Human Genetics Theses

The Joan H. Marks Graduate Program in Human Genetics

5-2023

Reflections of the Pioneers: An Oral History of the Early Years of Genetic Counseling

Talia K. Sanford
Sarah Lawrence College

Danielle J. Clynes
Sarah Lawrence College

Recommended Citation

Sanford, Talia K. and Clynes, Danielle J., "Reflections of the Pioneers: An Oral History of the Early Years of Genetic Counseling" (2023). *Human Genetics Theses*. 117.
https://digitalcommons.slc.edu/genetics_etd/117

REFLECTIONS OF THE PIONEERS: AN ORAL HISTORY OF THE EARLY YEARS OF GENETIC COUNSELING

Talia K. Sanford and Danielle J. Clynes

May 2023

Submitted in partial fulfillment
of the requirements for the degree of
Master of Science in Human Genetics
Sarah Lawrence College

Author Note

All of the uncited quotations herein derive from our oral interviews and submitted questionnaires by our participants.

We dedicate this paper to those we could not interview but left an indelible mark upon this field and the people within it with special mention to:

Beth Fine, Beverly Rollnick, Jane Engelberg, Joan H. Marks and Dr. Melissa Richter

We would also like to express our deepest gratitude to our thesis advisors, Caroline Lieber and Chantal Duteau Buck, for their continued enthusiasm, guidance, and unwavering support for all of our ideas. We could not have done it without you both.

We have no known conflicts of interest to disclose.

Abstract

It has been 52 years since the first class of genetic counselors in the United States graduated from Sarah Lawrence College and entered into the medical profession. The determination and spearheading mentality the first generations of genetic counselors had for their patients and proved to their colleagues is the apparent and undeniable reason they are referred to as ‘pioneers’. The aim of this study was to capture and preserve the early history of our still-young field of genetic counseling. The content was gathered via five group interviews of eleven individuals total and thirteen questionnaire submissions to represent the pioneering generation of genetic counseling. Our results demonstrated that these pioneers met both challenge and opportunity with tenacity, insight, and collaboration, enabling the profession to rapidly grow and evolve over the past half-century. Moments like the separation from the American Board of Medical Genetics and subsequent formation of the American Board of Genetic Counseling was the crucible in which the future of genetic counseling blossomed. It placed the ability to chart the course and direction of this field into our own hands. This agency is crucial in facing the current and future challenges that will shape this field. Change is our constant across generations and adaptation is necessary. While the demands we face have changed, this agency, sense of community, and pioneering mentality are traits that have and can continue to serve us in achieving greater heights.

“I think we have a lens for growth opportunities within our institution, within our field, [and] broadly in medicine and health care. And I do think there's a theme there, by chance or by design... but I think we've been uniquely suited to see and pursue growth opportunities.”
Diane Baker

Keywords: oral history of genetic counseling, pioneers, formation of ABGC, professionalization, genetic counseling

Introduction

This project aimed to capture and preserve the early history of the nascent field of genetic counseling via five group interviews of eleven individuals and thirteen questionnaire submissions; representing the generation of genetic counseling pioneers themselves. The interviews' subjects of discussion and inquiry were guided by pivotal historical moments from the 1960s to 2000s and were intended to be a retrospective space on the evolution of the field. We wanted to investigate the adaptive and innovative role of genetic counselors as they entered the medical field as professionals with a masters degree, whose set roles simply did not yet exist. By both defining and occupying their roles over the last fifty years, their personal perspectives become an invaluable reflection of the autonomy and mutability a genetic counselor has had within their role, within the medical field, and within broader society. Our overarching goal is to preserve the memories and pioneering experiences of these genetic counselors. This thesis is intended to allow genetic counselors to retell genetic counseling history from their perspectives.

Background

By unpacking their stories to learn more about what it was like to chart and to walk the trails they blazed, we hoped to capture what these pivotal years were like. Through the lens of oral history, we were able to hear many different nuanced and layered perspectives as "oral history is never the same twice" (Portelli, 2001). Rather than separating out individual genetic counselors, group interviews allowed us to lean into and investigate the community-minded and collaborative dynamic of the field of genetic counseling. Participants could reflect on their shared experiences and provide alternative viewpoints on events, relationships, and social processes that took place over thirty years ago (Huxford, 2022).

Oral history, unlike most other forms of historical work, is limited by lifespan. Due to this limitation, we opted to include a written component to our thesis to invite a broader selection of participants. Through this addition – though lacking the benefits of the communal dynamic and the adaptability of the interview format – participants could provide reflections and retrospectives that they themselves prioritized, in a medium that had no time or social pressure. These two methodologies allowed us and our participants to "...make sense of their past…connect individual experience and its social context… and [see] how people use it to interpret their lives and the world around them" (Frisch, 1990).

"Oral history…is at heart a deeply social practice connecting past and present" (Hamilton et al., 2006). We believe that these two mediums of oral interviews and written questionnaires provided agency in the retelling of their own histories, ensured thorough investigation into the pivotal events of the evolution of the field, and lastly, encouraged celebration of this community.

History

Hereditary "particles" – as the 'father' of modern genetics, Gregor Mendel (1822-1884), referred to them as – have been discussed in a variety of terms for centuries. Today, we call it the field of genetics. However, for many societies and cultures, as they began to learn about these hereditary building blocks, they began to use this knowledge to reinforce hierarchies. By attempting to link "negative" traits to genetics, the idea arose that it was possible to remove these traits from a population if those individuals were either removed from the population or kept from having children. In 1883, Francis Galton, an English anthropologist, defined this use of genetics as "eugenics," a practice that sought to "improve or impair the racial qualities of future generations either physically or mentally" (*Eugenics* *and Scientific Racism,* 2022). Eugenics was openly and enthusiastically practiced in the United States via sterilization laws beginning in 1907 in Indiana. Soon after, these ideas were implemented in Germany. The rise of the Nazi party in 1920 culminated in the murder of 6,000,000 Jews and 5,000,000 others including Soviet prisoners of war, Romany, Jehovah's Witnesses, LGBTQ+ people, and individuals with disabilities. As stated in the *Overview of Genetic Counseling: History of the Profession and the Reciprocal-Engagement Model of Practice*, "this part of the history of genetics in medicine and public health is important to remember because it may still color the public perception of the profession of genetic counseling" (McCarthy Veach et al., 2018). During this time and soon after, rapid advancements were being made in the genetics field, yet the language and motivations behind "genetics" was tarnished. For those who intended to use genetics for less malign ends, these traumatic events required a shift in perspective and language. Sheldon Reed, an American biologist and geneticist, renamed his original term of 'genetic hygiene' to 'genetic counseling' in 1947, coining the term we still use today (Rothman, 1986). He specifically wanted to center the patient's needs rather than focus on the eugenics-derived motivations. This idea would become a critical aspect to the genetic counseling approach. These developments led to the founding of the first master's program for genetic counseling in the United States at Sarah Lawrence College in 1969, spearheaded by Melissa Richter. As Stern explains in her 2008 paper, *A Quiet Revolution: The Birth of the Genetic Counselor at Sarah Lawrence College, 1969,* "the interest was so great that Richter launched the program 1 year ahead of schedule, welcoming ten students in the fall and two more the following semester." With faculty ranging from psychologists, medical geneticists, and pediatricians, the genetic counseling career seed was planted and that first cohort of students were on their way to becoming the first genetic counselors. As these newly created genetic counselors entered the medical field, other medical professionals worked alongside these new clinicians to discover and create the potential roles and responsibilities they could undertake.

Merely ten years after the first class began their studies at Sarah Lawrence College, the National Society of Genetic Counselors (NSGC) was born, with Audrey Heimler serving as the first president. In her opening remarks speech in 1979 she said,

> Being a member of a new profession can be a challenge. We have the opportunity to help shape the mold by fashioning the principles, standards and image of our profession. But, being a member of a new profession can also be intimidating. Few have gone before us. We must define our role, establish our identity with other professionals, bargain for our salary and benefits, and design a path for professional advancement (Heimler, 1980, p. 4)

This determination catapulted the career and continually gave it the energy and backing it needed for the years to come. The National Genetic Disease Act S.1715 passed in 1979 provided opportunities for genetic counselors in research and clinical settings. This Act expanded funding for genetic counseling and testing programs, education, research, diagnosis, and treatment programs, broadening job opportunities for genetic counselors throughout the United States. Enactment of the bill is credited to Senator Edward Kennedy, Dr. Leon Rosenberg (a geneticist), Dr. Robert Murray (a geneticist), Joan Marks (a genetic counselor and director of the Sarah Lawrence College genetic counseling program), and Marjorie Guthrie (an activist) (NSGC Timeline). Deborah Eunpu, as editor of the first NSGC newsletter, *Perspectives in Genetic Counseling,* provided job postings, resources, and articles for newly minted members. By 1980, there were eight genetic counseling training programs in the United States.

The subsequent decade in the field saw enormous growth including eighteen active graduate programs, the formation of The Canadian Association of Genetic Counselors

(CAGC) with Susan Creighton serving as its first president in 1990, the beginning of the Human Genome Project in 1990, and the publication of NSGC's code of ethics in 1992 (NSGC Timeline). To focus more on research within genetic counseling, the *Journal of Genetic Counseling* was created in 1990 with Deborah Eunpu as the founding editor. The early nineties also brought the next hurdle in the genetic counseling field: the separation of genetic counselors from the American Board of Medical Genetics (ABMG) in 1992. By joining the American Board of Medical Specialties (ABMS), ABMG could no longer certify masters-level genetic counselors. Although it was a strenuous and arduous endeavor, the American Board of Genetic Counseling (ABGC) was then established in 1993 to certify genetic counselors and accredit training programs, with Ann Walker serving as its first president.

The nineties were also rife with discoveries and innovations in technology and genetics. These discoveries included genes for Huntington disease (*HTT)*, Hereditary Breast (and Ovarian Cancer – the association with ovarian cancer was discovered later – *BRCA1 & BRCA2)*, Cystic Fibrosis (*CFTR)*, and Lynch syndrome genes. Due to these progressions in the field, genetic counselors established Special Interest Groups (SIGs) such as Cancer, Prenatal, and Pediatrics. The first edition of *A Guide to Genetic Counseling* was published in 1998, becoming the first genetic counseling textbook written by and for genetic counselors. In 2003, the Human Genome Project had sequenced the majority of the human genome (and completed it in April 2022). The Human Genome Project was an explosive growth of knowledge of genetics and technology, resulting in our modern use of cheap and quick gene sequencing, genetic databases, and whole exome and genome sequencing.

