Perspectives in Genetic Counseling
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President's Beat

Time is a funny thing. At the beginning of this presidential year, the thought of twelve months as an NSGC leader seemed daunting, and I was barely able to see past the ambitious mountain of strategic goals and initiatives before me. My volunteer time commitment loomed particularly large, given the endless schedule of conference calls and meetings that suddenly populated my calendar last January. Now as I enter the home stretch, I can't believe how quickly the time went by. Thanks to the collective efforts of the NSGC's Committees, Board of Directors, and SmithBucklin management staff, our organization has accomplished its annual objectives… and then some. Somehow, time expanded to accommodate our short-term goals, from Practice Guidelines and Position Statements to licensure and federal legislative efforts.

The timeline for long-term goals – such as accomplishments that chart the overall direction of our profession – is necessarily slower. The NSGC's leadership development process has taught me how to shift back and forth between short-term accomplishments and long-term outcomes, giving me a "Google Earth" view of where the genetic counseling profession has been, how it got here, and where it's likely to be headed. The human genetics field is experiencing rapid change, and it's easy to forget that our profession was established decades ago, long before whole genome sequencing and direct-to-consumer testing. Much time has elapsed since the NSGC was first incorporated in 1979 as our professional society, and to some, those early decades might seem irrelevant to today's more technologically sophisticated issues and conversations.

Shifting to a higher-level view, however, it is clear that those early efforts laid an impressively solid groundwork for our profession. Every year of the NSGC's leadership since then, by dutifully accomplishing its annual goals with an eye toward long-term outcomes, has steadily and surely led us to where we are today. It has been my privilege this year to be part of that ongoing effort to grow our profession, one step at a time, through the incremental accomplishment of focused yearly goals. I'm confident that the efforts of the NSGC's future leaders will continue to move it forward: the long-term evolution of our profession depends on the collective vision of its leadership.

Brenda Finucane, MS, CGC
2012 NSGC President

Developing effective communication tools for genetic counselors in France

By Souria Aissaoui, MSc, Christophe Cordier, MSc, and Hanaa Aissaoui, PhD

Genetic counseling in France: a recent establishment

The profession of genetic counseling has been established for several years in various countries, such as the United States, Canada, and the United Kingdom. However, the profession was only recently developed in France. The French Master's degree program was initiated during the 2004-2005 academic year, and the profession was officially recognized by a decree on April 10, 2008.

The French Association of Genetic Counsellors (Association Française des Conseillers Génétique, AFCG) was created in 2005 by the first students of the Professional Master's Program in Human Pathology specializing in genetic counseling and predictive medicine, based at Aix-Marseille University in the south of France. The AFCG was founded following the creation of the profession of genetic counseling in France, with an aim to promote this new health care profession in the country, and to inform its members about new career opportunities. It currently has more than 120 members across France.

Why create a newsletter in France?

With approximately fifteen students joining the profession per year[1], it became necessary to develop closer ties with the medical field.[2] A dedicated French genetic counseling newsletter was suggested as a means to raise awareness and communication amongst its members. In addition to the AFCG's website, a biannual newsletter was established in 2009, written by a team of volunteers. Newsletters are available on the AFCG website (http://asso.orpha.net/AFCG/cgi-bin/), kindly hosted by Orphanet.

This communication tool is rare in France, in that this particular model is not widely used in other professions in the country. In genetics elsewhere, however, this has been established – such as by the NSGC with *Perspectives in Genetic Counseling* and the Canadian Association of Genetic Counsellors with *Crossover*. The AFCG's newsletter contains information about administrative processes, news clips, references, conferences and job openings, and helps maintain a professional network. Its audience contains individuals affiliated with the Master's program, as well as supervising genetic counselors and prospective students.

How does it work?

A dedicated email address was created in order to correspond with and facilitate communication between those working on the newsletter (newsletterafcg@yahoo.fr). Thanks to this link with the team, members and/or readers can discuss their questions about the profession, comment on articles or an unusual situation, suggest ideas or submit a brief clinical report. The newsletter's staff teams are organized as shown in the table below.

Newsletter Team	Role(s)
Editor	• Manages newsletter overall
Professional Relations/Networking	• Interviews • Updates French legislature/regulations • Promotes profession
Employment	• Updates job and internship vacancies, upcoming conferences, training opportunities
Education	• Informs readers about relevant publications in the field • Coordinates clinical case reports
Communication	• Facilitates communication between newsletter participants, authors, readers, webmaster

The newsletter is submitted to a copy editing committee of genetic professionals before publication. A homogenous format of the newsletter has been established since the first issue, in order to give the readers the most updated information about the profession. It is in this spirit that we aim to make this newsletter useful to the professional genetics community in France.

A positive start

Dr. Jean-François Mattei, clinical geneticist and former French Minister of Health, honored the newsletter staff volunteers by writing an editorial piece for the first issue of the newsletter in March 2009, in which he emphasized the need for genetic counselors in France. The following is his entire editorial, translated from French:

"Essential genetic counselors"

"It is a rare event for a new profession to appear in the medical field, that it is worth expressing satisfaction and highlight all positive factors, which should ensure it a full success over time. Even if medical genetics is a recent field, the increased needs have very quickly overcrowded consultations and compromised the quality of exchanges with couples and families. This is particularly so in prenatal diagnosis where the demand is growing, where technologies are evolving, and where issues such as decisions must be thoroughly explained."

"The danger in a medical practice 'routine' would be to forget that this is a 'unique' moment for every couple, and that their experience of this moment is crucial for their future. It is why the role of genetic counselors is essential. It belongs to them to ensure, with renewed attention for one another, the transition from science to human, from developing technique to daily experience."

"This is indeed what is expected from them: knowledge, availability, patience and pedagogy. It belongs to them as well, to identify the most difficult cases, to bring them to the geneticist with whom they are attentive collaborators within teams, where everyone brings their own skills."

"Then they must ensure, if necessary, this crucial mission: that individuals, couples and families should never feel lost in front of genetic adversity. That's how I see the activity of genetic counselors – first and foremost deeply human."

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Acknowledgements

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Sharma, Anna-Gazelle Villard, Sarah Funtowiez, Eglantine Jolly, and Thomas Seytier – all of whom are fellow colleagues and AFGC members.

For more information, please contact Souria Aissaoui at souria.aissaoui@chu-lyon.fr

For Your Practice

From the Health Information Technology (HIT) Special Interest Group

Apps in the Genetic Counseling Field

By Brian Reys, University of Cincinnati Genetic Counseling Graduate Program, Class of 2013 and Heather Fecteau MS, CGC

Have you been bowled over by a smartphone user while walking down the hall? Have you ever bowled someone else over? If so, a new phone app may be the culprit. Besides turning smartphone users into walking hazards, apps are bringing new and creative resources to many fields, including the field of genetic counseling. The ever-expanding menu and versatility of apps has lead to the phrase, "There's an app for that." The Health Information Technology (HIT) Special Interest Group (SIG) recognizes the importance of technology to the growth of our profession, and today we seek to examine the current and future value of apps in genetic counseling.

Current Apps for Genetics Professionals

Apps (short for applications i.e. software) are downloadable programs specifically designed for mobile devices like smartphones, tablets and e-readers. They are available either free of charge or for a price through application distribution platforms. Apps are downloaded from platforms operated by the owner of the mobile operating system, such as the Apple App Store, Android Market, and BlackBerry App World, to a target device such as an iPhone, BlackBerry, or Android phone – and sometimes to tablets, laptops, or desktops. If you attended the National Society of Genetic Counselor's (NSGC's) 2012 Annual Education Conference (AEC) in Boston this year, you were likely bombarded with encouragement to download the app NSGC 2012 Annual Education Conference,® designed specifically for the conference.[1] The app allowed users to access the conference schedule, up-to-date alerts of room changes and, most importantly, maps of the Convention Center with bathrooms specifically labeled. The app personalized for the NSGC's AEC is a perfect example of how technology is quietly, but steadily, revolutionizing the world we live in.

