

The Dynamic Field of Genetic Counseling and How Students Can Best Prepare Themselves

by  
Malia Vaerine Bauder

A THESIS

submitted to  
Oregon State University  
Honors College

in partial fulfillment of  
the requirements for the  
degree of

Honors Baccalaureate of Science in Biochemistry and Molecular Biology  
(Honors Scholar)

Presented May 30, 2019  
Commencement June 2019



## AN ABSTRACT OF THE THESIS OF

Malia Vaerine Bauder for the degree of Honors Baccalaureate of Science in Biochemistry and Molecular Biology presented on May 30, 2019. Title: The Dynamic Field of Genetic Counseling and How Students Can Best Prepare Themselves

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Dee Denver

Genetic counseling, a healthcare profession centered on communicating genetic information to patients and helping them understand it, has been rapidly evolving with the development of genetic sequencing and editing technology over the past decades. Consequently, future and current genetic counselors must address societal and ethical implications, as well as historical applications, of these technologies. In addition to discussing some of these issues, including historic racial discrimination and the potential for disability discrimination, this thesis serves as a practical guide for undergraduate students interested in pursuing a career in genetic counseling.

Key Words: Genetic counseling, genetic technology, genetic screening, eugenics, graduate school

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I understand that my project will become part of the permanent collection of Oregon State University, Honors College. My signature below authorizes release of my project to any reader upon request.

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Malia Vaerine Bauder, Author



## Introduction

This thesis was written by a student of Oregon State University motivated to guide future undergraduates interested in genetic counseling. As the field is rapidly changing and evolving, it can be difficult for students to find resources to help with the process of preparing for this career. I am by no means an expert, but I have experienced this process myself and hope to share what I have learned. There is a need for future genetic counselors who are passionate about genetics and their patients.

There are two primary objectives of this thesis: to discuss ethical considerations of genetic technology and the societal impacts that genetic counselors will need to address, and to serve as a practical guide for students interested in pursuing this career.

## *About the Field*

Genetic counseling is essentially the process of providing genetic health care to patients by communicating their DNA-level characteristics in an understandable way. As the field has advanced, several different subfields have emerged, including cancer, prenatal, family, and pediatrics. These categories are mostly self-explanatory, and each comes with its own difficulties and challenges. In cancer genetics, there will likely be a point in your career where you will need to tell a patient that they are at a higher risk for a certain type of cancer because of their genetic test results. Prenatal genetics may involve supporting a pregnant couple after you tell them their child is at high risk for a genetic disorder and guiding them on the next steps they can take in their pregnancy. Regardless of the focus, there will be difficult moments, but there will also be rewarding ones. It is essential to give yourself the emotional tools necessary to communicate these things to your patients and to support them by providing resources.

Genetic counseling is rapidly expanding – according to the US Department of Labor, it is among the top 15 fastest growing jobs (Bureau of Labor Statistics, 2019). Job opportunities in this field are growing more quickly than the national average, and it is predicted that by 2024 it will have grown by 29 percent (Rogers, 2017). According to Mary Freivogel, the president of the National Society of Genetic Counselors, “Genetics permeates everything—there won’t be enough genetic counselors to see every patient who gets genetic information.” (Rogers, 2017). The demand for genetic counselors is high, and it will only rise as genetics become more integrated into our everyday lives.

The traditional career path taken with a Master’s in Genetic Counseling is working in a healthcare setting, such as a hospital or a private practice, but there are many other options available, including working with clinical labs, advocacy work, public health, and healthcare provider education. Oftentimes genetic counselors will be involved in research, particularly regarding human genetics studies. As genetic counselors are trained to interact with patients, it can be helpful for full-time researchers to utilize genetic counselors as a point of contact between the researchers and the subjects.



Additionally, as at-home genetic testing technology advances, those with a genetic counseling degree may want to become involved with the design, marketing, and implementation of these tests. Companies like the well-known 23andMe have begun offering screening tests for genetic disorders and mutations that customers can use from the convenience of their homes. These companies require genetic counselors with an understanding of both science and people to aid in the design of tests that will be as accurate and convenient as possible. There is also a need for trained genetic counselors to review and communicate the test results to the consumers through the companies. As the phenomenon of genetic tests for entertainment continues to grow, this need will increase.

It is common for genetic counselors to split their time between seeing patients and some form of research, so don't worry about committing to one or the other without being able to do both.

For more information about specific details of genetic counseling as a career, this guide from the National Society of Genetic Counselors contains helpful resources:

<http://www.aboutgeneticcounselors.com/About-Genetic-Counselors/Considering-Genetic-Counseling-as-a-Career>

## **How the Field is Changing**

### *Ethical and Moral Questions Surrounding Genetic Editing*

Genetic technology is advancing at an extremely rapid pace. With the future of genetic engineering quickly approaching, there have arisen ethical concerns about what will soon be – and already is – within our power. Recent scientific revelations that have come out of China, a global hub for biotechnology due to some of their historically more relaxed regulations on genetic experimentation, indicate a concerning future trend (Cryanoski, 2019). In late 2018, a Chinese researcher announced to the world that he had successfully utilized genetic editing technology to alter the DNA of twin girls for the purpose of ensuring their resistance to HIV (Normile, 2018). Although the scientific integrity and results of the experiment have been called into question, regardless of the validity of his claims, Pandora's box has been opened. We have now crossed the line of genetically editing human embryos, and we have begun widespread international discussions on the legality of utilizing these genetic editing tools on humans for both medical and aesthetical purposes.