The early 2000s began with yet another remarkable venture with the passing of a genetic counselor licensure bill, which is still an ongoing state-by-state process. Creating licensure allowed for better recognition by the healthcare system, assured reimbursement for essential genetics services, and furthered the responsibilities of genetic counselors. In 2008, President George W. Bush signed the Genetic Information Nondiscrimination Act (GINA) into law which “protects individuals against discrimination based on their genetic information in health coverage and in employment” (OCR, 2021). This provided specific legal protection for patients when going through the decision-making process to proceed with genetic testing. Some exceptions for GINA include life, long-term care, and disability insurance as well as businesses with less than fifteen employees, the federal government, and the U.S. military. As the field advanced, so did technology. In 2011, a non-invasive cell-free DNA prenatal screening test (NIPT) revolutionized the practice and clinical screening options for pregnant patients. In 2013, we saw the rise of cancer panels looking at multiple cancer-susceptibility genes, including *BRCA1* and *BRCA2*, and increasingly faster turnaround times. Additionally, in 2013, the Accreditation Council for Genetic Counseling (ACGC) separated from ABGC and became its own organization in order to accredit training programs.

As of 2021, there were over 5,629 recorded certified genetic counselors in the United States according to The Professional Status Survey (data from ABGC and NSGC jointly) (National Society of Genetic Counselors, 2021). Genetic counseling is a field that has been molded through waves of evolution, progression, and maturation. As we enter into the next semi-centennial years of the genetic counseling field, it is incumbent upon the genetic counseling community, professionals, students, and advocates to reflect upon its history, development, and future steps. Audrey Heimler’s concluding statement from her opening remarks at the first NSGC conference continues to ring true through the decades and for the years to come: “The future is before us. The process is exhilarating. Let us choose the way it will happen!” (Heimler, 1980).

Methodology

We conducted our own research on the pivotal moments and primary participants in genetic counseling history. We also had several discussions with multiple members of the NSGC Late Career SIG. Based on both historical accounts and first-person perspectives, we had a selection of individuals whom we believed would be valuable to interview. Emails were acquired through the NSGC member directory, our thesis advisors, or through members of the NSGC Late Career SIG. We reached out to twelve people via email with the offer for a group interview, including broadly what topics we intended to ask about and a consent form. Once our interview groups were established, we sent a “pre-interview form” with questions to jog their memories and to allow them to indicate the areas that they would like to focus on during the interview. Additionally, the form asked them to consider providing a photo, artifact, or object that has meaning to them from their own genetic counseling journey that will be used for an exhibition presentation of our thesis project. The five oral interviews were conducted with video and audio recording as well as the transcription service provided by Zoom. These recorded interviews are stored in a password-protected Google Drive account and will continue to preserve the stories of this select number of pioneering individuals.

Of the twelve people that were contacted to participate in the oral interview, eleven of them participated. These eleven interviewees (ten genetic counselors and one geneticist) are intended to provide an adequate sample size for our qualitative research. Oral interviews are an energy-intensive process and we attempted to sample some of the most integral perspectives. Of the ten genetic counselors, five of them received their Masters degree from Sarah Lawrence College, three from UC Irvine, one from Rutgers University, and one from the University of Michigan. Their years of graduation span 20 years from 1975-1995. The one geneticist we interviewed graduated from Albert Einstein College of Medicine in 1979. The average graduation year between all of our interviewees was 1981. We interviewed 8 women and 3 men.

Additionally, we sought to gain a broader sampling through a written questionnaire sent out to another twenty-eight participants who were also considered pivotal members of the genetic counseling field. Of those twenty-eight, thirteen responded (twelve genetic counselors and one geneticist) with different memories, experiences, and reflections. Of the twelve genetic counselors, eleven of them received their Masters degree from Sarah Lawrence College and one from Rutgers University. Their years of graduation span 28 years from 1973-2001. The one geneticist who responded graduated from Columbia University Vagelos College of Physicians and Surgeons in 1959. The average graduation year was 1981. We received written questionnaire responses from 10 women and 3 men. While we provided a large number of questions the written questionnaire participants could respond to, we only required responses to two questions at minimum. Providing space for open reflections, we made clear that these questions served as suggestions rather than strict guidelines. We encouraged participants to expand or include what they felt was important, interesting, or unique to their own experiences.

All topics and questions available within the “Pre-Interview Form” can be seen in Table 1a and Table 1b (see Appendix). Our general topics included: demographic questions; questions relating to their entry into the field of genetic counseling and their goals and experiences over their careers; questions relating to organizational, technological, or legislative changes; and questions relating to the genetic counseling community. All topics and questions available within the “History of Genetic Counseling Questionnaire Form” provided to the written questionnaire participants can be seen in Table 2a and Table 2b (see Appendix). Our general topics available within the questionnaire form were the same as the pre-interview form, but we asked additional and targeted questions within each section in order to prompt more specific reflections.

After we conducted our interviews and received the completed questionnaires, we edited the transcripts by hand and redacted any responses that were requested. We compiled and organized the responses by question prompts. In each category, we analyzed the responses for shared experiences and themes as well as counter-narratives and exceptions. We summarized our findings in the following discussion section with selected quotes, but provide open access to the interview recordings. In addition to stored oral history accounts, the artifacts provided by the interviewees (with QR codes linking to their recorded interviews) will be displayed in the Human Genetics Program building at Sarah Lawrence College, the birthplace of the genetic counseling field.

Discussion

In our discussion section we will dive into the specific questions and conversations we had with our participants. We have organized them in a relatively chronological order beginning with the first two decades of the field followed by the pivotal separation from the American Board of Medical Genetics starting in 1992. We then explore the professionalization of the field which accelerated in the nineties. Lastly, we discuss the universal themes and future directions of the field.

The Early Days

Through our interviews and questionnaire responses, we investigated how our participants found the field, got their first jobs, experienced the growth of this budding field, and their impressions and memories of the social relations between other genetic counselors and other medical professionals. In this period we saw the identity and role of a genetic counselor begin to solidify as NSGC was founded and the title of 'genetic counselor' versus 'genetic associate' was debated.

How You Came to Find the Genetic Counseling Field

The way people found the field of genetic counseling was encompassed by four general trends. The first one being via a professor or teacher they had at some point in their school experience.

> *I went to Marymount College and happened to have a wonderful, wonderful genetics professor there who just got me more and more interested in genetics. He mentioned something about genetic counseling, and I thought, man, this is it. It's taken the clinical part, the laboratory part, but it's combined with helping people and education, and then hands on and getting right in there. This is it.* - Ed Kloza

The second was within the framework of a college course. Still, the field of genetic counseling was often only briefly mentioned within the class or in an unassigned chapter to read in a textbook.

> *I signed up for this course called 'Genetics Heredity' and it sounded kind of interesting. Chapter 17 was not assigned, but was on genetic counseling, and when I read that, it really was like this is what I want to do rather than do loops and computer programs and punch cards.* - Debra Collins

The third trend was by hearing it from a friend, personal physician, or colleague.

> *I wasn't sure what kind of graduate school or medical school I wanted, but I was talking to my OBGYN at one point, and he said 'oh, you know there's this new field called genetic counseling,' and it was the first I'd heard of it.* - Ann Walker

The last trend was discovering the genetic counseling field simply 'by chance'. Chance encounters ranged from reading an article in a magazine, newspaper, course catalog, or brochure to sitting next to a genetic counselor and starting a conversation.

> *I started leafing through the magazine and, for some reason or other, Working Women Magazine was there. It had an article on genetic counseling. I said, oh, well, I can't change to a woman, but I can become a genetic counselor… I think it sounds like what I'm doing now [working with families in Illinois and Missouri with Alpha-1 antitrypsin (AAT) deficiency]. So maybe I'll look into it.* - Robert Resta

The lack of the internet meant discovery of the budding field often seemed to have an element of serendipity across the board. If you didn't meet someone who already knew about the field, then coming upon genetic counseling in physical sources – for example, searching through course catalogs (Robin Bennett and Michael Begleiter) or reading newspapers (Cheryl Shuman) – was the only other option. Publicity was crucial in this regard as people came across genetic counseling in *Working Women* magazine (Robert 'Bob' Resta), a March of Dimes brochure (Steven Keiles), a Newsweek single-paragraph article from 1986 (William Andrew 'Andy' Faucett), or the Sunday *New York Times*' article about the 'new' genetic counseling program at Sarah Lawrence (Matilda 'Tillie' Young).

Starting out

As these new graduates entered the field, there was no well-trodden path for them to take. When looking at the historical expansion of the field, we wondered prior to the interviews if there were any clear ambitions from these future pioneers from the start. When posing that question, our interviewees characterized those early days as casting a broad net for new roles and opportunities but without a clear vision or goal at first, as they often were

> *…just happy to have a job and not even sure what that job entailed. And I think this was probably true for a lot of us that is, unfortunately, not true from…talking to…our recent grads…There was a lot more flexibility in the positions and a lot more downtime. I was hired to start three outreach clinics in the State of Minnesota and also cover the weekly genetics clinic, which is not enough work. That's not a full-time job and so I was bored again. And so I wandered into the neurology clinic and said, you need a genetic counselor. And that wasn't a time where somebody said, 'and what is your chart string for that,' [or] you know, 'how am I gonna pay for that?' No one asked and I don't even know if we billed patients. I probably didn't. And so things…weren't as well organized. So no one knew what to look for and that was a good thing.* - Bonnie LeRoy

Over time, the efforts to expand the number of positions of genetic counselors became more purposeful. We saw this as Bonnie LeRoy described wanting colleagues and embarking on a plan. She went from clinic to clinic providing services as a genetic counselor before posing the question "does everybody like this service?" Upon receiving an emphatic 'yes', she declared "good, then you got to hire someone else because I can't do it anymore." She successfully acquired a cohort of genetic counselors and *then* got down to the business of deciding their specific roles.

The support and encouragement provided by other professionals bolstered the field. It was with seizing upon opportunities and support from other professionals that expansions of the field occurred.