Some apps that genetic counselors may find useful were actually designed for other specialties or the general healthcare professional. These apps include drug information references, pregnancy wheels, developmental milestones logs and growth charts, to name a few. To demonstrate, Pregnancy Wheel© creator Duprey Net claims their electronic wheel "…simply works like a real pregnancy wheel except that it is more accurate, factors in leap years, and no trees were cut down to make it."[2] It looks like a traditional pregnancy wheel, is always at hand, and no longer forces you to align the frustrating little lines on the pregnancy wheel to calculate an expected due date (EDD). It can be purchased for less than a dollar.

There are apps designed specifically for the genetics field, like Genetics 4 Medics®[3] or Genetics & Birth Defects.®[4] Genetics 4 Medics® has a list of over 200 common genetic disorders, 150 clinical features associated with them and differential diagnoses commonly associated with the disorders. The app also has definitions for common terms used in genetics like "alleles." Genetics & Birth Defects® similarly has a list of common genetic conditions and gives an overview of each, including any treatments available. Apps like these make great quick educational references for genetics or other medical health care professionals. There are apps that can be used for education and replace using a flipbook during a genetic counseling session. Using interactive apps on a smartphone or tablet would allow patients to understand complex issues more clearly. It would also allow the patients to potentially use the app on their personal devise to educate family members and others. Table 1 contains more apps that genetic counselors can use for reference and genetic counseling practice purposes.

Table 1. Apps for reference and genetic counseling practice purposes

Reference topic	**Description**	**Cost**
ICD-9 codes	ICD9 Consult 2013® gives the 2013 ICD-9 CM a finger touch away, which are also searchable	$14.99
Genetic syndromes	Genetics 4 Medics,® Genetics & Birth Defects,® Datagenno,® contain information about syndromes, including symptoms	$4.99/Free
Genomic data / Genome browsers	BioGene® provides information on a gene's location and function along with PubMed references, while GeneWall Genome Browser® is a native genome browser; it allows you to import genomic coordinates (compatible with hg19 build) and gives information on genes, genomic structure, and related pathways	Free
Medline search	PubSearch® a fast search tool for academic research papers	Free
Cancer screening guidelines	NCCN Guidelines® gives quick access to National Comprehensive Cancer Network (NCCN) clinical practice guidelines in oncology, to registered users	Free
Clinical trials	NCITrials@NIH® allows you to research the National Cancer Institute's Center for Cancer Research clinical trial database for current clinical trials.	Free
Genetic counseling practice topic	**Description**	**Cost**
Pregnancy dating	Pregnancy Wheel® is an electronic way of calculating gestational ages and expected due dates	$0.99
Pedigree generation	FHx® helps you build detailed pedigrees	Free

Plotting pediatric growth charts	STAT GrowthCharts® allows you plot growth parameters to quickly calculate World Health Organization (WHO) percentiles	Free/$5.99
Bayesian calculations	Medicine Toolkit® and Rx-Bayes® enable you to apply Bayesian calculations to patient care	$9.99/0.99
Teratogenic risk assessment	Reprotox® contains summaries on the effects of medications, chemicals, infections, and physical agents on pregnancy, reproduction and development. Must have subscription.	Free
Counseling Aids	Gene Screen® contains graphics relating to genes and inheritance (including calculations), information on genetic diseases more common in the Jewish population, and links to Internet resources. Punnett Calc® allows you to put in parental allele combinations (for up to five genes) and calculates the probability of each possible outcome.	Free/$0.99

The Future of Apps in Genetic Counseling

While it seems like the potential for apps may be limited only by the imagination of their creators, a major barrier to apps for medical professionals is security. Security and privacy are major concerns for any apps that could potentially hold personal health information (PHI), or that could access an electronic medical record (EMR) system. However, limitations based upon these concerns will only last as long as it takes mobile tool designers to find solutions. Some users are already able to access EMRs securely via laptops, and the use of tablets in hospitals is quickly growing.

As the field of human genetics moves into the future, genetic counselors are expected to keep up with the newest advances in testing technologies, like exome sequencing and non-invasive prenatal testing. Rest assured that health information technology also continues to improve, and will help us meet these challenges.

As more companies find ways to make apps for the health care professional, apps that access EMRs, draw pedigrees and help with pesky Bayes theorem calculations, as well as many more, will be emerging into our field. Users of 23andMe Mobile© can already see their genotyping results on their mobile devices,[5] and very soon you could encounter clients bringing smartphones to clinic asking for interpretation of their test results (if you haven't already). As we move forward and grow to meet the need of our ever-diversifying field, genetic counselors are encouraged to stay on top of technology, search for new apps to use in practice, and see these apps as the gift of technology that they are.

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Licensure / Billing & Reimbursement

Coding Corner

How does licensure affect billing and reimbursement?

By Pia Summerour, MS, CGC and Kaylene Ready, MS, CGC

The Coding Corner is supported by the Coding Subcommittee of the National Society of Genetic Counselors' (NSGC) Access and Service Delivery Committee and aims to assist NSGC members with the application and understanding of governmental regulations and guidelines regarding terminology and Current Procedural Terminology (CPT) / International Classification of Diseases (ICD) coding in genetic services as well as keep the membership educated regarding billing and reimbursement issues.

Thank you to those who participated in the Payer Subcommittee's Billing and Reimbursement Survey! In addition to asking many questions about how genetic counselors bill, the survey asked participants for areas in which the NSGC should provide additional education. One of the themes that arose was the relationship between licensure, billing and reimbursement.

But before the relationship can be elucidated, an understanding of the difference between licensure and credentialing is required.

Licensure

Licensure refers to the process of granting a license to practice to a specific profession. This form of regulation protects the public from unqualified providers. Licensure provides a framework for complaints and remedies, creates minimum standards, establishes a legal scope of practice, and provides title protection that enables the public to identify qualified providers.

Credentialing

Credentialing refers to the process of obtaining, verifying, and assessing the qualifications of a health care provider. Hospitals, managed care organizations, insurance companies, and private practices perform credentialing independent of one another to verify a genetic counselor's identity, and to assess his/her ability to provide competent care.

So what does all of this have to do with billing and reimbursement? Licensure is often the price of admittance to credentialing. There are certainly exceptions, as these policies are developed at the individual, institutional level.

Credentialing is often necessary to receive reimbursement for services. There are usually two processes that allow billing and reimbursement to occur as an independent provider: 1) Credentialing at the facility, and 2) Credentialing with individual payers, which is also known as "provider enrollment." All processes are separate and independent of each other, which makes it very inefficient.

Some hospitals have contracts with payers that automatically enroll a practitioner into a health plan once he or she becomes credentialed at the facility, but they are not commonplace. **The issue at hand is whether your facility and local insurers will allow you to become credentialed without licensure**. While some facilities and insurers will accept The American Board of Genetic Counseling's (ABGC's) certification to credential a genetic counselor, others won't – and in fact, some hospital bylaws specifically require a credentialed provider to be licensed first.

Whether you live in a state with licensure or not, we recommend that you work with your Medical Staff office or Human Resources department to become credentialed at your institution. Then work with your Provider Enrollment staff or your Contracts department to become a credentialed provider with your local insurance companies. In some facilities, credentialing and provider enrollment may be provided by the same department; at others, they may not.

In states that do not license genetic counselors, it is important to emphasize that services are provided by appropriately trained healthcare providers, and that ABGC certification ensures minimum standards. However, be aware that many insurance companies simply do not allow non-licensed providers to bill them directly.