As we consider the morality of genetic editing, there becomes a clear line between medical-related alterations and changes made for purely aesthetic or personality-related purposes. While highly controversial, the HIV-resistance experiment appears to have fallen in the former category. However, there is evidence of future plans for genetic editing that rest firmly in the latter. Beginning in 2013, the Beijing Genomics Institute undertook a global project to sequence the genomes of individuals with exceptionally high IQs (Yong, 2013). The project aims to identify essential genes involved in the determination of intelligence. Based on the history of genetic experimentation in China, it wouldn't be unreasonable to

assume that they may use this genetic information as a direct method to create what some refer to as “superbabies”.

There exist many ethical issues surrounding the future of genetic technology. Should we be permitted to edit the genomes of our unborn children to select desired traits? As genetic counselors, we must be prepared to have these discussions with each other, our patients, and potentially legislators as they attempt to determine the validity of the power we possess. There are several key concerns that fall under this primary ethical consideration. One question to contemplate is what are the potential negative consequences of allowing gene editing of embryos for traits beyond hereditary diseases? For example, if a couple desired to have a tall child for the purpose of being successful athletically, should they be permitted to select for this? Hypothetically, let’s say 85% of couples want the same tall trait in their children. If we allow all of these families to edit their embryos’ genomes to confer the “tall” gene, what impacts will this have on the genetic diversity of future populations? What will be the consequences if the “tall” gene is related to some type of genetic disorder that was previously unknown, and now the overwhelming majority of the population carries it? These are serious questions we must consider as we may never have a complete understanding of the complexity of the human genome.

Another concern with widespread genetic editing is access to the technology based on socioeconomic class. In 2017, 8.8%, or 28.5 million, of people living in the United States had no access to health insurance at any point during the year (Berchick et al., 2018). The uninsured rate was particularly harsh for minorities, with African-American and Latino communities suffering the most at 10.6% and 16.1% respectively (Berchick et al., 2018). These statistics represent access to basic healthcare. If and when gene editing becomes a healthcare option, it will almost certainly be expensive and difficult to obtain. Therefore, economic and ethnic groups with lower incomes and rates of health insurance will fall behind wealthier ethnic majorities, increasing the socioeconomic divide even further. Historically, genetic technology, specifically genetic screening, has favored those who fall under “favorable” categories – the mentally and physically able, members of social and ethnic majorities, and the wealthy.

### *Historic Discrimination Against Minorities*

In August of 2010, the National Collegiate Athletic Association (NCAA) instituted a widespread mandatory genetic screening policy for all Division 1 athletes prior to participation in any athletic events (Tarini et al., 2012). This was the result of a settlement with the NCAA and the family of Dale Lloyd II, a Rice University football player, who in 2006 collapsed during practice and later died due to complications from the sickle cell anemia trait (ESPN, 2009). From 2010 on, the NCAA required sickle cell trait testing in athletes as part of their medical exam. This has a serious potential benefit in that predictions estimated the policy could prevent about seven deaths over the course of 10 years (Tarini et al., 2012). However, it becomes more complicated when the demographics of NCAA athletes are taken into account. In 2012, 57.2% of Division I basketball players were African American, despite composing only 13% of the American population (Harriot, 2017).

Incredibly, black men made up only 2.5% of undergraduate students but 56.3% of football teams and 60.8% of men's basketball teams in the 2014-15 school year (Harriot, 2017). Although the sickle cell screening applies to all NCAA Division I athletes, it affects a disproportionate number of African Americans and there are concerns of discrimination against those who test positive for the trait. 63% of sports medicine physicians have expressed worry over possible discrimination by the NCAA or coaches towards athletes with the sickle cell trait (Acharya et al., 2011). Considering sickle cell anemia affects 73.1 out of every 1,000 African Americans but only 3 out of every 1,000 white Americans, there is a clear potential for racial discrimination with this screening policy (CDC, 2018). Additionally, mandatory genetic screening for sickle cell anemia touches on a nerve in our country's past with African Americans.

