Perspectives in Genetic Counseling

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The Genetic Counseling Foundation: Promoting Education and Global Access to Genetic Information and Counseling Services

By Kristen Smith, Executive Director, Bill Rusconi, GCF Chair and Angela Trepanier, MS

The Genetic Counseling Foundation (GCF) held its first face-to-face board meeting on June 9, 2006 in Chicago, led by Chair, **Bill Rusconi** (Myriad Genetics). The GCF Board of Directors developed the Foundation's mission, vision statements and bylaws, all of which were approved by the NSGC Board of Directors.

The Foundation Board created a list of goals:

1.) Fund validated programs that are beyond the financial resources of NSGC
2.) Receive grants from other organizations
3.) Enable the genetic counseling profession to reach out to other related fields through awareness and education programs
4.) Enable the development of innovative testing and pilot programs
5.) Provide opportunities for the direct involvement and support of individuals and organizations outside of the genetic counseling profession
6.) Provide additional means for fulfilling NSGC's strategic initiatives.

Achieving these goals will require a strong fundraising and volunteer effort. Three committees have been created for the purpose of fundraising and meeting the goals: Development, Grants and Marketing. Each committee met by conference call in July to develop objectives and implement the following plans of action:

- ***Development Committee (Chair, Susan Dickinson) –*** Develop a list of potential funding resources, identify and recruit people with the expertise to lead fund-raising efforts, evaluate donation options and create a donor recognition program.

- ***Grants Committee (Chair, TBA) –*** Determine which types of grants should be funded and how grants will be solicited and evaluated. Initially, the committee plans to solicit proposals for two categories of grants: those that support enhanced participation and diversity in the genetic counseling profession or increased visibility and utilization of genetic information in the provision of healthcare; and those that promote access to high quality genetic counseling services or seek to identify geographic trends, workforce issues, cultural sensitivities and rural practices. Grants will be awarded as early as 2007.

- ***Marketing Committee (Chair, Dawn Allain) –*** Develop a Foundation Web site, a communications campaign strategy, a logo and a tag line. The URL www.geneticcounselingfoundation.org has been secured. The GCF tag line reads, "A catalyst for quality genetic education and research." The committee is evaluating an online fundraising tool and plans to have a raffle and a GCF booth at the 2006 Annual Education Conference in Nashville in November.

The GCF is a volunteer-run foundation and relies on the talents, skills and resources of individuals like you to support its mission. No contribution of time or money is insignificant. To help the Foundation, please contact info@geneticcounselingfoundation.com or 312.321.6834.

Special Report

Licensure Update Series, Part 2

This is the second article in a four-part series by the NSGC Licensure Subcommittee addressing the issues involved in the licensure process. Below, the genetic counselors in Oklahoma describe the "give and take" involved in achieving licensure this summer.

The Oklahoma Licensure Bill: An Exercise in Compromise

By Jessica Mester, MS, on behalf of Genetic Counselors in Oklahoma

On May 22, 2006, Oklahoma Governor **Brad Henry** (D) signed Senate Bill 990: The Genetic Counseling Licensure Act. The Act defines genetic counseling, specifies board certification and continuing education requirements and directs the State Board of Health to implement licensing. The entire text of Senate Bill 990 can be viewed at www.sos.state.ok.us/documents/Legislation/50th/2006/2R/SB/990.pdf.

One Big Difference

Oklahoma's law is similar to those of other states in all respects but one: an amendment was added at the behest of Oklahomans for Life, a group affiliated with the National Right to Life Committee, which included two controversial provisions:

1.) Genetic counselors are not required to mention abortion as a legal option
2.) The State Board of Health can elect to administer board examinations specific to Oklahoma.

We were told there could be no negotiation.

So what does this bill mean for genetic counselors in Oklahoma and for the national licensure movement? This amendment does *not* prohibit Oklahoma genetic counselors from discussing the option of termination with patients. In fact, a licensure bill was removed from consideration last year because Oklahomans for Life supported an amendment that would do just that. We do not feel that this bill will change how genetic counselors in Oklahoma will practice. We are very cognizant of our code of ethics and feel that we can and do provide our patients with the information necessary to make informed decisions.

The educators in the University of Oklahoma's genetic counseling graduate program also will continue to train our students to provide quality, comprehensive genetic counseling and prepare them to work in all settings. We trust that every genetic counselor who successfully completes a genetic counseling program values nondirectiveness and will practice in an ethical, client-focused manner.

Lessons Learned
We come away from this experience having learned a few lessons.

- First, it is vital that genetic counselors be heavily involved in every step of the licensure process. It is easy to relax and let well-meaning politicians or their advisors steer the course of a bill.

- Second, it is important to remember that the sole purpose of a licensure bill is to license genetic counselors, not to explicitly define our profession. Considering the changing nature of the field of genetic counseling, it seems sensible to allow flexibility by referring to the current definition per ABGC. Writing the 2006 definition of genetic counseling into a licensure bill verbatim makes it technically necessary to amend the licensure law every time the definition changes.