> *I feel like most of my career, including where it started, began with happenstance. It was just in the right place, at the right time, taking advantage of opportunities. And so I think the biggest thing I'll give myself credit for is seeing an opportunity and taking it, not knowing where it's going to lead, and sometimes it was a bad idea, and sometimes it was a really good idea.* - Bonnie LeRoy

Geneticists were some of the strongest proponents and advocates for genetic counselors.

> *…we worked with amazing geneticists and people that really supported what we do. At that time very few people were hiring genetic counselors, but if they did, they knew why they wanted them. And they did want them, even if they didn't know really the limitations or what we all could do. They'd often ask us to do something and at least in my case, I'd say, 'That's a diagnostic thing. A physician has to make that diagnosis. I can do this part.' And so we kind of taught them what we were as well. But…[there was] that tremendous amount of support from really world-renowned geneticists a lot of us worked with. They knew what the field was and they knew what they wanted us to be involved with…We were fortunate that we worked with people that really advocated for us and gave us that freedom to do some of these other opportunities.* - Debra Collins

But there were other individuals ranging from social workers to psychologists who collaborated, taught, and advocated for genetic counselors. Bonnie LeRoy recalled the fervor with which Patricia McCarthy Veach, a psychologist who taught theory and how to teach in clinical settings, pushed for publications for and by genetic counselors and genetic counseling students, "She was like a dog on a bone to get these things published."

Over time, Bonnie expressed that she gradually realized "how little I knew about everything. But I mean everything - like how things worked, like what academia was, why it was different, and what the goals were of academia." There was a lengthy learning process of understanding how these systems worked, including hospitals, universities, State Health Departments, and national policies.

> *So it took us all a while to just learn what you could or couldn't do, or how you could [make] the systems work for you…Where's the best entry point and how long does it take? And who are the stakeholders that you needed to be involved with to get anything done that you can't do anything by yourself? You need other people to be involved in some of these issues, and…learn who they are and how to find them. So a lot of what we did, even at the meetings, [was] talking to people trying to figure out how things work."* - Debra Collins

Genetics was populated by pioneers across disciplines as Beth Balkite stated, "we worked with a lot of really great people, pioneers themselves." The expansive online resource 'Online Mendelian Inheritance in Man' (OMIM) was first published in 1966 by geneticist Victor

McKusick. It was, of course, known as Mendelian Inheritance in Man (MIM) at the time as there were no online resources. It consisted of 1,487 entries (Brownlee, 2017). For the next twenty years, the book was published every three to four years; after that, the publication rate increased further and as of March 2023, there are 26,851 entries on OMIM. As geneticist Dr. Robert Marion put it, “In 1969, Harold Nitowsky [a geneticist who taught at the Sarah Lawrence College genetic counseling program] could teach all of human genetics in a one year course. But now…you can't even teach one area of that if you're a single person." Michael Begleiter described the lengthy, dedicated, and collaborative work necessary in genetics.

> *Prior to online OMIM and online PubMed we had to have a copy of the Mendelian Inheritance in Man with us in the clinic at all times and reviewing the medical literature made it necessary to spend many hours in the library systematically working backwards year by year with Index Medicus. Identifying laboratory testing involved finding an article by a researcher who was working on the disorder you were interested in, contacting them and hoping that they would agree to accept your patient sample (with no promise of a rapid turnaround time).*
>
> *I can recall one experience with a prenatal diagnosis of Menke’s syndrome where I had to arrange for a specimen to be sent to Denmark. When the specimen arrived, the one nuclear reactor in Denmark was down and we had to wait till it was repaired before they could get the tagged copper they needed for the assay. Also, the researcher and I communicated by fax and when we were at work they were not so everything was on a time delay.*

Even without the far-sighted vision of future possibilities, Wendy Uhlmann summed up the spirit of persistence and curiosity that inevitably resulted in the expansion of genetic counseling roles.

> *I think there's a real curiosity about things…because we span across disciplines. This sense of wanting…to soak it all in and that we're willing to try things… I'm hearing the word ‘risk-taker’ and I'm thinking, am I a risk-taker? Am I risk-taker or is it more that I just kind of feel that I belong at these different tables? And I don't like being shut out the door, so I will just keep knocking and persisting.*

Genetic ‘Counselor’ vs. Genetic ‘Associate’

Many young graduates and current students might not know today that the people involved within the genetic counseling community were once not referred to as ‘genetic counselors’, rather they were called ‘genetics associates’. The collaborative work of genetics professionals in the twentieth century was usually helmed by a geneticist. Those geneticists, physicians, and even some genetic counselors believed that the term ‘counseling’ fell too far into the medical practice without having the proper licensure, whereas ‘associate’ or ‘assistant’ maintained the necessary distance. Ed Kloza states, “there were folks out there on the M.D. side, who refused to refer to us as genetic counselors, insisted on calling us genetic associates or genetic assistants and claimed that we were practicing medicine without a license.” The debate over these terminologies could have seemed inconsequential, but it was an indication of the continuing fraught negotiation of the potential duties and responsibilities a genetic ‘associate’ should and would be allowed to perform. It also demonstrated the intention of genetic counselors to start defining their roles beginning with their titles. Cheryl Shuman described the shift, “...to be recognized as genetic counselors rather than genetic associates or assistants. That might sound somewhat arbitrary but it required a fundamental shift.”

ACMG Board

For most masters and Ph.D. degrees in the medical field, once someone completes their classwork and studies, they must take their respective boards exam or certification test. Genetic counselors were no different and they began to take board exams under the purview of the American Board of Medical Genetics (ABMG). This tri-annual general board exam was taken by all genetic specialists and then required a secondary exam specifically for genetic counselors. This created a credentialing system for six specialties: genetic counseling, medical genetics, clinical genetics, biochemical genetics, clinical immunogenetics, and clinical cytogenetics (Smith et al., 1980). Some genetic counselors felt that passing the same general boards exam that geneticists took (and often scoring better) was a boost that helped level the ‘expertise’ monopoly. Diane Baker described it as, “it finally said, we are the same. There is a knowledge base that we all have to master, and if you can't master that, you can't practice in any field in genetics…It's when I started calling myself a geneticist. Now that didn't stick for our field…But…I still think I'm a geneticist, because I [did] test the same exam that everyone else did.” Others felt that this strict hierarchy still remained between the physicians and the genetic counselors. Wendy Uhlmann explains, “I always felt like there was a definite hierarchy with the geneticist being the one that was the clinical geneticist, being the expert, and the genetic counselor…kind of below there.”

As the field of genetics progressed, every member of ABMG from geneticists to genetic counselors could envision a bright future ahead of them and genetic counselors were slowly gaining seats at the table. Ann C.M. Smith and Audrey Heimler were the only two genetic counselors who sat on the board of the American Board of Medical Genetics (ABMG). Not only were they the sole genetic counselor representatives, they were the only ones with a Masters degree, rather than an M.D. or Ph.D.. While there was a hierarchy and debate around the role of genetic counselors, geneticists served as advocates and guides for genetic counselors. Individuals like Victor McKusick, Harold Nitowsky, and Kurt Hirschhorn became mentors rather than just names in a textbook. All of the clinicians at the table were there to help patients and families together.

Geneticists sought to expand, legitimize, and further integrate the field into the medical system. In 1991, ABMG applied to the American Board of Medical Specialties

(ABMS) for the creation of the American College of Medical Genetics (ACMG), and to their surprise, the response was quick: like with the recent inclusion of Ph.D.-level radiologists, the Ph.D.s could join, but no one without an M.D. or Ph.D. could be certified by the board.

It was a Catch-22 for genetic counselors at this point. ABMG members could receive the further legitimization, prestige, and financial reimbursement it wanted through its inclusion in ABMS, but only if genetic counselors were not a part of it. This was not an easy nor unanimous decision by any means. Genetic counselors would have to vote to approve this change in bylaws, and by doing so, remove themselves from the ABMG – the professional aegis and certification for medical genetics. This was not a unanimous decision for the geneticists either. Ed Kloza and Diane Baker recalled Ph.D. and M.D. members going to them and stating respectively "do not let them do this to you, stand your ground" or "if you tell us to hold the line here, we are not gonna vote for this." Others, like Ann C.M. Smith, experienced the following, "I was told by an M.D. who was pointing on my nose, 'You need to tell them they have to vote for this,' and I said, 'I don't tell them anything. They all have minds of their own. This is a democratic society, and they need to vote what they feel'."

The "Great Divorce" (Resta, 2010)

"It was a difficult divorce, but in retrospect I think it allowed each of the professions to continue to grow, and it was the right thing" - Ann C.M. Smith

The genetic counselors involved took it upon themselves to open up the conversation. They discussed the pros and cons of this split amongst as many people as they could.

> *To many, this separation truly felt like a great divorce because that would allow us to grow and take responsibility…it would allow our colleagues to grow within the confines of medicine. I remember traveling around the country for the American Board of Medical Genetics going to different regional meetings, going to different groups. I remember one time in Texas, sitting in a hot tub with a bunch of genetic counselors and people were pissed off. They did*

> *not want this separation. No one wanted this, and I gotta say I didn't work hard to convince people. I worked hard to have a conversation. 'Let's really think about the trade-offs. What do we give our colleagues and what do we gain for ourselves?' And that was a really challenging time for me, really challenging time.* - Diane Baker

This continued the theme of genetic counselors trailblazing uncharted ground. Not only were these genetic counselors speaking to colleagues, but they reached out to current students to educate them in what was unfolding in their career. As Beth Balkite recollects,

> *I was in Sarah Lawrence at the time. Ed [Kloza] encouraged conversation. He was just there for an afternoon, and had some slides and stuff like that – there were no hot tubs involved – but he was pretty convincing, he really was. I think we were very fortunate that we had a board with good vision because if we had a board that couldn't see beyond, I don't know where we would be today.*

The temperance and vision that these genetic counselors exhibited left a memorable impression for students that could be recalled years later.

Though with hindsight there was a theme of 'for the better' there still remained the bitter taste. There was no *real* other choice. If genetic counselors and even geneticists standing in solidarity refused to vote in favor, the working relationships and future of the field would come into question.

