Perspectives in Genetic Counseling

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Exciting Plans for Billing & Reimbursement

By Leslie Cohen, MS, Chair, NSGC Billing & Reimbursement Task Force

Billing and reimbursement (B&R) issues consistently have been a priority for the NSGC membership. While we have made great strides in several areas that relate to B&R, the ability to bill and be reimbursed for our services remains a challenge. To address these issues, NSGC's Billing and Reimbursement Task Force (BRTF), along with our Government Relations Department, has developed a five-year strategic plan with three interrelated prongs. While we want the membership to be aware of our plans, we also want to be systematic in building allegiances with outside organizations. As such, we respectfully request that any discussions with these organizations be funneled through the BRTF.

New Staff on Board

NSGC is now in the position to advance our B&R efforts with the aid of **John Richardson,** our Director of Government Relations. Richardson has over 10 years of experience in public policy as a lobbyist and has served as an associate to the House Committee on Appropriations. John's extensive experience at the local, state and federal levels will serve NSGC well as we move forward with our initiatives.

Federal Remedy

The first prong of our strategic plan involves obtaining federal recognition as providers by the Centers for Medicare and Medicaid Services (CMS). Although many of our clients are not Medicare recipients, commercial insurance companies often follow the policies established by CMS. In order for genetic counselors to gain status with CMS, an act of Congress is necessary, which will likely take several years to accomplish. The BRTF has reviewed a draft copy of the legislation that incorporates key components similar to other federally recognized providers.

In the next few months, Richardson will present the draft bill on the Hill, solicit support and feedback and reach out to other allied health organizations. The American College of Medical Genetics is aware of our plan. Our goal is to introduce the bill by the spring of 2007 into the House, the Senate or both and strive for bipartisan sponsorship.

Although efforts to gain support will be initiated by NSGC leadership, involvement of all NSGC members is crucial for this measure to be successful. The membership will be asked to respond to e-blast Action Alerts requesting that you write your legislators or visit their local offices to encourage support of this bill. Additionally, if you (or someone close to you)

have a relationship with a Congressman or Senator, please inform **Leslie Cohen** (see below), as these connections may be beneficial for increasing support.

State Licensure
The second prong of the plan is to continue to support State licensure efforts. Outcomes at the State level could have an impact on our Federal efforts. It is imperative to consider the language in State licensure bills and to recognize instances where it may be better to forego State licensure rather than to enact a poorly written bill.

The Licensure Subcommittee will create "guiding principles" as well as model licensure language. This will help to ensure consistency between State bills and with the Federal bill. Genetic counselors practicing in States *with* licensure will be guided by the rules in their State regardless of Federal bill language. Genetic counselors practicing in States *without* licensure generally will be bound by Federal rules once a Federal bill is enacted.

At present, licensure efforts should continue for several reasons:

1.) A Federal remedy will take several years.
2.) We may be unsuccessful in passing Federal legislation.
3.) Many third party payers may still require licensure.

If you are involved in obtaining licensure in your state, Richardson is available to review proposed language for your bill, and we encourage you to take advantage of his expertise.

Third Party Payers (Commercial Insurance Companies)
The third prong of the plan is to engage with third party payers (TPPs). TPPs often follow the lead of CMS; however, they may require additional information from us in order for genetic counselors to practice under their plans. Initially, the top 10 insurers nationally will be targeted. Medical directors will be approached by members of the NSGC leadership in the latter half of 2007 and 2008. As we enter into these discussions, the BRTF will determine the necessary steps to achieve TPP recognition.

These are exciting times for the genetic counseling profession as we turn a corner in our B&R efforts.

Contact Us
Do you have questions about the strategic plan or know a legislator?
Contact: Leslie Cohen, leslie.cohen@UHHospitals.org

Do you have questions about the B&R Subcommittee or wish to get involved?
Contact: Karen Heller, Karen.Heller@UTSouthwestern.edu

Do you have questions about licensure?
Contact: Cheryl Harper, CHARPER@beaumonthospitals.com or Judy Miller, miller12@uiuc.edu

Contact John Richardson at jrichardson@smithbucklin.com.

Career Watch

Using Traditional Genetic Counseling Skills in an Expanded Role

By Brissa Martin, MS, Lori Ross, MS and Steve Keiles, MS

We constitute the genetic counseling team at Ambry Genetics. Our careers as genetic counselors started in a very traditional way. Each of us worked in prenatal diagnosis right after graduation. Lori and Brissa attended the Genetic Counseling Program at the University of California, Irvine, and Steve attended Sarah Lawrence College. Lori worked as a genetic coordinator before joining the Ambry team as Associate Product Manager. Steve joined Ambry at the company's inception and is now Director of Genetic Services. Brissa graduated from Irvine in 2005 and has worked at Ambry Genetics for seven months. Our jobs at Ambry Genetics combine all aspects of our professional training in an expanded, "nontraditional" role for genetic counselors.

Client Services and More

Ambry Genetics is a company that specializes in molecular genetic testing for conditions that cause pulmonary disease, such as cystic fibrosis, alpha-1-antitrypsin deficiency and surfactant protein B and C deficiencies. Ambry also offers genetic tests for chronic and hereditary pancreatitis, Tay-Sachs disease, Canavan disease and beta thalassemia.

As the genetics team, we act as liaisons between our laboratory and the institutions that use our tests; we are an integral part of the client services department. Our main interaction is with physicians, laboratory personnel, clinical nurse coordinators and genetic counselors. We help coordinate testing, recommend specific testing strategies for patients, explain results and address issues such as insurance coverage and costs.