- Third, a bill with fewer words is easier to understand and creates less controversy over semantics. In our first attempt at licensure, "decision-making" was included in the definition of genetic counseling, which led Oklahomans for Life to make the amendment prohibiting genetic counselors from discussing abortions with patients. Abortion is controversial, and licensure proponents in all states should prepare a response in the event of action by the state's Americans United for Life lobbyists.

- Lastly, politics is all about compromise. To pass this licensure bill, all parties involved were forced to give a little. Nobody got the genetic counseling licensure bill of their dreams, but we are hopeful that potential negative repercussions of this bill will be softened when the licensure rules are written.

The State Board of Health shares our goal to provide all citizens of Oklahoma with ethical, quality health care. As long as genetic counselors continue to practice with our patients' best interests at heart and according to the NSGC Code of Ethics, this compromise will achieve the long-term goals motivating the nationwide licensure effort.

On the Road

Pharmaceutical Genetics: An Inner View of Industry

By Kristin DeMarco, MS, and Ashley Simpson Volz, MS

Our current positions are with BioMarin Pharmaceutical Inc. as regional Medical Science Liaisons (MSLs). Following our individual genetic counseling training, we each worked in traditional genetic counseling roles. Ashley worked in cancer genetics and Kristin in prenatal genetics. We both learned of BioMarin from a job posting on the NSGC listserv. The company listed the position with NSGC because of genetic counselors' knowledge of genetic diseases and experience interacting with genetics centers and genetics professionals. For both of us, this new job was our first experience on the "industry" side of genetics.

Patient and Provider Liaison

As MSLs, our main interactions occur with health care providers; we are the interface between the company and sites where providers may be using BioMarin's therapies. We develop ongoing relationships with physicians, nurses, pharmacists and other genetic counselors. We offer training about BioMarin products for staff members at medical centers and provide continued educational and medical support for these sites.

We also have contact with patients and advocacy groups. When patients or families have questions about our treatments or services, we assist with their needs. Our current position allows us to help collaborate with support advocacy groups and family societies.

Multi-Tasking In-House

Within BioMarin, we work with various operating departments, connecting the field and the home office. We assist in sales and marketing to establish mechanisms for patient and physician education. We conduct training for the sales team and help solve medical and scientific issues. With the clinical research team, we review and evaluate protocols for various trials and registries. We attend conferences to meet health care providers in relevant fields and answer questions about BioMarin products.

Job Adjustments

The MLS position differs in many ways from traditional genetic counseling.

- We have significantly less contact with patients and more contact with health care providers in a range of specialties.
- Our positions require a focused area of knowledge related to the services of the company, compared to the broad base of knowledge needed in many general genetic counseling positions.
- We are "field-based," rather than in-house. BioMarin is headquartered in Marin County, California, while we live in various regions of the country (Ashley in Indiana, Kristin in New York). It is a diverse lifestyle to work out of a home office and travel on a regular basis. Flexibility is required, and communication is tied to email and teleconferences.

When we started our jobs at BioMarin, there was a host of new information to learn. We have gained experience with clinical trials, the FDA approval process, drug research and development, drug manufacturing, reimbursement processes and legal/regulatory issues relating to pharmaceutical products. It is extremely rewarding to work with treatments for rare genetic disorders and see how they benefit patients. As with any job, there are challenges and learning curves to climb, but it has been a great experience so far.

Around the Globe

Promoting Transnational Collaborations in Genetic Counseling Education

By Chris Horn and Janice Edwards, MS

Genetic counseling educators from around the world are exchanging ideas and information through a new alliance formed at the May 2006 conference, “Genetic Counseling Education: Connecting the Global Community.”

Janice Edwards, Director of the University of South Carolina (USC) Genetic Counseling Program and former accreditation chair for the American Board of Genetic Counseling, first contacted genetic counseling educators several years ago to assess the evolution of genetic counseling instruction outside of the United States. Communications led to international student exchanges and other collaborations among program directors.

A Global Gathering

This past spring, Edwards organized an international genetic counseling education conference in Manchester, England. The conference was funded by the 2004-2005 Jane Engelberg Memorial Fellowship, with additional support from the National Human Genome Research Institute, the American Board of Genetic Counseling and GlaxoSmithKline. Seventy-one participants from 15 countries attended, representing 45 genetic counseling education programs and 15 professional organizations. (See the conference website at www.igce.med.sc.edu.)

The conference began with the address, “Academic Globalization: Transnational Potential Within Genetic Counseling.” Breakout sessions explored global perspectives on the developing profession, credentialing and reciprocity issues, models and methods of teaching, potential research collaborations and international student experiences. Proceedings from the conference will be published next year in the *Journal of Genetic Counseling*.

Forming a Transnational Alliance

Eager to continue the conversations sparked in Manchester, conference participants formed a collaborative network called the Transnational Alliance for Genetic Counseling (TAGC). Edwards will chair the group, and representatives from the 15 countries in attendance will form the working committee.

USC's Genetic Counseling Program is developing a Web site for the Alliance to foster contacts and exchanges among genetic counseling education programs, including listservs for program directors and students and links to international programs and professional organizations. The site will include a wiki section, which allows several individuals to contribute to a written document from anywhere in the world. Watch for the web launch at www.tagc.med.sc.edu.

