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President's Beat

What is the NSGC Doing for You?

Happy Summer! As I thought about what to discuss in this President's Beat article, I could not settle on which of our many activities to highlight. My inability to select one point of focus actually made me quite proud of us; we have so much going on! This Spring was a busy time of year for all of us, and the NSGC is no exception.

The 2011 Annual Education Conference (AEC) "Save the Date" reminders have gone out and the call for abstracts closed on May 18, 2011. You will probably have received the Preliminary Program by now! We've signed the contract confirming that the 2012 AEC will be held in **Boston, Massachusetts** from **October 24 to October 27, 2012**. The 2012 Board of Directors interviews are underway, Special Interest Group and Committee Chairs have completed their second quarterly reports, and our 2012-2014 Rolling Strategic Plan is finalized. We are preparing to look at next year's budget and outline our 2012 Plan of Work. New Position Statements and Practice Guidelines are being rolled out as we speak; the NSGC is never standing still! Please see our new section appearing periodically within "NSGC News" in *Perspectives* entitled, "NSGC Committee Updates" to view the ongoing activities of our management committees as well.

As I was thinking through these busy few months, I also thought, do our members know of these efforts? And, what does all this activity do for you in your practice as a genetic counselor and NSGC member?

To try to answer that question, I decided to focus on two distinct areas of current NSGC efforts: those of the Government Relations office and the Communications Committee. Both of these groups are engaged in activities that will impact you directly, no matter what your specialty or expertise.

Our Government Relations (GR) office is extremely busy and diligent. Their strategic efforts, which are perhaps not as visible as others by the NSGC, strive to promote the profession of genetic counseling and increase patients' access to genetic counselors and genetic services. Recently, genetic counselor representatives of the NSGC met with Congressional staff on Capitol Hill to provide information about genetic counselors and seek support for our legislation to amend the Social Security Act to recognize genetic

counselors as providers under Medicare. They met with Senators from California, Iowa, Utah, and Michigan. The Congressional staff members were open to learning more about our profession and how patients would benefit as a result of our legislation.

Additionally, the GR office continues to support licensure efforts and we are making great progress in this area. We have ten states currently issuing licenses, three more that have bills passed and are in rule making, and eighteen additional states that have introduced or are in the process of introducing licensure bills.

The NSGC also submitted comments to the Food and Drug Administration's (FDA's) Molecular and Clinical Genetics Panel of the Medical Devices Advisory Committee. This panel is helping the FDA determine the proper scope of regulation over clinical direct-to-consumer genetic tests. Our comments applauded the panel's recognition of genetic counselors as qualified healthcare providers who should be involved in the appropriate utilization of genetic tests and interpretation of test results. Many of these ongoing activities are listed under the "Advocacy" menu on our website. No matter your level of engagement with the NSGC, you will benefit from the GR team's hard work.

Another area I want to highlight is the Communications Committee's efforts in transitioning all of the NSGC's listservs to Discussion Forums. Like many of you, I am not immediately comfortable with change. In fact, I can be highly resistant to it. I like the listserv and benefit from the many conversations, discussions, and sharing of information. But I have learned that with the Discussion Forums, those aspects are not disappearing, they are just a little bit different! Discussion Forums are a new way to discuss practice issues and continue to network with your NSGC colleagues. They are actually quite easy to use, easier than a listserv, and personally customizable. One of the greatest highlights of this technology is the threaded topics. This means that all posts relating to the same initial topic or question are grouped together within the forum. This makes it much easier to track and follow a single conversation. Additionally, the Discussion Forums have a centralized discussion archive that allows instant access to relevant knowledge. This makes searching for past topics and information simple and fast.

The Communications Committee has developed "How To" documents and a number of very brief, helpful webinars to guide you through this new, updated technology. All of these resources are posted on the website: http://www.nsgc.org/MemberCenter/DiscussionForums/tabid/390/Default.aspx. While change can be challenging, I hope we give this new, user-friendly technology a chance, ultimately realizing this is a change for the better!

Remember, the NSGC is your professional organization and we are working for you. Our mission is to "advance the various roles of genetic counselors in health care by fostering education, research, and public policy to ensure the availability of quality genetic services." All of our initiatives are geared toward our mission and we are always engaged in activities and efforts that are designed to benefit you and your practice. Do not hesitate to ask what the NSGC is doing for you! This year has gotten off to an incredible start, but there is still much we can and will do!

Karin M. Dent, MS, LCGC
2011 NSGC President

My Perspective: Our Evolving Profession

By Janice L. Berliner, MS, CGC

About a year and a half ago I was eating lunch at my desk and reading through my piled-up emails, as I often do. One caught my eye, as it was written by a genetic counselor from Informed Medical Decisions, Inc. (InformedDNA). I had only vaguely heard of the company, and didn't know much of what it was about. But something in the language of the email intrigued me enough to go to their website. Some people think InformedDNA is a genetic testing company, but it's not; or that it engages in direct-to-consumer marketing, but it doesn't.

InformedDNA is an independent genetic counseling provider network offering telephone, and in some cases web-based, genetic counseling services to individuals and families

who might not otherwise be able to access them due to geographic or other circumstances. I have to admit that I was quite skeptical at first. Being a bit of a "traditionalist," I felt that face-to-face counseling was the way genetic counseling was meant to be, and I doubted that a telephone-based approach was appropriate, effective, or perhaps even necessary. However, the more I navigated this professional and inviting website, the more I became a believer. And I'm not alone in my now-evolved thinking, as InformedDNA has been recognized by the Institute of Medicine and the Surgeon Generals' National Call to Action on Cancer for innovations and clinical excellence.

The original idea for InformedDNA came from a genetic counselor and the organization has been growing and evolving ever since. Much of the leadership is made up of board certified genetic counselors. In addition, Dr. Rebecca Stephen, President and Chief Medical Officer, is a board certified clinical and molecular geneticist. The company fills a much-needed void in services across the country and, while I still believe that face-to-face counseling is the gold standard, it turns out, so does InformedDNA. No one in the company is trying to take the place of a traditional counseling model or take the job of another counselor; the company quite simply provides services if none would otherwise be offered and patients would otherwise go without.

At this point I approached the leadership of the company to see if we might work together, and I have been a consultant ever since. In this capacity (in addition to my regular, *traditional*, job), I do various projects focused on education and marketing and I firmly believe in the company's mission. One of InformedDNA's missions has been to elevate the profession of genetic counseling by working with insurance companies to require that pre-test genetic counseling services be covered. In this, they have been very successful. In 2009, they worked with United HealthCare to launch their new *BRCA* policy recommending genetic counseling for patients undergoing genetic testing. Then in 2010, they helped Priority Health to initiate its policy requiring genetic counseling before it will cover certain genetic tests. According to Norma Nixon, Chief Operating Officer of InformedDNA, "we are working to educate and engage other health plans that are at various decision points along the way to requiring genetic counseling." The idea that we will achieve our long-awaited goal of requiring genetic counseling as the result of private company efforts is, I think, something that would probably surprise most genetic counselors, as we tend to think of that as the purview of the National Society of Genetic Counselors or other volunteer professional organizations.

In fact, the NSGC is partnering with InformedDNA on a "payer initiative" that leverages the resources of both organizations. In June of 2010, the NSGC reached out to collaborate with InformedDNA to expand its resources and utilize the company's experience and assets in working with payers to write coverage policies to cover genetic counseling. InformedDNA agreed to share outcome data on genetic counseling patients as well as access to genetic counselors in geographic areas where face-to-face counseling may not be available. This should be a win-win situation for both organizations and ultimately lead to the best outcome for patients in terms of access to and coverage for genetics services.

Because InformedDNA does not do any testing of any kind, none of the contracted counselors, employees or owners have any vested interest in whether a patient has testing

or where a sample is sent. This minimizes bias and maximizes expert information and support. And, because the counseling is done by telephone, multiple family members can be counseled at once, if necessary, regardless of geographic location. This removes many barriers to the process, so that individuals in rural communities without prior access can now have genetics services provided in English, Spanish, or American Sign Language.

I am very proud to say that I am part of the only independent nationwide network of genetics experts available by telephone to help patients and providers harness the power of genetics to achieve the promise of personalized healthcare. For more information, go to www.informeddna.com. Like I was, you may be surprised!

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40 Years in the Making: A Celebration of the History of Genetic Counseling at Sarah Lawrence College

By Christine Colón, M.S., The Joan H. Marks Graduate Program in Human Genetics at Sarah Lawrence College, Class of 2011

The 1971 Commencement was an historic one at Sarah Lawrence College – eight women graduated as the very first class of genetic counselors anywhere. **Hope Adams**, **Peggy Blattner**, **Beverly Ginsberg**, **Phraedie Gold**, **Amie Hample**, **Audrey Heimler**, **Gay Sachs**, and **Eva Taben** were breaking ground as ambassadors to a new profession. As these women left their training, they made their way out into the field to begin laying down the foundation of what genetic counseling is today.

While creating a training program for genetic counselors was an exciting first step in a new direction, it did not come easily. In 1968, Melissa Richter and a few supporters began to research the idea of opening such a program. Richter herself graduated from Sarah Lawrence College (SLC) in 1951 and had taught biology and psychology. She believed a genetic counseling training program was needed, and that the Continuing Education Center at SLC would be the ideal place to house one. She began contacting and gathering the opinions of other medical professionals, and found very little enthusiasm for the proposed program. Most felt a program like this would never work. Richter, along with volunteer Gay Sachs, continued working despite criticism and negative opinions, confident that they were on the right path. In fact, that path would take an unexpected turn because of one little mistake.

In 1969, *The New York Times* printed an article about how pregnant patients can be affected by genetic counseling, entitled "Will the Baby Be Normal?" The author of the article, Robert Stock, incorrectly wrote, "Sarah Lawrence College has plans to establish a program to train"[1] genetic counselors. Immediately following this, letters of interest poured into SLC requesting information on their genetic counseling program. Of course, it was not yet established, so Richter and her colleagues hurried to build a program. In

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[1] Stock (1963)

September 1969, the first graduating class of the Human Genetics Program (HGP) began their studies. Since then, hundreds of students have trained at SLC and gone on to become successful counselors, educators, and leaders in the field.

Although technically "middle aged," The Joan H. Marks Graduate Program in Human Genetics (formerly the Human Genetics Program, HGP) is in its prime. It continues to be the largest program in the country; this year it graduated 26 brand new genetic counselors, students who were picked from a variety of locations. Each year, the program receives applications from all over the United States, Canada, and many other countries. Students have come from as close as Yonkers, New York, as far away as the Ivory Coast, Africa, and everywhere in between, including India, Albania, and Kosovo.