Ambry Genetics is expanding at a rapid pace, and we have the opportunity to contribute to its direction. In the development of new tests, we research literature, give our input about the clinical significance of the test, help direct marketing efforts and develop advertising materials.

Within our laboratory, we make sure that the right test is requested for each sample we receive. We oversee processing to make sure results stay within our turn around time, and we report results when they are completed. We also participate in medical conferences to meet and educate health care providers about the services our company can offer.

Leadership within the Cystic Fibrosis Community

Ambry Genetics was the first laboratory to offer full gene analysis of the cystic fibrosis gene. Ambry's relationship with different advocacy groups and experts in the field has made it a company that patients trust.

We receive calls from parents, spouses and patients themselves, asking about the benefits of Ambry's tests. We also act as a resource on cystic fibrosis for other medical professionals. We can provide genetic counselors and physicians with information about disease symptoms and severity associated with certain combinations of mutations in the cystic fibrosis gene.

Traditional Skills in a "Non-traditional" Setting

As genetic counselors in a "nontraditional" role, our collective experiences in the fields of prenatal diagnosis, pediatrics and medical research help us deal with the challenges of our jobs. Our training in science and psychosocial issues makes it possible for us to explain to a

researcher how many nucleotides into the intron of a gene we sequence, and next, support a pregnant patient who just found out she is a carrier of cystic fibrosis through prenatal screening. Obviously, the needs of each individual vary greatly, but our role in both situations is the same: to provide the appropriate information in order to help each individual make an informed decision.

As knowledge of genetics expands, so will the need for genetic testing and the opportunities for genetic counselors. We enjoy using our skills in the varied facets of our jobs, and we appreciate working with other genetic counselors all over the world on a daily basis.

For Your Practice

AsktheGeneticist[SM]: A Regional Model for Online Genetics Education

By Catherine Tesla, MS

AsktheGeneticist[SM] (www.askthegen.org) is a collaborative effort of the Department of Human Genetics at Emory University and the Department of Genetics at the University of Alabama at Birmingham (UAB). The mission of this Web site is to answer questions about genetic concepts and genetic disorders, including etiology, treatment, research, testing and predisposition. By providing a portal to information about genetics, AsktheGeneticist[SM] seeks to promote education and awareness for the public and for those working in health care.

Enhancing Access

Because it's on the Web, AsktheGeneticist[SM] is not just a local service – it's a model for online education. According to **Lynn Holt,** Senior Genetic Counselor at UAB and part of the Web site team, "Patients are not only learning about genetics and clinical services they did not know existed, but also accessing them." In an ongoing survey of Web site users (as of August 15), 16% did not know about the existence of clinical genetic services prior to visiting the site. Unexpectedly, 19% sought contact with a genetics health care provider *after* utilizing the Web site, demonstrating that information on the Web helps connect patients with clinical genetic services.

Getting Questions Answered

Genetics Home Reference is the National Library of Medicine's Web site for consumer information about genetic conditions and the genes or chromosomes responsible for those conditions. The *Genetics Home Reference* has a Q&A at the end of each condition summary that links to AsktheGeneticist[SM]. In January 2006, this reciprocal link gave an immediate increase in the number of questions submitted to the Web site, from an average of 32 questions per month to 35 questions per week.

From the types of questions the Web site receives, people are searching for information about genetic conditions in their family. The Web site seeks to provide appropriate resources, especially information about how to find genetic counseling and clinical genetic services in their geographic area. The Web site also receives a multitude of questions from students gathering information about genetic conditions and careers in genetics. These questions highlight a global community need for information about genetics.

"We are seeing an explosion of knowledge in the understanding of human disease, thanks in large part to discoveries made every day in the field of genetics. It's expected that the public will want to understand this information," says **Stephen T. Warren, PhD,** Chairman of the Department of Human Genetics at Emory and an advisor to the AsktheGeneticist[SM] team.

AsktheGeneticist[SM] is sponsored in part by the small grant program of the Southeastern Regional Genetics Group (SERGG, Inc.) and the Maternal and Child Health Bureau, Health Resources and Services Administration in the Department of Health and Human Services.

Catherine Tesla (ctesla@genetics.emory.edu) is the PI of AsktheGeneticist[SM].

Publications by Genetic Counselor

This is the first installment of a new feature in Perspectives *highlighting the publication activities of genetic counselors in peer-reviewed journals (other than the* JOGC*). Each issue will list the articles published during the previous quarter and will spotlight one publication in which a genetic counselor served as first or senior author. Featured papers are chosen at the discretion of the* PGC *Editorial staff.*

Featured Paper

(Names of genetic counselors appear in bold.)

Street NJ, Yi MS, **Bailey LA,** Hopkin RJ. Comparison of health-related quality of life between heterozygous women with Fabry disease, a healthy control population, and patients with other chronic disease. *Genet Med.* 8:346-53. 2006.

Natalie Street currently is a fellow at the Centers for Disease Control where she is a member of the Single Gene Disorders and Disability Team in the National Center on Birth Defects and Developmental Disabilities. Her work primarily involves coordinating several public health projects on Duchenne muscular dystrophy and fragile X syndrome. Natalie is a 2005 graduate of the University of Cincinnati Genetic Counseling Program, and her publication is the culmination of her master's degree thesis work.