> *Nobody was talking about a plan B, because I think they were afraid that it might be attractive. But I don't know what would have happened. I think that it would have engendered so much animosity within the field. Generally, that it would have made working relationships perhaps 'challenging' and I think we had to be very cautious about being viewed as upstarts…there was so much of a team approach to the delivery of genetic services – generally that that was the model – and it just seemed kind of unseemly for part of that model to, you know, pick up its toys and go home. It certainly would have left a hugely bad taste in a lot of mouths and I think it would have made the professional relationships extremely difficult.* - Ann Walker

There was no perfect solution and the split seemed inevitable. Even if this *current* effort was stopped, Ed Kloza stated, it would have only been a delay to such efforts. And so, enough genetic counselors agreed to vote themselves out and the vote carried. As part of the ‘settlement’, genetic counselors were given money to establish a board for their own separate certification process. From this momentous crossroad and period of discord, genetic counselors reflected on the benefits and evolution in working relationships.

> *I think that there was a perception among a subset of medical geneticists that kind of used to joke that the genetic counselors were the ‘hamburger helper’ of the genetics world. That was how some of the physicians viewed us: as somebody to do the scut…the stuff that wasn't interesting to them or that they didn't want to take the time to do, whether it was a pedigree or writing a patient report…But I think that after that episode that there was a great deal of respect for us as a profession,...not just handmaiden to the physician, and I think that was a huge leap for the profession. Painful as it was.* - Ann Walker.

Beside the changes in how genetic counselors were viewed by their colleagues, the genetic counseling community was also transformed in how they viewed themselves. Ginny Corson described, “it was a contentious time for the profession, and there were many hard feelings. In the end, we were likely better off needing to establish our own credentialing organization and taking control of our own destiny.” There were other important moments where genetic counselors truly distinguished themselves as distinct from the rest of the medical genetics field, such as voting for the separation of NSGC’s annual conference from the American Society of Human Genetics’ (ASHG) conference in 1998, but this moment was a leap forward. Robin Bennett explains the anxiety and concern that genetic counselors felt at the time regarding how they would be looked upon professionally once they were no longer in the same “league” as the geneticists.

> *The formation of the ABGC was initially painful because of concerns that genetic counselors would not be recognized in the same way because we were not taking the same boards as the geneticists. It actually was the best thing for the profession. Interest in the profession blossomed. I was on the board of NSGC when the "split" was being discussed. Around that time we also stopped meeting with ASHG, another painful decision.* - Robin Bennett

In Diane Baker's NSGC presidential address in 1987, she quoted a poem by Christopher Logue. "Come to the edge. We might fall. Come to the edge. It's too high! Come to the edge! And they came, And he pushed, And they flew" (Logue, 1971). Ed Kloza, who was in the audience during the speech, recalled it years later, "that poem stuck with me and it became so clear…the reason it stuck with me. Because at that time ABMG was pushing us to the edge. We really didn't want to be there, but we knew that it could be the start of something big, and it was, and they pushed us over."

Despite fears that separation from ABMG would remove that professional aegis and result in loss of status, as of 2021, there were 5,629 genetic counselors (National Society of Genetic Counselors, 2021) and 1,240 geneticists (Office, 2020). While we cannot determine that this explosive growth in genetic counselors would only have happened due to the separation from the ABMG, we can observe that throughout the thirty years since the separation, the genetic counseling community has grown tremendously under the visionary guidance of genetic counselor leadership.

Professionalization

This arc of growth for the profession was characterized by a desire for legitimacy, a quiet demand to simply do 'what needs to be done', and a healthy dose of serendipity. When establishing the ABGC, genetic counselors knew that this was a crucial step in that legitimization.

> *One of the challenges was 'how do you set this up in a way that's credible and meaningful?'...I remember one week, which was supposed to be a two-day meeting in Bethesda…and there was a huge snow storm. And so those of us who were there for the meeting were there for the week [and] that included Beth Fine and Diane Baker…we got a hell of a lot done there basically incarcerated in a hotel room. So the entire bylaws of the American Board of Genetic Counseling got written that week, and that was a very productive time...It was stressful and there was the overlay of…concern about what if our*

> *physician [and] Ph.D. colleagues were going to think that we were getting uppity…or that we were running amok, or whatever, which turned out not to be the case. I think that we ended up with…probably greater respect from our colleagues than we had before, because we made it work. And all of a sudden we had codified things about education and training that really had been left to individual institutions…It legitimized…[the] profession.* - Ann Walker

Developing our own boards, accreditation of programs, and establishing practice-based competencies and standards of ethics all demonstrated the professional standards of genetic counseling for the broader medical field. Ginny Corson, who served as president for both NSGC and ABGC stated, "Some of the professional issues and goals from that time were to establish a professional identity, support educational opportunities for genetic counselors, recognize the 'expanding roles' beyond the clinical setting, establish professional certification in conjunction with other genetics specialists, and develop norms for graduate programs." Aspects like practice-based competencies were useful for individuals as Debra Collins pointed out, "I do think it also helped with jobs, so that when you were going out and working, or maybe [were] the first person in your institution [you could say]: this is what I can do for you…These are the things that I'm capable of doing."

One of the largest changes over the nineties was in both defining the field for ourselves and having a hand in our own production of knowledge. By developing practice guidelines, Robin Bennett, who described her involvement in guidelines for pedigree nomenclature, consanguinity, and counseling of Fabry disease, thought it became "another way for genetic counselors to show their expertise and shine as leaders in defining our practice instead of having the practice defined for us." Robert Resta found that not only were we creating standards for ourselves, "we were setting standards for genetics outside of genetic counseling. We were saying…if you're going to call yourself a geneticist, these are the standards that you should use. And they were readily adopted."

In 1990, the *Journal of Genetic Counseling* was established. Before the *Journal of Genetic Counseling*, genetic counselors did not have a clear venue for publication. Robert Resta recalled that prior to the establishment of the journal, the only genetic counseling publications were "an article or two [in each issue of the American Journal of Medical Genetics] that was sort of genetic counseling, as John Opitz [geneticist and Editor-In-Chief of the journal] was good about letting some of that in." Bonnie LeRoy was president of NSGC (1994-1995) when "Debbie [Deborah] Eunpu said, 'We need a journal' and I have to admit I looked at her and thought, you've lost your mind. Really, we're barely a profession and you want a journal? How are we gonna do that…And she did."

> *But it took me a long time to realize what is incredibly obvious to me now, which is, the publications that we have in genetic counseling define us. They define who we are, they are our outside. That's what the outside looks at when they see us and they don't know what genetic counselors do. And they see these publications and they see what genetic counselors* <u>*can*</u> *do…It's our literature about us instead of somebody else writing about us. How important that was! I did not recognize that for a long time.* - Bonnie LeRoy

As research and publications increased, Debra Collins described her motivation for publishing as "...it was always the world needs to know this. We've seen this. We've observed this. It needs to be published. So a lot of it was driven by feeling like you needed to make a contribution to everything."

Serendipity, connections, and the continued theme of rising to the occasion can be seen in the creation of the first edition of *A Guide to Genetic Counseling*. This is a textbook so ubiquitously used in genetic counseling programs world-wide that it is often known by genetic counselors as simply the 'green book' due to the green cover of the second edition. Diane Baker received a call one day from Charles Epstein, "a prominent geneticist on the West Coast and someone I've served with on the board." Wiley, an academic-focused publishing company, had asked him if he would write a genetic counseling textbook. He told them, “I shouldn’t write a genetic counseling textbook” and then called Diane Baker, “Diane, why don’t *you* write a genetic counseling textbook?” At first, Diane was dismissive of the prospect but when relaying the conversation to Wendy Uhlmann and Jane Schuette at a meeting over breakfast at Angelo’s, a small restaurant on the campus of the University of Michigan, she and the other two managed in short order to talk themselves into writing a textbook.

> *‘Okay, guys, I got this crazy call about writing a textbook. Wiley's looking for someone to write a genetic counseling textbook. But we're not gonna do that, are we?’ And they're like, ‘Oh, no, we're not gonna do that.’ And then we started tossing out ideas and ‘well, we could address this,’ or ‘well, it should have something like…’ and pretty soon we've talked ourselves into writing this textbook by starting with, well, we would never do this, would we? And that's how I remember it starting, and then we started rather disciplined regular meetings in one office or the other.* - Diane Baker

They made outlines of all the subjects needed for a general textbook and spoke with genetic counseling program directors as both content experts and for help in implementing the book into their curriculums. It was the idea that they did not have to do this alone that made the textbook possible. They reached out to the surplus of exceptional pioneers and experts in the field and two years later, in 1998, the first textbook made by and for genetic counselors was published.

Besides this textbook, other genetic counselors like Bonnie LeRoy, who was director of the University of Minnesota’s Genetic Counseling program, got involved in publishing in areas of theory. Her therapist colleague, Sue Petzel, after being requested to lecture for the program’s course ‘Psychosocial Issues in Genetic Counseling’ asked,

> *‘But what's the theory of genetic counseling?’ And I went ‘I don't know,’ and she said, ‘No, what's the theoretical background?’ And I went, ‘Don't even know what you're talking about. Nope. Hate to sound like an idiot. But no, we don't have that.’ She said, ‘What do you mean? You don't have that?...How do you learn?’ And I said, ‘See one, do one, teach the next.’ I don't know…we say*

> *we're like social workers, we're like psychologists, we're like geneticists. We're 'like', but there's…no genetic counseling book. There are very few papers that are in genetic counseling and most of them are written by people who aren't genetic counselors and so you're trying to [learn] genetic counseling from something else.* - Bonnie LeRoy

But despite this dearth of standard learning material (of which Bonnie LeRoy was a major factor in changing), when she "got all the program directors together to talk… about the major components to genetic counseling…everybody said the same thing." Debra Collins recalls the meeting, sitting at these round tables with genetic counselors from different areas, both geographically and in specialty.

> *It still sticks with me because…no matter what you worked with - prenatal or whole genome, or cancer, or cardiology, or pediatric…it was: this is how we all concentrated when we're talking to a patient. It's like your whole body was listening to the patient and at the end of the day you would come home exhausted…I thought, Oh, I've had that and everybody at the table, no matter what you worked in, had had that experience, and I thought, [I've] never been in a room to really talk about some of these things. About…what it's like to be a genetic counselor and to realize that it's universal among everybody at the table, no matter what kind of genetic counseling you do.*

It was in this remarkable synchronicity that establishing professional and academic standards of genetic counseling was possible - at least without major dissent.