The class of 1971 consisted of eight women, ages 27-50, all married with children. The majority of the students are still women: there have been less than forty male graduates in total from the program so far, but efforts continue to try and admit more every year. Ages of candidates have always depended on the applicants – there was never an age "limit" or "requirement," so most classes comprise a variety of ages. The class of 2011 consists of twenty-five females and one male, with an age range of 23-53 years. Six members of the class are married, and five have children/step children. Four of the five students with children hold part-time attendance status.

The program continues to grow and change in other ways. The curriculum has been steadily evolving over the last 42 years, making the type and content of classes and rotations more suited to the needs of the students and the profession. One such change is the recent partnership with Richmond Community Services in nearby Yonkers, NY, an organization that offers support services to children and adults with developmental disabilities and their families. This unique ten-week rotation offers students the chance to gain hands on experience working with people living with disabilities through participation in group activities and one-on-one interaction with staff and residents. Established in Fall 2008, the rotation is, to date, a successful one. "It's a positive experience," said a student in program. "It takes you out of the textbook idea of disability and puts the human element back in."

As a member of the 40th graduating class, sorting through the program's long history was educational and interesting for me. One task I completed was recording the name of each and every graduate of the program, over 830 people. I was familiar with many of the names as supervisors, lecturers, faculty, colleagues, or other contributors to the field. It was exciting for me to realize the number of accomplished people with whom I will share a Sarah Lawrence College diploma.

SLC's Class of 2011 (left to right, from back row): *Katy Eso, Laura Wallace, Kayla York, Gillian Blaber, Brianne Baier, Laura Defenbach, Lindsey Alico, Paul Kezmarsky, Director Caroline Lieber, Christine Colón, Malka Sasson-Venouziou, Adriana Korpela, Rimi Joshi, Christa Sherburne, Blerta Pani, Leslie Harless, Eleanor Griffith, Leah Fried, Jie Feng, Emilie Creede, Associate Director Jamie Speer, Leichelle Little, Kate Gardiner, Divya Moorthy, Emily Bloom, Ny Hoang, Ruthie Godoy-Astelarra*

One such person is **Caroline Lieber**, Program Director. Caroline graduated from the SLC program in 1980 and, after years of working in the field, took the position once Joan Marks retired in 1998. "I have always had a passion and a keen interest in the education component of genetic counseling," she said. SLC's program encourages students to become involved in education by requiring the completion of an outreach project/presentation for local schools and other community organizations, and by hosting a genetic counseling summer camp for high school students interested in the profession.

As part of the 40th anniversary celebration, Caroline and I visited the Sarah Lawrence Archives to gather information from past documents for upcoming festivities. We looked through folders filled with various program letters, articles, and reports outlining the HGP history. However, the real fun began when Caroline started thumbing through the photographs. While she made the occasional comment, ("Look at those hairdos!") she mostly sat in silence, smiling as she made her way through the piles.

After having the chance to review the past, Caroline spoke about the future of the program. "Our program has been a leader in the field in the past 40 years. I believe it will continue to lead. We are training our students to create new jobs in the areas of complex disorders, public health, policy, and research. In the future, I see more of our graduates being able to utilize genetic counseling skills beyond clinical settings."

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Tort Reform and Genomics: A Future Odd Couple?

By Sandra B. Factor, MS, JD

***Editors' Note**: Sandra Factor is a genetic counselor who subsequently pursued a law degree (M.S. Sarah Lawrence, Human Genetics, 1978; J.D. Pace, 1988; admitted to the Bar CT, 1988, New York, 1989.). She earlier provided a primer to our readership on torts ("civil wrongs") and the intersection of the practice of medical genetics and litigation. This article is about torts and their implications for genetic counselors. It contains hypothetical situations concerning genetic counselors and potential lawsuits.*

In the previous article, we discussed the general nature of medical malpractice and products liability litigation as it currently exists. It was pointed out that each State has its own criminal and civil rules and procedures, which control the litigation. Some cases are heard in the Federal District Courts (under the Federal rules), but most are heard in the State courts.

Medical malpractice is the name given to a form of tort, in which an alleged injured plaintiff brings a legal action (e.g., the lawsuit) against the alleged medical persons and/or entities that caused the physical and emotional injury (e.g., the defendants).

Genetic counselors (defined as Master's level, board-certified) are the professionals who are often the first to take a family pedigree and, later, educate and counsel the individual and family in the medical genetic practice.

So, what is a genetic counselor's risk of being sued? Is it high or low? Will it change if states enact "tort reform?" Will it change as genomics research (like personalized medicine) becomes developed for more conditions and perhaps more widely available?

Nuts and Bolts of a Lawsuit

Before outlining the stages of a medical lawsuit, it is important to remember that there is a litigation concept that prevents a plaintiff from bringing repeated lawsuits for the same injury. This is called "no two bites of the apple." In other words, the injured patient may only bring one lawsuit for her injury, which she claims was negligently caused by someone caring for her medical condition, which resulted in an otherwise unnecessary

injury (e.g. not a known side effect of which she was informed and for which she signed an informed consent).

Now, how does a lawsuit happen? A patient who has experienced a bad outcome consults with a lawyer (the "Trial Lawyers") and must sign an authorization releasing a copy of her medical records to the lawyer. The hospital or medical entity must respond and send the complete medical records to the lawyer. When the authorization arrives at the hospital, it goes to the Risk Management department, which obtains and keeps the medical records. Risk Management then reviews them and the hospital's litigation counsel is notified. A copy of the records will be sent to the defense law firm after the hospital's insurance company is informed. They will all receive copies of every piece of paper written by both sides of the lawsuit. This takes place before a lawsuit is really "started."

The plaintiff's lawyer will then review the medical records. A large law firm will have nurses and trained paralegals to complete this review. The lawyers will conference and decide whether to accept the patient as a client. Their decision is not based upon only the fact that the patient may have suffered an injury. Their decision is based upon the amount of money at which the injury will be valued. Most plaintiffs' lawyers work on a contingency fee basis, which means that they only make money if they win a settlement or a judgment for the plaintiff. Their fee is commonly 33%, plus reimbursement for all up-front expenses. In total, the plaintiff firm will usually take almost 40% of the amount awarded to the plaintiff.

Is there a risk for a genetic counselor in this current medical system? Yes – a risk of being sued, but not much risk of making a cash payment from personal funds. This is because of the vicarious liability of the employer, hospital, medical center, and/or other for the supervised employee/genetic counselor.

If the plaintiff's law firm decides to start a lawsuit, they must follow the timetable set by the rules of civil procedure. First, all the potential defendants are identified from the entries in the medical records. Since there is the "no two bites of the apple," the lawsuit must sue <u>all</u> the possible defendants at the same time. Often, it is not clear exactly where, or when, or by whom, the alleged negligence occurred, so the plaintiff must sue <u>every</u> medical professional who treated the patient who may have had a responsible role. In the case of a genetic diagnosis, where there is often information given about predictions of recurrence, types of treatment, prevention, and other facts, there may be many individuals who have talked to and counseled the patient, performed tests, reviewed results, and had other clinical roles. They may all be sued.

The lawsuit begins with the filing of a Summons and Complaint with the appropriate court. These documents are then served on <u>all</u> of the named defendants within a specific number of days (for example, this is specified as 120 days in New York). If a genetic counselor receives such documents, there are probably many colleagues who have also received them. The summons requires that the named person appear at the court. This is usually a formality that is handled by the defense counsel. The complaint explains what the plaintiff alleges has occurred due to negligence. This document may be many pages long, and will allege that each separate named defendant committed the negligence(s).

In these situations, a genetic counselor should take the documents to his/her employer's legal counsel's office or to Risk Management department. The employer will handle the legal arrangements, obtain the defense counsel, and probably have an in-house investigator speak personally with each defendant.

(As an aside, will any "tort reform" change any of this? No.)

The defense counsel will reply with an Answer, technically making an "appearance" for each defendant, and will request a Bill of Particulars from the plaintiff. This document is a greatly expanded version of the complaint.

Then, the "Discovery" phase begins. All the defendants are required to appear before the plaintiff's lawyer, to be questioned at a deposition, also known as an examination before trial (EBT). Defense counsel will attend with the defendant to supervise, and will prepare the defendant beforehand by reviewing pertinent parts of the medical records. The reason that medical records must be accurate , complete, signed and dated is that they are the existing evidence, even years later, of what occurred between the patient and the medical staff.

Usually, the defense counsel will make a Motion for Dismissal after the depositions if it seems clear that certain named defendants did not commit the negligent acts. In a hypothetical genetics case, if it seems that a laboratory made a diagnostic error, and this lab result was communicated by a physician or by a genetic counselor supervised by a physician, the genetic counselor could be let out of the case at this point. Typically, the plaintiff only cares about winning and being awarded a monetary judgment, and not about how many defendants are found liable.

However, in a different sort of case, if the family history was not obtained according to the accepted "standard of care," or if significant statistical information was not correctly communicated, a genetic counselor could be found liable for negligence if it was the "proximate cause" of the injury. Being employed covers the genetic counselor with the "vicarious liability" protection of the employer, which will bear the costs of the defense and judgment.

(This process may change a bit under some kinds of proposed tort reform, which may include medical panels instead of trial by jury. However, depositions will still occur, since by law the plaintiff is allowed to obtain all relevant information about the cause of the injury.)

In summary, genetic counselors may face a professional risk of being named in a lawsuit but, if employed and as part of a team, may not have much to fear in their personal monetary risk. However, genetic counselors that want to work independently, even if licensed, would potentially be at much greater risk for this.

What would "Tort Reform" do? In states that are trying to make changes to their medical malpractice procedures, suggestions for change are designed to lower the cost to insurers and medical providers. Shortening the Statute of Limitations, capping the damages for

"pain and suffering", instituting medical screening panels, and other suggestions have all been proposed.

Genomics and Public Health: A Brief Note

Personalized medicine is the mission of genomics research. The goal is to tailor new medicine to the individual's genome so as to maximize treatment and minimize harmful or deleterious side effects. It is a wonderful goal. The significant issues are the cost of the research, where the funds will come from, and which patients will have access to new and possibly expensive treatments. Instead of tort reform lowering the cost of doing business in the future, genomics may raise the overall cost of medical treatment by inventing expensive new medicines for fewer patients. Medical malpractice litigation is designed to compensate the injured victim after the fact with monetary damages. Genomic medicine is designed to prevent injury or inefficient treatment.

It becomes a public policy issue, not necessarily a medical issue, when the expenditure of public funds is involved. Currently, there are reports in the press about states attempting to legislate different medical care for Medicaid recipients based simply on their lack of income, and not on their medical need.