While a first year student, Natalie was fascinated by the quality of life issues for female carriers of Fabry disease. She felt that research in this area could impact the lives of these women, and it became clear to her that there was not enough attention being paid to the real medical and psychosocial issues that these women face. Natalie credits her co-authors, who also served as her thesis committee, as a major factor in the success of her work, offering both direction and encouragement. Natalie's thesis inspired her to pursue a career in research genetics.

In her current work with Duchenne muscular dystrophy and fragile X syndrome, Natalie is finding that the traditional perception of carriers of X-linked diseases is changing. She notes it is "far more involved than just being a carrier." Natalie hopes to be part of future studies on this important topic.

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To include a recent peer-reviewed publication that you have co-authored in the next issue of Perspectives*, please submit the article citation in the above format to: Deborah A. McDermott, dam2001@med.cornell.edu.*

NSGC News

Outgoing President's Message from Nancy Callanan

As my term winds to a close, I want to thank the membership for the opportunity to serve as President of NSGC. I also want to recognize the tremendous talents and contributions of the 2006 Board of Directors, our Executive Director, Kristen Smith, and our dedicated staff and many volunteers. In a year marked by significant change, there have certainly been some challenges, but also many opportunities. I hope that as we reflect back on 2006 we will view this year as a turning point in the history of NSGC, a time in which the organization was able to seize opportunities and resources to reach a new level of maturity and effectiveness.

One way that NSGC is investing in the future of our organization and the genetic counseling profession is by increasing our administrative support as well as obtaining expert consultation in critical areas, such as government relations, educational programming and planning, marketing and communications. The 2007 Strategic Plan is broad and ambitious, but fully consistent with the NSGC vision, and our mission to "promote the genetic counseling profession as a recognized and integral part of health care delivery, education, research and public policy."

As I started my term as president a year ago, the NSGC Board of Directors asked for your trust and support as we made decisions that would likely have an impact on NSGC for a long time to come. The NSGC leadership still relies on this trust and support as we continue to set the vision for the Society, and on your active participation as we strive to meet our strategic goals. The continued success of NSGC depends on strong and visionary leadership to set the direction, an experienced and effective staff, and, as always, the active engagement and involvement of the membership. More than ever, every member of NSGC

needs to be committed to the organization, and to demonstrate this commitment through constructive dialogue, and active volunteerism.

Again, thank you for this opportunity to serve as President of NSGC. It has truly been an honor.

Sincerely,

Nancy Callanan, MS
2006 NSGC President

President's Beat

Congratulations to the Annual Education Conference (AEC) Planning Committee and the staff of NSGC for putting on such a great meeting in Nashville! It was wonderful to see all of you, and I hope everyone got a chance to meet our new staff from SmithBucklin. They did a fabulous job, and the 25th Anniversary Welcome Reception was a huge hit. In addition, the Advocate Partnership Program, sponsored by NSGC and the Genetic Alliance, was very successful, providing an opportunity for participants to share and discuss information presented during the conference. We look forward to continuing this important program in 2007.

Thank You, Nancy
Congratulations to outgoing President, **Nancy Callanan,** who has led NSGC through a big turn in our path. Nancy kept us focused and moving forward throughout the transition of our Executive Office. In addition, Nancy helped us complete our 2007-2010 Strategic Plan. This document will help guide NSGC in the upcoming three years. The Billing & Reimbursement article in this issue of *Perspectives* highlights NSGC's Strategic Initiative I: Expand access to genetic counseling services by actively pursuing reimbursement for certified genetic counselors.

An Active Season
We had a busy couple of months before the AEC. In September, I was fortunate to be able to represent NSGC at the National Genetics Policy Summit hosted by the Genetics and Public Policy Center. This two-day event covered many topics including oversight of genetic testing, direct-to-consumer testing and preimplantation genetic diagnosis. In addition, I represented NSGC at Genetics Day on the Hill, hosted by the Genetic Alliance. I visited several congressional offices with the intent of encouraging members to co-sponsor GINA, the Genetics Non-Discrimination Act.

In October, Nancy Callanan, **Dawn Allain, Kristen Smith** and I represented NSGC at the American Society of Human Genetics (ASHG) meeting in New Orleans. We met with the leaders of ASHG, ISONG and ACMG to continue areas of collaboration. In addition, ASHG had its first Trainee Event with a Career Fair Meet and Greet. Many students interested in pursuing graduate training in genetic counseling attended the event.

Several important documents were released shortly before the AEC: the Long Term Executive Office Planning Document, the Scope of Practice and the joint NSGC ISONG Position Statement. Please take time to familiarize yourself with all of these documents. The 2006 Professional Status Survey also was completed, and preliminary data was presented at the AEC. The complete report will be available soon.

Internal Review
In February, the Board of Directors will meet in Chicago to discuss governance issues. **Mark Thorsby,** Vice-President of Consulting Services at SmithBucklin, will help us formulate our Board culture statement and critically examine our Board structure to ensure that it enables us to be nimble, move forward and meet our strategic goals.

We have an exciting year ahead of us, and I am looking forward to working with all of you as the next President of NSGC. During my Presidential Address, I asked you to join me on this journey - and I will do my best to make this as exciting and rewarding (and fun) as I can.

Best wishes and a Happy New Year!