Licensure is one of the biggest hurdles today for the continuing advancement of the profession with several genetic counselors such as Susan Creighton characterizing it as "a key component (in my opinion) to the continued advancement of the GC [genetic counseling] profession." With licensure, institutions can be more confident that genetic counselors will be able to practice independently. As genetic counselors are sometimes the only genetics professional on a team or within an institution, the ability to practice independently and bill for services is a necessary step to its continuing professional development. Hence, for clinical purposes, licensure generally allows for genetic counselors to independently order genetic tests and to get reimbursed for their services. Additionally, licensing provides genetic counselors with the respect that is customarily given only to qualified medical providers and standardization protects their work from unqualified individuals, who may provide related services.

> *I think one of the rate limiting factors has been billing for one's own services and I think that there's still a lot of concern about what is perceived as practicing medicine without a license. That is an impediment and I don't know whether that's still the case or not…But I think that there was a threat that this person might be unable to practice independently and I think that that's still an issue.* - Ann Walker

Tillie Young describes that when she "retired in 2003, there still was no licensure, and some physicians had begun to do their own 'genetic counseling' or to defer it to nurses in their offices, thereby bypassing our professional standards and serving patients less well." A state-by-state process, the first licensure bill to pass was in California in 2000. By 2010, eight states had licensure legislation. Today, thirty-one states have licensure and four states have bills that are passed. Fifteen states remain without successfully having passed legislation for licensure, despite heroic and sometimes Sisyphean efforts. Caroline Lieber's work in licensure for New York State, the state with the oldest genetic counseling program at Sarah Lawrence College, "was a VERY frustrating process, going on unsuccessfully for many years. It was always about the public and the legislators not really understanding what GCs [genetic counselors] do. We struggled." Licensure was not wholly embraced by genetic counselors from the start either, as Joy Larsen Haidle described drawbacks that she had to address to gain support for licensure,

> *Acceptance of licensure has grown amongst GCs especially given the large number of states now having successful licensure bills. For a while it was hard to prove the benefit of the bill given the personal expenses for the application fees, annual renewal fees and CEU requirements. We have steadily worked towards getting these fees reimbursed by employers just as other mid-level providers are reimbursed.*

Michelle Fox, who was involved in this first success in California, stated,

> *Recognizing the need for it was extremely important to the profession and it is difficult to see the state[s] that are still struggling to obtain licensure. The most disturbing challenge to our profession is the lack of recognition on the Federal level. NSGC has not done enough to obtain this recognition leading to a crisis for our community in regard to reimbursement for our services.*

On the federal level, genetic counselors have been involved since the early days. Joan Marks, the second program director of the Sarah Lawrence College genetic counseling graduate program, was credited as a major contributor to the passage of the 1979 National Genetic Disease Act S.1715. Joy Larson Haidle described lobbying in Washington, D.C. for the federal *Access to Genetic Counselor Services Act,* known as either S. 1450 or HR. 2144. Andy Faucett pointed out that even with licensure, Federal Centers for Medicare & Medicaid Services (CMS) recognition will be a necessary step (but not a sufficient measure on its own) to help solve the billing issues that current genetic counselors have.

Community

Although genetic counselors may be few, the genetic counseling community is widespread. That community often began with their cohort in their masters program and expanded from there. Some characterized their genetic counseling community as forming through shared experiences as genetic counselors, while others described an ever-growing genetic counseling community wherever their jobs or life took them, evolving to include colleagues, mentors, classmates, and friends over the years.

One way in which this generation felt a strong bond was due to the technology at the time, which made continuous communication and dialogue difficult. Therefore, the necessary time and devotion it took to converse with fellow genetic counselors within your own state or across the country aided in the strong relationships formed. This communication and collaboration was necessary when dealing with rare and newly discovered genetic conditions. For example, when seeking guidance or knowledge when faced with a difficult case or patient, as Ann C.M. Smith describes,

> *We're gonna see one patient a year with trisomy 18 where we are, and you call 10-15 people around the country, and you get 15 patients, rather than just one patient. So that network really helped in advancing research. They were kind of designated experts in certain areas who you would contact if you had a specific question about a specific problem. Like skeletal dysplasia…[Johns] Hopkins...And then their skill set metastasized to another community.*

This bond was maintained over long-distance relationships for most of the year and then for few euphoric days of the year at the in-person annual conferences.

> *We had regional representatives. So all of us in the Midwest got together once a year, and then there was the public health things that got [us] together: Great Plains Genetics Network…we would see each other three to four times a year so there were lots of opportunities for not just working on projects, but networking, having dinner, having lunch – adding that extra day – we had a lot of face-to-face time.* - Debra Collins

Having a shared experience with anyone naturally creates a bond, yet when a group of people endure challenges and exhibit pioneerism together, this creates kinship.

> *We have a common mindset, a "calling" to this field and are dedicated to its success, as well as to the goal of serving families to the best of our abilities. We challenge each other in the best ways to improve and develop our field. It has changed for me, as many of my professional colleagues have now become friends with whom I share my personal life. That is a wonderful added benefit.*
> - Caroline Lieber

Ginny Corson writes, “we spent many hours together over the years and feel a camaraderie that will last forever.” As time goes on, we naturally meet new people, create more connections, and so, our oldest communities may fall to the wayside. However, Susan Creighton described her reinvigorated connection to her Sarah Lawrence College classmates,

> *My community initially was the like-minded colleagues I worked with, my SLC classmates, and the NSGC. Over the years, it broadened to include my GC colleagues, [and] the CAGC… Interestingly, with COVID and the advent of*

> *Zoom meetings, I have reconnected with some of my classmates from SLC which has been rewarding, fulfilling, supportive, and interesting. Our 40th anniversary is planned for June this year. We all recognize we were pioneers.*

Some more non-traditional expansions of this sense of community included Laura Hercher describing feeling connected and representing the genetic counseling community via the work done through journalism and science communication. Joy Larsen Haidle encompassed the immediate bond often felt between genetic counselors that several other participants described,

> *We challenged each other for personal growth and vision for the future. The profession was small then, so I knew the vast majority of GCs. But now, the profession has expanded so quickly that there are colleagues I haven't met yet. Now, if someone says they are a GC, it is an immediate bond…I am proud of GCs, our passion for our patients/profession and our life long love of learning.*

No matter where or how these individuals found their like-minded people, it was and remains to be an extremely durable and "supportive community where people take care of each other and help each other" as Steven Keiles put it.

Being a member of a field that was still in its 'infancy' stage did not inherently mean that it was unsophisticated or lacked deep bonds. On the contrary, it was powered by individuals filled with determination and potential, who were willing to contribute to and support their tight knit community and this is where our pioneers excelled.

Looking Towards the Future

Genetics as a newly evolved field meant that there were relatively few thought leaders in directing policies around genetics. When genetic counselors began to speak up, their voices had an impact not only in the practice of genetics, but in broader arenas of healthcare. Genetic counselors have advocated for their patients and that has extended to advocacy on a public policy level, whether that's legislation, guidelines on testing and screening, or providing mission statements and working towards solutions for issues relevant to the field of genetics.

> *I love one-on-one genetic counseling…but if I get universal tumor screening done for Lynch syndrome on every single colon and every single endometrial cancer that's diagnosed in the world, I'm going to diagnose a lot more people with Lynch Syndrome than I can ever in my lifetime counseling people [on my own]…We do need to think about this…Where can we affect policy? [Affect] change to get better outcomes and get at the bottom of the pyramid? Public health…was not something I went into knowingly…when I was talking about universal tumor screening, I'm like, 'oh, I guess I am doing public health genomics!' But I think it's very important to think about things like that. You can make a much bigger impact than we can seeing one family at a time.* - Heather Hampel

Additionally, the rise of new technologies and discoveries in genetics outstrip the legislation and guidelines to regulate their use. As genetic counselors witnessing these ethical dilemmas and conflicts, it was and continues to be necessary to help both the patients and the healthcare system navigate them.

> *Regarding new technologies…With the introduction of novel laboratory tests, our genetic counselor group, along with an MFM/OB geneticist, would need to decide when/whether to implement a new option. When should we offer cystic fibrosis, or spinal muscular atrophy, or Canavan disease carrier screening? When should we offer expanded carrier screening? When do we offer a microarray on fetal samples? When do we offer a triple screen? When do we offer cell free fetal DNA? And on and on. Do we implement these tests before professional organizations set guidelines or do we wait? There were so many decision points like these over my professional career.* - Ginny Corson

Yet, Michelle Fox reminds us that amidst the deep questions and ethical dilemmas that may keep many up at night, genetic counselors are a unique set of individuals who were trained to take on any challenge or opportunity, "there is nothing a GC cannot do!! We are trained to take on whatever needs to be done and figure out a way to accomplish our goals."

The Reflections From the Pioneers

Who would have guessed that that little flyer about this field would end to all of this? And so the other piece of it is what you get out of your career. Maybe beyond just the academic…
- Ann C.M. Smith

While obtaining our data, one question that we wanted to focus on were reflections from our participants. It is evident through our discussion that this early generation fought for themselves and their careers, making it through many hurdles and challenges along the way. When reflecting on these hard-won achievements, several noted that it was only in retrospect that they realized the import and magnitude of their actions. Ann Walker said, “it's nice to be at the point that we have the long view because there were a couple of years in there that I wasn't sure I could keep putting one foot in front of the other.” In addition to the many uncertain years, the work itself – the patients that clinical genetic counselors and geneticists would see on a day to day basis – came with its own hardships. Dr. Robert Marion explains,

> *We see devastating conditions. We see kids with disorders that are lethal. They're gonna die. It's really depressing..So, how do we survive that? How* <u>*do*</u> *you? How do you go on when that's the case?... And I think the answer is that you look at the good that you can do…You can help the family get through that terrible crisis and go on with their lives. I think that's what I've learned from being a clinical geneticist through the years is that you really have to take a step back and understand the dynamics of the family and the community, and try to make the best of what is undoubtedly a terrible situation, and I've managed to do that.*

Some of them marveled at their own ambition and achievements despite those uncertain beginnings. Beth Balkite stated, “I think we're risk takers, I mean, who else would get a degree in genetics when there were no jobs and nobody knew what a genetic counselor was? And we did that.” Although these qualities and characteristics may not have been verbalized or realized in the moment, the people surrounding them took note of their pioneerism and steadfast determination to not only get the career on its feet, but to keep it advancing and flourishing. Heather Hampel, a 1995 graduate of Sarah Lawrence College articulated the admiration she and her cohort felt toward the first generation of genetic counselors, “they set quite a good example for the second wave of genetic counselors, so that there really were no limits. You know they had to make the career, it didn't even exist...I think we…didn't feel like there were any limits, because they didn't act like there were any. *They* created that limitless mindset.”