Torts and genomics are thus two aspects of present day medical care, the old and the new. The public health advocacy community should play an important role in obtaining access for all patients in need of medical care. Technology companies should be encouraged to invent medicines for large segments of the population who suffer from common and chronic conditions such as allergies, diabetes, obesity, heart disease, arthritic and gastrointestinal conditions, and cancer. Genomics is not necessarily only for purely genetic diseases, as such.

Hypothetical Scenarios Pertaining to Genetic Counselors

What situations could put a genetic counselor at risk of needing to defend him/herself from a finding of liability in a medical malpractice lawsuit?

- **Failure to keep complete, detailed, and dated notes on all conversations with patients, including those via telephone or the Internet.** Remember, the statute of limitations may run ten or more years in the case of an "infant" patient. The patient's memory is fallible, and a signed "informed consent" form does not immunize the medical practitioner.

- **Failure to keep all team members informed of a patient's concerns.** Teams should have regularly scheduled conferences, so that all genetic counselors, physicians and other health care providers who deal with the patient have the same information.

- **Failure to perceive that English is not sufficiently understood by the patient or by his/her family.** Patients may say that they understand the information,

being polite and anxious, but may not. Giving written materials to take home will reinforce the communication, and a copy should be placed into the medical chart, signed and dated by the patient.

- **Failure to provide easily understood printed educational and community resource materials for the patient to take home, with access to the genetic counselor for follow-up discussions or referrals for further assistance.**

- **Failure to question and prepare a detailed health history of a new patient, as well as the family health history.** Often, signs and/or symptoms develop slowly over time, but in other cases there is a sudden serious episode without prior warning. For example, sudden cardiac arrest in young athletes, ruptured aortic aneurism, seizures, anaphylaxis, and adverse drug reactions may have an acute onset with serious outcome.

These simple types of situations are easily avoidable, and misunderstandings can be prevented if documentation is completed correctly. It is common to all types of medical litigation that a plaintiff patient will deny hearing or speaking about a significant issue. Documentation in the medical record that the issue was, in fact, discussed will hold weight in court.

What happens if the genetic counselor has to attend and participate in a trial?

If a case progresses past the Discovery phase without a settlement or a dismissal, the Court will set the case for trial. The judge controls all the schedules at this point, and both parties and their lawyers must conform their work to the court's requirements.

The lawyers for both sides have the right to pick the jury from a jury pool, citizens who have been called by the Court to be present for "voir dire," or examination for their fitness to serve as a juror. The parties to the case are not involved in this. Some states require twelve jurors, some only six. The lawyers may object to certain possible jurors and must not use ethnic or racial traits as disqualifiers. Often jurors are chosen for their lack of medical or scientific knowledge. This is to allow the trial attorney to shape their ideas of what happened in the medical situation; they do not want jurors with preconceived ideas of the issues that will arise in the presentation of evidence.

Both the previously held deposition and the testimony at trial are "under oath." When a defendant is called to take the stand and testify, the other defendants are not present in the courtroom. The genetic counselor will be asked personal questions about her professional qualifications and education, and then will be questioned in a carefully detailed cumulative manner about her previous work, her current job description and duties. Finally, the questions will usually be about the actual evidence in the medical records. The defense attorney will then question the genetic counselor in a manner intended to counter any negative answers already heard by the jurors. This can be a difficult experience.

Unfortunately, jurors often make decisions based upon the demeanor and appearance of the defendant, such as her speech and clothing, or her attitude towards the lawyers and the jurors. All lawyers coach and prepare their clients before the trial to help them present the best calm and authoritative manner.

One of the most significant presentations heard by the jury is from the expert witnesses. Each party may offer expert testimony. In a complicated medical case, with defendants of several medical specialties, each defendant will present an expert to address his or her particular role in the case. For a genetic counselor, another genetic counselor would be presented by both sides. His or her opinion carries much weight, since the genetic counselor's professional conduct regarding the appropriate "standard of care" is not being compared to that of the physician, nurse or other health care professional.

A major problem for litigants on both sides is finding a willing "expert," -- one who will review the medical records and the depositions, prepare an evaluation and a professional opinion, and who will agree to testify in court. Litigation is an adversarial activity, and the experts are set against each other, offering opposite opinions based upon the identical factual evidence. Their appearance, comportment, dress, age, speaking ability, authoritative manner, and other non-medical, superficial elements may have strong influences on the jurors. The two attorneys will usually each try to attack and discredit the other side's expert, and will argue that the opposing expert's opinion is incorrect.

If a state's legislature enacts tort reforms and alters its existing civil rules, it may create medical panels that may reduce the need for expert witnesses. A medical panel would, at a minimum, be composed of a legal expert, sometimes a retired judge, or an administrative law judge, and medical professionals suitable for each case; for example a cardiologist for an alleged failure to diagnose heart disease, or a medical geneticist for an alleged failure to properly diagnose a genetic disease. If the medical panel is itself composed of experts, outside expert testimony may not be required. Panels have been created and used in several states as a pre-trial screening procedure. If a plaintiff loses her case when it is evaluated by a neutral panel, the plaintiff might withdraw the lawsuit to prevent the high monetary cost of trying the case in court before a jury and risk losing.

If the plaintiff wins before the panel, often the defense counsel will re-evaluate its position and offer to settle the case prior to trying it in court. This is a decision that must be reached by agreement of both the defendant and her legal counsel. If the defendant refuses to settle, the case must be tried. Thus, medical panels may be helpful in decreasing the cost of litigation for the insurance company and the court system, which is funded by the state's taxpayers. Also, what may happen at this stage is a defense counsel "Motion to Dismiss" some of the defendants from the lawsuit, prior to a trial, if the evidence against them for negligence is weak, or shows that the defendant played no significant role in causing the alleged injury.

What should a genetic counselor do if he or she is asked to be an expert witness?

First, of course, is to determine whether it would be for an injured plaintiff, or for the defense. For the plaintiff, the genetic counselor would have to testify to the failure of a

fellow genetic counselor to follow the appropriate standard of care. She or he will be observed and listened to by a courtroom full of jurors, lawyers, the parties, and spectators. Often the expert witnesses utilize computer projected photographs, statistical graphs, or other visual aides to explain the facts to jurors who may have little knowledge of human genetics.

If the genetic counselor is an accomplished public speaker and is comfortable educating large groups without notes, the experience may not be anxiety provoking. However, his or her professional opinion, professional areas of expertise, and credibility will be attacked by opposing counsel. He or she will be asked about their income and about how much he or she is being paid to testify. This may be very disturbing, and many physicians have refused to testify against another physician because of this procedure, even if the facts seem to indicate that the plaintiff has a strong case. The genetic counselor may decline to participate in a lawsuit as an expert witness.

What should a genetic counselor do if he or she is served with a Subpoena to testify as a nonparty witness?

In this situation, the genetic counselor will be called by one of the parties to testify about something in the medical records in which he or she had participated. This cannot be declined without a Motion to the court explaining the reason why the genetic counselor cannot testify. The jurors will hear the genetic counselor's testimony, but he or she will not be subjected to the stronger adversarial contest, since she will be testifying as a "fact witness" and not as an "expert witness."

What may happen in the case of an out-of-state lawsuit?

A genetic counselor may change employment and, perhaps, move to a different state to live and work. Years may go by before a Summons and Complaint are served on her/him, initiating a lawsuit. These documents will be served on all of the named defendants at their various new places of employment or at their homes, by a sheriff or by a process server. Law firms hire licensed investigators to locate potential defendants because the legal documents must be served and received personally.

Since the plaintiff was a patient at a previous place of employment, the genetic counselor must contact the Risk Management office of his/her previous employer, not their current one. That employer will notify the insurance carrier, which will hire the defense counsel. The rest of the procedures are the same, except that the genetic counselor (and any previous colleagues who are co-defendants) will have to travel into the plaintiff's state for the depositions and trial. The travel expenses are not covered by the employer's liability insurance and must be paid for by the defendants.

Often, two to three overnight stays are required for preparation prior to deposition. These allow for the establishment of a relationship with the defense counsel, a review the medical records (that will have been kept by the employer during the intervening years), and coaching of the defendant (i.e., how to manage the deposition questions and give

appropriate responses). A trial may occur months later, again requiring all defendants to travel to the plaintiff's state, pay their own expenses. These out-of-pocket expenses are not covered or reimbursed, even if the plaintiff loses her case and the defendants are found to have no liability.

Considerations for Genetic Counselors

- **A genetic counselor may choose to purchase a personal professional liability insurance policy or an umbrella liability policy.** It is important to confirm that professional exposure is specifically covered, and to obtain at least two to five million dollars of coverage.

- **A genetic counselor may choose to place the ownership of their family home and financial assets into the name of their spouse or a trusted family member, with the genetic counselor as the beneficiary, to shield them from attachment by a winning plaintiff.** Any assets held in joint ownership may be at risk if the employer is under-insured. The plaintiff has a legal right of recourse against all defendants, even as a lien against future income. An uninsured defendant may face personal bankruptcy if there is insufficient insurance coverage. Although the risk of a genetic counselor being sued and losing a medical malpractice lawsuit is low, the financial effects can be difficult.

- **Genetic counselors may choose to keep yearly diaries in a bound and dated ledger, not a computer file.** Each day that a genetic counselor sees or communicates with a patient, a notation should be entered, including the patient's full name, a case number (if available), and the medical issue. For example, "Jane Doe, case #xx, infant with Down syndrome," or "John Roe, Case #xy, early onset colon cancer." No personal details are necessary and no violations of the Health Information Portability and Accountability Act (HIPAA) should occur. A diary allows the genetic counselor to review the extent of his/her involvement with the patient and where in the medical records it has been documented. If the genetic counselor changes employment, note in the diary the full legal name of the employer, its mailing address, the names of her/his direct supervisors, the name of the chairman of the department, the phone number of the Risk Management office, and a brief summary of her/his job description and salary. These details may become important years later, especially if the plaintiff is an "infant" (legally, a child younger than 18 years, when the statute of limitations may extend ten years or more), or a pregnant woman who gives birth years later to another affected child.

- **The issue of whether or not a genetic counselor should inform her/his current employer or a pending lawsuit may be resolved by the conditions of the genetic counselor's employment.** For future employment, one's resume does not have to include lawsuit information, but it must be disclosed if the future employer directly requests the information.

Conclusion

Genetic counseling, as a profession, often involves communicating about serious quality of life issues for the patients. Emotions are volatile, and fear, anxiety, or profound grief may last for a long time. Patients may decide, after years have passed, that they were negligently cared for and, as a result, had a seriously bad outcome. There are many "trial lawyers" looking for cases such as this, by which to earn their living. There is no solution to this situation, but attempts are being made to improve the procedures.

The good news is that most genetic counselors will never be sued. If it does happen, the genetic counselor generally has a low risk of personal exposure to the money damages awarded to a winning plaintiff if he or she is externally employed and covered by their employer's medical liability insurance.