Sincerely,

Cathy Wicklund, MS
2007 NSGC President

Meet Your NSGC Board of Directors

Below are the new (*) and returning leaders for NSGC in 2007. The new members of the Board of Directors take office on January 1, 2007. All of these people have been selected by YOU – the membership – and they want to hear from you. Keep this list handy in the coming year to email your leadership with your questions, ideas and accomplishments.

Executive Committee

President: Catherine A. Wicklund, MS, CGC
President-elect: Angela Trepanier, MS, CGC
Secretary: Peter J. Levonian, MS, CGC*
Treasurer: Susan Manley, MS, CGC
Past President: Nancy Callanan, MS, CGC
Past President II: Kelly Ormond, MS, CGC
Executive Director (non-voting): Kristen Smith, CAE

Regional Representatives

Region I: Reneé Chard, MS, CGC
Region II: Ellen L. Schlenker, MS, CGC
Region III: Tene Hamilton Franklin, MS*
Region IV: Elizabeth A. Leeth, MS, CGC*
Region V: Karen Copeland, MS, MBA, CGC
Region VI: Fiona M. Field, MS, CGC*

Standing Committee Chairs

Communications: Steven Keiles, MS, CGC*
Education: Susan Schmerler, MS, JD, CGC
Finance: Jennifer Farmer, MS, CGC
Genetic Services: Elinor Langfelder Schwind, MS, CGC
Membership: Jolie Matheson, MS, CGC

Professional Issues: Maria DelVecchio, MS, CGC
Social Issues: Barbara Willis Harrison, MS, CGC*

Get to Know the NSGC Executive Office Staff Team

To better acquaint NSGC members with the Executive Office Staff, Perspectives is featuring profiles of those involved in the behind-the-scenes operations of NSGC. This issue features ***John Richardson,*** *Director of NSGC Government Relations.*

John Richardson comes to NSGC with over 10 years of experience in the public policy arena. John has been Director of SmithBucklin's Health Care Practice for five years. His clients include heath care organizations, national medical and dental societies, and high technology firms. In serving his clients, John regularly engages the legislative and regulatory process, working with the U.S. Congress and the Executive Branch of government. He has successfully assisted in the drafting of various health care bills and obtained Congressional earmarks and provisions.

John's past work of gaining federal recognition for an allied health care provider through a demonstration program will serve NSGC well. The national demonstration program was approved by the U.S. Congress and has been implemented by the Centers for Medicare and Medicaid Services. Genetic counselors' access to patients and payment for services will significantly improve if genetic counselors also become recognized by the federal government. He also serves as a business development consultant to many clients providing contacts within the federal bureaucracy.

Prior to joining SmithBucklin, John served as a Senior Legislative Aide and Associate to the House Committee on Appropriations for Congressman **John E. Sununu** of New Hampshire, now a U.S. Senator. Sununu was a member of both the Appropriations Committee and Vice-Chair of the House Budget Committee. John served as an advisor on issues related to health care, national security, trade, and the budget. Preceding his work for Mr. Sununu, he gained extensive political and grassroots experience as a campaign consultant to local, state and presidential candidates. He has a B.A. in Political Science from Roger Williams University in Bristol, R.I.

The Genetic Counseling Foundation Needs Your Feedback and Support

The Genetic Counseling Foundation (GCF) Board of Directors is currently evaluating its grant offerings for 2007 and beyond. Currently, the GCF is looking for feedback from NSGC members and is soliciting suggestions regarding grants that NSGC members would like to see offered by the GCF. To provide your suggestions, please visit the online survey: http://www.nsgc.org/instapoll/survey_index3.cfm. The online survey will be available until December 31, 2006.

The Genetic Counseling Foundation also invites you to visit its newly developed Web site at www.nsgc.org/GCF/index.cfm. Please take some time to familiarize yourself with the members of the GCF Board and the mission of the organization. If you are interested in providing monetary support to the GCF, you may access the donation form by visiting: www.nsgc.org/client_files/GCF_Donation_Form.pdf.

Congratulations to the 2006 Leadership Award Recipients

The 2006 Awards Committee would like to thank all members that nominated their colleagues during the Call for Nominations. Many outstanding NSGC volunteers and leaders were nominated during this process. The Awards Committee is pleased to announce the winners of the 2006 Natalie Weissberger Paul and Regional Leadership Awards. Please congratulate the following individuals on their accomplishments!

Natalie Weissberger Paul Award - Debra Lochner Doyle, MS
Region I Leadership Award - Lori Ann Correia, MS
Region II Leadership Award - Joan Scott, MS
Region III Leadership Award - Troy Becker, MS
Region IV Leadership Award - Heather Hampel, MS
Region V Leadership Award - Vickie Venne, MS
Region VI Leadership Award - Sylvia Au, MS

Please stay tuned for announcments regadting the 2007 Call for Award Nominations this Spring!

Public Eye

Media Watch

By Angela Geist, MS and Roxanne Ruzicka, MS

August 8, 2006 - *The New York Times* Health section, "Genetic Test for Diabetes May Gauge Risk, but is the Risk Worth Knowing?"
A woman with a strong family history of type II diabetes reviewed a genetic test that can predict which individuals are more likely to develop diabetes. Carriers of one gene variant, who reportedly make up more than a third of Americans, have 1.4 times the risk for diabetes of non-carriers. Homozygotes have about twice the risk. A company called Decode Genetics plans to market a test for this gene variant in the next year or so. The narrator discussed the reasons why she would or would not consider undergoing this test. The article also explored concerns with direct-to-consumer marketing for "questionable genetic tests."