Historically, the United States has a habit of ignoring pervasive issues that affect primarily African Americans, particularly regarding health care. Baltimore is a good example of this. In Cheswolde, a wealthier, more white area, the life expectancy is a high 87. However, a mere nine miles away in Clifton-Berea, a neighborhood populated by African Americans, the life expectancy is two decades shorter at 67 (Khazan, 2018). This stark disparity can be attributed to health complications arising from racial discrimination. In the year 2000, an estimated 176,000 deaths in America were due to racial segregation (Galea et al., 2011). This historic refusal to address health issues affecting minorities is part of the reason for the surprise that met President Nixon in 1971 when he announced a special effort to combat the previously obscure sickle cell anemia (Culliton, 1972). Consequently, twelve states passed legislation by 1972 mandating sickle cell genetic screening specifically targeting African Americans (Culliton, 1972; Lobo, n.d.).

The intentions behind these screening policies were presumably noble, as are the intentions behind the NCAA regulations: to reduce the deaths and complications resulting from sickle cell anemia, which can include vision loss, chest pain and difficulty breathing, and a higher risk of infections (CDC, 2017). However, during the 1970's, the government faced outrage from African Americans who felt they were being discriminated against because of their DNA. Although President Nixon and Congress passed the National Sickle Cell Anemia Control Act in the spring of 1972, requiring that screening be voluntary in order to reduce the discrimination, inequality continued (Lobo, n.d.). African Americans were denied employment opportunities, insurance, and education throughout the 1970's simply because they had tested positive for the sickle cell trait (Lobo, n.d.). Furthermore, doctors were often uninformed and communicated poorly with their patients on the subject of the sickle cell trait, leading to distrust between African Americans and their health care providers (Naik and Haywood, 2015). Although the intentions were good, the policies themselves led to racial discrimination and social stigmatization for the African American population. We would hope that in the future, these genetic technology and screening tools will be used in a more just way.

Unfortunately, we already have an indicator of how genetic screening policies will be applied in the near future, and it appears to be following the same historic trends of racial targeting. In May of 2019, the Department of Homeland Security announced they will begin using RapidDNA technology at the U.S. border with Mexico to discern true families seeking asylum from those attempting to pass children as their own in an effort to receive more

lenient treatment at the border (Molteni, 2019). Families intending to cross the border may be forced to submit a DNA sample for testing in case of fraudulent behavior. The issue with this strategy is that the DHS is effectively weaponizing DNA sequencing technology, using it as a threat or deterrent to families seeking asylum in our country. While the former DHS Secretary justifies this application with the “cases of fake families [that] are popping up everywhere,” the actual statistics demonstrate that rates of fraud in family units apprehended at the southern border in 2018 are close to 1% (Molteni, 2019). Although it may prove useful in cases of human trafficking, DNA sequencing can’t account for non-traditional families with adopted children or step-children, in which case the DHS may confiscate the child, separating more families. There are also no guarantees that the genetic information will not be stored in a database for later use. Finally, as the vast majority of people crossing the southern border are of Latin American descent, this is just another example of genetic technology being used to target a particular minority ethnic group. I hope we can prevent history from repeating itself in the future.

### *Crossroads of Disability Rights and Genetic Technology*

While gathering information for this guide, I interviewed George Estreich, a writing professor here at OSU who is well-renowned for his disability advocacy. He is particularly motivated for advocacy by his teenage daughter with Down Syndrome. George mentioned to me that as recently as 1969, when he started elementary school, people with Down Syndrome weren’t allowed to attend public school. The right to public school education was only granted to disabled children in 1975 with the Education of All Handicapped Children Act (Meldon, n.d.). Thankfully, societal acceptance of those with disabilities has come far since then. We now have legally-mandated “special education” courses in public schools and anti-discrimination policies that serve to protect our disabled population, but has our perception advanced as well as our legislation?

Historically, public perception on disability has been dynamic – at times positive, but at other times severely negative. During the 16th century, many Christians believed that disabilities were a result of being possessed by evil spirits and thus subjected the disabled to mental and physical “cleansing”, oftentimes bordering on torture, to exorcise the spirits (Thomas, 1957). In the early 20th century in the United States, the rise of eugenics – the pseudoscience of directed evolution to enhance the human race – specifically targeted those who were “feeble-minded” or deemed unworthy of reproducing and passing on their genes (Rivard, 2014). There were mandatory sterilization laws widely passed, requiring those with physical and mental disabilities (as well as other population groups, including alcoholics and criminals) to be sterilized before marriage so as not to allow the disabled to reproduce (Lombardo, n.d.).

Fortunately, our attitudes regarding disabilities today have improved drastically since the height of eugenics popularity in the US. Although things aren’t perfect, we are no longer outright forcing sterilization on those with genetic disabilities. However, it appears that the majority of our population perceives quality of life to be lower in those with disabilities, a misconception that disability rights advocates have contested. Generally, people with Down Syndrome rate their quality of life as very high, with one study finding 99% of those

surveyed indicated they were happy (Skotko et al., 2013). This prejudice may contribute to our current and future application of these biotechnology tools, such as prenatal screening and genetic editing, that we have and will have access to.