Which of course brings us right back to our original question – *How does licensure affect billing and reimbursement?* In a nutshell, **licensure allows genetic counselors to become independent credentialed providers, which is a necessary step for billing and reimbursement at facilities with their payers.**

For more information about billing and coding, we recommend the "Credentialing, Coding, and Compliance" online course, which will be available for purchase in 2013 on the NSGC website. You can also post your questions to the Billing, Coding, and Licensure Ask the Expert Forum.

The Coding Corner is your resource for questions about coding. If you have questions you wish to be considered for this section, please send them to ***Pia Summerour*** *(pia.banerji@utsouthwestern.edu) or* ***Kaylene Ready*** *(kaylene@counsyl.com)*

SIG Speak

From the Public Health Special Interest Group

Public Health Genetic Counselors: Activities, Skills and Sources of Learning

By Mallory Sdano, MS, LCGC

I first became interested in non-traditional roles when I shadowed a genetic counselor working in a state newborn screening lab. Throughout my graduate training I met more genetic counselors in various roles, from traditional clinical roles to non-traditional roles, such as public health. With the help of my capstone project committee at the University of North Carolina-Greensboro, I was able to create and administer a survey about genetic counselors engaging in public health activities.

Recent National Society of Genetic Counselors (NSGC) Professional Status Surveys (PSS) have shown that genetic counselors are working in public health roles. However, these results are difficult to compare due to changes in the way the questions have been asked in different years. This has caused the total percentage of "public health genetic counselors" to fluctuate between 6% (2006) and 0.6% (2012). Most recently, the PSS only captures the genetic counselors whose primary role (>50% of their time) is "public health," although the report includes other roles that could be considered public health (such as education, research, newborn screening, teratogens, etc). Many genetic counselors may participate in these public health-related activities but may not consider themselves to be "public health genetic counselors," or do not realize that the activity relates to public health. The goals of our study were to determine the number of genetic counselors engaging in public health activities, the skills they are using to participate in those activities and where the skills were learned.

For this study we assessed respondents' participation across five categories of public health: population-based screening programs, education of the public and/or health care professionals, research, lobbying/public policy and state chronic disease programs. Any genetic counselor that graduated from an accredited genetic counseling program and was working in the United States or Canada at the time of the survey was eligible to participate. The majority of participants reported engaging in education of the public and/or health care providers and population-based screening programs.

Some key things we learned from this study were:

- **A majority of respondents (131/155) spent up to 40% of their time participating in public health activities (such as newborn screening programs, genetic education for the public, committees to assess delivery of genetic services, communication with senators/representatives, and grant writing).** These individuals are not captured on the PSS and may not consider

themselves to be "public health genetic counselors," but are still involved in public health-related activities.

- **All participants who reported participating in at least one public health activity reported using at least one of the skills addressed in this study.** Commonly used skills included reviewing patient demographics to assess accuracy of screening results, working with interpreters to disclose screening results, creating and assessing educational materials, developing Institutional Review Board (IRB) submissions, and conducting appropriate literature reviews. Participants also provided several write-in skills; therefore, this study did not capture a complete skill set for each public health activity.

- **The primary source of learning for skills in all categories was "on-the-job," and the secondary source of learning for all categories was genetic counseling training programs.** These results suggest that genetic counselors learn a skill set in their training program that allows them to continue to learn and acquire skills "on-the-job." Additionally, this suggests that the practice-based competencies, upon which genetic counseling training programs rely, are adequate for training future counselors for public health activities.

After graduation, I accepted a position with Lineagen, Inc. Lineagen provides genetic counseling and testing services for physicians and families of individuals with autism spectrum disorder, developmental delay, and/or intellectual disability. As part of this service, I provide pre-and post-test telephone genetic counseling for the families, educate physicians and families about genetic testing, write detailed test reports for various conditions, and assist in the creation of marketing materials and product development. In this non-traditional role I find myself re-living my survey: I have engaged in many public health activities mentioned in the survey, used additional skills not mentioned in the survey, and learned many skills through "on-the-job" training. For me, this experience supports the accuracy of the survey results, and the quality of the training that genetic counselors receive in graduate school.

I would like to extend a special thank you to **Karen Powell**, **Nancy Callanan**, and **KirstyMcWalter** for being a part of my capstone committee. Additionally, I would like to thank the Public Health SIG for funding this project.

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NSGC News

From the Payer Subcommittee of the Access and Service Delivery Committee

Can referring healthcare providers and potential patients find you? Tips to improve your accessibility.

A longtime initiative of the National Society of Genetic Counselors (NSGC) has been to ensure that genetic counselors are seen as THE expert resource in genetic health for our stakeholders. These include our referring health care providers, health care colleagues, insurance providers, policy makers, and patients. This has included emphasizing our brand, the development of a new website, and educating many of our collaborators about our training, our expertise, and how to find a genetic counselor in their areas. As demand has grown, so has the need to demonstrate our accessibility. The NSGC website is a useful tool for external audiences to find qualified genetic counseling providers and also offers general education.

The use of many new service delivery models, such as telephone genetic counseling and telegenetic counseling, has increased the ability of our expertise to reach further distances. However, the ability of our stakeholders to locate genetic counselors providing services using these models has unfortunately been limited. This year, new features have been added to the "Find a Genetic Counselor" tool on the NSGC website to increase the ability of our stakeholders to find a genetic counselor that can meet their needs!

In order to enhance accessibility, we need participation from all of our members! We encourage you to be sure that your NSGC provider profile is as up-to-date and as accurate as possible. We also encourage you to make your profile public, so your name and work contact information is viewable in a provider search by non-members. It is also time to update your profile to highlight whether or not you provide clinical patient services, and if you are able to provide genetic counseling using telephone or telegenetic services. Telephone genetic counseling is defined as counseling sessions provided remotely, by telephone, and may be supplemented by written, online or other resources. Telegenetic services are defined as genetic counseling provided remotely using videoconferencing.

To update your profile:

1. Log into your profile at www.nsgc.org
2. Select "View/Update My Profile"
3. Under the "Professional" tab, indicate whether you see patients, your certification status, and whether you provide services via telephone or telegenetics
4. Save Information!

To ensure that referring health care providers and stakeholders can find you using the "Find a Genetic Counselor" feature, your profile must be set as "public." Note that the NSGC respects your privacy and will never share your personal email, home address or social media address with non-members.

To help patients and health care providers find you:

1. Log into your profile at www.nsgc.org
2. Select "View/Update My Profile"
3. Under the "Personal" tab, there is a box titled "Find a Genetic Counselor Search Preferences." If there is a check mark in the box next to "Never display my profile," then referring health care providers and your patients may not be able to find you! Keep this box **unchecked** if you want to be found when patients and health care providers use the "Find a Genetic Counselor" search tool.

On behalf of the membership, the NSGC continues to advocate for our profession by meeting with stakeholders and negotiating with policy makers and payers. To help ensure success with this, we as members need to be able to demonstrate our numbers, and that we are making our best efforts to meet the needs of our patients and fellow health care providers. By following the suggestions above, you are able to contribute to these efforts and market your services.

If you have questions about how to manage your profile or the many ways in which the NSGC is advocating for you, please contact the NSGC Executive Office at nsgc@nsgc.org.

ABGC Update

American Board of Genetic Counseling 2012 Examination Administration Results

By the ABGC Board of Directors

The American Board of Genetic Counseling (ABGC) successfully administered another certification examination. Administration was open from August 12 to September 15, 2012, during which 305 individuals took the certification (CGC) examination. A summary of the examination statistics is included in this article. For more information or to ask questions, please contact the Executive Office at info@abgc.net.