August 24, 2006 – *The New York Times*, "Insurance Company Yields in Fight with Parents of a Tay-Sachs Child"
This story told how the parents of Benjy, a child with Tay-Sachs disease, battled their insurance company for coverage of services for their son. The article described Tay-Sachs as "a usually fatal genetic disorder for which there is so far no cure" and said that "certain white ethnic groups, including the Ashkenazi Jews, are carriers of the gene that causes Tay-Sachs." It did not mention that other ethnic groups also could be carriers or that not all individuals of high-risk ethnic groups are carriers. Benjy's parents started a Web-log campaign to garner support, and they now hope to form an advocacy organization that will inform families and insurance companies about experimental therapies.

September 3, 2006 – *The New York Times*, "Couples Cull Embryos to Halt Heritage of Cancer"

This article documented the ethical and emotional debate about the use of preimplantation genetic diagnosis (PGD) for genetic forms of cancer. The divergent views of family members, medical professionals and the legislation from various countries were discussed, as couples tried to determine if PGD for genetic forms of cancer was appropriate for them. The issues of eugenics, genetic engineering and the possibility of a genetic class divide due to barriers of affordability of PGD were also raised.

October 22, 2006 – *The Huntsville Times*, "Genetic counseling helps assess risk"
Genetic counselor **Carla Badenhop** discussed in this Alabama newspaper article how genetic counseling and testing can clarify prevention and treatment options for patients and families that are at risk for hereditary cancer. The article stated that an estimated 10 percent of cancers are hereditary and listed the red flags that have become commonly accepted indicators for cancer risk counseling.

November 4, 2006 – *Science Daily Online*, "New Study Finds Amniocentesis Safer For Pregnant Women"
Results of the FASTER trial, published in *Obstetrics & Gynecology,* found a significantly lower rate of miscarriage from amniocentesis than the commonly quoted 1/200 risk. The lead author of the study stated that, "Women should be counseled that this older loss rate is archaic, and their decision about whether or not to have an amniocentesis should be based on contemporary information about miscarriage rates with newer screening techniques, rather than just relying on general age-based risks."

November 14, 2006 – *The New York Times* Health section, "Chronicle of Descent, and a Stark Reflection"
A man made a documentary of his mother's life, a film that powerfully revealed her gradual physical and mental deterioration from Huntington disease. The filmmaker also inherited the gene change for Huntington disease, which was described as "a criminal that wants to steal his brain….the worst of the dementias, with its early onset and its inevitability." The filmmaker's genetic counselor, **Andrea Zanko,** was mentioned in the article. By making the film, the filmmaker hoped he could accept his mother's condition and move on with his life. He also hoped that if people see the film they will support research on Huntington disease.

NSGC Media Highlights June-October, 2006

StarRosen, NSGC's PR agency of record, works closely with members to promote the Society and its initiatives through aggressive media relations activities. Recently, the agency pitched family history and direct-to-consumer testing and continued to offer NSGC members as experts to discuss prenatal testing, breast cancer and general genetic counseling issues. The items below provide a sampling of the work the agency has done on NSGC's behalf.

- We are working with producers at *60 Minutes* to develop a segment on direct-to-consumer testing. **Kelly Ormond** has recently been interviewed by producers for background information. The segment is in the beginning stages.

- *The Today Show* interviewed Robin Bennett about the importance of family medical history. The taped piece is slated to air by the end of December.

- We arranged for **Jodie Lasher** to be interviewed by Gannett News Services about genetic embryo testing. The piece was released on the wire in late November.

- We pitched **Martha Dudek** as a local expert on family history to the *Kingsport Times-News* in Tennessee. Dudek was interviewed on October 17 by a reporter who was interested in pursuing our family history pitch. The run date has yet to be determined.

- *The Dayton Daily News (OH)* published our family history release on October 14.

- We arranged for **Scott Weissman** to be interviewed about genetic links to breast cancer and BRCA testing. Weissman was a source of background information for a story in the October issue of *Shape* magazine.

- We arranged for Kelly Ormond to be interviewed by nationally syndicated columnist **Judy Foreman** about direct-to-consumer testing. The piece ran in the *Boston Globe* on August 7 and was also picked up by the *Baltimore Sun* and *Los Angeles Times*.

- **Holly Peay** and **Jehannine Austin** were included in a piece in the June 16 issue of the *Baltimore Sun* that discusses the genetic link to mental illness. The piece was picked up by *The Repository* (OH), *Daily Press* (VA), *Philadelphia Inquirer* and *Orlando Sentinel*.

- We arranged for **Nancy Callanan,** Scott Weissman, **Jill Fonda** and Kelly Ormond to be interviewed by a reporter at the *Washington Post* for a piece on direct-to-consumer genetic testing. The article ran on June 13. Aside from including NSGC expert quotes, the article featured a sidebar piece and, with our prompting, listed the NSGC Web site, phone number and email address as resources for readers.

- Nancy Callanan was interviewed by a freelance writer regarding genetic screening for a parenting magazine. The writer is currently pitching the piece to publications.

- Kelly Ormond was interviewed by the *Chicago Tribune* to discuss direct-to-consumer testing. The piece is on hold.

- We worked with **Kristen Shannon** to gain local publicity for genetic licensure. Shannon was interviewed by the *Boston Herald* and *Boston Globe* about the issue of genetic licensure and the proposed bill in Massachusetts.