A strange cultural and biological phenomenon is occurring in Iceland. The proportion of people with Down Syndrome in the population is essentially zero. In 2009, there were only 3 babies born in the entire country with Down Syndrome (Will, 2018). This is due to the increasing popularity of non-invasive prenatal testing (NIPT), where parents are provided with an estimate of the likelihood that their unborn baby has Down Syndrome or another genetic disorder. The abortion rate for pregnancies determined to have a high risk of Down Syndrome is nearly 100% in the country. Critics say this high abortion rate is a result of “heavy-handed genetic counseling”, and that Icelandic genetic counselors are persuading expecting mothers to abort (Will, 2018). Is this an indicator of future global trends?

Essentially, we are living in an age where there is a collision of the rise of biotechnology and the social acceptance of people with disabilities. While it is true that acceptance and accommodation of the disabled population has never been higher in the history of the United States, it is also true that our recent advances in technology are offering us an opportunity to eradicate disability – or at least come close – using a method that some may consider to be more ethical than outright genocide. The moral aspects of editing genetic abnormalities out of every embryo are unclear because this step would hypothetically occur prior to the birth of the child. Does this mean we should allow this removal of disabilities using our new biotechnology, or does it fall under the same category as prior treatment of disabled babies, where historically they were either killed or left to die? And is it ethical to allow parents to decide for themselves on a case-by-case basis?

Clearly there are many questions that we don’t yet have answers to, and access to this technology will likely become a hot topic in legislative circles. The field of genetic counseling will require professionals with the ability to thoughtfully consider these questions and provide patients with the most unbiased care possible. There are several important considerations for future genetic counselors with regards to this collision of disability rights and biotechnology:

1. Communication, while already an essential aspect of providing genetic healthcare, will become even more important when discussing disabilities with parents. The ability to clearly portray the potential risks of every procedure, along with the potential benefits, is crucial to the healthcare field.
2. There will be a need for genetic counselors capable of emotionally supporting parents when they discover the narrative of their pregnancy has changed. Different couples will react in unique ways to the news that their child likely has a genetic disorder, and it will be important to be equipped with tools for handling each situation and offering potential next steps in their pregnancy.
3. Providing parents with resources for learning about each disability, and thereby giving them tools to aid in their decision-making process, will help them process new information they have received about their pregnancy. This can be difficult as the first instinct for many couples will be to do an internet search, which can result in a sea of

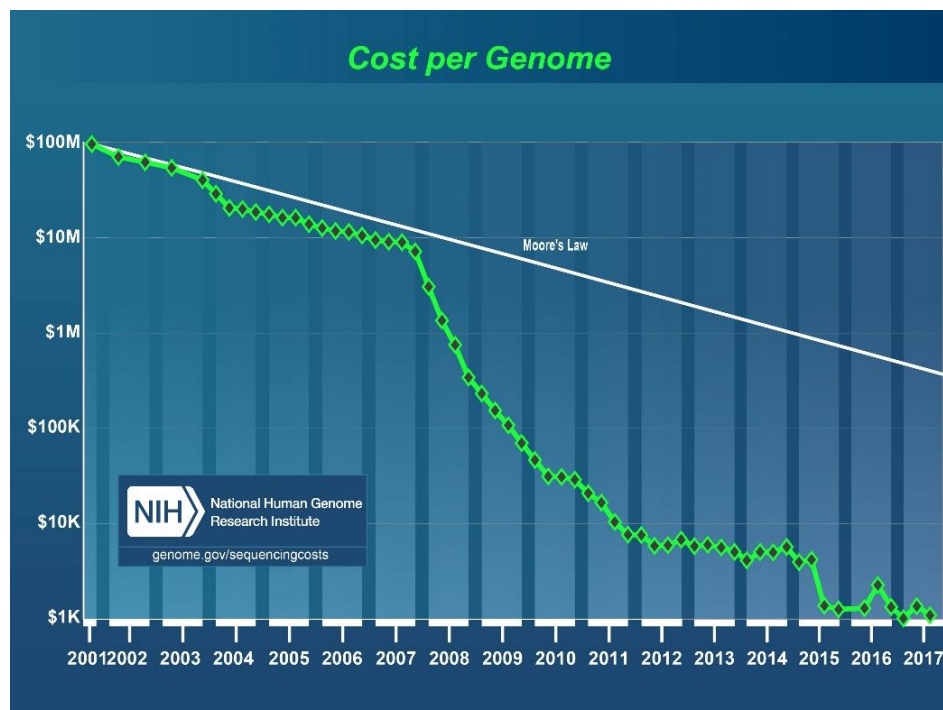
misinformation as it can be challenging to discern credible sources from unreliable ones. I have listed a few resources below:

- a. <https://www.lettercase.org/>, a balanced portrait of Down Syndrome to answer parents' questions.
- b. Dr. Brian Skotko's website, a Board-certified medical geneticist who specializes in disabilities, and has published several resources as well as hosted workshops.

Whatever the path the technology and corresponding legislation take, it will be essential for future genetic counselors to be compassionate and thoughtful and communicate well regarding this sensitive topic.