“The majority of work and communication for the Transnational Alliance will happen electronically through the USC-hosted web site,” Edwards said. “We'll meet in person every other year, next in Europe in 2008. The energy created at the conference was very exciting, and the potential collaborative impact on genetic counseling throughout the world is fantastic.”

NSGC News

Update on the NSGC-SmithBucklin Partnership

By Susan Manley, NSGC Treasurer, Jennifer Farmer, NSGC Finance Chair and Kristen Smith, SmithBucklin Executive Director

NSGC entered an exciting new phase last December when our national office moved from Pennsylvania to Chicago. We selected SmithBucklin as our new management firm, due in large part to their expertise working with healthcare and allied healthcare associations. NSGC volunteer leaders have worked closely with headquarters staff over the past several months. The following is an update on our accomplishments and plans for the future.

Current Achievements

By partnering with the nation's largest association management firm, NSGC now has access to many new resources, including:

- The ability to learn industry "best practices" from other healthcare-related associations
- Strategies to reduce costs at regional meetings and the AEC through SmithBucklin's "buying power" and expertise in contract negotiations
- One centralized database that serves as the repository for all membership information
- A finance team that has helped us to implement standardized, general accounting principles along with improved money-management techniques
- Access to a larger staff with more rapid response time and increased member accessibility to staff.

Future Directions

As NSGC develops its strategic plans for 2007 and beyond, we will review other services available at SmithBucklin to assure we are using the right resources to achieve our goals. These services include:

- A Washington DC-based government relations staff (which could include lobbying efforts)
- New approaches to conference management
- Expanded and cutting-edge marketing techniques
- Consulting to effectively and economically enhance our online capabilities and offerings.

Honing Our Efforts

With our new national office and headquarters staff, NSGC leaders and volunteers are now able to devote efforts to governance rather than administration. Our energies are focused on pursuing billing, reimbursement and licensure, attending strategically important meetings, inviting media opportunities and, most importantly, creating a viable strategic plan to advance the genetic counseling profession.

NSGC is in a strong financial position, and we anticipate making significant advances over the next several years. Both the national office staff and your NSGC leaders are committed to serving you – our members – and we are excited about taking our organization to the next level.

Get to Know the NSGC Executive Office Staff

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* ***Jennifer Snider****, Association Assistant.*

Describe a typical day at the NSGC Executive Office.
If you have contacted the NSGC Executive Office, chances are that you have communicated with me! I handle all of the daily operations for NSGC as well as the membership database. I process all membership requests and orders, whether it is joining a SIG, finding out your website login, troubleshooting with the listserv, purchasing a publication or posting a job with the Job Connection. I also take care of all inquiries coming into the Executive Office. If you have any questions regarding your membership with NSGC, contact me at jsnider@nsgc.org.

What is the most unusual question you have received from an NSGC Member or Non-Member?
Many questions I receive are from non-members. Students want information about becoming a genetic counselor, and potential patients are trying to find a genetic counselor. I have heard many stories from people, some of them quite personal, so it is difficult to pick just one as the most "unusual." I encourage callers to use NSGC's Family History Tool and help them with the "Find-A-Counselor" public search to contact a GC in their area.

What do you find interesting about NSGC?
The members of NSGC have so much going on! Members are busy in their professional and personal lives, and yet a high number are volunteers. It shows just how committed the members are to their Society and profession.

What would people be surprised to learn about you?
I have had a lot of vocal training and performing experience. My focus was in jazz and classical, both competitively and recreationally.

What are your hobbies?
I love to read, take dance classes and spend time with my husband and our friends.

Advertising the *Journal of Genetic Counseling* in the UK

By Anna Middleton, PhD, and Clara Gaff, PhD

The *Journal of Genetic Counseling* (*JOGC*) is fast becoming the main academic journal read by genetic counselors across the UK. While there is easy access to *Community Genetics, Journal of Medical Genetics* and *European Journal of Human Genetics* (which are all published on our UK doorstep), these journals often contain articles written by and for our genetics or molecular colleagues rather than for genetic counselors.

Overview of Genetic Counseling in the UK

In the UK, clinical genetics services are found in major teaching hospitals through the National Health Service. The Association of Genetic Nurses and Counsellors is our professional body, with nearly 300 members. Most practitioners use the "genetic counsellor" title, whether they have an MSc in genetic counseling or nursing.

The registration (certification) process is the same for genetics and nursing backgrounds. In order to certify, one must work for two years after qualifying and produce a portfolio of 50 cases (in addition to those completed for the MSc), three in-depth case studies, video/audio-taped consultations, evidence of continuing education, a personal essay and an interview.

All written work is assessed at the Masters level and needs to contain good critical analysis of the medical, nursing and social sciences literature. As such, keeping up with articles from a host of genetics and psychosocial journals, including the *JOGC*, is paramount.

Promoting the *Journal of Genetic Counseling*

As members of the *JOGC* Editorial Board and genetics practitioners in the UK, we have been pleased this year to promote the *JOGC* at three key conferences for genetic counselors.