For Your Practice

One counselor's cultural competence journey, striving for a professional network

By Nancy Steinberg Warren, MS, CGC, Genetic Counselor and Educator, Genetic Counseling Toolkit, LLC

Editors' Note: *We approached Nancy Steinberg Warren, recipient of the 2009 Jane Engelberg Memorial Fellowship (JEMF), to share her experiences as a JEMF Fellow: how she became interested in the issues of cultural competency and diversity, what she has learned along the way, and what she has created through her tenure.*

Progressing in a personal, cross-cultural competence journey involves reflecting on and striving to enhance one's experiences, strengths, weaknesses, cultural knowledge, desire to continue learning, and skills to communicate effectively with others. Taking this type of journey may not seem relevant to a genetic counselor like me who doesn't counsel clients anymore. In fact, embarking on this was not one of my professional goals until very recently.

I had spent many years trying to research and understand why under-represented minorities were not applying to enter the genetic counseling field. I developed workshops and materials that I hoped would address this issue, and many of my genetic counseling program director colleagues were doing the same. Despite our efforts, the challenge remained daunting. It was not until 2004, when I convened a two-day invited retreat to discuss our profession's recruitment challenges, that I could appreciate the naiveté of our well-intended approaches.

The attendees at this retreat were the directors of Midwestern genetic counseling programs, each partnered with an individual from our respective institutions with expertise in minority recruitment or multicultural affairs. Importantly, we also invited several national experts in diversity and cultural competence from other health care, science, and counseling fields. This interdisciplinary mix of attendees helped elucidate why the genetic counseling programs had not made much progress in effectively reaching underrepresented minority candidates.

From the experts, I learned that genetic counseling is not inherently attractive simply because I happen to think the field is great. I had to admit that genetic counseling has some negative "baggage." For example, the salaries often do not match our formidable roles and responsibilities. Many people fear genetics and worry about discrimination based on their genes, diseases, or family history. We serve only a tiny segment of the population and the demographics of our clients are skewed towards those who have higher education and socioeconomic means. Genetic counselors are predominantly Caucasian women. There are many better known, better funded, and, perhaps, even more important careers.

Rather than avoid or deny these limitations, the retreat experts emphasized that we need to accept and address them, so we can move forward effectively in our agenda of promoting the field. Beyond that, we could enhance recruitment of under-represented minorities by enhancing cultural competence, which has been linked conceptually to reduce health disparities in health care. Brach and Fraserirector present a model of how nine cultural competency techniques could reduce health disparities[1]. In this model, training is identified as a factor that can promote changes in clinician and patient behavior (e.g., improved communication, increased trust, greater knowledge and understanding of cultural and environmental factors). These behaviors can lead to provision of appropriate services (e.g., patient education, prevention, screening, offering treatment in light of cultural beliefs) that can lead to good outcomes (e.g., higher levels of health status, increased functioning, improved satisfaction). While these factors are complex, interrelated and difficult to test, this model makes sense in the context of genetic counseling.

Developing an educational program or resource to enhance cultural competence and potentially reduce health disparities in genetics service provision sounded like a great, yet overwhelming, opportunity. I kept reading about this issue and thinking about how to move forward professionally and personally. Several years later, when the opportunity presented to apply for a Jane Engelberg Memorial Fund (JEMF) grant, I outlined a vision that was approved with enthusiasm by the JEMF Committee. As the 2009 JEMF Fellow,

I was able to spend intensive time learning more about cultural competence and diversity from experts, attend national meetings such as the Diversity Rx conference and the International Medical Interpreters meeting, and do lots of reading and thinking. Many experts in our field contributed to the end project, a website that was launched recently: the **Genetic Counseling Cultural Competence Toolkit** (www.geneticcounselingtoolkit.com).

The website includes many links to multi-lingual resources, information about health literacy, clinical and teaching tools, assessment tools, government documents, and more. There are nine extensive cases that were approved for over fourteen hours of genetic counseling continuing education learning by the NSGC. The cases are suitable for genetic counselors, nurses and other health care providers whose professions accept continuing education programs approved by the International Association for Continuing Education and Training (IACET). In response to expressed interdisciplinary interest, continuing education approval was also obtained from the International Medical Interpreters Association (IMIA) for medical interpreters, and from the American Translators Association (ATA) for translators. Genetic counseling program students and pre-genetic counseling students are encouraged to use the resource and register for a Learning Certificate. Complete registration information is available at: http://geneticcounselingtoolkit.com/ceu.htm

The website is a hub of information, or a resource portal, that can be added to and shaped over time. We, as adult learners, decide what information we want and we access it when we need it. All of the information on the website, including the cases, is accessible to anyone at any time of day or night. Its design is consistent with the recommendation of the retreat experts to involve everyone in every aspect of a field. Simply adding an extra course or lecture is inadequate; we need to involve the practitioners, administrators, professional organizations, faculty, educators, students, supervisors, clinics, staff, labs, and institutions involved in the clinical, laboratory, and research aspects of the field. We

need to touch the curricula, clinical rotations, recruitment practices, research projects, and the faculty, staff, and administration of the training programs. *Infusing cultural competence* into every facet of the profession of genetic counseling should be our goal. That lofty task is made up of doable baby steps, if we all add our unique contributions.

From my perspective, every human interaction is a cross-cultural interaction. Whatever our role in the field, each one of us is a multi-layered multi-faceted cultural being, which impacts our ability to communicate effectively with others who are somewhat like and somewhat unlike us. The ability to communicate effectively has been linked to increased client satisfaction, understanding, and follow-through in health care settings. These are all critical elements of reducing health disparities.

Effective communication with others stems from an awareness of our own background and the factors that have shaped our lives. Some of you know me professionally as a genetic counselor with a passion for educating students in and out of our field, recruiting new students into genetic counseling, and making linkages for integrating the genetic counseling role into interdisciplinary health care. Some of you may know me more personally as a wife, mom of three kids, avid vegetarian cook, knitter, and follower of modern Orthodox Judaism. These are aspects of my public and semi-private life, all of which influence my communication with others.

Hardly anyone knows, however, that I grew up in a racist household, or that mental illness runs rampant in my birth family. I did not understand these things when I was growing up, but now I can appreciate the impact these experiences have on my worldview. While I cannot deny my past, I can use these experiences to gain a better understanding of how I relate to others and to improve how I relate to others. Though this is not an easy exercise, this self-introspection is an important step for anybody who wishes to better understand and improve his or her communication.

While I am still learning, I am excited to share some of the knowledge I gained by focusing on cultural and linguistic competence as the 2009 JEMF Fellow. I am working with a team of genetic counselors affiliated with the NSGC Diversity Task Force to present an interactive workshop at the NSGC Annual Conference in San Diego. Also, as a consultant, I am offering workshops on cultural competence issues for genetic counselors, training programs, and/or genetics centers, as well as organizational cultural assessments for genetics service providers. My personal learning expedition continues!

I offer my sincere thanks to the *Perspectives* Editors for the opportunity to share the personal and professional background behind the Genetic Counseling Cultural Competence Toolkit. Now that the Toolkit has been launched, let's turn to the future. I believe we are just at the beginning of an exciting new professional adventure. I hope everyone in our field learns from, and contributes to, the content of the Genetic Counseling Cultural Competence Toolkit. Many genetic counselors submitted "tips:" (http://geneticcounselingtoolkit.com/gctips.htm) and each case includes a commentary by an expert in our field at the end of each. The case menu can be accessed at: http://geneticcounselingtoolkit.com/genetic_counseling_cases.htm

These contributions are wonderful, but they are just a start. My hope for the genetic counseling profession is to have an interlocking network jam-packed with the richness of our individual cultural competence pathways, our personal, professional, and cultural knowledge, and the insights we have gained from our cross-cultural encounters. No matter what our expertise, we have much to learn from each other. This collective professional network will support more effective genetic counseling and help place our profession at the forefront of national efforts for reducing health disparities. Our individualized, client-centered genetic counseling practice is a model for other health professions, implemented through the genetic counseling tasks of contracting, listening, providing empathy, providing balanced information and assistance with decision making, reframing, and providing support within the context of family and community.

I envision each of you enhancing the Toolkit content over time and using it as our springboard for sharing experiences, tips, projects, presentations, translated materials, or other elements of our cultural competence journeys. Help create a professional network of intersecting and evolving cultural knowledge, values, and skills. If you have thoughts or documents to share, now or in the future, simply contact me at geneticcounselingtoolkit@gmail.com.

References

1. Brach C and Fraserirector I. Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model. *Medical Care Research and Review*. 57(4) Supp 1:181-217. 2000.

Licensure / Billing & Reimbursement

The Coding Corner

Quantifying and Evaluating the Benefits and Value of Genetic Counseling to Health Plans and Third Party Payers

By Janet L. Williams, MS, CGC, Kimberly Banks, MS, CGC, Shanna Gustafson, MS, MPH, and John Richardson, NSGC Government Relations Director

The Coding Corner is supported by the Coding Subcommittee of the 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 CPT/ICD coding in genetic services as well as keep the membership educated regarding billing and reimbursement issues.

We are happy to report that advocacy efforts this spring have been very active! As reported in the NSGC President's Blog (http://nsgcpresident.blogspot.com/), representatives from the NSGC met with senior executives at United HealthCare Services, on April 11, 2011, to demonstrate the roles genetic counselors can play in helping payers improve patient care while reducing wasteful health spending.

Additionally, members of the NSGC Access and Service Delivery Committee were invited to present at the Medical Policy and Molecular Diagnostics/Genetic Testing Forum in Washington, D.C. on April 26 and 27, 2011. This meeting was a two day forum, had a target audience consisting of policy executives from multiple private payers, and included workshops and presentations for payers regarding the topic of genetic testing. Genetic counselors played a prominent role in the content presented and contributed significantly to the discussion throughout the presentations. The targeted aims of this conference were to help payers formulate their policies, evaluate their pre-authorization strategies, determine clinical validity of new tests, and evaluate genetic risk prediction for preventive medical management. All of these are areas where the expertise of genetic counselors can be utilized.

There were many presentations that discussed the pros (e.g., better control) and cons (e.g., higher administrative costs) of prior authorization policies for coverage of genetic tests. Data presented in abstracts regarding the amount of inappropriate testing, duplicate genetic testing, and high cost sequencing versus site-specific or target screening all supported the process of review before authorization of genetic testing coverage. Decision making about coverage of testing was recognized as completely inadequate to ensure patient satisfaction, encourage appropriate testing, and to avoid unnecessary testing. The consensus in the room acknowledged the large contribution that genetic counselors make in sorting through appropriate genetic testing.