### *Information Access*

Nearly three decades ago in 1990, the Human Genome Project was undertaken to generate a reference library for the human genome. At the time of the first successful human genome sequence production, it cost roughly \$500 million to \$1 billion (Schwarze, 2018). Since then, the cost has decreased to less than \$1,000 per genome, mainly due to the development of faster, cheaper, and more efficient genome sequencing technologies (Schwarze, 2018). Previously, high costs were a barrier to sequencing in a clinical setting, but now it is much more feasible. An image from the National Institutes of Health demonstrates the dramatic drop in whole-genome sequencing cost:



<https://www.genome.gov/about-genomics/fact-sheets/Sequencing-Human-Genome-cost>

The straight line indicates Moore's Law, which assumes the doubling of 'compute power' every year, driven by social change, economic growth, and productivity (Keyes, 2006). Technologies that maintain pace with Moore's Law are considered to be very successful.

As genetic sequencing technology becomes cheaper and more accessible, it is becoming more common. Companies like 23andMe and Ancestry have capitalized on this new technology and are primarily offering sequencing services for entertainment purposes (for example, to learn about your genetic ethnicity), although 23andMe and other companies have ventured into the market of health-related sequencing. The popularity of these services is evident in the number of social media posts, blogs, and pop culture articles documenting this entertainment. Additionally, with the increasing convenience of whole-genome sequencing, it appears that we may be headed towards a future of healthcare where one goes to the doctor, spits in a plastic cup, waits around for an hour, and is then given their sequencing results that reveal what was ailing them. We may soon be using our genomes as identifiers instead of fingerprints. As this potential future is on the horizon, we must ask ourselves a key question about the practicalities of a world where the most intimate information about every individual is available within a matter of minutes:

Who should have access to this information, and what should they be allowed to do with it?

If we are not careful with our legislation, it may become even easier for insurance companies and employers to take advantage of their dependents and employees. For example, let's say a person has a genetic mutation that makes them more likely than the average person to develop heart disease later on in life. If his insurance company has access to that information, should they be allowed to charge him more than the average person in case of an incident involving his heart? Or if he later suffers a heart attack, do they reserve the right to refuse payments on his medical bills because possessing that genetic mutation qualifies as a pre-existing condition? Do they have a right to have access to his genetic information in the first place? Currently, insurance companies don't have an inherent right to access medical records, but if you don't sign a release allowing them to review your records, it is extremely likely that your claim will be denied. Based on the current regulations that permit insurance companies to do this, it seems probable that genetic records will follow the same path.

Let's go back to the same example of the man with the heart disease mutation. Let's say he is in the process of searching for a new job. He interviews at a company where he thinks he would be a good fit. Hypothetically, if the company executives gain access to his genetic information and see his increased likelihood of developing heart disease, do they have a legal right to refuse to hire him? This genetic information could fall under two categories that we have today. It could be treated in a similar way to a background check, where a company has a right to know an applicant's criminal history. Or it could be treated like a pregnancy, where the company is not allowed to ask if an applicant is pregnant.

We are fortunate to have a federal policy in place already, the Genetic Information Nondiscrimination Act (GINA) of 2008, that prevents discrimination in health insurance and employment to a certain extent (USEEOC, 2008). However, GINA and related laws do not protect citizens from genetic discrimination in every circumstance. It also does not prevent the government from accessing these genome databanks that have developed with the

popularization of ancestry genetic testing. Additionally, genetic technology and its implications have evolved significantly since 2008, and legislation rarely, if ever, keeps up with the rapid pace of technology advancement. GINA may be a start, but we will need more extensive legislation that accounts for a wider range of situations and technologies developed.

Another entity that may want access to the genetic information of individuals is the federal government and corresponding law enforcement agencies. DNA sequencing technology has drastically changed the field of forensics. In early 2018, three decades after the case went cold, the Golden State Killer was identified and arrested thanks to genetic information from a relative that had used an online genealogical website (Associated Press, 2018). Our new genetic technology has the potential to revolutionize the criminal justice system by finally allowing identification of dangerous criminals.

Some will argue that this is a violation of our right to privacy, while others will say that these entities have a right to information, and particularly in the case of solving decades-old murders, is worth the risk of a privacy breach. I truly don't know which way the scales will tip, but here is another opportunity for genetic counselors to play a non-traditional role as lobbyists and science advisors to politicians. There will be a great need for trained scientists with a strong background in genetics who are also skilled at science communication and can consider broad moral and ethical implications of the technology being addressed.

Although the social and moral considerations are extensive in this field, genetic counselors are provided certain guidelines and recommendations on how to handle certain situations. These are taught in graduate programs and serve as a guide when working in the field. For further reading and a more comprehensive discussion on ethics in genetic counseling, the National Society of Genetic Counselors has published Position Statements on the Society's Code of Ethics, which I have linked below:

<https://www.nsgc.org/p/bl/et/blogid=47>

Similarly, there are official NSGC Practice Guidelines available for review online:

<https://www.nsgc.org/page/practiceguidelines>

## **How to prepare yourself as an undergraduate student**

Just like any field, there are many paths you can take on your way to this career to be very successful. The things I include here are suggestions that I have found will make you a more competitive applicant for master's programs and help prepare you for a career in genetic counseling.