The first meeting was the Association of Genetic Nurses and Counsellors (AGNC) Spring meeting at Guy's Hospital London, a single day of presentations on current practice and new research. This year's focus was pre-implantation genetic diagnosis. We brought over 100 hard copies of the *JOGC* for conference delegates – all were taken.

The next meeting was the NSGC Education and Genetic Counseling Conference in Manchester (see article in this issue of *PGC*). We displayed *JOGC* posters at this meeting (photo) and included a *JOGC* postcard in each delegate pack.

The third conference was the COMET (Communication, Medicine and Ethics), a three-day meeting in Cardiff, England. Attendees were predominantly researchers in social science and health communication. With over 200 delegates and a whole day devoted to genetic counseling research, there were many potential authors and readers of *JOGC*.

Dr. Clara Gaff, Consultant Genetic Counsellor, and Dr. Anna Middleton, Consultant Research Genetic Counsellor, both work at the Institute of Medical Genetics, Heath Park, Cardiff, Wales, UK.

President's Beat

I am always glad for this opportunity to provide an update about NSGC activities. I hope you have a chance to visit the Members Only area of our Web site to view the quarterly report in the new format developed by NSGC Secretary **Angela Trepanier**. Below are some additional NSGC activities during the past few months. Each of these helps NSGC to increase our visibility and expand our influence.

- NSGC was invited to partner with Kartemquin Films in their production of "In the Family," a documentary film and outreach campaign about predicting hereditary breast and ovarian cancer, the consequences of knowing and the women who live with the risk. As part of this partnership, NSGC will provide expert consultation during the development of the film and the accompanying educational modules that comprise the outreach component of the project.

- In partnership with the Genetic Alliance, NSGC has established an Advocate Partnership program. This program provides support for up to 10 genetic advocacy organization leaders to attend the Annual Education Conference (AEC) and participate in daily briefings with NSGC leadership and members. This is an excellent follow-up to the workshop, "Opportunities for Partnerships: Advocacy Groups and

Genetic Counselors" conducted by President-Elect **Cathy Wicklund** and NSGC members **Diane Baker** and **Misti Williams,** at the recent Genetic Alliance Annual Conference.

- **Eleanor Langfelder Schwind**, representing NSGC, and **Dale Lea**, representing the International Society of Nurses in Genetics (**ISONG**), drafted a joint position statement that recognizes the common goals of these organizations and promotes collaboration in areas where the missions of each organization overlap. Membership comments on the proposed statement were obtained, and the statement is currently under review by the Board of Directors.

The Board of Directors met recently to consider the future strategic directions for NSGC. Our facilitator challenged us to envision where NSGC and the profession might be in five to 10 years and to use this vision to identify strategic initiatives for the near future.

Ongoing strategic planning and implementation is key in ensuring that NSGC continues to serve the needs of our members. With input from the membership survey, the Board will develop the 2007 Strategic Plan, which will be presented and discussed during a special session at the AEC and Short Course in Nashville this November 9-14.

2006 marks the 25th Anniversary of the AEC, and I look forward to seeing many of you there. As someone who has attended every AEC since 1981, I am always excited to update my knowledge, catch up with old friends, become acquainted with new members and leave energized by the experience of being with so many people who are committed to this profession. The AEC is an ideal time to become more involved in NSGC activities by attending the NSGC Business Meeting and Committee and SIG meetings.

It has been a wonderful experience serving as president of NSGC, and I am grateful to have been given this opportunity. NSGC has a dedicated and talented Executive Director and Board of Directors as well as numerous committed volunteers. I thank each and every one of them for their efforts this year. NSGC is strong, and I am optimistic about our future! I hope you will join me in congratulating and supporting **Cathy Wicklund**, our incoming president.

AEC Update

See you in Nashville in November!

By Cheryl Dickerson, MS and Daragh Conrad, MS, 2006 AEC Co-Chairs

You will not want to miss the 25th Annual Education Conference! The AEC planning committee has packed lots of learning into this four day conference, with extra time for reconnecting with colleagues and opportunities to get active in your National Society.

A Unique Performance to Open the Conference

In conjunction with the Beverly Rollnick Memorial Committee, the conference will begin with a special performance entitled, "Afraid to Look Down," written and presented by playwright and father, **Cullen Douglas.** Mr. Douglas brings his acting skill from supporting roles in film and television and his experience as a father of an affected child, to lead the audience through the first year of his son Gabriel's life.

As one reviewer commented, “Button up. Your heart is about to go exploring in your chest.” “Afraid to Look Down” promises to remind us of the numerous emotions brought on by parenthood and by coming to terms with a genetic diagnosis. Mr. Douglas will be available after the performance for more intimate conversation, and he hopes you will make time to introduce yourself.

25th Anniversary Reception

Please join us after the performance for a special reception celebrating the 25th anniversary of the AEC. The reception will be held in the Exhibit Hall and will feature light hour d'oeuvres and drinks. Celebrate this proud anniversary with your fellow attendees and exhibitors.

Still Time to Register

The Planning Committee has selected a diverse group of topics to be presented by an equally diverse group of speakers throughout your four days in Nashville. If you have not yet signed-up, go to www.nsgc.org for easy links to registration and travel planning.