- Robin Bennett was interviewed by a freelance writer for a piece on family history. The reporter is pitching the story to *Ladies' Home Journal* and is awaiting feedback.

- Nancy Callanan was interviewed by *Hamodia*, a Jewish Orthodox newspaper in the US and UK, regarding genetic screening before conception, during pregnancy and in adults. The run date has not been determined.

If you have any additional media opportunities or story ideas, please contact your SIG chairperson, and they will relay the information to StarRosen.

Student Column

Tennessee Sounds Good to Me!
Our Visit to Music City, USA for our First NSGC AEC Experience

By Sarah Savage, BS, Devki Saraiya, BS, Sandra Donkervoort, BS, and Ellen Regalado, MS from Sarah Lawrence College

The welcoming sounds of Southern hospitality…
The soothing flow of the Gaylord Opryland cascades…
The gentle chatter of friends reunited, glasses clinking, laughter floating….

We were warned that our first NSGC AEC experience might be a little overwhelming. Many of us expected to feel exhausted, lost, maybe even a bit intimidated, but as we stepped into packed auditoriums and wandered around the vast exhibition hall, we were excited, energized, and surprisingly comfortable. For once we were in a room full of people and not a single one of them would ask us for an explanation about what a genetic counselor actually *does*. As we watched old friends, classmates, and colleagues greet each other, we began to understand how small the GC world truly is. Additionally, thanks to a focus on integrating student members, we began to see our place in this growing community.

At the resonating chime of the NSGC bell, we pulled ourselves away from the job bulletin board, while stuffing PGD paperweights, pens and pregnancy wheels into our official navy blue all-purpose conference bags, and went off to the next lecture. Although it was sometimes difficult to decide between conflicting SIGs and breakout sessions, each of us had a few events we just could not miss. We heard about new advances in genetic research, we had a chance to check out the inner workings of NSGC and we were able to get involved in our own unique areas of interest.

Finally, to a soundtrack of clattering applause and shuffling footsteps, we left the auditoriums and headed our separate ways. At last, feeling newly inspired and enthusiastic, we were ready to head off to the Wild Horse Saloon for a little country line dancing.

Book Reviews

Facilitating the Genetic Counseling Process: A Practical Manual

Authors: Patricia McCarthy Veach, Bonnie S. LeRoy and Diane M. Bartels
Publisher: Springer-Verlag New York, Inc. 2003, 320pp, Softcover $44.95
Reviewed by: Pat Steele, MS

Just when I thought I was too busy to read another genetic counseling book, I read *Facilitating the Genetic Counseling Process: A Practical Manual…*and I'm very glad that I did. From the first chapter entitled "Guidelines for Manual Users: Instructors, Supervisors and Students," the book is clearly directed as a resource for practicing genetic counselors, genetic counseling students and student supervisors. The book also has great value for many other healthcare providers such as nurses, physicians and social workers.

Building Self-Awareness

The book is an easy read and is structured with chapter headings and subtitles so you quickly can find specific topics. Several chapters focus on evaluating (or re-evaluating) our skills as genetic counselors to help us "hear" our patients/clients through verbal and non-verbal communications. The authors delineate the steps of initiating the session, contracting and ending the session, all with the focus on positive patient/client experiences. Three chapters are devoted to difficulties in counseling: self-involvement, professional ethical challenges and recognition of individual limitations. Most chapters outline strategies for genetic counseling in specific cases, traps to avoid and exercises for skill development. There also is a chapter on Internet resources that may be especially valuable for students.

A Welcome Reminder
Overall, I thought this was an excellent book. Not only does it break down the components of the genetic counseling session, it incorporates self-care in the practice of genetic counseling. I would recommend that genetic counselors either have this in their personal library or suggest it for their institution's library. This book not only helps refresh our skills, but reminds us of why we chose this profession.

Am I Next In Line? Confronting Hereditary Breast and Ovarian Cancer

Author: Monique Achtman
Publisher: Monique Achtman, Library and Archives Canada Cataloguing Publication, 2nd rev. ed. 2007, pp 140, Softcover $25
Reviewed by: Nancie Petrucelli, MS

Am I Next In Line? Confronting Hereditary Breast and Ovarian Cancer chronicles one woman's journey through childhood and adulthood as she copes with her family's secret of cancer, which is found to be attributed to a BRCA1 mutation. The book was written by **Monique Achtman,** a wife and mother who continues her family's legacy after learning that she has inherited the family mutation.

The Journey Towards Good Health
Monique's discovery of the family secret begins as a child when she accidentally walks in on her grandmother and sees her badly scarred body from her breast cancer treatment. In the next eight years, Monique suffers a profound loss when her mother is diagnosed with and dies from ovarian cancer. Her quest for good health and her desire to live to see her own grandchildren takes the reader on a tumultuous ride as she explores her fear, grief, loss and decision-making related to her family history. Opting for prophylactic surgery of both her breasts and ovaries, Monique uses her choices to raise awareness about hereditary cancer.

Taking Action on Your Health
Throughout the book, Monique urges readers to take responsibility for their personal health, using her own often agonizing choices as an illustration. At the conclusion of each chapter, Monique includes a section entitled, "Taking Action on Your Health," to challenge and empower the reader to serve as his/her own health advocate. She also acknowledges that her own personal decisions are not necessarily best for other people with similar concerns and family history.