## *Programs of study*

Although genetic counselors most commonly have undergraduate degrees in biological fields, some have degrees in psychology or other areas. Oftentimes students major in healthcare or social science related degrees. Pre-medicine majors are also beneficial because they often include biomedical ethics and psychology courses with biological sciences. The majority of graduate programs do not require a specific degree. However, a strong background in genetics can help you stand out from other applicants and make you a more competitive candidate, so a beneficial major would place an emphasis on biochemistry and molecular genetics.

## *Classes*

There are several classes that are required or strongly recommended to have as a background before applying to a master's program. Some of the more apparent ones are biology, genetics, and psychology, but there are also other classes that are recommended. These include calculus, organic chemistry, and statistics. A schedule of classes offered at OSU can be found here:

<https://classes.oregonstate.edu/>

For psychology and statistics, a lower-level course will likely be fine, but it is recommended to take advanced upper-division courses in biology, biochemistry, and genetics. In addition to becoming a more competitive applicant, experience in these upper-level courses will provide a solid background for the advanced courses required in graduate school.

## *Shadowing experiences*

Shadowing genetic counselors is very important in order to get an idea for what the day-to-day responsibilities actually look like. The admissions offices at the master's programs will want to see that you know what the career entails and you have gathered enough information to know that this is truly what you want to pursue. Many genetic counselors are open to speaking with students or having them spend a day at their place of work, but at times the Health Insurance Portability and Accountability Act (HIPAA) laws, which provide data privacy for medical information, can make it tricky to sit in on interactions with patients (Rouse, 2015). At the very least, it can be extremely helpful to speak to a genetic counselor and ask them questions, whether over the phone, in person, or through email.

If the genetic counselor you reach out to is open to a shadowing experience, it will typically be about a day in length and consist of you meeting them at their clinic or place of practice. A typical day working as a genetic counselor consists of counseling patients, reviewing test reports to ensure the results are clinically accurate prior to sending them to patients and their doctors, answering questions from other healthcare providers about genetics, and business

paperwork. You may follow them into their appointments with patients and listen as they provide health care, which involves explaining test results and providing paths to take. Your ability to sit in on these sessions does depend on the wishes of the patients and the genetic counselor, so you may not always have access to these patient meetings. Between appointments, you will likely sit with them in their office as they work, which often means building pedigrees (a visualization of a patient's family history and potential disease heredity) and other paperwork. As there tends to be confusion from the general public on genetic counseling as a career, there are several resources for you to read more about the day-to-day responsibilities involved. I have linked a few helpful websites below.

<https://www.coopergenomics.com/blog/disease-awareness/a-day-in-the-life-of-a-genetic-counselor/>

<https://www.chop.edu/news/day-life-genetic-counselor>

If the genetic counselor is very busy or you are unable to sit in on sessions with patients, it may be a short shadowing experience of just a few hours, but this also provides an opportunity to ask questions directly. This is an excellent way to experience the daily tasks of a genetic counselor and learn if you are interested in this career. It is highly recommended to shadow at least one genetic counselor before applying to graduate school. Additionally, as it is currently a smaller field (although growing quickly), shadowing can be a great resource for building connections. A recommendation from a genetic counselor can go far in your applications for jobs or other opportunities in the field.

The National Society of Genetic Counselors makes it easy to find someone near you. Their home page can be found here:

<https://www.nsgc.org/>

Their website includes a feature where you can search for genetic counselors in the U.S. and Canada by location.

<https://www.nsgc.org/page/find-a-genetic-counselor>

You can narrow it down to student contact:

[https://www.nsgc.org/page/student\\_physician-contact](https://www.nsgc.org/page/student_physician-contact)

Underneath the name of the genetic counselor, it will be listed whether or not student contact is welcome. Below is an email template that you may use for contacting a genetic counselor the first time:

*Dear \_\_\_\_\_,*

*My name is \_\_\_\_\_ and I am a student at \_\_\_\_\_. I'm studying \_\_\_\_\_ and I am interested in pursuing a career in genetic counseling after graduating.*

*I am currently looking for opportunities in shadowing genetic counselors. I saw on the NSGC website that you are open to student contact. I would love to meet with you to ask some questions and learn more about the field. If you are available and interested, I can suggest some dates that I would be able to meet.*

*Thank you so much for your time, it's much appreciated. I look forward to hearing from you.*

*Sincerely,*

---

Some questions that you might ask include:

How did you learn about genetic counseling and what drew you to the field?

What was your undergraduate degree in?

Where did you attend graduate school?

What made you choose that program?

What does an average work day look like for you?

What is your favorite part of your job? Your least favorite part?

What do you think is required for a person to be a successful genetic counselor?