The concern about access to genetic counselors was also voiced – if requirements for genetic counseling are established, then broad access to genetic counselors needs to be available. The payers at this meeting met genetic counselors representing a variety of genetic counseling service options; including traditional face-to-face counseling, public health and policy genetic counseling presented by **Debra Duquette** and **Karen Powell**, telephone counseling (presented by Informed Medical Decisions, Inc. and DNA Direct), and direct involvement of genetic counselors within payer companies as presented by **Karen Lewis** from Priority Health.

Many payer representatives in the room affirmed the roles of genetic counselors in their payer organizations and were quite surprised to learn of the problems that genetic counselors face in actually being reimbursed. After these discussions, many in the audience even remarked that they plan to take a closer look at what their actual reimbursement processes are with regard to genetic counselors!

Additionally, having this meeting in Washington, D.C. allowed for lobbying by NSGC members for the federal effort to introduce legislation for Centers for Medicare and Medicaid Services' (CMS) recognition of genetic counselors. Staff from the offices of Senator Orin Hatch (Utah), Senator Debbie Stabenow (Michigan), Congressman Jim Matheson (Utah), and Congressman Dave Camp (Michigan) all heard our proposal for

CMS recognition and asked very relevant questions. Overall the discussion was positive and encouraging that, although slowly, progress is being made!

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 ***Shanna Gustafson*** *a*t *shannagustafson@gmail.com or* ***John Richardson*** *at jrichardson@nsgc.org.*

SIG Speak

From the Cystic Fibrosis and CFTR Spectrum Special Interest Group

Introducing the Cystic Fibrosis and CFTR Spectrum SIG

By Amy Powers, MS and Sumedha Ghate, MS

Holding a genetic testing result in hand, you might hear a cystic fibrosis (CF) team member ask: "So, does this person have CF?" This question is one of several that a genetic counselor in a CF clinic might encounter. Although not historically integrated into many CF Centers, the implementation of nationwide newborn screening for CF (often with a DNA component) has been a catalyst for increasing involvement of genetic counselors. Genetic counselors play an important role in providing education and support to families who are seen due to an abnormal newborn screen result. They can also be integral CF team members when working up diagnostic dilemmas and explaining the implications of a diagnosis such as cystic fibrosis related metabolic syndrome (CRMS). Additionally, clinical trials are underway for mutation-directed therapies. These new opportunities in the CF arena create a need for genetic counselors to network and have access to good resources. Thus, the Cystic Fibrosis and CFTR (Cystic Fibrosis Transmembrane Conductance Regulator) Spectrum Special Interest Group (SIG) was formed.

While many genetic counselors are already integrated into a CF team, others are trying to identify ways to participate more fully in caring for patients and families with CF. Most CF Centers have been around for decades and have established dedicated teams who work quite passionately on behalf of their patients. Here are some tips on how to integrate genetic counseling services into a CF team:

How do I get started in a CF Clinic?

- **Accept that there is a steep learning curve.** CF is a complex multi-system disease with a multitude of unique psychosocial and medical issues. Integrating into your CF team is best accomplished through experience with CF. It cannot be learned didactically.

- **Acknowledge your strengths and weaknesses, and don't be shy about sharing how you can educate and advocate for your patients.** CF Centers know their patients well, and it may take time for team members to fully trust you with their patients.

- **Participate in CF team meetings when you can.** Be comfortable continuing to educate the CF team about the role of a genetic counselor, and have respect for blurred boundaries between team members' contributions. Shadow team members to learn their approaches to caring for those with CF. This will help you learn about each other and help you to define how a genetic counselor will fit in with the team.

- **Keep working with your CF team in <u>any</u> way you can, even if not directly related to genetic counseling.** Reviewing, organizing, and updating educational resources will help team members get to know you, your knowledge of CF, and your commitment to the team.

<u>I'm in a CF Clinic – now what?</u>

- **Be a genetic counselor – of course – but be creative.** Update the CF team email list. Be aware of CF resources online and in your community. Provide education, resources, and support to a family with a new CF diagnosis. Communicate what you know about the family with the CF team when relevant. Continue to be involved in any way to help build trust within your team.

- **Help coordinate tracking efforts and additional testing, when indicated.** Having someone who understands genotype nomenclature can be very helpful to a CF Center when recording patients' mutations.

- **Try to meet with families on an annual basis, even if there is no clear indication.** At first you will introduce yourself and your role, but over time families will remember you and feel comfortable seeking you out when they have questions. Genetic counselors can be especially helpful at the time of initial diagnosis, during a subsequent pregnancy, or when adolescents start to have questions about their own futures and reproductive issues.

- **Stay informed about relevant clinical trials and update families with this information.** A great way to learn the latest information is to attend the North American CF Foundation Annual Conference. Families are always eager to hear a report from team members when they return!

- **Offer to educate others.** Speak at CF family education day, and participate in CF Foundation fundraising events (like "Great Strides").

<u>Educational Resources for the Genetic Counselor and Patients / Families</u>

There are a multitude of CF resources and references, and it can be difficult to find the best ones. Here are a few that may be most useful when working with families with CF:

- Patient-friendly newborn screening resources from the Cystic Fibrosis Foundation: www.cff.org/AboutCF/Testing/NewbornScreening/

- CF Diagnosis Guidelines: "Guidelines for diagnosis of cystic fibrosis in newborns through older adults: Cystic Fibrosis Foundation consensus report." Farrell PM *et al*. *J Pediatr*. 153(2):S4-S14. 2008.

- CFTR-Related Metabolic Syndrome Diagnosis and Treatment Guidelines: "Cystic Fibrosis Foundation practice guidelines for the management of infants with cystic fibrosis transmembrane conductance regulator-related metabolic syndrome during the first two years of life and beyond." Cystic Fibrosis Foundation *et al*. *J Pediatr*. 155(6 Suppl):S106-16. 2009.

- COMING SOON - The Cystic Fibrosis Mutation Database (www.genet.sickkids.on.ca/cftr/app) is joining a new project called CFTR2 - The Clinical and Functional Translation of CFTR. This is an international initiative led by a team of researchers and clinicians and supported by the U.S.'s Cystic Fibrosis Foundation to provide complete, advanced and expert-reviewed functional and clinical information on CFTR mutations.

We hope the Cystic Fibrosis and CFTR Spectrum SIG will be a resource to all genetic counselors and healthcare providers on the topic of CF. Networking and talking with genetic counselors working in CF Clinics can often be helpful, so please contact your local "CF expert" or our SIG Co-Chairs **Christina Zaleski, MS, CGC** at zaleski.christina@marshfieldclinic.org or **Sumedha Ghate, MS, CGC** sghate@stvgb.org with any questions or issues to discuss. If you work with patients with cystic fibrosis and their families, we hope you will join our SIG and help us grow!

NSGC News

NSGC Committee Updates

Have you wondered what type of activity is taking place within the NSGC's five management committees? Below, you will find an update on many exciting activities that were underway during the first quarter of 2011. Updates will be presented in *Perspectives in Genetic Counseling* each quarter to keep you informed and help you determine where you might want to get involved!

Access and Service Delivery Committee

Monica Marvin, Chair
Shanna Gustafson, Vice Chair

- The Payer Task Force developed a presentation module for use by genetic counselors in discussions with payers and participated in piloting the module with select national and regional payers.
    - Following the pilot phase, the Payer Task Force will make improvements and provide education and support for members involved in coordinated and targeted presentations with regional payers.
- Committee members presented at the World Research Congress on Genetic Testing and Counseling on April 24, 2011.
- The Service Delivery Models Task Force continues to work on analysis of a 2010 survey of the NSGC membership to identify existing and innovative models for delivery of genetic counseling services. Data from the survey is being used to inform interviews with select genetic counselors to better understand ways to optimize access to genetic counseling.
- The Practice Guidelines Subcommittee continues to foster the development of multiple practice guidelines. The committee has two practice guidelines in press: "Practice Guidelines for Communicating a Prenatal or Postnatal Diagnosis of Down Syndrome: Recommendations of the National Society of Genetic Counselors" will be published in the *Journal of Genetic Counseling*, and "Genetic Counseling and Testing for Alzheimer's Disease**:** Joint Practice Guidelines of the American College of Medical Genetics and the National Society of Genetic Counselors" will be published in *Genetics in Medicine*.
- The NSGC Board of Directors has approved ten additional guidelines, which are in various stages of review by the practice guideline subcommittee (four Cancer, two Prenatal, two Adult; two Pediatric).
- The Committee is working to partner with the Special Interest Group (SIG) leadership to encourage more practice guidelines, especially in the areas of referral recommendations for genetic counseling.
- The Committee developed an online Credentialing Course that was approved for 1.0 CEUs, which will be launched in the coming weeks.

Communications Committee

Amy Sturm, Chair
Kimberly Barr, Vice Chair

- Provided input on the development of the second phase of the branding tactical plan and implementation of tactics in 2011, including development of a one-page guiding document to be used by the NSGC's leadership and staff
- Currently working with SIGs to provide overall direction for development of specialty-specific website content, including developing provider information in line with the NSGC's brand messages
- Working to implement the new NSGC Discussion Forums, moving from the current listservs to this new communication platform offering enhanced technology

- Beginning an assessment of currently available NSGC publications. Recommendations will be made regarding updates or new publications that are needed.
- Started initial discussions for development of marketing tool kits. This will be a customizable resource available for the NSGC members to use in marketing themselves to referring healthcare providers.

Education Committee

Julianne O'Daniel, Chair
Leigha Senter, Vice Chair
Renee Chard, Interim Chair

- The Annual Education Conference (AEC) Subcommittee has selected the Preconference Symposia, Plenary presentations, and Educational Breakout Sessions for the 2011 AEC. The Abstract Subcommittee will select concurrent papers and posters following the close of the Call for Abstracts on May 18, 2011.
- The Webinar Subcommittee held the first 2011 webinar on State Licensure on March 30th, 2011. Six webinars will be held during 2011 on the last Wednesday of odd-numbered months at 12:00pm Central Standard Time.
- The Online Course Subcommittee is currently developing the 2011 course, focused on genomic medicine. Additional information will be available in early June 2011.
- The Outreach Education subcommittee is developing a proposal for outreach education with the Association of Community Cancer Centers (ACCC), a multidisciplinary association targeting all members of the cancer care team.
- To keep up with the demand for reviewing both Category 1 and Category 2 Continuing Education Unit (CEU) applications, the CEU Subcommittee has added three review teams in 2011, for a total of 15 review teams.