First, a "Thank You" to the Certification Examination Committee

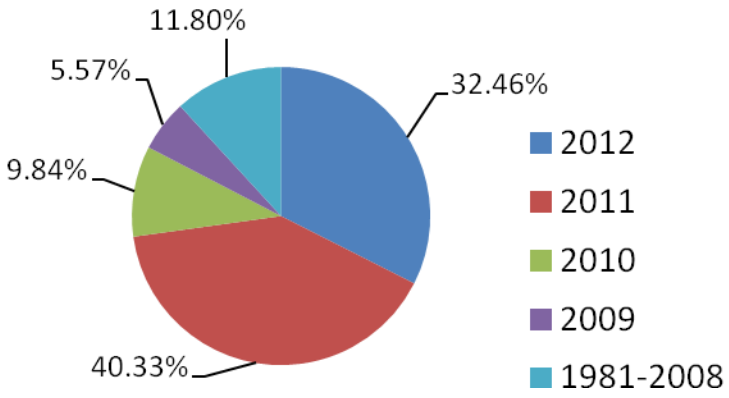
The Board of Directors would like to take this time to acknowledge the tremendous amount of work the Examination Committee undertakes each year in order to prepare each examination administration.

Susan Hahn, **MS**, **CGC** (Co-Chair, Board Liaison)
Bronson Riley, **MS**, **CGC** (Co-Chair)
Joline Dalton, **MS**, **CGC**
Elizabeth Denne, **MS**, **CGC**
Catherine A. Fine, **MS**, **CGC**
Jacquelyn Halliday, **MS**, **CGC**
Elizabeth Hoodfar, **MSc**, **CGC**
Nancy Palmer, **MS**, **CGC**
Ana Morales Reyes, **MS**, **CGC**
Jenna Scott, **MS**, **CGC**

Candidate Graduation Information

Of the 305 examinees during this administration, 123 graduated in 2011 and 99 graduated in 2012 (see Figure 1). These 99 examinees represent 44.5% of the 222 genetic counselors that graduated from accredited programs in 2012. The percentage of graduates taking the exam in the same year that they graduated increased from 35% in 2011.

Figure 1. Breakdown of CGC Exam Candidates by Year of Graduation



36 individuals who graduated between 1981 and 2008 attempted the examination this year. As a reminder, Category 5 (that allows individuals who for any reason did not become certified prior to 2009) will close in 2014.

Overall Passing Rates

The overall passing rate for all candidates was 76.1%. Out of the 305 examinees, 234 of them were first-time examinees with a pass rate of 81.6%; repeat examinees (n=70), including those taking the exam for either the second or third time, had a pass rate of 57.1% (see Table 1).

Table 1. Pass Rate Among First Time and Repeat Examinees

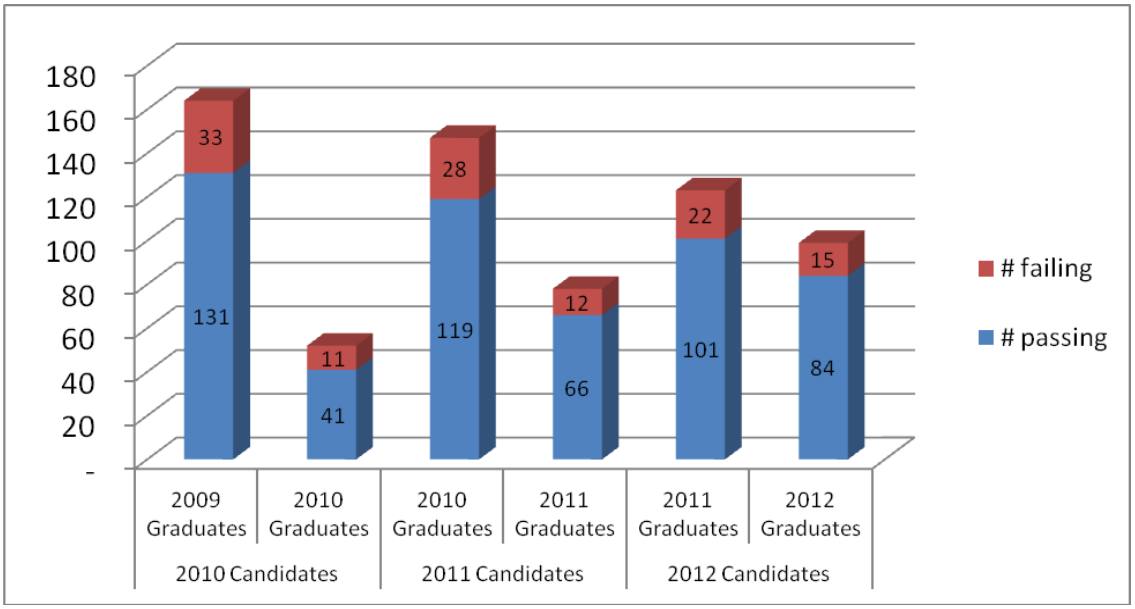
	Total Tested	Pass	%	Fail	%	Total
First Time	234	191	81.6%	43	18.4%	234
Repeater	70	40	57.1%	30	42.9%	70
Total	305*	232	76.1%	73	23.9%	305

*** Total includes 1 examinee that took the exam for re-credentialing; pass rate not shown**

As the number of candidates taking the exam immediately following gradation has increased, we have monitored passing rates for this group versus those who chose to wait

a year prior to taking the exam (see Figure 2). Data from the 2012 examination show a pass rate of 82% for 2011 graduates, as compared to a pass rate of 85% for 2012 graduates. This suggests that those who take the examination immediately after graduation are as equally prepared for the exam as those who choose to wait.

Figure 2. Pass/Fail Statistics for Examination Candidates Graduating from 2009-2012



Practice Examination

In May 2012, the ABGC was excited to launch a 100-item practice examination. The practice examination questions are pulled directly from the bank of questions that could be used for the exam, with questions distributed across all content domains, therefore mirroring the actual certification examination. The practice exam is administered using the same software as the exam, to help make the experience as close to the real exam experience as possible.

2013 Fees

The 2013 Exam Bulletin is posted online and available now. There has been no change to the 2013 exam fee as compared to 2012. The application requires a one-time cost of $1,300 for new or first-time candidates and $1,200 for repeat candidates. The testing application deadline is **July 1**, **2013** and the testing window is **August 1-August 30**, **2013**.

New Initiatives!

In order to meet demand and assist candidates in licensure efforts, two testing windows will be available, beginning in 2014. The windows are currently scheduled for **February 3-28**, **2014** and **August 1-29**, **2014**. In addition, we are working towards offering instant scoring no later than 2014.

Global Genetics

From Genetic Counseling to Biobank Ethics: A Genetic Counselor's Experience in Germany

By Katherine L. Helbig, MS, CGC, ELSI Coordinator, PopGen 2.0 Biobank Network (P2N), Institute of Epidemiology, Christian-Albrechts-University of Kiel

Life is a compromise. We have all heard this cliché. I kept this mantra in mind while I completed my Master's degree at Arcadia University from 2007 to 2009. My then-fiancé and now husband, a German physician, had begun his Child Neurology residency in Kiel, a small city in Northern Germany, while I spent two years in Pennsylvania. The plan had always been for me to move to Germany after graduation, and I welcomed this new change of scene with a sense of excitement and open arms. I have always enjoyed traveling, had previously lived overseas, and saw this new adventure not only as an opportunity for personal growth, but also as a chance to help establish genetic counseling in a new country. I boarded the plane to Hamburg full of ambition, and determined to make waves in my new home.

The realities that greeted me when I arrived in Germany were harsher than what I had envisioned in my adventurer's mind. After speaking to several clinical geneticists at various university medical centers in Northern Germany, it became clear that clinical genetic counseling in Germany was unfortunately not in my future. I came to realize that Germany is one the few European countries in which genetic counseling is carried out exclusively by medical doctors. The enactment of the Genetic Diagnostics Act (*Gendiagnostikgesetz*)[1] in 2010 further excluded non-physicians from being involved in any part of genetic diagnosis or genetic counseling. I found myself in a position where I was eager to work clinically, but was not allowed to because of a healthcare system that paradoxically tries to meet the increasing need for genetic counseling by restricting the number of providers. Months of unsuccessful job hunting left me feeling defeated and discouraged. I started to ask myself if I had perhaps compromised too much.