How do you see the field changing?

If you weren't a genetic counselor, what would you choose to be?

Is there anything you wish you had done differently leading up to your career?

Do you have any recommendations for me as a student and a future genetic counselor?

### *Advocacy and crisis counseling*

Experiences with advocacy and crisis counseling are essential prior to applying for graduate school. An important aspect of genetic counseling is being able to deliver potentially difficult medical news to patients and support them emotionally and professionally. The majority of volunteer organizations involved in advocacy will train you in counseling, so it is not necessary to have these skills prior to volunteering. This type of experience is widely looked for in graduate school applicants. There are involvement opportunities with the Center Against Rape and Domestic Violence, a shelter local to Corvallis. Their website is listed here:

<https://www.cardv.org/>

They often look for volunteers to aid in services such as the 24-Hour Crisis and Support Line, Restraining Order Assistance, and the 24-Hour Emergency Shelter.

Additionally, there are many organizations where you can volunteer regardless of your location. For example, the Crisis Text Line is always looking for volunteers to work from their cell phones:

<https://www.crisistextline.org/>

Another example is The National Suicide Prevention Lifeline (NSPL), a national organization that has local centers all across the country:

<https://suicidepreventionlifeline.org/>

If you are proficient in Spanish, there are opportunities to help with native Spanish speakers. The NSPL has categories of focus such as youth, disaster survivors, Native Americans, veterans, LGBTQ+, and more.

Be sure to research crisis counseling volunteer programs local to you as there may be opportunities in the summer and over breaks if you return home. No matter your availability or skills, there will be a program that could use your help.

Additionally, if working in crisis counseling isn't possible or realistic, there are other options for types of volunteering opportunities, particularly with organizations that provide healthcare or mental health services to underrepresented or underprivileged populations. Some of these organizations include the Ronald McDonald House, Planned Parenthood, or Camp Attitude, a summer camp for disabled children, which is linked below:

<http://www.campattitude.org/>

Working in a therapy group, such as music therapy or horse therapeutic riding camps, will also be beneficial.

### *Student jobs and experiences*

Genetic counseling is a field that doesn't require as much laboratory experience as some other medical careers. That being said, it is important to have a solid understanding of genetics and the types of genetic technology used for sequencing and editing. If you have the ability to, working in a genetics-related lab is a helpful experience as a background for understanding the type of research that goes on in the field of genetic counseling. However, any type of job that teaches you skills for interacting with people will be helpful. Other options include working at the front desk of a medical clinic, becoming a pharmacy assistant at Student Health Services on campus, or working in a customer service type position. It is important to gain experience in science communication, working with people, and the medical field. Volunteer opportunities in crisis counseling and advocacy (as detailed above) are crucial.

Summer internships are not required but may be helpful for developing these skills. The Oregon Museum of Science and Industry (OMSI) in Portland, OR has unpaid science internship positions available during the summer, which is a great way to learn about science communication. There are also science museums in Eugene and in Ashland that you may want to look into depending on your convenient location. There are summer camps that happen on OSU campus with opportunities for both volunteer and paid positions. It can be

very difficult to find genetic counseling internships because the majority of these are reserved for graduate students in their programs, but there is at least one in Texas specific to undergraduate upperclassmen:

<https://gsbs.uth.edu/genetic-counseling/files/CCG%20Summer%20Internship%20Application%202017.pdf>

During the school year, there are volunteers needed for Discovery Days (watch for emails about this) or other events for science outreach. Catherine Law, the director of the STEM Academy at OSU, is consistently looking for volunteers to run Lego Robotics sessions at local elementary schools, both in English and in Spanish. (Don't worry - there is no requirement to understand Lego Robotics before volunteering!)

After graduation, it is common for students to take at least one gap year before applying to graduate school. During this gap year, it would be helpful to find a full-time job related to the field – again, the front desk of a medical center or other similar institution is great experience. There are limited positions available as a genetic counseling assistant, but as these positions are almost always filled by students planning on attending grad school, the turnover is fairly high so a new position could appear at any time. Unfortunately, there aren't many positions like this in Oregon, so it is likely that you will need to apply out of state to find one. Some states that I have found to have positions on a more regular basis include Texas, Utah, and Pennsylvania, although new programs become accredited every year which may provide more opportunities.