For information contact Daragh Conrad at dconrad@wfubmc.edu or Cheryl Dickerson at Cheryl.Dickerson@carolinashealthcare.org

Special Student Forum at the AEC: What You Didn’t Learn in Graduate School

By Michelle Strecker, MS, and Jon Weil, PhD

"What if I don't know enough, and my boss decides she’s sorry she hired me?"
"What if I make a mistake and tell a patient wrong information?"
"What if I can't figure out how to manage the office politics?"

If you have ever had any of these or similar thoughts about the prospect of starting your first job as a professional genetic counselor, you are definitely NOT alone. The move from graduate school to a career is filled with exciting and eagerly-anticipated changes such as getting paid to do what you love, gaining autonomy and developing your own counseling style. It also may be a time fraught with concerns about your training, knowledge base, diplomacy and negotiating skills.

An EBS For Students Only

At this year's Annual Education Conference in Nashville, genetic counseling students can participate in a specialized Educational Breakout Session (EBS) exploring the move from life as a student to life as a genetic counseling professional. We will discuss common concerns and worries (from the mouths of recent grads themselves), as well as techniques to help you identify your personal strengths and the resources you can utilize for a successful transition into your first job.

The EBS, entitled “Psychosocial Genetic Counseling: Making the Transition from Training to Practice,” will be held on Monday, November 13 from 2:30 to 4:30 pm. We hope you will mark your program books and join us for a lively, candid and interactive discussion of this genetic counseling “rite of passage.”

SIG & Committee Updates

2006 Election Results

By NSGC Nominating Committee

The Nominating Committee would like to thank all NSGC members who participated in the 2006 Call for Nominations and election process. Additionally, the committee would like to congratulate those individuals who received nominations as well as those who were placed on the ballot. The Nominating Committee is pleased to announce the results of the 2006 NSGC Board of Directors Election!

President-Elect
Angela Trepanier, MS, CGC

Secretary
Peter J. Levonian, MS, CGC

Region IV Representative
Elizabeth A. Leeth, MS, CGC

Region VI Representative
Fiona M. Field, MS, CGC

The new members of the Board of Directors will take office on January 1, 2007.

The NSGC Board of Directors also announces that **Claire Singletary**, current Region III Representative has accepted a new job position and has moved to Texas. Because Claire no longer resides in Region III, she will step down as Region III Representative at the end of the year. Per the Bylaws, the NSGC President has appointed a new Region III Representative to fill the vacancy. The Board of Directors welcomes **Tene Hamilton Franklin** as the new Region III Representative.

Addressing Leadership Within our Organization

By Kelly Ormond, MS, and the NSGC Nominating Committee

The NSGC Nominating Committee, made up of the Past President I and Representatives from each region, is charged with the yearly task of selecting a slate of individuals for election to the Board of Directors. NSGC's nominating committees have always strived to put two highly qualified candidates up for election in each position. This year, despite a large volume of nominations, a number of factors, including the qualifications of the nominees and the nominees' interest in being considered for the ballot, made it impossible to place two candidates in all positions. The nominating committee felt it was a priority to present a highly qualified slate, even if it meant running an individual candidate in an uncontested election.

Leadership at the Forefront

Members should know that the Board of Directors has been evaluating leadership issues for the past several years. Our discussions have resulted in:

- changing the term of the Board from two to three years
- formulating leadership opportunities beyond serving on the Board and
- developing approaches for mentoring upcoming leaders in our organization.

Governance Committee Established

We are assessing the requirements of various Board positions. We are establishing a Governance Committee which will be charged with ensuring the constant effectiveness of the Board and the work it performs. This appointed committee will advise the Nominating Committee regarding the desired Board composition and will provide NSGC volunteers with opportunities for leadership development.

Enhancements to the Nominating Committee

The Board approved a term extension for Nominating Committee members, and we are in the midst of transitioning from two to three-year rotating terms. We hope this increased continuity will allow historical memory and a “training process” for Nominating Committee members.

Every Bit Helps

Our organization depends on *each of us*, as volunteer members, to contribute. As a member, what can *you* do to enhance the leadership within NSGC?

1) Get involved, at any level.
2) Share your opinions with the NSGC leadership in a constructive manner.
3) Encourage new genetic counselors to get involved early; we should foster leadership as our membership grows.
4) Nominate candidates from all areas of genetic counseling - clinical, research and industry.
5) Strongly consider future nominations or other leadership positions for yourself when they are offered.

The 2006 NSGC Nominating Committee:
Kelly Ormond, Chair 2006
Susan Berg (2006-2008)
Karen Brown (2005-2007)
Eric Fowler (2006-2008)
Shelly Cummings (2005-2006)
Cynthia Frye (2005-2007)
Sylvia Au (2005-2006)

Public Eye

Media Watch

By Angela Geist, MS and Roxanne Ruzicka, MS

June 2006 - CBS, “The Young and the Restless”

Two interconnecting story lines dealing with prenatal diagnosis were portrayed with misinformation. Although no genetic counseling occurred on the show, one scene implied that genetic counseling had taken place and that the patient was alarmed by the session.

