities, and implications of genetic testing in pediatric settings. It also includes sessions on the history of genetics and ethics, to better contextualize current controversies. BETH 412 has now been taught for two semesters with excellent evaluations/reviews from both bioethics students and genetic counseling students. Students have consistently rated the interactive nature of the course and its focus on both historical and current topics in genetics and ethics very highly.

While the Genomics and Ethics Course is required for students enrolled in the Genetic Counseling Training Program, thus required for those students enrolled in the dual Degree Program, it will also be available to other students in the Bioethics Program, the Genetics Department and other graduate programs across the CWRU campus. To date, students from Bioethics, genetic Counseling, Medical Physiology, and Nursing have enrolled in the course.

#### 2. Genetics-Ethics Research Project

Currently, the Genetic Counseling Program is under Plan B of the School for Graduate Studies. In addition to both a written and oral comprehensive examination, the Program requires a research project be carried out for the completion of the Program. This scholarly project may be literature-based, a clinical or counseling project, or laboratory-based project and must relate to some aspect of genetic counseling. At the completion of the project there is a committee oral defense. The final research project is submitted to the research committee in manuscript format suitable to submit for consideration for publication.

For the dual degree, students will be required to choose a research project that includes ethical, legal, or social issues of genetic counseling practice, clinical genetics or genomics, or genetic research. Students will also be required to include at least one Bioethics Faculty member on their Research Project Committee.

#### F. Dual Degree Governance

The program will be administered by the Directors of the MA Program in Bioethics (Goldenberg) and the Director of the Genetic Counseling Training Program (Matthews). Drs. Goldenberg and Matthews will act as student advisors for each of the two program individually, but will meet monthly to assess student progress, address any student or faculty concerns, and assure that student progress in each of the programs, and their overlapping components, are being achieved.

#### **G.** Admissions

Students who would like to enroll in the dual degree program will apply and be admitted into <u>each program separately</u>. While admissions committees for each program will communicate with each other regarding applicants, each admissions committee will decide independently about the suitability of the applicant to their program. Fulfillment of the requirements for admission to the School of Graduate Studies at Case Western Reserve University must be met as well as those required by the Genetic Counseling Training and Bioethics Programs. There may also be situations in which a first year genetic counseling student may wish to add the bioethics degree to his or her program. Because the first year of the dual degree consists of only genetic counseling coursework, this would be possible. In these cases, the students would still need to apply to the Bioethics program and be admitted to pursue the dual degree. In addition to applicants who have completed their undergraduate and/or graduate degrees, students in the Integrated Graduate Studies program (IGS) at CWRU would be eligible for consideration for admission into the Genetic Counseling/Bioethics dual degree program.

Admission requirements for the Genetic Counseling Program include successful completion of the following:

- Prerequisite courses: Biology minimum of one year; Genetics minimum of one semester; Biochemistry minimum of one semester; Statistics minimum of one semester and Psychology minimum of one semester
- Results of Graduate Record Examination scores on the general examination.
- Advocacy Experiences. Counseling experiences that are relevant to genetics, medical genetics and genetic counseling are highly recommended. Such experiences as counseling with a crisis hot line, Planned Parenthood program, peer/community counseling centers (paid or volunteer), working with individuals with disabilities and shadowing a genetic counselor are examples of experiences that highly desirable. Experience working in a DNA/molecular genetics/cytogenetic laboratory, or teaching assistant positions in biology or genetics courses are also very appropriate. The applicant should strive for experiences that provide for one-on-one interactions with others. Moreover, in the application personal statement, applicants should demonstrate an understanding of the field of genetic counseling, what led to choosing this field as a career and discuss how previous experiences have enriched his or her understanding of the profession of genetic counseling.
- Interview. A personal interview is required. All interviews are by invitation only to assess maturity, written and oral communication skills, an awareness of the professional role of the genetic counselor and the genetic counseling profession.

Admission requirements for the Bioethics Program include successful completion of the following:

- Results of Graduate Record Examination scores on the general examination.
- Interview. A personal interview is required. All interviews are by invitation only to assess maturity, written and oral communication skills, an ability to complete graduate level work.

# Program Evaluation and Outcome Assessment

Outcomes data to assess the dual degree Program's efficacy will be evaluated based on graduates' performance on the American Board of Genetic Counseling certification examination and graduates' employment and professional activities following graduation. Graduates will be contacted on a yearly basis and asked to update their contact information and provide a short narrative of their current activities. They will also be queried via an on-line survey approximately two years after graduation and asked to provide information about their employment, the types of positions they hold, their involvement in national organizations, types of research they have participated in and how their ethics training has expanded or promoted their professional roles.

# Appendix A: Dual Degree Curriculum

# Total Credit Hours = 59 Genetic counseling = 32 hrs; Bioethics = 18; Count for both = 9 (BETH 412 – 3; GENE 601 Research – 6)

	FALL			SPRING				SUMMER	
	Course #	Name	Credit Hrs	Course #	Name	Credit Hrs			
YEAR	GENE 524 AM	G: Cyto/Molecular Gene	tics 2	GENE 529	Psychosocial Genetic	c Counseling	3	GENE 532 Clinical	
1	GENE 526 AM	G: Quant/Genomics	2	GENE 525	AMG: Clinical Geneti	ics	2	Practicum	3
	GENE 528 Prin	ciples Genetic Counselir	ng 3	GENE 531	<b>Clinical Cancer Gene</b>	tics	2		
	SASS 477 Practice Foundation Methods & Skills 3			GENE 601	Research – Seminar 2				
	Total Credit Hours = 10				Total Credit Hours = 9			Total Credit Hours	= 3
YEAR	GENE 532 Clin	ical Practicum	4	GENE 532	Clinical Practicum		4	GENE 601 - Resear	ch
2	GENE 527 AM	G: Metabolism	2	BETH 412	Ethical Issues Genet	ics / Genomics	3	3 credit hrs	
	2BETH 401 Fou	undations in Bioethics I	6	BETH 402	Foundations in Bioet	thics II	6		
Total Credit Hours = 12					Total Credit Hours = 13			Total Credit Hours	= 3
YEAR	GENE 601 Rese	earch	3						
3	BETH 405 Clini	ical Ethics Rotation I & I	I 3						
	BETH Elective		3						
Total Credit Hours = 9									