The rise of new technologies aided in the growing independence of genetic counselors.

> *Where it seemed that some geneticists felt we threatened their space, the specialty physicians and other health practitioners have embraced our skills and sought them out (especially neurologists, cardiologists, oncologists). These relationships have broadened the scope of genetic counseling practice. There are so many ways to be a genetic counselor now (as an educator, a variant scientist, a research genetic counselor, a cancer genetic counselor, neurogenetics counselor, etc.). It is rewarding to be an expert and now that you are an equal contributor to a health care team and to patient care. You can never be bored with this profession. One of the aspects of being a genetic counselor that I find most satisfying is the ability to be a chameleon and learn the skills necessary to embrace new technologies and tools while continuing to put the patient's interest at the forefront.* - Robin Bennett

Dr. Marion pointed out some of the issues of the expanded access to genetic testing and the need for more genetic counselors to collaborate with those specialists,

> *In a lot of places…the specialists…don't really even understand that they have a problem. They love the fact that they're able to send off genetic testing, get a result, and be able to tell the patient something. But they don't really understand the complexity of it. And so they're not willing to surrender the responsibility to somebody other than themselves.*

Cheryl Shuman elaborated on the major transformations throughout her career: technological, professional, theoretical, and personal.

> *At a basic level, the roles remained much the same but in other ways, it changed dramatically. Some of the changes in my practice were prompted by advances in science and technology such as tremendous advances in knowledge generated via research, genomic testing options, internet tools for professionals and for patients/families, even the use of EMR [electronic*

> *medical record] for documentation. Other changes were associated with our evolving profession, including the overdue abandonment of non-directiveness, the promotion of autonomous decision making and shared decision making models amongst others, the incorporation of unique attributes and voices of diverse cultural communities and disability rights groups, the establishment of new roles for genetic counsellors as specialists and in non-patient facing settings and others. Some changes were certainly associated with my personal and professional growth over the years and the multitude of lessons I had learned from patients and their families. I was also driven to consider approaching our practice in new ways rather than trying to keep adapting or tweaking a practice model that was buckling under the weight of complex new information and testing options along with increased patient volumes.*

One Piece of Advice

We asked for one piece of advice from our participants for newly graduated and future genetic counselors. To wit, these pioneers recommended to connect, invest, and get involved; to actively investigate opportunities; to know your value; to find passion and meaning; to be open, present, and listening; to push yourself, do the work, and never give up; and to seek self-determination for yourself and for this profession. No matter where you might be within your career, we hope to leave you wisdom and guidance with their words (see Appendix, Figure 1).

Conclusion

Our thesis has produced historically and personally situated accounts of the establishment of genetic counseling in the United States. Despite the relatively recent formation of the field, we are at risk of losing these perspectives from the annals of history. These perspectives are from the movers and shakers of the genetic counseling field’s inception and therefore hold remarkable insights and testimonies. The pioneers set the genetic counselors that followed after them on a serendipitously yet hardwon path, filled with possibility and opportunity. We hope that by preserving and presenting these stories, we will create a bridge between past and future generations.

The first genetic counselors may have come to their roles by initial chance, finding the field through word of mouth or through newspaper or magazine articles, but they were a self-selecting population as well. While grand ambitions for the "field" were not a focus, their individual ambitions to create new roles, opportunities, and provide much needed services for new technological advancements inevitably expanded the potential roles. Genetic counselors were never islands unto themselves. They had support from other clinicians, including social workers, psychologists, and geneticists. There was a steep learning curve; more than just genetics, they had to learn how to work within broader institutions, including legal, medical, and academic systems. Still, genetic counselors persisted, trying to find space at tables across disciplines that would benefit from the inclusion of a genetic counselor.

While trying to figure out the extent of their roles – an effort met with both support and pushback – genetic counselors' work and legitimacy was backed by the American Board of Medical Genetics (ABMG), which certified genetic counselors starting in 1982. Despite this legitimization being stripped away from genetic counselors in 1992 so genetics could be accepted into the American College of Medical Specialties, genetic counselors continued to prove and establish their own legitimacy and professionalization. They did this by creating their own boards and accreditation of genetic counseling programs following the separation from ABMG; forming societies, including the American National Society of Genetic Counselors (NSGC) in 1979 and the Canadian Association of Genetic Counselors (CAGC) in 1990; by publishing, with the creation of the first newsletter in 1979, creating the *Journal of Genetic Counseling* in 1990, publishing textbooks for and by genetic counselors by 1998, and by establishing standards of practice within genetics like pedigree nomenclature; and through federal and state involvement, with efforts in both access and protection for genetics care, federal recognition, licensure, and insurance coverage.

The small yet dramatic steps, the slow moving yet impressive impact on medical teams and patients, the emotional and demanding separation into their own organization all culminated in the genetic counseling field as we know it today. The necessary organizational and professional work that previous generations achieved have created stability that is easy to take for granted when entering the field as a new genetic counselor. Yet, for many, realizing the impact of their pioneerism only occurred years later. These interviews and time completing the questionnaires were an opportunity to reflect on their groundbreaking work.

One common theme across these pioneers was that even when spreading far and wide in both geography and specialty, there were tight-knit and strong bonds uniting them. Perhaps this was because of the small number of genetic counselors during the early years; everyone knew one another, so this kinship survived the decades. The occasional times they would see each other at conferences were crucial in reaffirming those bonds. Some of those occasions they met involved setting the foundation of the field, thereby creating momentous memories together, another element that cemented their relationships. This is a point where a disconnect is present with the current generation of genetic counselors. With the advent of the internet and the booming growth of the genetic counseling field, the deep communal bonds established at conferences and through weathering trials within the field are no longer inevitable. Community is necessary for survival within small populations but becomes less of an imperative when the population grows large enough. The spirit of pioneerism has been slowly stifled as well. The previous uncertainty within their roles as the first generation of genetic counselors allowed for unbounded possibility and their work to expand the field allowed for subsequent generations to embrace new roles. While the rapid progression of science demands adaptation, there are increasingly onerous demands of the medical system (e.g. patient load, documentation, etc.) on genetic counselors. These demands limit the necessary time and space that would allow this pioneering mentality that was once the trademark of the field to flourish. Yet, the constant of change and needing to adapt to all that change brings is a commonality that continues to bridge the generations.

These shifts are symptoms of a growing profession. In the face of this progression, are these traits of community and pioneerism ones that we are willing to abandon or at least not fight to keep?

This profession was forged by this community of pioneering genetic counselors in the crucible of (unexpected) challenges and adversity over the last fifty years. The challenges we faced in the past, the challenges we face today, and the challenges we will inevitably face in the future will define this field and determine whether or not genetic counselors will remain key players at the forefront of the genomic revolution. Currently, genetic counselors are grappling with the role of new technologies like gene editing or Artificial Intelligence; new legal frameworks like the recent reversal of Roe v. Wade on the role of abortion in prenatal counseling; and field-specific challenges like licensing at state and federal levels for genetic counselors. How we choose to engage with these challenges will shape the direction of this field.

The exact sense of community and pioneerism that these early genetic counselors had can never be achieved again. We will not know every person running for leadership positions or sitting on a committee as those pioneers once did. However, we achieved these heights through community and this sense of pioneerism; and despite our growth, we are still a minority within the healthcare system. To successfully meet these challenges now and in the future, we believe we need to fight to maintain this spirit of tight-knit community, support, and connection.

Advocate for yourself and for the genetic counseling community. Reach out, connect, ask for help, and offer your help. Though it can never be the same, there is a community for us still and together we can go far. The field could not exist without these pioneers. We owe it to them, ourselves, and our field to give back, to connect, and to ensure we all reach greater heights together. As Isaac Newton paraphrased, "if I have seen further [than others], it is by standing on the shoulders of giants" (Chen, 2003).

> *...people know what genetic counseling is now and they think it was always like that. And it wasn't. It wasn't. There's a history to this profession that was a lot of blood, sweat, and tears shed...New genetic counselors have a fairly easy life and I've always, always tried to get people to understand...Give back. So much has been given to you and made it easy for you. You have an opportunity to volunteer to be on a committee, to be on a workshop, to contribute this, somebody asked you to present something – do it, don't hesitate. You owe it. In the profession you owe it to the students that are yet to graduate. You owe it to contribute to this great organization and this great profession which you decided to make part of your life. So do it. Get out there.* - Ed Kloza

If you are interested in becoming more involved in the genetic counseling community, please find resources of links to organizations below:

1. **NSGC**: https://www.nsgc.org/OnlineEducationCenter
2. **NSGC Special Interest Groups (SIGs)**: https://www.nsgc.org/SIG
3. **Accreditation Council for Genetic Counseling:** https://www.gceducation.org/students-volunteers/
4. **Canadian Association of Genetic Counselors:** https://www.cagc-accg.ca/
5. **Genetic Alliance:** https://geneticalliance.org/
6. **American Society of Human Genetics (ASHG)**: https://www.ashg.org/advocacy/

References

Brownlee, C. (2017, May). *OMIM turns 50: A genetic database's past, present, and future*. Johns Hopkins Medicine, based in Baltimore, Maryland. Retrieved April 23, 2023, from https://www.hopkinsmedicine.org/research/advancements-in-research/fundamentals/in-depth/omim-turns-50-a-genetic-databases-past-present-and-future

Chen, C. (2003). On the Shoulders of Giants. *Mapping Scientific Frontiers: The Quest for Knowledge Visualization*, 135–166. https://doi.org/10.1007/978-1-4471-0051-5_5

Eugenics and Scientific Racism. Genome.gov. (2022, May 18). Retrieved April 23, 2023, from https://www.genome.gov/about-genomics/fact-sheets/Eugenics-and-Scientific-Racism

Frisch, M. H. (1990). *A Shared Authority: Essays on the Craft and Meaning of Oral and Public History*. State University of New York Press.