June 10, 2006 - CNN
A piece on conditions that affect brain functioning featured **Dr. Suzanne Cassidy** speaking on Prader-Willi syndrome (PWS). Dr. Cassidy reviewed the eating and behavioral problems of PWS and the difficult choices families make when putting their child or relative in an assisted-living home.

June 13, 2006 - *Washington Post,* "Too Much Information"
An in-depth article discussed the benefits and risks of direct-to-consumer (DTC) genetic testing. **Elissa Levin,** genetic counselor at DNA Direct, described the safeguards established by the company as well as the positive experiences of many of their customers. **Scott Weissman, Kelly Ormond** and **Jill Fonda** expressed their concerns about DTC testing. NSGC and other resources were listed.

July 2006 - Univision (Spanish TV), "Despierta America" ("Wake Up America")
Ana Morales was interviewed about the services offered by genetic counselors, the role of genes and DNA in genetic disorders, dominant/recessive inheritance and the importance of collecting your family history for genetic counseling.

July 6, 2006 - News Channel 4 (New York City)
This news broadcast included a short piece on Tay-Sachs disease, particularly the incidence of Tay-Sachs among the children of couples of non-Jewish descent that are not routinely screened. The speaker said that screening for Tay-Sachs is available through a "simple blood test."

July 23, 2006 – *Parade* magazine, "Could You Have a Rare Disease?"
This story discussed the challenges in diagnosing and treating the more than 6,000 diseases in the database of rare illnesses kept by the NIH. Several resources were cited, including The National Organization for Rare Disorders, The Office of Rare Diseases at the NIH and Genetests. Upon reading the article, **Heather Shappell** noted that a reference for NSGC was missing, so she wrote an online comment asking people to find a local genetic counselor at www.nsgc.org if they are concerned about a hereditary or genetic condition in their family.

July 24, 2006 – *Time* magazine, "A Very Special Wedding"
This heartwarming article featured the courtship, marriage and support system for two high-functioning individuals with Down syndrome.

July 24, 2006 - *HealthOrbit*, "Genetics Provides One Family With a Death Sentence – And an Escape"
The Bradfield family's experience with genetic testing for stomach cancer and subsequent prophylactic gastrectomies was described on this online health-related news service. Genetic counselors were depicted as an important part of the testing experience. One family member stated, "Anybody with cancer in the family needs to go to a genetic counselor."

July 24, 2006 – KTVN Channel 2 News (Reno), "Ask the Doctor"
Robbin Palmer was a guest on this news segment. She answered questions regarding the role of genetic counselor, insurance discrimination and what happens in a genetic counseling session. On May 18, July 28 and August 3, the *Reno Gazette Journal* ran articles about the Katrina Family Find project for which several genetic counselors, including Robbin,

volunteered. Robbin was interviewed on a local public radio station on May 3 regarding the Find Family project. Robbin also taped a radio program entitled, "Stem Cell Research," that aired on three local stations on August 6.

August 2006 – *Laboratory Industry Report*, “Labs Succeed with In-House Genetic Counselors”
Given laboratories’ increasingly complicated job of interpreting, reporting and communicating genetic test results, there is a growing need for genetic counselors to be integrated into genetics laboratories. Both LabCorp and ARUP Laboratories commented on how they employ genetic counselors. A definition of genetic counselors was provided.

August 7, 2006 – *Philadelphia Inquirer*, “Home Genetic Test for Schizophrenia”
A company called SureGene featured its plans in the next two years to market “AssureGene,” a home test designed to help consumers determine whether they are genetically susceptible to schizophrenia. The article raised issues inherent in genetic susceptibility to adult-onset disorders.

Getting - and Staying - Listed in the Phone Book

By Robbin Palmer, PhD

In the summer 1999 issue of *Perspectives*, I wrote an article about obtaining a listing with the local Pacific Bell Yellow Pages to promote my private practice genetic counseling business, Northern Nevada Genetic Counseling. The listing’s heading was “Genetic Information, Counseling and Testing.” I was cautioned that this heading would be trial marketed for three years, and after that, continuation of this heading would depend on use by telephone consumers. I’m happy to report that this heading and my listing persist (more, I think, because of changes in company ownership of my local telephone service than in consumer demand/directory assistance queries). My business and name are still the only listings under this heading.

Research Network

National Eye Institute Seeks Families for Studies of Two Rare Eye Diseases

X-linked Juvenile Retinoschisis

Dr. Paul Sieving is exploring the causes and eye problems of X-linked juvenile retinoschisis (XLRS), an inherited disease that causes vision loss primarily in young males. Patients nine months and older with XLRS and females who are suspected carriers of the gene responsible for the disease may be eligible. Other family members also may be enrolled.

Familial Exudative Vitreoretinopathy (FEVR)

Dr. Ekaterini Tsilou is examining the extent of the vision problems in familial exudative vitreoretinopathy (FEVR) and is trying to identify the genes responsible for this hereditary and progressive eye disorder. Patients of all ages with FEVR, as well as their family members, may be eligible.

For both studies, patients can participate locally at the NEI in Bethesda, MD, or long distance through submission of medical records. Participation includes personal/family medical history, eye exam and a blood sample for DNA analysis. Patients with FEVR also will undergo a DEXA scan for osteoporosis.