Having accepted that a clinical career would not be possible for me in Germany, I turned my eye reluctantly towards research positions. After working in a research capacity for over three years prior to grad school, I had hoped to use my new skills in a clinical

setting. I wanted to work with patients and was not particularly thrilled about the idea of jumping back into academic research. My lack of doctoral level training also left me at a disadvantage in a system that values hierarchy and titles to a seemingly higher degree than the United States. With this in mind, I applied for positions as a PhD student and eventually accepted a position within the Section of Epidemiology at the University of Kiel. Genetic epidemiology had always interested me, especially as genetic counseling gradually has become part of clinical care for non-Mendelian inherited disorders, and I looked forward to this next challenge.

In the Section of Epidemiology, I investigated the role of gene-environment interactions in the etiology of inflammatory bowel disease, a complex genetic disorder about which I knew little, but was excited to learn. The position offered me a great deal of intellectual independence and flexibility, and I was able to apply many of the analytical genetic counseling skills that I acquired during my studies to my research. Of particular value were skills in research methodology, epidemiology, and analytical thinking that I had learned at Arcadia. My research resulted in a scientific publication about the interactions between genetic factors and smoking in the etiology of Crohn's Disease[2], before I went on maternity leave for the birth of my first child.

Taking the twelve months of maternity leave customary in Germany allowed me time to re-evaluate my career trajectory. Personnel changes within the department and a new federally funded biobank project coincided fortuitously with my return from maternity leave. Just as I had decided that the life of a PhD scientist was perhaps not for me, an exciting professional opportunity within our department arose.

The Federal Ministry of Education and Research (BMBF) awarded the University of Kiel 4.5 million Euros to establish an integrated biobank infrastructure at the University Hospital Schleswig-Holstein (UKSH). Within the funding proposal was the position of ELSI Coordinator, who would be responsible for handling all of the Ethical, Legal, and Social Issues related to modern biobank research. I enthusiastically applied for, and was subsequently appointed to, this position.

Since January 2012 I have been working as the ELSI Coordinator for the popgen 2.0 Biobank Network (P2N), which aims to integrate seven existing biosample collections at the UKSH and eventually become a unified, campus-wide biobank infrastructure. This biobank will then represent one of the largest in Germany. As the ELSI Coordinator, I have been able to define my own responsibilities to a large extent. My role involves supervising and managing informed consent documentation, the development of informed consent documents for future collections, the development of ethical guidelines regarding governance of the biobank, the development of donor materials including website and flyers, and holding informational lectures for clinical and scientific UKSH staff, amongst other things. An additional goal is to address quality control issues for biobank informed consent procedures. I have designed a study assessing the quality of the informed consent process among biobank participants and the development of a standardized instrument for the assessment of informed consent quality.

My training as a genetic counselor has prepared me for the challenges of my current role by training me as a patient advocate, giving me an understanding of the issues relevant to clinicians, scientists, and patients regarding genetic research, and providing a solid foundation of the understanding of ethical, legal, and social issues involved in patient care and research. I am a core member of the P2N project management team and work autonomously, with the respect of my colleagues.

Although my career trajectory has led me down a different path than I had originally intended, I am happy to be working in the field of research ethics and am gratified to be treated as a respected authority in my workplace. The experience and skills I am learning in my current role will no doubt serve me well in whatever endeavors I undertake in the future, whether clinical, research, or administrative.

On a personal level, my transition to life in Germany has also been rewarding, although not necessarily seamless. When I first arrived, my language skills were proficient at best. Furthermore I lacked the social support of friends or family, and Kiel is too small of a city to have much of an ex-pat community. These factors propelled me into a six-month period of culture shock, which unfortunately coincided with my unsuccessful job search and dampened my initial enthusiasm. However, as I got to know people in Kiel and my German improved, I started to feel more at home in my new city. I began to see the challenges of living in a foreign country as an opportunity rather than an obstacle. I went to the beer garden with my husband, made a *Feuerzangenbowle* with friends on New Year's Eve, and enjoyed leisurely bike rides along the Baltic Sea coast on long summer days. Having been here for three and a half years now, I have a network of friends, my husband and I have welcomed our daughter, and my German is approaching fluency, although I am reluctant to say so. I couldn't have imagined it in the beginning, but now I feel like an honorary German.

To answer my own question from several years ago, yes, I did make some compromises, but no, they weren't too much. Sometimes life's compromises take us to more interesting and rewarding places than we could have ever imagined. The broad training I received as a genetic counselor has made this possible.

References

1. German Federal Parliament. "Human Genetic Examination Act (Genetic Diagnostics Act - GenDG)." 2009. (http://www.eurogentest.org/uploads/1247230263295/GenDG_German_English.pdf)
2. Helbig KL, *et al*. A case-only study of gene-environment interaction between genetic susceptibility variants in *NOD2* and cigarette smoking in Crohn's disease aetiology. *BMC Med Genet*. 13:14. 2012.

*If you are or know of a genetic counselor with an interesting international story, please contact **Janice Berliner**, column editor, at berlinej@mskcc.org to discuss submission of an article.*

Student Forum

Harmonic Frequency

By Carmen Williams, Center for Genetic Medicine Program in Genetic Counseling at Northwestern University, Class of 2013

Every object has a harmonic frequency (or set of frequencies) at which it naturally resonates when struck, plucked, or otherwise disturbed. A crystal champagne flute sings its frequency when a damp finger glides across its rim and, likewise, shatters when an opera singer hits that frequency while sustaining a high note. When an object is placed in an environment where its harmonic frequency is matched, the object begins to vibrate. At this frequency, extraordinary things begin to happen.

I have found my harmonic frequency in genetic counseling. Often when I finish a day of clinic, I feel like my bones are vibrating inside my body because I loved it so much. Many aspects of genetic counseling are in line with my harmonic frequency. These are things like digging voraciously through the literature trying to find the key to a puzzling pedigree; beginning treatment on an apparently healthy newborn that will prevent her metabolic disorder from destroying her brain tissue or stealing her life away; meeting new parents in a neonatal intensive care unit and telling them their child's medical condition is not their fault. It is telling a man with a genetic predisposition to cancer that we can offer him, and his family, hope through increased screening and medical prevention, or giving a woman bad news and watching her press forward with the strength of human resilience. Discovering my harmonic frequency has been a rewarding experience.

Many of the most rewarding things in life come with a tremendous amount of work, or even struggle. At times during graduate school I have found myself immersed in the work and feeling distracted or overwhelmed. Then I have stopped to look at all that we have learned, and found great satisfaction in all that we have accomplished. And I ask myself, "Does it get any better than genetic counseling?!" We are poised at the edge of scientific and medical knowledge peering out into the future. We get to use this knowledge, and from a psychosocial stance, usher patients into this new and exciting genetics-filled future.

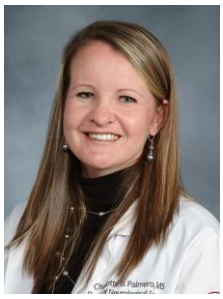
When I think of my graduate school experience, I often think of the Tacoma Narrows Bridge, a bridge known in 1940 as "Galloping Gertie," because it was noted to oscillate vertically in windy conditions. I know what you might be thinking. No, I do not think of Galloping Gertie because tensional, compressional, and sheer stress combined forces on this bridge causing her to collapse. I think of Galloping Gertie because she remains one of the most spectacular examples of the power of harmonic frequency. All it took was a precise 42 mile-per-hour wind passing over the Puget Sound to cause a structure made of concrete and steel to reach its harmonic frequency and oscillate like waves on the ocean. All it took was a vigorous graduate program for me to reach my harmonic frequency.