Membership Committee

Samantha Baxter, Chair
Bronson Riley, Vice Chair

- Carried out the 2011 membership retention project for the general membership and piloted this process with the SIGs
- The Awards Subcommittee administered the 2011 Student Rotation Scholarship program, awarding three summer rotations with Myriad Genetic Laboratories and one summer rotation with InformedDNA, Inc. to NSGC student members.
- Launched the new cycle of the NSGC Mentorship Program and is preparing for the next session launch in June 2011
- Reviewed the 2010 Nominations process and provided recommendations for improvement to the Nominating Committee and Board of Directors

- The Leadership Task Force is currently working on a leadership development program for NSGC volunteers.
- The Professional Status Survey (PSS) Subcommittee finalized the 2010 PSS Executive Summary, completing all 2010 reports, and started work on the 2012 PSS.

Public Policy Committee

Susan Hahn, Chair
Flavia Facio, Vice Chair

- Submitted a presentation entitled, "The Evolving Landscape of Genetic Testing Oversight: Gaps from the Past, Present Status, and Potential Implications for the Future." This was selected for a plenary session at the 2011 AEC.
- Completed the NSGC Position Statement on Oversight of Genetic Testing
- Completed the NSGC Position Statement on Disability
- Convened task forces to work on revising:
  - Direct-To-Consumer Position statement
  - Health Care Reform Position Statement
  - Nondiscrimination Position Statement
- Reviewing and updating the NSGC's bibliography for distribution to legislators in support of the NSGC's proposed federal legislation
- Designed a new liaison education and reporting process to ensure liaisons have the appropriate level of support and information to effectively represent the NSGC with various external organizations

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NSGC News

The Next Match Phase for the Mentor Program

By Holly Zimmerman, MS, CGC and Emily Malouf, MGC, CGC;
NSGC Membership Committee

The NSGC Membership Committee is announcing the next match phase for the Mentor Program in **June 2011**. The program is designed to enhance networking opportunities for the NSGC's members, both students and practicing genetic counselors. Mentors can offer support, guidance, and insight while mentees can seek advice from peers, learn about a new specialty, and network professionally. Mentees can choose from a variety of selection criteria to find a mentor who best meets their needs and self-match to a mentor through an online matching website. Discussion topics are also provided on a monthly basis to facilitate continued communication.

The initial Mentor Program pilot project ended in April 2010 and was reviewed positively among participants. By incorporating the valuable suggestions for improvement from mentors and mentees alike, the Mentor Program offers an excellent network opportunity for counselors. During the most recent Mentor Phase, there were nearly 200 participants and over 40 mentor-mentee matches – and even more are expected this year.

If you are a student and unsure of what this program can offer you, previous mentee, **Katie Dunn**, speaks of her experience during the Pilot Mentor Program:

> *"I can't say enough good things about having a mentor. Having a mentor meant having a person cheering for me – a person in my corner. Participating in the Mentor Program was a valuable experience."*

The Mentor Program has also been a great resource for working genetic counselors just starting a new position or considering a specialty change.

For busy counselors who are uncertain about the benefit of the NSGC Mentor Program, consider mentor **Holly Zimmerman's** experience:

> "*Being a mentor gives you the opportunity to reflect on your own career and experiences as well as the chance to renew your passion for the profession through the enthusiasm of someone new entering the field. I have thoroughly enjoyed mentoring a first year student and hearing her sincere excitement as she journeys through her training to become a genetic counselor."*

If you are ready to get involved in the Mentor Program, mentor sign-up begins June 1, 2011 and mentee sign-up begins June 16, 2011! Mentors and mentees of all ages, years of experience and areas of specialty are needed to make the Program a success. The time commitment for participation can be as short as four months or as long as twelve months, and mentors and mentees will decide how often they will contact one another. Look for e-Blasts in June announcing enrollment periods.

To join the NSGC Mentor Program, please visit www.nsgcmentor.org.

ABGC Update

The Value of the ABGC Credential

By the ABGC Board of Directors

The American Board of Genetic Counseling (ABGC) is responsible for accrediting U.S. and Canadian genetic counseling training programs and certifying their graduates. These activities ensure the title of Certified Genetic Counselor is synonymous with competence in genetic counseling, and that we, as practitioners, are regarded as the experts. Ensuring the sustainability of our niche and maintaining our professional value is a shared responsibility; this is shared between the ABGC, the National Society of Genetic Counselors (NSGC), and each of us as genetic counseling professionals.

Maintaining our professional value depends largely on the strength of both the certification and accreditation process. Failure to ensure the continuity of a high standard for the genetic counseling profession devalues the existing certifications and accredited training programs; however, maintaining high standards is costly. This financial responsibility is shouldered partly by new examinees and training programs, while certified genetic counselors support the standards of the profession through the Certification Maintenance Fee (CMF). Although it goes against human nature to embrace an additional expense, the CMF should actually be something to be celebrated and supported. It signifies not only advancement, but also the increasing strength of our profession. It is a typical and vital component of the allied health care professions, of which we are a part.

As a frame of reference, we can look to our colleagues in the allied health professions: physician assistants (PA). The first PA program began around the same time as the first genetic counseling program (1965 vs. 1969). However, the PA profession has outpaced us in professional development, largely because of its size. PAs are certified, licensed, and recognized under Centers for Medicare and Medicaid Services (CMS). The certification body for PAs is the National Commission on the Certification of Physician Assistants. To maintain certification in this profession, PAs must pay a CMF, take a recertification exam every six years, and maintain 100 hours of Continuing Medical Education every two years. This is in contrast to our requirement of 125 hours of Continuing Education Units or recertification by exam every five years.

At the annual ABGC business meeting held at the NSGC Annual Education Conference, the ABGC Board shares information about the budget and activities supported by its fees. In addition to supporting the administrative costs of running the ABGC, a large portion of

our operating expenses are used towards the development of the exam and the accreditation process. The quality of both processes reflects upon our profession, and thus upon each of us, long after we have become certified. Funds also support volunteer committee efforts to evaluate and improve various aspects of the profession.

This year alone, these efforts include a new practice analysis (used to ensure that the certification exam accurately reflects the current practice of genetic counseling), evaluation and improvement of the practice-based competencies, and evaluation and improvement of the required criteria used by training programs. Also of significance, we have revamped the ABGC website and added a new Professional Activity Credit (PAC). Future planned activities include converting to an online recertification process and enhanced efforts to verify credentials as we move toward licensure.

In summary, we are entering a new era for our profession. The ABGC takes its responsibility to protect our profession and the public it serves seriously, as well as our commitment to maintain the value of your certification and keep you, our Diplomates, well informed.

Student Forum

A Year of Growth: Transitioning to Graduate School

By Leslie Gress, University of Cincinnati Genetic Counseling Program, Class of 2012

Early this spring, I was watching a group of potential genetic counseling students sitting in a room at Cincinnati Children's Hospital, waiting to be interviewed by program staff of the University of Cincinnati Genetic Counseling Program. They were dressed in business suits and skirts with their hair done just right. They had only sipped on water and asked a few questions. They were trying hard to assert themselves – to show us they were great candidates. As I was sitting chatting with them and assuring them to just be themselves, I thought, "Wow – you were here just one year ago, Leslie."

When I think back from last year when I was an interviewee to now wrapping up my first year of school, I cannot believe the changes in myself, my work ethic, my view of this profession – my life. I knew coming to graduate school would be a transition, but I think I highly underestimated all that was in store for me in this twelve-month span.

I chose to attend the University of Cincinnati (UC) at Cincinnati Children's Hospital for my genetic counseling training. A native Ohioan from Cleveland, I came straight from a three-year stint at the University of Dayton (UD). I have been passionate about genetic counseling since I first learned about it during my junior year of high school in biotechnology class. At that time, I never thought, five years later, I would be halfway through my degree.

I expected transitioning to graduate school to be an experience full of challenges and growth. Yet when I reflect on my years at UD and my first year in Cincinnati, I have come to truly appreciate the transition; it is one I thought would last a few months, but I am quickly learning it will continue through my entire career.

College is completely different from graduate school, as most people who have experienced it can verify. While some of my classmates took time off and worked in labs or other settings, I kept steamrolling through school. I have been blessed with naturally doing well in school. I remember during my interviews that everyone said the key to being in any program was "time management." I thought I had that down! I juggled a full course load, drove to Cleveland to visit my family, enjoyed the social aspect of college, and worked full time jobs. What did I need to learn?

Oh, how naive I was.

Six months after my interview, I was moving to a new city and decorating my apartment, placing knick-knacks here and picture frames there. Little did I know those shelves would quickly fill up with books and articles that I would not get the chance to read. I paid my first bills, got lost in the city, and signed my first lease. These changes made me feel like a grown-up more than ever, yet I was nervous for my first quarter of school.

Eight months after my interview, I was learning the ins and outs of genetics, seeing patients in clinic, and beginning research for my thesis. I realized that time was the most precious thing in my life – that one hour in clinic could give me an experience I would remember for the rest of my training and perhaps career; that one class discussion would open my eyes to just how diverse the class of 2012 at UC truly is, and how I am surrounded by such wonderful people.

During this time, I recognized and came to appreciate the large difference between my undergraduate and graduate school experiences. My classes are AWESOME. No longer do I have to sit through Philosophy 101 or Physical Chemistry to complete my degree audit. Everything I learn every day is directly applicable to my career and training. While I have always had the desire and need to succeed in my studies, I feel that graduate level education truly relies on your passion: I *want* to learn everything about hereditary breast cancer, I *want* to role play in class to enhance my psychosocial skills, I *want* to go on a consult at 6pm on a Friday to talk to a family about autosomal dominant inheritance.

However, while I expected that I would be excited and involved in my schoolwork, I never thought I would dive right in with such responsibility and an endless “To-Do” list.

Ten months after my interview, I was on Christmas break. I came to learn that between work as a Graduate Assistant and trying to see my family, I would have little chance for relaxation on this break. This was completely unlike college, where I would spend my vacation in my pajamas snuggling with my cat and watching hours of “chick flicks.” This break was spent learning that the thesis portion of my program would be one of my biggest challenges. Beginning a background literature review, deciding what I was researching, and realizing how little I knew about this process soon became overwhelming.

Since then, our entire division of Human Genetics analyzed my research question (which has changed three times), and I have learned the frustrations – and joys – of a thesis project. A year ago in my undergraduate work, I would have changed projects to a more relatable topic, or cried. In graduate school I have to be my own advocate – I have to be able to say no to seeing a patient in order to begin initial analysis for my thesis; I have to allow myself to take a nap on a Saturday and play with my dogs instead of doing school work. I need to be able to truly have balance.

Now, twelve months after my interview and with the end of my first year of school approaching, I am coming to see myself as a more mature, professional, and passionate student than I ever thought I could be. My parents and family always joked that I was a “dork” when it came to my studies, but now, I am a full-fledged, genetic-counseling-loving, business clothes-wearing, Gene Reviews-searching, GEEK. I cannot even compare myself to the student that I was when I first interviewed.