For information: Meira Rina Meltzer, 301.402.4175 meltzerm@nei.nih.gov;
or www.clinicaltrials.gov and search for “retinoschisis” and/or “FEVR”

Four Studies at the Cleveland Clinic Genomic Medicine Institute

Funny Polyp Study

This study expands on the November 16, 2005 JAMA report, "Molecular Classification of Patients with Unexplained Hamartomatous and Hyperplastic Polyposis.” The project will test for mutations in PTEN, BMPR1A, SMAD4, LKB1, Endoglin and MYH in people with five or more GI polyps, at least one being hamartomatous or hyperplastic.

For information: Christina Rigelsky, 216.445.0524, rigelsc@ccf.org

PTEN Hamartoma Syndrome Studies

PTEN analysis is offered to individuals or families with features of Cowden syndrome or Bannayan-Riley-Ruvalcaba syndrome as part of a cancer DNA banking protocol. A questionnaire study is open to anyone with a PTEN mutation, variant or polymorphism. The questionnaire is administered annually for five years.

For information: Jennifer Stein, 216.444.5809, steinj@ccf.org

Familial Barrett’s Esophagus Study

Families with a strong history of esophageal disease are sought to study causes, treatment and prevention and to identify genetic differences in family members affected with Barrett’s esophagus (BE) and esophageal cancer (esophageal adenocarcinoma or EAC).

For information: Diane Clements, 216.445.0839, clemend@ccf.org

SDH Gene Study

People with paraganglioma(s) and/or pheochromocytoma(s) are needed for testing of the SDHB, SDHC and/or SDHD genes. Testing for MEN2A and VHL should be negative prior to enrolling.

For information: Amy Shealy, 216.445.1251, shealya@ccf.org

Natural History Studies on Angelman Syndrome or Rett Syndrome

The Greenwood Genetic Center is one of multiple sites enrolling individuals with:

1.) a clinical or documented molecular diagnosis of Angelman syndrome or
2.) complete MECP2 gene analysis and a clinical diagnosis of Rett syndrome (with or without mutations in the gene) or MECP2 mutations without clinical Rett syndrome.

All ages are eligible to participate. These studies are sponsored by the NIH and involve an initial visit with annual or bi-annual follow-up for five years at participating sites. Studies include interview, physical assessment, developmental testing, neurological studies and/or blood work.

Additional sites for Angelman syndrome: Baylor College of Medicine, Boston Children's Hospital and Children's Hospital San Diego. Additional sites for Rett syndrome: Baylor College of Medicine and University of Alabama-Birmingham.

For information: Bridgette Aufmuth, 888.442.4363, bridgette@ggc.org; or www.rarediseasesnetwork.epi.usf.edu/arpwsc/index.htm

Heart Defect Study at The Children's Hospital of Philadelphia

Dr. Elizabeth Goldmuntz is recruiting patients with structural congenital heart defects to identify changes in specific genes and chromosomes that might lead to heart malformations. A small blood sample and medical history is required from the proband and family members.

For information: Shannon Wieloch, 215.590.5644, wieloch@email.chop.edu

NIH Funded Studies on Marker Chromosomes and Telomere Imbalances

Dr. David Ledbetter and **Dr. Christa Lese Martin** in the Department of Human Genetics at Emory University are collecting samples from individuals with marker chromosomes or telomere rearrangements of known origin (www.molecular-rulers.org). Fine mapping studies to delineate the size of the imbalance will be carried out to develop genotype/phenotype correlations. There is no cost to participants, and results will be reported back to the referring provider.

Centromeres: Marker Chromosomes

Individuals are needed with a supernumerary marker chromosome of known origin (excluding those derived from chromosome 15) and a normal or abnormal phenotype. Identification of the origin and euchromatic content of supernumerary marker chromosomes aids in determining their significance to a clinical phenotype.

Telomeres

Two categories of telomere rearrangements (that were not discovered by standard chromosome analysis) are being recruited:

1) rearrangements of an individual's phenotype or

2) apparently benign familial variants that were identified in an affected individual but subsequently were found to be carried by an unaffected family member.

For information: Nikki Brady or Vanessa Rangel Miller, 404.727.7098, research@molecular-rulers.org

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Bulletin Board

Conference Calendar for Fall 2006

Perspectives in Genetics, 2006 Region III Conference
September 30 - October 1, Atlanta, GA
This year, the Region III meeting will be joined with the Southeastern Regional Genetics Group (SERGG) meeting, September 27-30. Attend both meetings to take advantage of this networking opportunity.
For information: www.nsgc.org/conferences/region_3_2006.cfm
or Dawn A. Laney, dlaney@genetics.emory.edu

Winds of Change, Whispers of Hope; Remembering Precious Lives
15th National Perinatal Bereavement Conference
October 12-15, Chicago, IL
The Pregnancy Loss and Infant Death Alliance (PLIDA) presents this comprehensive national conference, focusing on the experience of the death of a baby during pregnancy, birth or infancy.
For information: www.plida.org/