I have heard countless patients say, "Genetics is so interesting!" I agree, and I consider myself fortunate to have been given the opportunity to join this profession. I look forward to the months ahead with great anticipation, and I am excited to complete my training and step into a career that resonates so deeply within me.

The New Graduate Life

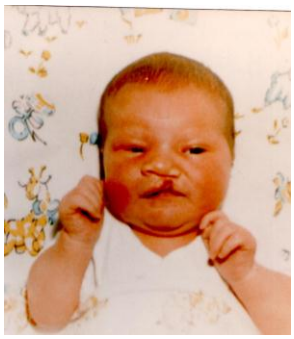
Full Circle Moments in Life

By Charlotte Palmero, MS

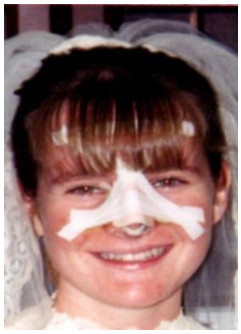


When I was initially contacted to contribute to the "New Graduate Life" column for this issue of *Perspective in Genetic Counseling*, I was extremely honored and humbled. I viewed it as a unique opportunity that allowed me to reminisce and reflect on my journey up to this point, in both my personal life and my professional endeavors. Few people in this world are fortunate enough to find a career that complements their talents and interests, allows them to draw positively on their personal experiences, and provides them with a sense of reward and accomplishment at the end of each day's work. In choosing to pursue a career in genetic counseling, I feel as though I achieve these every day.

Like many genetic counselors, my introduction to the field of genetic counseling started with my own personal life events. I was born with a complete unilateral cleft lip and cleft palate, to the total surprise of my parents. My mother did not have any prenatal ultrasounds while she was pregnant, and had no indication this would happen. In fact, my parents had never heard of cleft lip or cleft palate before. After my diagnosis, they were consumed with what they later described to me as "dark moments" -- feelings of guilt, shock, disbelief, anxiety, and fear of the unknown. They had no idea what the road to recovery would entail for me. I spent twenty-two years enduring numerous extensive surgeries, such as palate closure, multiple bone grafts, jaw reconstructive surgery, several rhinoplasty procedures, and countless inpatient and outpatient corrective plastic surgeries. In addition, I underwent over fifteen years of orthodontia and dental work and hours of speech therapy.



Charlotte Palmero as a newborn



Charlotte Palmero at age 18, after a nose reconstruction procedure

After all of my years spent on the "patient side" of heath care, it is not surprising that the medical field strongly influenced my decisions in selecting which career path I wanted to pursue. In fact, I knew at a very young age that I wanted to join the medical profession; however, it took a while for me to become introduced to genetic counseling.

At my undergraduate institution, graduating seniors had to design and complete a thesis/capstone project. Because of my personal history with cleft lip and cleft palate, I chose a topic that allowed me to intimately work with families at a local craniofacial clinic. It was at this clinic that I was first introduced to genetic counseling. For me, the intimate bonds that can be formed with patients throughout the genetic counseling process are profound. When experienced in conjunction with the ability to personally relate to the emotions patients and families are experiencing, it can be a very powerful and gratifying feeling. Working closely with a genetic counselor was a defining moment for me; I immediately knew that genetic counseling would be my chosen profession.

I applied and was accepted to the Joan H. Marks Graduate Program in Human Genetics at Sarah Lawrence College in 2009. While in the program, I was exposed to a variety of clinical settings. Even though I was fortunate to see a plethora of cases throughout my training, I still dreamt of finding a job where my sole responsibility would be working with families dealing with diagnoses, repair, and recovery from craniofacial abnormalities. So many colleagues that I spoke with were able to understand my longing to attain such a position, but felt there was little chance for me to find a full-time job working with this population, especially since craniofacial clinics often are only held once per month. Despite the odds, I still had a strong feeling that I would be able to use my training and personal experience to find a job working with a population that I totally adored.

My first hope of this becoming a reality came on February 28, 2012, in the form of an email. That morning, I received an email from the New York State Genetics Task Force, a not-for-profit professional educational organization that extends membership to persons engaged in the delivery of care related to clinical genetics and birth defects in New York State. The Genetics Task Force was advertising a job opportunity for a Craniofacial Program Coordinator at Weill Cornell Medical College (WCMC) in New York City.

Even better, the job requirements were a Master's degree in human genetics or genetic counseling! I was immediately awestruck; to this day, I vividly remember reading that email three times in order to allow it to truly resonate with me. Needless to say, I immediately applied for the job.

About a week later, I was scheduled for my first set of interviews with the immediate supervisor, Dr. Mark Souweidane, and one of the department managers. These interviews were among the most pleasant interactions I have ever had. During the process, I was asked to describe my personal experiences with craniofacial anomalies. After I finished sharing my story, the manager was in tears. She then told me I was the perfect candidate for the job. Soon after, I was invited back for the second round of interviews with other members of the department, which also went very well. Shortly thereafter, I was invited to meet with Human Resources. On April 13, 2012, WCMC called me to inform me that my salary negotiations were accepted and the position was mine, if I wanted it. Filled with joy, excitement, and relief, I graciously accepted their job offer.

I started my job as the very first full-time Craniofacial Program Coordinator on June 4, 2012. It has been more fulfilling than I ever imagined it could be. With some patients, I can honestly relate to exactly what they are going through. This is very satisfying for me and their heartfelt appreciation is humbling. My passion for and interest in his patient population makes my job enjoyable, and definitely one that I look forward to going to every day. My role is one that has never been fulfilled by a full-time employee at WCMC; so much of my time is currently spent trying to develop our program into one of the best craniofacial programs in the country. While building a craniofacial clinic can be overwhelming at times, I also feel very fortunate. I am able to contribute to this process by offering my ideas, thoughts, and personal viewpoints, as well as my training in genetic counseling. I am quickly learning that there are many hats that genetic counselors can wear!

Like everyone else, I have had days that are emotionally tiring. Because I'm so passionate about these patients and understand firsthand what these children are facing, it does take its toll on me. When I was growing up, the bullying I was subjected to by others was very difficult for me. I hate the saying, "Sticks and stones may break my bones, but words will never hurt me." To me, that could not be further from the truth. When parents ask me questions about psychosocial issues, I find it difficult to answer them positively. I was fortunate and had a great family support system, but even still, I had some very negative experiences. Not all of our patients have a great support system, and I find myself worrying about them the most. I can relate to them almost too much, and that is when it becomes hard to separate professional duties from personal feelings. Those are the days I find very psychologically challenging and emotionally taxing.

For the moment, I am not finding that the personal/professional line is too blurred; however, I am selective with whom I share my personal stories. I usually just listen to my gut instincts, and if I think a family member will benefit from hearing about my past, I share it. Thus far, the families with whom I have chosen to disclose have been very receptive and appreciative, and thankfully, no one has had a negative reaction to date. I

met a first-time mother of a baby born with bilateral cleft lip and cleft palate recently in the Neonatal Intensive Care Unit (NICU). Even though my cleft lip and cleft palate were not bilateral, I chose to share my story with her because she was obviously very scared. I wanted her to know that reconstructive surgeries are phenomenally effective for these types of congenital anomalies. She was astonished to learn about me, and said she would have never suspected I was born with cleft lip and palate. In this case, my real-life story was able to offer her reassurance and hope when she really needed it.

In another case, I also chose to share my history with a mother whose son was born with Pierre Robin sequence and has a large cleft palate. She and her husband were extremely concerned (almost sounding like they were convinced) that their son's speech would never be normal. After telling her about my cleft palate, she was literally in shock and disbelief, and was very thankful I was so open with her. I enjoy these interactions because it is so apparent that the parents are sincerely relieved. Those are the days that really make me love and appreciate my job.