### *Taking the GRE*

Although there are rumors of graduate programs no longer requiring the GRE, as of now, it is still necessary to take. There are two options: on paper and on computer. The paper GRE is offered very infrequently so if you are able, I would recommend taking the computer version. The link to finding the dates and locations of the tests offered is below:

<https://www.ets.org/gre>

The GRE has three main sections: writing, reading, and math. The process on computer takes about 3 to 4 hours. There are practice tests available online and through the GRE website, which I recommend taking advantage of. Successful applicants of grad programs fall in the 50th percentile or higher, but don't fret if your scores aren't as high as you want them to be on the first try because you can re-take the GRE as many times as you need to (although there is a limit on how close together you can take it). Once you are satisfied with your

scores, they are valid for 5 years after the date of the test. A chart with information from the 2010 round of applications is shown below:

	All Applicants	Matriculants (Admitted)
GPA (Mean)	3.4	3.5
GRE Verbal (Mean)	63%	72%
GRE Quantitative (Mean)	61%	65%
GRE Analytical (Mean)	51%	60%

*From the Association of Genetic Counseling Program Directors*

### *Selecting a program*

A list of accredited masters programs can be found on the Accreditation Council for Genetic Counseling website:

<https://www.gceducation.org/program-directory/>

There are many factors to take into when considering different programs. One is out-of-state cost. Unfortunately, there currently aren't any programs in Oregon or Washington, but there are options in California (although California tuition rates tend to run high). The University of Texas program in Houston has one of the least expensive tuition rates for out-of-state students that I have found so far. There is also an online program through Boise State University that may be more cost-effective than moving to another state.

Additionally, because all programs must be accredited through the NSGC, this means there won't be drastic differences in the quality of education you receive. Essentially it comes down to location, cost, and cohort size. Cohort size can range from 8 students to 20-something students, and depending on your personal preferences, you may want a smaller or a larger group. You may also want to look into the specific structure of the program, as some place more emphasis on clinical experiences than classroom experiences and vice versa. For example, at UT Health, there is a summer program between the first and second year where

the student would gain experience providing healthcare in Spanish, which may be of interest to bilingual students.

Unfortunately, it can be challenging to find financial help for these graduate programs because they are small and don't include a PhD. Each program may have specific scholarships for minorities or men (as the field is widely dominated by women), but they can be difficult to find. Therefore, it may be safe to assume as you look for programs that you will need to pay the full tuition listed.

If you are curious about or interested in a program, be sure to reach out to faculty there. They will be happy to hear from you and taking the initiative will reflect well on you during the application process. Some schools will host recruitment events where you can learn more about the program and the city in which it is located, which can be very helpful for deciding where to apply. Additionally, you may have the opportunity to learn inside information that you wouldn't hear otherwise by speaking to them in person or over the phone.

When it comes time to apply, be wise in the number of programs you decide to apply to. Statistically, the likelihood of being accepted by at least one school is no higher after 5 or 6 applications. Remember that if you are invited for an interview to all of them, that may be expensive and very time-consuming!

### *A helpful resource for the application process*

Two former professors/advisors here at OSU, Kevin Ahern and Indira Rajagopal, put together a book that is available online as a guide for students applying to medical school. Although some of it is not applicable to genetic counseling, it provides many helpful tips and recommendations for writing a personal statement and preparing for graduate school interviews. The book, called "Kevin and Indira's Guide to Getting Into Medical School", is linked below (underneath some free Biochemistry textbooks written by Kevin and Indira):

<https://biochem.science.oregonstate.edu/content/biochemistry-free-and-easy>

The interview portion of the book mentions Multiple Mini Interviews (MMI), a new format that is gaining popularity in medical and graduate school interviews, and includes several questions to practice as a medical school applicant. These are helpful to think about, but Kevin also provided the following questions that are specific to genetic counseling:

*1. Your client has a DNA analysis performed and wants you to look at it and give them some guidance relevant to having children. He/she specifically does not want to know about the likelihood of developing dementia, which can be determined genetically. You see that he/she does not have the trait that would likely lead to dementia and you know it would ease his/her mind to know this. What do you do?*

*2. You are counseling a family on genetics and get the results of their DNA as well as that of their child. It is apparent to you that the father in the family is not the father of the child. What do you do?*

The book details the structure of responding to these questions, which includes gathering your thoughts for about a minute and then speaking for 8 to 10 minutes. You may want to run through some practice interviews with a friend or family member using these questions. It is better to do poorly during practice than during the real thing!

## **Conclusions and Acknowledgements**

Although some of these steps are more essential than others, all of them will help you in your process to becoming a competitive applicant. It is absolutely critical to have shadowed a genetic counselor, volunteered in crisis or victim advocacy, and successfully taken courses in genetics, biology, and psychology, apart from the common graduate school requirements such as taking the GRE. It can strengthen your application to have research and/or laboratory experience in a genetics-related field. It is also extremely helpful to make as many connections as possible in the field. Current genetic counselors and students at graduate programs will be able to answer your questions and give you advice specific to your circumstances. They may also be able to provide you with opportunities that you may not have learned about otherwise.

I hope you have found this guide to be helpful as you decide the path you want to take to reach your career. Clearly, we are in need of genetic counselors who will carefully consider the social and ethical issues I have outlined and are passionate about providing quality health care to individuals and families. The field is rapidly changing and passionate and driven genetic counselors will help shape the future of genetic health care. Of course, these path suggestions I have provided are things I have learned through my own process, and they are by no means hard and fast rules. Reaching out to current genetic counselors and faculty at various programs can offer you more specific information about the process. Feel free to reach out to me with questions or comments:

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