Not Just for Cancer Pre-vivors
Though many women coping with a high risk for hereditary cancer will appreciate and identify with Monique's journey and personal struggles with genetic testing and medical

decisions, genetic counselors also will benefit from Monique's candid account of learning that she is at high risk for breast and ovarian cancer. *Am I Next In Line* gives genetic counselors insight into what it's like to live close to cancer and will encourage them to become more thoughtful and compassionate health care professionals.

SIG Update

The Pediatric SIG: Making Our Presence Known

The Pediatric SIG is picking up steam – membership is up, ideas are flowing and the fruits of last year's labors were visible at the recent Annual Education Conference (AEC) in Nashville.

EBS Opportunities
At the AEC, we had two well-attended Peds SIG-sponsored Educational Breakout Sessions: "Inversions, Translocations and Rings, Oh My!" and "Rett Syndrome and MECP2: Understanding Genotype/Phenotype Correlations." For those who did not have an opportunity to attend these sessions, the PowerPoint slides from both presentations will soon be available on the NSGC Web site. Watch for an announcement in the near future.

An Active Year to Come
We also were excited to have over 40 attendees at the Pediatric SIG meeting during this year's AEC. We were especially glad to have several students and non-SIG members join us and contribute to shaping the SIG's goals and projects for the upcoming year. Objectives for 2007 include:

- Expanding our web page on the NSGC Web site
- Initiating a project to help characterize the highly variable nature and scope of practice of pediatric genetic counselors across the nation
- Beginning a practice guideline for autism.

Join Our Team
If you have a passion for pediatrics, please consider lending your talents to this enthusiastic SIG. There are a variety of tasks and projects to fit whatever level of commitment you'd like to make. If you are interested in joining, or have any questions, contact the SIG co-chairs:

Sue Moyer, sue.moyerharasink@tenethealth.com
Michelle Strecker, streckerm@peds.ucsf.edu

AEC Update

Save the Date for the 2007 AEC in Kansas City

We are already thinking about the 26th NSGC Annual Education Conference (AEC) in Kansas City, Missouri! Save the dates **October 12-16, 2007**. The 2007 Short Course entitled, "Survival Skills for the 21st Century: How to Shape Your Future as a Genetic Counselor,"

takes place **October 11-12**. Both the AEC and Short Course will be held at the Westin Crown Center, located between downtown and the Country Club Plaza, just across from the Hallmark Cards' Crown Center and Union Station.

Kansas City promises many entertainment options, and the Outreach Committee (previously Logistics) has information on many family friendly events available in the area. If you have been to Kansas City and know of fun activities, please contact the Outreach Committee so they may add it to their list.

Plenary sessions and Educational Breakout Sessions (EBS) are the highlights of our meetings. If you have any ideas for plenary or EBS topics or speakers, please contact our Co-Chairs below. They are very receptive to new and exciting ideas.

We look forward to seeing you next year in Kansas City!

AEC Co-Chairs
Courtney Rowell, crowell@myriad.com
Karen Potter Powell, klpowel2@uncg.edu

Communications Co-Chairs
April Studinski, studinski.april@mayo.edu
Beth Wood, ewood@jhmi.edu

EBS Co-Chairs
Jennifer Hoskovec, Jennifer.e.malone@uth.tmc.edu
Debra Keelean-Fuller, djfuller@med.unc.edu

Outreach Co-Chair
Lenna Levitch, lenna.levitch@hcamidwest.com

Plenary Co-Chairs
Patti Furman, pjfurman@texaschildrenshospital.org
Sarah Noblin, sarah.j.noblin@uth.tmc.edu

Short Course Co-Chairs
Sandra Blum, sblum@myriad.com
Emily Gutter, egutter@myriad.com

Resources

New Edition of the Ethics Casebook Published

By Myra Roche, MS

Title: *An Ethics Casebook for Genetic Counselors, 2nd Edition: Ethical Discourse for the Practice of Genetic Counseling*
Authors: Logan B. Karns, MS, Myra Roche, MS and Beverly Yashar, MS

Which ethical issues faced genetic counselors 12 years ago? A quick look at the *Journal of Genetic Counseling* from 1994 shows that our attention was focused on CF population screening, predictive testing for HD and the implications of DNA testing for fragile X syndrome. It was in this environment that *An Ethics Casebook for Genetic Counselors* was published, written by **Dr. Julie Maley McClellan** in collaboration with NSGC's *Ad Hoc* Committee on Ethical Codes and Principles. Since then, our profession and our resulting duties and responsibilities have dramatically expanded. The morphing of genetics into genomics, accompanied by exciting technological advances, has permanently stretched the ethical boundaries of our profession.

An Ethics Evolution
The original Casebook broke new ground by applying NSGC's (then) newly-adopted Code of Ethics to a series of cases that showcased the Code's ability to support and guide genetic counselors' professional ethical behavior. Throughout the succeeding years, while serving on the NSGC Ethics Subcommittee, Logan, Bev and I, repeatedly heard from thoughtful colleagues who felt uncertain and unprepared not only in their abilities to define their professional roles but also to identify and analyze the underlying ethical issues at stake in a case. We attempted to address this need by writing a more extended discourse that focused on several recurring themes including autonomy, confidentiality, veracity and disclosure. The result is the newly published, *An Ethics Casebook for Genetic Counselors, 2nd Edition: Ethical Discourse for the Practice of Genetic Counseling.*

Buy Your Copy Now
Funded by a generous grant from the Audrey Heimler Special Project Fund, and heeding the advice provided by an informal survey of genetic counseling graduate program directors, the Casebook begins with three introductory chapters that weave together the historical methods of ethical analysis, the evolution of the Code of Ethics and a demonstration of case analysis. The final chapters demonstrate how these principles can be applied to three complex examples:

- A case in which patient autonomy was explicitly violated in pursuit of a genetic test.
- A conflict between a genetic counselor's clinical and research responsibilities in truth-telling and disclosure.
- The intersection between the needs for confidentiality, privacy and veracity.