10th Annual Meeting of The Collaborative Group of the Americas on Inherited Colorectal Cancer (CGA-ICC)
November 9-10, Nashville, TN (just before the NSGC AEC)
Learn about prevention, diagnosis, treatment and research options for inherited colorectal cancer. The CGA-ICC is offering 13.0 Category 1 contact hours and a free shuttle to the NSGC meeting. Meeting registration includes a one-year free membership to the CGA-ICC.
For information: www.cgaicc.org/Portals/2/WebBrochure.pdf
or Anna Leininger, aleining@bitstream.netpg

Genomics in Everyday Medical Pactice
December 1-2, Scottsdale, AZ
Sponsored by the Mayo Clinic, this meeting will offer an array of lectures beginning with a review of basic genomics and progressing to clinical applications. CEU's are available for genetic counselors.
For information: Katherine Hunt, hunt.katherine@mayo.edu

Genetics in the Classroom: Behavior, Learning and Interventions for Students with Genetic Syndromes
December 14-15, Baltimore, MD
This conference will focus on educational, behavioral and psychiatric issues in fragile X, 22q11.2 deletion, Smith-Magenis and Angelman syndromes. This program has been approved by the ABGC to offer 1.1 category I CEUs.
For information: Brenda Finucane, 610.891.2313, www.elwyngenetics.org

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Letters to the Editor

Making the Professional Status Survey Work for You: Another “Success Story”

We have all heard anecdotes of how data from the NSGC's biannual Professional Status Survey (PSS) has helped genetic counselors across the nation attain higher starting salaries, salary increases and benefits such as reclassification to faculty status, increased reimbursement for certification or meeting-related expenses.

Eager to capitalize on others’ success, the genetic counselors at the University of California, San Francisco (UCSF) faced an interesting situation in the process of seeking across-the-board salary increases. Despite support from UCSF’s Department of Human Resources (HR), genetic counselors were told that the data from the PSS wasn't “specific” enough. UCSF couldn’t apply the salary information from the PSS because it included data from counselors employed by for-profit companies and laboratories, which UCSF felt were inappropriate comparisons. To add complexity to the situation, UCSF genetic counselors have mandatory representation by a union that sets and negotiates all salary ranges and raises.

Kari Danziger and I decided to spearhead an effort with union representatives and HR representatives to determine the most effective course for seeking salary improvements. Based on the need for more specific salary and benefit data from equivalent institutions within the San Francisco Bay area, we designed the “Bay Area Genetic Counseling Professional Status Survey.”

The format of the survey followed the NSGC's PSS. Data was collected anonymously via online survey from five major institutions in the greater Bay Area. Data were compiled into a summary report, which was made electronically available to all respondents. The data clearly demonstrated that UCSF genetic counselors' salaries of all classifications (GCI, GCII and GCIII) significantly lagged behind those of our local colleagues.

We designed a PowerPoint presentation outlining the lag in UCSF salaries and the inconsistent compensation between individuals with the same job classification and years of experience. We proposed that HR consider across-the-board increases for all GC classifications and perform an internal review and restructuring of the GC designations. Knowing that HR must negotiate contracts with our union, we shared our data with the union representatives.

Interestingly, the union advised us not to share our data with HR prior to the bargaining process. We learned that our union may have encouraged us not to share information so that they could use it to leverage other bargaining points, which may or may not have affected genetic counselors. Luckily, by ensuring that both sides had our clear-cut data, highly favorable recommendations for genetic counseling salary increases proposed by HR were accepted by the union. Now, based on the administrative structure and department under which any genetic counselor is employed, UCSF GCs are seeing salary increases which range from a modest percentage to over 30 percent!

Our experience shows that, as a united group, we can improve our professional status and compensation. We hope that others will be inspired to draw upon this success and unite to obtain appropriate compensation for all genetic counselors. GO TEAM GC!

Michelle Strecker, MS and Kari Danziger, MS
University of California, San Francisco

ABGC Recertification Deadline Fast Approaching

Genetic counselors certified by the American Board of Genetic Counseling (ABGC) in 1996 have time-limited certificates and are required to recertify by December 31, 2006 to remain a certified genetic counselor and ABGC diplomate. Failure to recertify will result in expiration of the ABGC certificate and loss of certification.

Genetic counselors certified before 1996 are encouraged to voluntarily recertify. The certificates currently held by ABMG and ABGC diplomates certified before 1996 are valid for life. Voluntary recertification in no way compromises the original certificate.

Recertification demonstrates a dedication to maintaining knowledge and skills in an evolving and dynamic profession. This commitment to lifelong learning is an essential professional standard to ensure the provision of competent genetic counseling services by ABGC certified genetic counselors. It is also important for licensure, professional advancement, hospital credentialing and insurance reimbursement.

To facilitate the first recertification cycle and encourage participation by diplomates who do not have time-limited certificates, ABGC has not been collecting fees during this first 10-year cycle. A yearly fee will be instituted next year as part of ABGC's ongoing recertification process.

Visit the new ABGC Web site (www.abgc.net) for additional information about recertification. The Recertification Application and CEU/PAC Declaration forms can now be completed online. Contact the ABGC Administrative Office at info@abgc.net or 301.634.7315 with questions.