In reflecting back on my transition from a college to a graduate student, from interviewee to a first year student, I feel that even if you come to expect a change in your life, it is never actually what you believed it would be. I knew the classes would be harder, but I never knew they would be so integrative. I knew that I would get along with some of my classmates, but I never thought that I would love some of the girls like sisters. I knew I would succeed, but I never thought I would see such growth in myself over a year’s time.

I strive to maintain balance in my life and education daily, something I have never been so aware of until my journey to become a genetic counselor began. I feel that I am continually an elephant on a ball at the circus – one lean away from falling off but somehow still balancing. I think I am learning important lessons in school that will carry through my career: the hard work will always be required, the patients will always be interesting, research will always need to be done, and most importantly, the learning – and transitions – will never end.

The New Graduate Life

When Plans Go Astray

By Lily Servais, MS, CGC

The current economic climate is dismal at best and many new graduates have had a difficult time finding genetic counseling positions, let alone their "dream job." This challenge is not endemic to the Bay Area, where I reside, but is commonplace throughout the country. My story includes the challenges of having to re-work post graduation plans, deal with unknowns, face the disappointment of not getting jobs, and staying positive and involved with the genetic counseling community throughout.

Best laid plans

When I was a senior in high school I took a biotechnology course. As part of the curriculum we had a guest lecture from a woman who had undergone genetic counseling while pregnant. As she described her experience, I recall thinking, "I could do that. I'm going to be a genetic counselor." I devised a plan: go to college, major in genetics, go to graduate school for genetic counseling, be a genetic counselor.

While in college at the University of Wisconsin-Madison, I applied to and subsequently interviewed at six different genetic counseling graduate programs. When the admission date rolled around I was incredibly nervous. I was wait-listed everywhere and ultimately did not get into any of the programs. I was devastated. While an undergrad, I had the pleasure of doing an independent research project with **Casey Raiser**, the program director at the University of Wisconsin. She helped me process this experience and encouraged me to submit my application materials to the match program (genetic counseling programs that are willing to be contacted by unmatched applicants to determine if they have any unfilled positions). When nothing came of this, I decided that

I would take the following year to strengthen my application and re-apply, or so I thought.

At the end of the summer, **Laurie Nemzer**, the director of the California State University Stanislaus Program, contacted me. One of their admitted students had dropped out at the last moment and they wanted to offer me the spot. In the time span of two weeks, I quit my job, packed up everything I owned, and drove across the country to start graduate school. My original plan was back on track.

Facing disappointment – A good opportunity for personal growth

Fast forward to June 4, 2010, graduation day! Unfortunately, the recent economic downturn had made genetic counseling positions scarce both in the Bay Area and nationwide. By graduation, not one of my nine classmates had a genetic counseling position lined up; in fact, no one had even gotten an interview. I decided since it didn't look like I was going to be working as a genetic counselor anytime soon, I would spend the summer studying for boards. Luckily, the marathon of studying paid off; I passed.

While studying for boards I also kept myself open to other things that would help build my resume and set me apart from other candidates. I worked as an in-home support attendant for a man with cri-du-chat syndrome, Gabe. Working with Gabe was a tremendous learning experience and is something interesting on my resume. In the beginning of the summer I collaborated with **Liz Kearney**, NSGC Past President and one of my past supervisors, to try to provide free genetic counseling to University of California Berkeley students who decided to undergo genetic testing as incoming freshman. I also did something I should have done as a student: I joined the Student/New Member Special Interest Group (SIG). However, I didn't just join; I made an effort to be an active member.

Mid-summer, a maternity leave position opened up at the clinic where I had done my first student rotation. I had a good rapport with many of the genetic counselors and felt that I had a fair shot at getting the job. The majority of my classmates were also offered interviews for the same position – the first one for most of us. Ultimately, I was not whom they chose to hire. I was sad and disappointed, which was made bittersweet by the fact that it was my close friend who was offered the position. It was hard to feel disappointed for myself and happy for her at the same time. This was only the second time in my life I was experiencing rejection and disappointment of this magnitude. I was given advice to allow myself to feel upset for a period of time, own those feelings, grow from them, and then do the rational thing; figure out what was to be learned from this situation. I had a "student-supervisor" relationship with the counselors who interviewed me, so I felt comfortable approaching them for feedback about my interview.

I took that feedback and used it in the winter when I got another opportunity to interview for a maternity leave position at a large prenatal center where I had also interned. I interviewed much better this time; I was confident, I had pertinent questions to ask, and I highlighted the things I thought would make me stand out from other candidates. In the end, I was not offered this position either. I was told that I was a strong candidate but

they wanted someone who spoke Spanish. Again, I was disappointed, though mostly with my sixth-grade self for deciding to take French instead of Spanish. Again, I asked for feedback in hopes of improving and learning from this experience.

In January 2011, things started to look up. Liz Kearney approached me once more, this time to work as a contractor for her new company, Genomic Strategy Consulting (GSC). Her company currently offers marketing services and scientific medical affairs writing for genetic/biotech companies. At the same time, I interviewed at Kaiser-Sacramento for a temporary, maternity leave position that would give me some valuable clinical experience. With past interviewing experience under my belt, this interview was the best yet. In the end, I was the second choice; they hired a genetic counselor that had been out of practice for a few years but had clinical genetic counseling experience at Kaiser – experience I couldn't compete with. I was disappointed, though I felt slightly validated that it had taken them over a week of deliberation to decide between me and the other candidate.

My current situation

Over the next few months, I began to gain comfort working as a contractor for GSC. I worked on a multitude of projects – researching technologies, writing patient materials, and helping explore the business ideas that Liz develops. GSC has been evolving and changing constantly since I began working with them, and I really like the versatility and unpredictability. For someone who likes to have a plan and know what is going to happen next, I am surprised and count it as a measure of my personal growth that I enjoy not knowing what I will be working on from month to month. I am learning a lot about marketing, and liking it so much that I'm considering taking some marketing classes.

Through my connections at GSC, I was offered another genetic counseling contract at DNA Direct. I will soon start some clinical work but currently I conduct literature reviews, write materials for patients or physicians and collaborate to develop marketing strategy – not what I would have traditionally defined as "genetic counseling." My definition of genetic counseling has expanded and evolved, helping me shape my professional identity. Genetic counselors have valuable skill sets that lend themselves really well to other areas outside direct patient care; we shouldn't be afraid to take advantage of that.

As "classic" genetic counseling positions become scarcer, it will be important for new graduates to consider settings that may be outside the box. Many new graduates are getting their start outside of the clinic, "non-traditional" roles are no longer exclusively for genetic counselors that have years of clinical experience. As genetic counseling students, we develop a vast array of skills that are applicable to many different types of work. If you are a new graduate looking for work, consider the less traditional positions. If you are a student, take advantage of rotations or internships that are not strictly clinical. You may be surprised what new skills develop or interests arise.

I know firsthand how difficult rejection can be and how the job hunt can seem hopeless, but hang in there – improve your interview skills, build your resume, keep in touch with

the people you worked with as a student, and use this time for introspection. Find support from your fellow classmates who are likely going through similar trials and tribulations. For me, it took close to a year to be fully employed as a genetic counselor, but it was worth the wait. The work I am doing is a great fit for me and I am excited for the next chapter of my story.

Genetic Counselor Publications

By Jamie Fong, MS, CGC

Articles co-authored by genetic counselors from January – June 2011

(Names of genetic counselors appear in bold)

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Zierhut H, **Austin JC**. How inclusion of genetic counselors on the research team can benefit translational science. *Sci Transl Med*. 3(75): 75-6. 2011.

Please send references of published articles by genetic counselors to Jamie Fong at jfong@memory.ucsf.edu

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AEC Update

By Elizabeth Wood Denne, MS, CGC, 2011 AEC Chair and
Claire N. Singletary, MS, CGC, 2011 AEC Vice-Chair

Something for Everyone!

The Annual Education Conference (AEC) is turning 30! Check your mailboxes soon for your official conference booklet detailing the NSGC 30th AEC. The conference will be

held **October 27-30, 2011** in San Diego, California. The NSGC membership has grown significantly in the number of members and the variety of professional environments in which we practice. As such, the AEC will feature a wide variety of content focusing specifically on the genetic counselor in the hopes of addressing the educational and professional needs of our diverse group.

Plan Ahead: Stay for the Entire AEC

The 2011 AEC will begin on Thursday with the "Welcome to the AEC" orientation, followed by the opening plenary Janus Series and Best Abstract Awards. Concluding this kickoff will be the Welcome Reception in the Exhibitor Suite on Thursday evening. There will be three full days of outstanding educational opportunities within the Plenary and Educational Breakout Sessions on Friday and Saturday, followed by a shorter day on Sunday and the conference's conclusion at 4:15pm. East coast attendees, in particular, may wish to fly home on Monday so that you are able to stay for the entire conference; you won't want to miss opportunities for learning and CEUs that occur later on Sunday.

Attendees can earn up to 2.8 CEUs or 28.0 Contact Hours at this year's AEC. With a wide variety of plenary and educational breakout sessions, there is something for everyone! Topics span the depth and breadth of genetic counseling, ensuring that all members of our diverse community can have a valuable educational experience.

Pre-Conference Symposia

Based on the positive feedback from the past two years, we will again have six Pre-Conference Symposia on the opening day, Thursday. The Pre-Conference Symposia are high level, in-depth sessions for specific specialty practice areas, new issues in genetics and genomics, or professional development topics. Each session will last five hours, allowing for a deeper review and discussion of a particular topic. The attendance at each symposium will be smaller than at the Educational Breakout Sessions, which will allow for a more interactive experience. Pre-Conference Symposia will require separate registration from the AEC and will have limited space available. Sign up early!

Outreach in San Diego

In an effort to reach out to the community of our host city, the NSGC annually conducts an Outreach Event during the AEC. This year's event is being coordinated by **Debra Han**. Debra and her Outreach Committee are already hard at work presenting a PowerPoint presentation entitled "Genetic Counseling as a Profession" to high school and college students in the San Diego area. The students who attend these presentations have been invited to join us for an afternoon during the AEC to attend educational sessions and to hear a panel discussion of genetic counselors from a variety of job experiences and work settings. If you are interested in being on the panel to discuss your career in genetic counseling, please contact Debra at debrahan@cox.net.