Hamilton, P., & Shopes, L. (Eds.). (2006). *Oral History and Public Memories*. Temple University Press. http://www.jstor.org/stable/j.ctt1bw1kn9

Heimler, A. (1980). Perspective in Genetic Counseling. *The Newsletter of the National Society of Genetic counselors, 2*(3) 2-5.

Huxford, G. (2022). 'There is No Icebreaker like a Tiny Child': Reuniting British Military Families in Cold War Germany. *Contemporary European History,* 1-18. doi:10.1017/S0960777322000248

Logue, Christopher. *New Numbers*. Cape, 1971.

McCarthy Veach, P., LeRoy, B. S., & Callanan, N. P. (2018). Overview of genetic counseling: History of the profession and the reciprocal-engagement model of Practice. *Facilitating the Genetic Counseling Process*, 33–49. https://doi.org/10.1007/978-3-319-74799-6_2

National Society of Genetic Counselors. 2021 Professional Status Survey- Executive Summary. (2021, May 3). Retrieved May 1, 2023, from https://www.nsgc.org/Portals/0/Executive%20Summary%202021%20FINAL%2005-03-21.pdf

NSGC Timeline. NSGC. (n.d.). Retrieved April 23, 2023, from https://www.nsgc.org/About/About-NSGC/Timeline

Office, U. S. G. A. (2020, July 31). *Genetic services: Information on Genetic Counselor and Medical Geneticist Workforces*. Genetic Services: Information on Genetic Counselor and Medical Geneticist Workforces | U.S. GAO. Retrieved April 23, 2023, from https://www.gao.gov/products/gao-20-593#:~:text=The%20data%20show%20there%20were,1%2C240%20as%20of%20April%202020

(OCR), O. for C. R. (2021, June 28). *Genetic information*. HHS.gov. Retrieved April 23, 2023, from https://www.hhs.gov/hipaa/for-professionals/special-topics/genetic-information/index.html#:~:text=The%20Genetic%20Information%20Nondiscrimination%20Act,health%20coverage%20and%20in%20employment

Portelli, A. (2001). *The death of Luigi Trastulli, and other stories: Form and meaning in oral history*. State University of New York Press.

Resta, R. (2010, April 11). The Great Genetic Counseling Divorce of 1992: A Historical Perspective On Change In The Genetic Counseling Profession [web log]. Retrieved April 23, 2023, from https://thednaexchange.com/2010/04/11/the-great-genetic-counseling-divorce-of-1992-a-historical-perspective-on-change-in-the-genetic-counseling-profession/.

Rothman, B. K. (1986). *The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood*. Viking.

Smith, A. C. M., Heimler A. (1980). *Certification of Genetic Counselors.* Perspectives in Genetic Counseling 2, 2(1).

Stern, A. M. (2008). A quiet revolution: The birth of the genetic counselor at Sarah Lawrence College, 1969. *Journal of Genetic Counseling*, *18*(1), 1–11. https://doi.org/10.1007/s10897-008-9186-8

Stillwell, D. (2013). *Interpreting the genetic revolution: A history of genetic counseling in the United States, 1930-2000* (thesis).

Appendix

Table 1a. Pre-Interview Form for Interviewees. Sections 1-3.

Pre-Interview Questionnaire	**Questions Relating to the Genetic Counseling Field:**	**Questions Relating to Organizational, Technological, or Legislative Changes:**
Name	1. Your journey in finding, entering, and adapting to changes within the field of genetic counseling.	1. Both the integration and delineation of genetic counselors' roles in the medical industry have resulted in the creation of the NSGC in 1979, forming ABGC in 1993 to provide certification, and efforts of gaining licensure in different states since the 1990s.
Email	2. As pioneers and advocates for both patients and for yourselves, what visions and goals did you have when creating the roles of 'genetic counselor'? How did they change over time and why?	2. Technological innovations have rapidly altered the resources, tools, and roles available to genetic counselors. What was it like as a genetic counselor in creating and integrating these innovations, such as newborn screening in 1963, the creation of online resources like OMIM in 1987 or the Helix/Genetic Test Registry in 1993, or testing for single gene disorders? Did you feel that new ethical quandaries were raised with patients?
Phone number		
Where did you get your Genetic Counseling or medical degree from?		
What year did you graduate?		3. We have come full circle recently, as Roe v. Wade has been overturned by the current Supreme Court. Legislative efforts have affected this field and the perspectives of the populace, ranging from Roe v. Wade in 1973, the National Genetic Disease Act S.1715 in 1979, the Americans with Disabilities Act in 1990, and the Genetic Information Nondiscrimination Act (GINA) in 2008. Have you been involved in these or other legislative efforts? How do you think they've impacted the genetic counseling field?
What year did you begin working in the field and are you still working?		4. There have been a great number of important events in genetic counseling history. If there is an event you feel you have unique insight into or would like to discuss in the group interview, we encourage you to list it here:

Table 1b. Pre-Interview Form for Interviewees. Sections 3-6.

Questions Relating to YOU, as a Genetic Counselor:	**Questions About Your Own Experiences in the Field:**	**Concluding Thoughts**
1. How do you describe what you do now as a genetic counselor? Is it different from how you originally described it when you began?	1. Think about *your* 'genetic counseling community' and what it means to you. Has that changed over the years?	Are there any other anecdotes, memories, opinions, stories, or experiences that you would like to discuss during the interview? Briefly describe.
2. Did training as and working as a genetic counselor transform the way you viewed science and medicine?	2. Is there an encounter or conversation with patients or colleagues that has stuck with you throughout the years? Why do you think it has remained with you? Did you learn something specific from this encounter	
3. How did your personal identities affect the way you counseled patients and viewed genetic counseling?	3. If you could give one piece of advice to incoming genetic counseling students and newly graduated students entering the field, what would you say?	

Table 2a. History of Genetic Counseling Questionnaire Form. Sections 1-3.

History of Genetic Counseling Questionnaire:	**Questions Relating to the General Genetic Counseling Field:**	**Questions Relating to Organizational, Technological, or Legislative Changes:**
1. Email	1. How did you find the genetic counseling field?	1. Both the integration and delineation of genetic counselors' roles in the medical industry have resulted in the creation of the NSGC in 1979, formation of the ABGC in 1993 to provide certification, and efforts of gaining licensure in different states since the 1990s. a. Have you been involved in this process? Feel free to elaborate on any stories you might have.How have you felt about these changes over the years?
2. Have you signed and sent us the consent form?	2. Where/ what/ how did you find your first job as a genetic counselor? a. How were you received at this job by different medical providers? Nurses, doctors, etc.?	
3. Name	3. How did your role as a genetic counselor change throughout your professional career?	2. Technological innovations have rapidly altered the resources and tools available to genetic counselors. Did the integration of these new technologies [e.g. Newborn screening (1963), creation of online resources like OMIM (1987) or Helix/Genetic Test Registry (1993), or testing for single gene disorders]
4. Where did you get your Genetic	4. As pioneers and advocates for both patients	

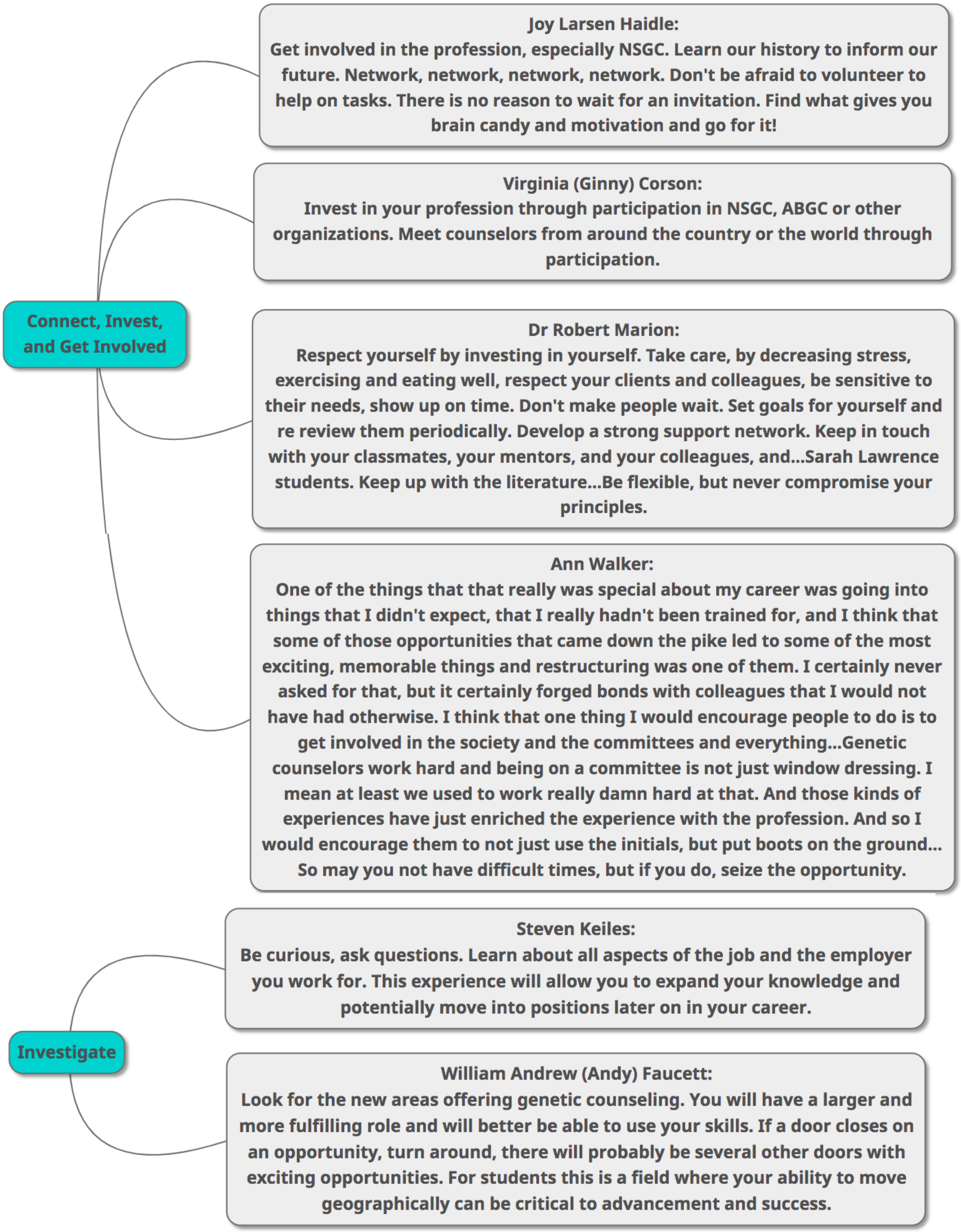
Counseling degree from?	and for yourselves, what visions and goals did you have when creating the roles of ‘genetic counselor’?	change how you viewed your role and practice as a genetic counselor? a. Did you feel that genetic counselors were involved in these changes? How were they involved in integrating them into practice? Did you feel that new ethical quandaries were raised with patients?
5. What year did you graduate?	5. When integrating these visions within the bounded limitations of the healthcare system, what was abandoned, what was necessary to innovate, and what surprised you?	3. We have come full circle recently, as Roe v. Wade has been overturned by the current Supreme Court. Legislative efforts have affected this field and the perspectives of the populace, ranging from Roe v. Wade in 1973, the National Genetic Disease Act S.1715 in 1979, the Americans with Disabilities Act in 1990, and the Genetic Information Nondiscrimination Act (GINA) in 2008. a. Have you been involved in these or other legislative efforts? How do you think they’ve impacted the genetic counseling field?
6. What year did you begin working in the field?		
7. Are you still working? (Y/N/Part Time)		