Although cleft lip and/or cleft palate may not be considered as "life-threatening" as other birth defects or genetic conditions, they are common and can bring many emotional and financial hardships to families. The repair procedures for orofacial clefts are extensive, and can take decades to completely correct. I truly believe now that the reason I was born with cleft lip and cleft palate was so I could provide help and hope to families that I come into contact with through my job. After twenty-two years of enduring the physical adversities such as surgeries, hospital stays, long recovery periods, continuous dental work and speech therapy, coupled with the psychosocial sufferings of bullying and enduring some of the biggest adversities in my life, I feel it was all worth it. Now, I have the opportunity to help families through the many phases of this process. The bonds I form with families, and the relief I see in parents' eyes after they meet someone who has experienced firsthand the very procedures their child is facing, creates emotions that are completely indescribable. I am immensely grateful for the way things have turned out, and feel extremely blessed to have a job that I absolutely love.

If you are or know of a genetic counselor with an interesting story about life as a new genetic counseling graduate, please contact ***Chris Colón****, column editor, at ccolon@gm.slc.edu to discuss submission of an article.*

Genetic Counselor Publications

Feature Article

By Christine Colón, MS, CGC

Hurst C, **Corning K**, Ferrante R. Children's Acceptance of Others with Disability: The Influence of a Disability-Simulation Program. *J Genet Couns*. 2012 Aug 14. [Epub]

Christina Hurst, MS, CGC

In 2006, The Genetic Counseling Definition Task Force of the National Society of Genetic Counselors (NSGC) defined genetic counseling as "...the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease."[1] As students, genetic counselors are trained in that process; to be able to learn, develop, and use techniques to assist families who are trying to understand and adapt to how their precise circumstances are going to impact the rest of their lives. As professionals, genetic counselors must then impart that knowledge to patients and their families in a balanced and non-directive manner. However, outside of the genetic counselor's office, patients and families can encounter those who may have difficulty understanding and/or accepting the patient's unique situation and needs. This in turn can be a source of additional stress, and can complicate the building and maintaining of social and educational relationships for not only the family, but those outside the family unit as well.

Genetic counselors that work directly with populations coping with disabilities can find themselves in the position to raise awareness and educate others about a particular disease or disability. As a genetic counseling student, **Christina Hurst**, **MS**, **CGC**, decided to face this challenge head-on. During her education at the University of South Carolina Genetic Counseling Program, she chose to focus on the idea of facilitating

[1] Resta R, Biesecker BB, Bennett RL, Blum S, Hahn SE, Strecker MN, Williams JL. A new definition of Genetic Counseling: National Society of Genetic Counselors' Task Force report. *J Genet Couns*. 15(2):77-83. 2006.

positive experiences to promote acceptance of children with disabilities for her thesis project. She, along with co-authors **Ken Corning**, **MS**, **CGC** and Richard Ferrante, PhD, Director of Disability Resources at the University of South Carolina School of Medicine, piloted a study to find out if children who experienced a disability-simulation program would exhibit greater acceptance towards those with disabilities.

The study design included groups of second- and third-grade children in two schools in South Carolina who took part in a disability-simulation program called "Awareness: The Key to Friendships." Students were given a survey before starting the program to measure their acceptance of those with disabilities. Groups then participated in activities designed to simulate four categories: physical, visual, auditory, and learning disabilities. They were also asked specific questions by adult volunteers, and encouraged to explain the difficulties they experienced while performing the various activities. Another survey was given after the completion of the program to identify any changes in levels of acceptance, and to help gauge the overall effectiveness of the program.

The results of the study suggest that the disability-simulation program activities were especially effective in improving the students' attitudes toward those with disabilities in three of the four categories (physical, auditory, and learning). One of the eight questions that addressed disability actually showed a decrease in acceptance (visual). One possible explanation for this is that activities simulating the visual disability were less effective, and actually encouraged students to be less accepting of that type of disability. However, the overall response to the two visual questions when averaged together did improve. Another possibility is that the finding for this question may be partially explained by the fact that the pre-survey responses were already so accepting (72% answering strongly accepting or accepting, and only 7.6% were non-accepting or strongly non-accepting) that there was not much room for improvement for this type of disability. A third possibility is that this question was biased because of its placement at the beginning of the survey. Of note, the activities did <u>not</u> trigger negative responses in the students, an outcome which has been cited in some previous studies. While this type of program would likely not be implemented by a genetic counselor due to time constraints, scope of practice, and other factors, the authors suggest this type of program may be a useful approach for families who are struggling to gain acceptance within their child's peer groups.

After finishing this project and graduating in 2006, Christina began her career by accepting a position at the University of Alabama at Birmingham (UAB), working as a clinical genetic counselor. After two years, she transitioned into a more researched-based position at UAB and was involved with various clinical trials. In 2010, she became the Assistant Program Director and Assistant Professor at the newly established UAB Genetic Counseling Program. "It was a little daunting," Christina said. "My first day on the job was the first day of class, in the first year of the program, and the first day we ever had genetic counseling students." However, she quickly settled in, and in addition to her academic and administrative roles, Christina continues to spend one day a week in the UAB clinic. "I've always been interested in research, in writing, and teaching," she said.

Although the research itself was conducted several years ago, Christina did not submit her work for publication until 2012. As an educator, she recommends students present, publish, or share what topics they have investigated, and data they have collected so that audiences have the opportunity to make use of such information. That lesson "really struck a chord with me," she said. "In encouraging my students to publish, I felt that I should 'walk the walk.'" Luckily, although six years have passed, her research topic and data are still relevant to the field of genetic counseling and have not drastically changed in the interim. "I had to update my literature review, and make sure I incorporated some of the more recent things that had come up in the past six years," Christina notes. "But it was really fortunate that my topic was one that could still be applicable."

In addition to being valuable to health care providers, Christina feels this research is also important to those living with disabilities. "You are not only getting to talk to patients about their medical or developmental issues, but you may be the only person involved in their care that is paying attention to how they are coping with something, or how this is affecting their lives day-to-day – whether that's in school, in relationships with other family members, or with other psychosocial needs. They are in a world where most people around them aren't aware of what they struggle with day-to-day, and that's really hard. I think this research crosses the bridge between helping the general public not be fearful of something they don't understand, and also helping our patients understand [it's important] to be an advocate, and to find someone to advocate for them to help other people understand."

To those students or genetic counselors looking to publish their research, Christina offers the following guidance: "Read a lot of research. Be familiar with how papers are written. I think you learn a lot about writing by reading other people's work." She also recommends honing a critical skill – patience. "Be patient. Writing is a process, and can take a long time. Be open to feedback and getting someone else's perspective, because it is hard to be objective when you read your own work. Be open to that feedback, and understand it can really add value to a piece."

AEC Update

Save the Date for the 2013 Annual Education Conference in Anaheim, California

By Quinn Stein, MS, CGC, 2013 AEC Chair and
Katherine Dunn, MS, LCGC 2013 AEC Vice-Chair

Did you know that preparation for the National Society of Genetic Counselors' (NSGC's) Annual Education Conference (AEC) starts fifteen months in advance? We are now several months into planning for what has become the premier genomics conference in the country for learning real-world application of the latest genetic technologies. The 32nd AEC in Anaheim, California promises to build on the momentum and success of the 31st AEC in Boston and be a conference you'll be excited to attend. **Mark your calendars and plan to join us in Anaheim, California October 9-12, 2013.**

The 32nd AEC will be held at the Anaheim Convention Center, which is located on the lush gardens of the Anaheim Resort. The 1,100-acre Anaheim Resort District includes two Disney parks (Disneyland and Disney's California Adventure), the Anaheim Convention Center, and convention hotels. The green palm trees, inviting Southern California sunshine, and the exterior glass walls of Anaheim Convention Center make this an attractive destination for the AEC. More importantly, the Convention Center itself is large, and should contain ample space to accommodate all attendees (even another record-breaking crowd!).