Prepare for San Diego

The San Diego area has so much to offer for NSGC attendees. The AEC will be held at the waterfront San Diego Marriott Hotel and Marina, which is less than five miles from the San Diego International Airport (SAN). The world famous San Diego Zoo in Balboa Park is less than five miles from the Marriott, as is historic Old Town San Diego. The Seaport Village and the Gaslamp Quarter are both within walking distance to the Marriott and feature great restaurants and shopping. San Diego is famous for its waterfront beauty, nearby beaches, golf courses and sports; the Major League Baseball's Padres and the National Football League's Chargers both call San Diego home. For more information and to book your hotel room, please visit the AEC web page at http://www.nsgc.org/Education/2011AnnualEducationConference/tabid/356/Default.aspx

Many Thanks

We would like to thank our Conference Subcommittee members – **Carrie Atzinger**, **Mary Jarvis Ahrens, Julie Culver, Erynn Gordon**, **Brandie Leach, Rebecca McClellan**, **Krista Redlinger-Grosse**, **Quinn Stein, Meredith Weaver** and **Emily Windsor –** we owe them all a huge debt of gratitude. This conference is the result of the tireless efforts of this outstanding Subcommittee. Without each and every one of these individuals, this conference would not be possible. We would also like to thank **Julianne O'Daniel**, **Leigha Senter** and **Renee Chard**, Education Committee Chair, Vice-Chair and Interim Chair, and **Sheetal Parmar**, NSGC Board of Directors liaison, for their constant guidance during the planning for the 30th AEC.

We look forward to seeing you in San Diego!

If you have questions, please contact **Elizabeth Wood Denne** (ewdenne@jhmi.edu) or **Claire N. Singletary** (Claire.n.singletary@uth.tmc.edu)

Resources / Book Review

Reviewed by Brianne Kirkpatrick, MS, CGC, LGC

Handle With Care

By: Jodi Picoult
Publisher: Simon & Schuster Adult Publishing Group, 2009
Pages: 496
Retail Price: $16.00 (paperback)
ISBN: 1439156301

Introduce a genetic counselor to the works of a modern-day fiction writer with a penchant for medical ethics and court room drama, and what do you have? A fan for life. If you have heard of the book or movie entitled My Sister's Keeper, then you are familiar with at

least one work of award-winning novelist Jodi Picoult. Rarely are novels highlighted in *Perspectives in Genetic Counseling*, but the works of Picoult force an exception. She has tackled a variety of ethical issues including the hotly debated use of assisted reproductive technologies to help design “matching donor” siblings, understanding the circumstances that could lead to teenage suicide, and defending the behaviors of an individual with Asperger syndrome in a world designed for the neurotypical.

One particular novel of Picoult’s deserves special recognition by the genetic counseling field. Handle With Care surrounds the drama of one fictional family’s "wrongful birth" lawsuit against the physician who failed to diagnose their daughter’s osteogenesis imperfecta (OI) prenatally. Reading a series of letters addressed to five-year old Willow with OI type III, the reader is invited into the inner lives and thoughts of Willow’s mother, father, adolescent sister, and the family friend who was also the obstetrician who delivered her. The letters document the time shortly before, during, and briefly after the “wrongful birth” case is brought to court. Each shared perspective covers divergent viewpoints on the validity of such a lawsuit, but instead of being left with a clearer understanding of who should triumph in the courtroom, the reader discovers a mucky ethical quagmire of right versus wrong.

Like many of Picoult's novels, Handle With Care is a thoroughly researched and suspenseful medical ethics thriller. Picoult makes medical ethics personal and relates the story in a way that makes readers forget they are reading a work of fiction. While many genetic counselors might cringe at the way medical information is portrayed by the popular media, a Picoult reader would be hard pressed to find a single misleading or inaccurate explanation involving ultrasound soft markers, prenatal testing, or osteogenesis imperfecta. Even the description of a sonogram’s use as a screening rather than diagnostic tool was crafted with such attention that even the most particular genetic counselor would have difficulty finding fault.

For those who have not had the opportunity to see a child with OI type III or hear about the experiences the family goes through, Handle With Care enables a fuller understanding of how a life-altering genetic condition permeates the life of the individual affected by it, irreversibly affects family dynamics, and places strain on relationships between friends, family, and medical care providers.

The book further explores incongruities that can arise between what people say they would do in a given medical situation and what they actually do. A point that Picoult makes with her novel is that parents often make predictions of how they would act regarding pregnancy management (e.g., continuation "no matter what"), which they later reconsider when faced with prenatal test results or the reality of raising a child with special needs. Through the courtroom battle in Handle With Care, Picoult challenges us to think about the possible real-life implications of discrepancies between thought and action.

A nail-biter to the end, no other book has left me feeling as acutely aware of my vulnerability to legal prosecution as a medical professional. Nor have many other novels made me as cognizant of the ripple effect that a genetic disease can have on the lives of others. The reader who picks up Handle With Care should be prepared to sacrifice sleep

or free time in an attempt to eagerly reach the end. Regardless of which side of the courtroom to which the reader is drawn, one will be left with the unsettling feeling that nothing is black and white in medicine and the law.

Research Network

By Emily Place, MS, CGC

The Inherited Cancer Registry (ICARE) Initiative

ICARE is a research study at the Moffitt Cancer Center in Tampa, Florida collecting information about families at risk for inherited cancer. Our objectives encompass research in all aspects of familial cancer, from prevention and detection to treatment. Participants may learn about other research studies and receive up-to-date information about advances in the management of hereditary cancer. Participation involves giving consent and completing a questionnaire.

Contact: Christina Bittner, MS, CGC or Shannon Hendrix-Buxton, BA at 813-745-6446 or ICARE@moffitt.org

FaceBase Biorepository

The FaceBase Biorepository at the University of Iowa is recruiting individuals with craniofacial anomalies, especially cleft lip and palate, to serve as a resource for investigators studying these disorders. Individuals with both syndromic and non-syndromic craniofacial anomalies and their family members are eligible to participate. Participation involves providing a biological sample and completing a questionnaire. Referring clinicians are asked to send relevant medical records. De-identified samples and data will be provided to researchers; participants and the referring clinician(s) will receive general research updates.

Contact: Kate Durda MS, CGC at 1-866-520-8982 or 319-335-9632, kate-durda@uiowa.edu or Jeff Murray, MD at jeff-murray@uiowa.edu

Hereditary Pancreatitis Study

Hereditary pancreatitis is a form of acute and chronic pancreatitis that runs in families, usually in two or more affected people in two or more generations. In some cases, the family history is unclear. Pancreatitis usually develops before the age of twenty years. Dr Whitcomb's group at the University of Pittsburgh is currently recruiting participants and family members for a genetic and environment research study. The primary aim of the study is to investigate the genetic factors that increase risk for pancreatitis and factors that

are linked with complications. Individuals with pancreatitis with onset before age twenty years, individuals with a suspected or unknown history of pancreatitis, and their related family members may be eligible to participate. Participation involves providing a blood sample or saliva sample as well as completion of study questionnaire.

Contact: Pancreas Study Office at 1-888-PITT-DNA

Genetic Epidemiology of Pancreatic Cancer (PACGENE) Study

Researchers at Wayne State University, Mayo Clinic, Johns Hopkins University, MD Anderson Cancer Center, Dana Farber Cancer Institute, and the University of Toronto aim to map one or more pancreatic cancer susceptibility genes. The study is enrolling families with at least two cases of pancreatic adenocarcinoma. Participation includes a phone interview or mailed questionnaire, medical record review, contacting family members and donation of a blood, tissue, or saliva sample. Families will not receive individual test results. Affected individuals need not be living; however, a DNA sample, such as blood or tissue, must be available on at least one affected individual if there are three or more cases in the family, or must be available on both if there are two affected individuals. Travel is not necessary; participants are compensated financially for their time. For more information, visit the website:
www.karmanos.org/cancer.asp?id=927&cid=19

Contact: Kate Sargent, MS, CGC at 313-578-4240 or sargentk@med.wayne.edu

Genetic Study of Hirschsprung Disease

Dr. Aravinda Chakravarti's laboratory at Johns Hopkins University has an ongoing study of the genetic basis of Hirschsprung disease. The focus is to continue the search for genes involved in Hirschsprung disease and to further characterize the known genes and interactions between them. The study requires volunteers to complete a medical/family history questionnaire, sign a medical records release, and submit a blood sample(s) from the individual(s) with Hirschsprung disease and his/her parents. Individual results will not be disclosed to participants.

Contact: Courtney Berrios at 410-502-7541 or hirschsprung@igm.jhmi.edu

Family members Mental Illness – Internalized Stigma (FaMIL- IS): Scale Validation Study

A team of researchers at the University of British Columbia have developed a new questionnaire to assess internalized stigma in close family members (parents, brothers, sisters, and children) of people with mental illness. We are looking for family members of people with schizophrenia, bipolar disorder, or schizoaffective disorder to complete the questionnaire to help us validate it. Participating in the study involves a telephone

interview and completing questionnaires (which can be completed from home) at two different time points.

Contact: Angela Inglis, MSc, at mental.illness@ubc.ca or 1-604-875-2000, ext.4733

Genetic Contributions to Autism Spectrum Disorders

The goal of this study is to identify genes that influence the development of autism spectrum disorders (ASD) and identify gene expression profiles that may be used as diagnostic and prognostic tools. Children older than eighteen months of age with a diagnosis of an ASD are eligible to participate. Participation takes less than two hours to complete and travel to Boston is not required. Medical and family history information as well as a blood or saliva sample will be collected from participants. The blood draw can be performed by a participant's physician. There is no cost to participate. Visit the website to learn more about this study: www.facebook.com/AutismResearch.

Contact: Joanna Reinwald, M.S., C.G.C. & Caitlin Kreitman, B.S., C.H.E.S., at Caitlin.kreitman@childrens.harvard.edu or 866-982-5827

Autoimmune Diseases in Pregnancy Project

The Organization of Teratology Information Specialists (OTIS) is researching the effects of autoimmune diseases such as Crohn's disease, rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis, and psoriasis, as well as the medications used to treat these conditions during pregnancy. Participants will not be asked to take any medication as part of this study. We are also enrolling controls for this study (women who do not have an autoimmune disease but who are pregnant). Visit the website to learn more about this study: http://www.otispregnancy.org/autoimmune-studies-s13049
Contact*:* Dee Quinn at 520-626-3547**,** or dquinn@email.arizona.edu

Genetic Basis of Inherited Reproductive Disorders

The Reproductive Endocrine Unit at Massachusetts General Hospital is conducting a research study to learn about the hereditary basis of reproductive disorders. Individuals with precocious puberty, delayed puberty, or absent puberty (Kallmann syndrome, hypogonadotropic hypogonadism), and individuals with adult-onset disorders (i.e., hypothalamic amenorrhea, very low testosterone) are eligible. Participation involves a blood sample, family history collection, a questionnaire, and olfactory testing. Screening is conducted for *KAL1*, *FGFR1*, and a growing list of candidate genes. Results may be released to participants, if desired.

Contact: Cassandra Buck, MS, CGC at 617-726-5526 or ReproEndoGenetics@partners.org

Please send Research Network items to emily.place@gmail.com