Table 2b. History of Genetic Counseling Questionnaire. Sections 3-6.

Questions Relating to YOU, as a Genetic Counselor:	**Questions about your own experiences in the field:**	**Concluding Thoughts:**
1. How do you describe what you do now as a genetic counselor? Is it different from how you described it when you began?	1. Describe *your* 'genetic counseling **community'** in your own words and what it means to you. a. Has that changed over the years?	1. If there are any other anecdotes, memories, opinions, stories, or experiences that you would like to share, feel free to write below:
2. Was there a moment or time where you had feelings of “burnout”? a. How did you approach these situations?		
3. Did training as and working as a genetic counselor transform the way you viewed science and medicine? In what ways?	2. Is there an encounter or conversation with patients or colleagues that has stuck with you throughout the years? a. Why do you think it has remained with you? b. Did you learn something specific from this encounter? (Reminder to not include PHI in your response)	
4. How did your personal identities affect the way you counseled patients and viewed genetic counseling?		
5. Were you a prenatal or preconception counselor at any point in your career? (Y/N)	3. If you could give one piece of advice to incoming genetic counseling students and newly graduated students entering the field,	

a. If YES to above, were you or your partner pregnant at all during your years of working as a genetic counselor? Did having the knowledge of a genetic counselor affect how you viewed the pregnancy?	what would you say?	

Figure 1. One Piece of Advice to Incoming or Newly Graduated Genetic Counselors



Connect, Invest, and Get Involved

Joy Larsen Haidle:
Get involved in the profession, especially NSGC. Learn our history to inform our future. Network, network, network, network. Don't be afraid to volunteer to help on tasks. There is no reason to wait for an invitation. Find what gives you brain candy and motivation and go for it!

Virginia (Ginny) Corson:
Invest in your profession through participation in NSGC, ABGC or other organizations. Meet counselors from around the country or the world through participation.

Dr Robert Marion:
Respect yourself by investing in yourself. Take care, by decreasing stress, exercising and eating well, respect your clients and colleagues, be sensitive to their needs, show up on time. Don't make people wait. Set goals for yourself and re review them periodically. Develop a strong support network. Keep in touch with your classmates, your mentors, and your colleagues, and...Sarah Lawrence students. Keep up with the literature...Be flexible, but never compromise your principles.

Ann Walker:
One of the things that that really was special about my career was going into things that I didn't expect, that I really hadn't been trained for, and I think that some of those opportunities that came down the pike led to some of the most exciting, memorable things and restructuring was one of them. I certainly never asked for that, but it certainly forged bonds with colleagues that I would not have had otherwise. I think that one thing I would encourage people to do is to get involved in the society and the committees and everything...Genetic counselors work hard and being on a committee is not just window dressing. I mean at least we used to work really damn hard at that. And those kinds of experiences have just enriched the experience with the profession. And so I would encourage them to not just use the initials, but put boots on the ground... So may you not have difficult times, but if you do, seize the opportunity.

Investigate

Steven Keiles:
Be curious, ask questions. Learn about all aspects of the job and the employer you work for. This experience will allow you to expand your knowledge and potentially move into positions later on in your career.

William Andrew (Andy) Faucett:
Look for the new areas offering genetic counseling. You will have a larger and more fulfilling role and will better be able to use your skills. If a door closes on an opportunity, turn around, there will probably be several other doors with exciting opportunities. For students this is a field where your ability to move geographically can be critical to advancement and success.

Know Your Value

Susan Creighton:
Find your allies, don't try to reinvent the wheel, and never feel you are alone. Do not succumb to "imposter syndrome"; you were smart enough to get into your program and some of the skills will take time to mature. Forgive yourself for being normal. Know that the work we do is hard, and there will be difficult patient situations that will be hard for you. Find your escape valves (destressors) and use them. And welcome to an incredibly interesting profession that will keep you learning and growing for the rest of your career!

Laura Hercher:
Your job, and your knowledge base, will keep changing. But understanding the basic concepts of genetics and how to communicate to people is a powerful combination and valuable. Who knows how you will use it! But it will be exciting. Know your value.

Heather Hampel:
If you are not afraid to contribute, your value will be seen very quickly. And so you just have to not be shy.

Debra Collins:
Hang in there. Look for different ways to do things. You're creative. You have the skills. You're going to really be able to do amazing things. And you've got all these colleagues to tap into for information...Have a lot of confidence in yourself. We don't know what we're doing half the time, but you guys have the skills to do all kinds of things. And that's what's exciting about genetic counseling. It isn’t prescribed, and it attracts people that want to try something new and different. Whatever your ideas, there's a way you're gonna be able to do it.

Passion and Meaning

Michael Begleiter:
I would want to say that this is a great job, that you will have the opportunity to meet many wonderful families and hopefully doing some meaningful things to help them on their journeys.

Robert (Bob) Resta:
It’s a great profession. Most days it's a great profession, and you shouldn't let the crappy days offset the good days. So my calculus about retirement was I decided to retire when the when they were more bad days than good days. That were more unhappy than happy. Plus, I wanted to retire a 300 hitter rather than a 200 hitter for those baseball fans out there.

Robin Bennett:
You will never having a boring day as a genetic counselor.

Be Open, Present, and Listening

Caroline Lieber:
Learn to listen.

Michelle Fox:
To be open to all that the field holds and not be afraid to take a risk to do something you have never done before.

Matilda (Tillie) Young:
Enjoy the ride! You'll keep learning, and never be bored. A wise supervising doctor once advised me, "keep your eyes open and your mouth shut!" That's an exaggeration, but he meant, observe, and think before you speak.

Cheryl Shuman:
Be open, that is pause, observe and really process the words and actions of your patients and their family members so that you can learn from them. Also, take a moment to reflect on how lucky you are to have chosen a profession filled with so much stimulating science and so many enriching interactions with colleagues.

Dr. Ann CM Smith:
Engage your passions and don't be afraid to try something new. Seek knowledge and instill a love of lifelong learning. Share it and pass it along to the next generation of your counselors or mentees, etc. We already talked about the team approach. The last would be serendipity. Serendipity is likely to happen, and let it also be something that you welcome with exuberance and enthusiasm. It may redirect your path from where you thought you were going to a new direction and be open to those changes.

Beth Balkite:
I would say just always remember: what is the best you can do for the person that's in front of you that day? Come back to that person. Counseling is part of our title, and the science has gotten so slick and just so fascinating and in-depth, and it's...everywhere. But just you need to keep your focus on the patient, or the client, or the board members that you're sitting with. Whatever situation you're in, be sure and keep your focus on the human and the humanity behind it all.

Jessica G Davis, MD:
Listen, listen listen. Learn about your patients.

Push Yourself, Do the Work, and Never Give Up

Wendy Uhlmann:
Find mentors and to take risks and to never really stop putting yourself out there. What's that quote? 'Better to have tried and failed than not to have tried at all.' To really be willing to learn from things that didn't go well. And so part of the teaching I do is to take cases that were challenging to me and to turn them into learning experiences. They were a learning experience for me and I think it's really important for us to be able to learn from what goes well as well, as from things that don't go so well–but to never give up.

Edward (Ed) Kloza:
Don't let other people do the work. I mean there's plenty of work to be done... Look back at the history of what's been done. Think of how you can make history going forward worth it.

Diane Baker:
It's not gonna make sense, but it would be: Don't get comfortable. It's advice to the long term. When you get comfortable you're slacking. Be uncomfortable. I see that sometimes in colleagues where they get comfortable. 'This is what I do, I don't do that.' It's like they're an automatron. They're not a human being who can be agile and respond. So my advice is, don't get comfortable.

Self-determination and Control of the Profession

Bonnie LeRoy:
I think the most important thing that the genetic counselors in the past did was was make sure that they were in control of the profession...the genetic counselors in the past made sure that we wrote the scope of practice. We wrote the practice guidelines. The board was set up with the practice based competencies that we wrote. We say who we are and what we can do. Nobody else says that...That is so critical: to never lose control of the profession, because once you do other people tell you who you are and then it won't work.

Debra Collins:
...what I keep seeing is the administrators are wanting you to see more and more patients and [that] doesn't give you the free time. They want to write algorithms for everything you do...there's a tendency to try to put you into the peg of an already existing system or profession... But... continu[e] to show examples of something that if you'd stayed with a protocol you wouldn't have been able to serve your patients right or [as] well. And you know, [rely on] having this backup of a profession that feels the same way...But it's really quite the system to be entering into and trying to hold onto genetic counseling as a profession. That's really important.