The NSGC will provide program directors with a copy of the new edition of the Casebook. Copies may also be purchased through the NSGC Executive Office.

Featured on www.nsgc.org – NSGC & Amazon Publications!

Did you know that www.nsgc.org has all of the reference tools and publications for your genetic counseling practice AND your personal and professional development?

NSGC's Amazon Program
NSGC has partnered with Amazon.com to offer essential books and resources to NSGC members. Books identified as key resources are available in an online, searchable publications directory at www.nsgc.org/resources/amazon_books.cfm. Publications in the directory are linked to the Amazon.com Web site. Every time an individual purchases a publication by linking to Amazon.com via www.nsgc.org, NSGC receives a portion of the revenue. Support your professional organization by linking to and purchasing on Amazon.com.

Publications Catalog
The NSGC Publications Catalog features essential patient and professional resources developed by expert NSGC members and SIGs such as:

- Booklets from the *"Your Baby Has…"* series
- *"Cardio What?"*
- *"FAP and Me: A Kid's Guide to Familial Adenomatous Polyposis"*

The Catalog also offers members a significant discount off the list price on professional publications such as *The Genetic Basis of Common Diseases*, *Practical Genetic Counseling, sixth edition* and more. Download the NSGC Publications Catalog at www.nsgc.org/resources/list_orderform.cfm.

Bulletin Board

2007 Online Board Review Course Announcement

Three Great Reasons to Register for the University of Pittsburgh Online Review Course in Medical Genetics and Genetic Counseling

1. Study for boards when and where you want. You can even download the lectures to your iPod or MP3 player.
2. Brush up on medical genetics and earn up to 3.0 CEUs toward recertification, right from the comfort of your desktop or at the gym.
3. Save hundreds of dollars in travel expenses – do the math and think of the possibilities!

This course includes study materials in PowerPoint *and* outlines, tutorials with instant feedback, pre-tests and post-tests. Thirty hours of audio-downloadable lectures will go live in March. Bonus! Registrants will be able to email questions to specific faculty members.

Discounts are available for NSGC members. Deeper cost reductions apply to study groups.

For information about the course goals, course content, lecturers, registration fees and more, visit www.BLCommunications.us.

The University of Pittsburgh Department of Human Genetics Genetic Counseling Program gratefully acknowledges support of this program provided by the NSGC.

Audrey Heimler Special Projects Award Announcement

The deadline for the 2007 Audrey Heimler Special Projects Award is **May 15**. Awards are available in amounts up to $5,000 in support of projects that focus on the future of genetic counseling or the provision of genetic counseling services. In the past, awardees have used these funds for such purposes as creating educational materials for patients, developing practice guidelines for genetic counselors and exploring ways to involve newer genetic counselors in the NSGC leadership structure. Additional details can be found in the

members' area of the NSGC Web site. Select the "funding opportunities" link for details regarding the application process.

All proposals must be submitted to the Executive Office by May 15.

If you have questions about a proposal, please contact one of the co-chairs of the Audrey Heimler Special Projects Award committee:

Sonja Eubanks, Sonja_Eubanks@uncg.edu, 336.256.1174
Leslie Evans, leevans2@uncg.edu, 336.334.5724

20th Annual ISONG Conference

Mark your calendars for the 20th Annual ISONG Conference: Global Issues in Genetics, May 18-20, 2007, Marriott Bristol City Centre, Bristol, England. For more information visit the ISONG Web site, www.isong.org.

Letter to the Editor

Educational Outreach in an Unlikely Place

I thought you might get a kick out of the power of NSGC.

I had a personal computer that was stolen about a year ago from Sarah Lawrence College (bummer). I reported the theft to SLC, it was replaced, and I had not thought much more about it until last Monday when I got a call from Detective Sergeant **Stephen Fottrell** of the White Plains police department. The conversation went something like this:

Fottrell: "I think I might have a piece of your property. Did you recently have a computer stolen?"

Caroline: "Well, it was some time ago, but yes."

Fottrell: "I think I have it. Do you work at Sarah Lawrence College?"

Caroline: "Yes..."

Fottrell: "This computer was found in the possession of someone who says it came from Sarah Lawrence."

Caroline: "How do you know it is mine?"

Fottrell: "Well, that is the interesting part, and some good detective work, I must say. In the computer case there was a CD with some pictures on it, and in one of the pictures is a person wearing a T-shirt with the National Society of Genetic Counselors written on it. So I looked the organization up on the Internet, found the Web site and went to the "find a counselor" feature. I put in 50 miles around

> the White Plains area, and your name came up at Sarah Lawrence. So now I can get your computer back to you."

I complimented him on his fancy detective work, and told him that genetic counselors were detectives also. I explained a bit about what GCs do. It was definitely an opportunity for some educational outreach in a place that I had not thought of before!

Caroline Lieber, MS
Director, Joan H. Marks Graduate Program in Human Genetics
Sarah Lawrence College
Bronxville, NY