More information regarding hotel room blocks and travel information will be available Spring 2013.

AEC Format Continues in 2013

The AEC will continue to utilize the Wednesday-Saturday format, which was implemented during the 2012 AEC. The Pre-Conference Symposia will take place on **Wednesday, October 9, 2013** followed by the "*Welcome to the AEC: How to Make the Most of the Conference and NSGC*" orientation for students and first time attendees! The AEC will kick off in the afternoon with opening remarks, Plenary Janus Series and Best Abstract Awards. Rounding out the day will be the Welcome Reception in the Exhibitor Suite on Wednesday evening. Thursday and Friday will be two full days of outstanding educational opportunities within the Plenary, Educational Breakout Sessions (EBS) and Concurrent Papers. Saturday will be shorter, with the conference concluding in the late afternoon.

Small changes for 2013

The AEC Subcommittee recognizes that the genetic counseling profession encompasses a continually widening array of disciplines. In order to provide a broader appeal to all genetic counselors, the 32nd AEC will be adding four additional Educational Breakout Sessions (for a total of twenty sessions), allowing the conference to promote a wider spectrum of topics. One extra topic will be added to each Educational Breakout Session track, meaning that five (instead of four) sessions will be running concurrently in 2013.

Each year the NSGC AEC is led off with the Janus Series. The Janus Series provides updates and current information regarding a specific genetic condition and highlights genetic counselors widely considered to be experts in their field. This year's submission process will include an option to more easily submit a proposal for consideration, specifically for the Janus Series.

Call for Speakers – November 14, 2012 to January 10, 2013

The AEC continues to be a successful conference because of the high quality of proposals submitted each year. We need your help to recruit the best topics and speakers possible! The NSGC is actively inviting members to submit presentation proposals for sessions including the Janus series, Plenary Sessions, Educational Breakout Sessions and Pre-Conference Symposia. We are seeking relevant, forward-thinking, informative, and timely presentations by genetic counselors, physicians, researchers, and other industry leaders that will help advance our knowledge within the profession of genetic counseling. The Call for Speakers is open and the deadline for submission is **January 10, 2012**. Applicants will be notified of their acceptances in late February. Watch for additional information in upcoming NSGC e-mails and on the NSGC's Web site. Please consider submitting a proposal, or encouraging experts in your region or specialty to consider doing so.

Submission Guidelines

AEC presentation submissions need to contain a brief descriptive paragraph outlining the proposed content (<300 words), as well as three learning objectives written to the continuing education standards. Submissions that present a well-defined content outline and speaker plan generally score more favorably than those that contain minimal information. Please be reminded that a Plenary Session is typically one hour, an EBS will run ninety minutes this year, and a Pre-Conference Symposium is typically six hours total, with five hours of content and a one-hour break. The Janus series features three expert genetic counselors, each providing a thirty-minute overview on their areas of expertise. All presentations must be educational in nature and not include any industry, sales, product, or marketing information. Speakers are encouraged to prepare and present original material. Members of the 2013 AEC Planning Subcommittee will carefully

review all submissions. Proposals may be considered for other session formats, in addition to the format requested.

Please note: If you are submitting/coordinating the proposal but do not plan to speak, you will have the opportunity to list yourself as such. You will be considered the main contact for the proposal. You will also need to provide contact information for all of the speakers at the time of submission. It is important that the Subcommittee knows ALL speakers for each proposal during their review, as this will impact the sessions selected.

Submit your proposal by completing the online submission. Instructions and the submission form can be found at the following link:
http://www.nsgc.org/Education/2013AEC/2013CallforSpeakers/tabid/491/Default.aspx

Questions may be directed to AEC Chair **Quinn Stein** at quinn.stein@sandordhealth.org, AEC Vice-Chair **Katherine Dunn** at Katherine.Dunn2@va.gov, or to **Ashley Melvin** at the NSGC Executive Office at amelvin@nsgc.org.

Submissions become the property of the NSGC and will not be returned. The NSGC also has the right to publish each selected submission in promotional materials, such as the AEC Preliminary Program.

The 2013 AEC Subcommittee

Please feel free to contact Subcommittee members with ideas, comments, and suggestions:

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Resources / Book Review

Reviewed by Prescilla Carrion, MSc, CGC, CCGC

How to Talk with Families About Genetics and Psychiatric Illness

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Holly Peay, **MS**, **CGC**, and **Jehannine Austin**, **PhD**, **MSc**, **CGC**, **CCGC** are certified genetic counselors that have extensive experience in providing genetic counseling to clients affected by psychiatric illness and their families. Their goals in writing this book were to help health care practitioners become more comfortable with how to share accurate and reassuring information about psychiatric genetics, and to promote a better understanding of its complexity. The authors' sincere accounts of their genetic counseling sessions with clients share insight into how to facilitate a thoughtful discussion about genetics and psychiatric illness. The question-and-answer format allows readers to gain perspective on common concerns that can arise during these conversations, and offers effective strategies to meet clients' needs. The "case examples" at the end of each chapter provide readers with illustrations of how the key concepts are applied in clinical practice. Another review of this book has also highlighted the value in these experience-based insights:

> "Genetic medicine is relatively new, and many clinicians self-report that they are uncomfortable with the coming onslaught of enormous amounts of data. For these reasons, the book's experienced-based discussions on a wide variety of topics can be extremely helpful in providing methods to clarify the issues." (Coors M. "Book Forum." *American Journal of Psychiatry.* 168:994-995. 2011.)

The authors give an overview of how genetic counselors can modify their approaches to contracting, taking a family history, risk assessments, and communication to better appreciate the deeply emotional experiences and stigma encountered with psychiatric illness. A holistic approach is described for translating empiric risks, together with family history information and life experiences, into meaningful personalized information for clients.

In addition to tables of empiric risks for psychiatric illness, the reader is introduced to additional tools that can be used in discussions about psychiatric illness. The "jar model" counseling aid is an illustration of how genetic susceptibility, together with environmental factors, can lead to some people developing mental illness. This model

helps clients to visually grasp the concept of how each person has a "mental illness jar," and although the genetic vulnerability factors remain constant, environmental factors can be added and removed, and protective factors may restrict access of environmental vulnerability factors to the jar. An additional useful tool, the "Ulysses pact," is a voluntary agreement that allows a person with mental illness to outline what others should or shouldn't do to provide support. Another review of the book references this below:

> "I learned about the Ulysses pact, and found the jar model a neat way to present the multifactorial/threshold model for susceptibility." (Clarke Fraser F. "Book Review." *American Journal of Medical Genetics*. Part A 155(7):1767. 2011.)

Managing uncertainty and dealing with perceived risks for psychiatric illness can be particularly daunting, and the authors describe ways to facilitate this process for clients. For example, they encourage readers to ask clients to think about what would be an "acceptable" level of risk, and at what point they would feel the risk to be too high to consider having children. Another way to encourage clients to think about how they will be impacted by the risk assessment and help them manage the new information is to ask them, "What do you think that you might do with the information about risks for family members?"

The authors give further details into specific issues, such as pregnancy and parenting in the setting of psychiatric illness. Cognizant of the growing field of direct-to-consumer testing, the authors suggest how to approach clients with psychiatric illness who have paid for genetic susceptibility testing and are struggling to understand their results. Further, they offer suggestions on how to engage in discussions of personalized medicine, particularly psychopharmacogenomics.

This book provides readers with a deeper look into the complex issues within genetic counseling about psychiatric illness through the authors' shared personal experiences, along with concrete resources genetic counselors can use in discussions with their own clients. This book is particularly useful for genetic counselors that would like to expand their knowledge and comfort level with genetic counseling for mental illnesses. Non-genetics health care professionals may also find this book a good resource to help them facilitate a conversation with patients about psychiatric genetics.