Perspectives in Genetic Counseling - Volume 30, Number 1

President's Beat

Two Important Surveys Are Coming Your Way! ABGC Practice Analysis Survey and NSGC Professional Status Survey

By Angela Trepanier, MS, CGC, NSGC President and Robin E. Grubs, PhD, CGC, ABGC President

Two important surveys will be sent to you this year. To help the genetic counseling community understand the purpose of these surveys as well as the distinction between them, we would like to take this opportunity to provide you with some information. Your participation is essential for the successful completion of both of these surveys, and the results will greatly benefit the genetic counseling profession.

ABGC Practice Analysis Survey

The ABGC Board of Directors is pleased to announce the first-ever genetic counseling practice analysis. A practice analysis (PA) is critical for credentialing organizations like ABGC because it provides the basis for identifying and validating elements of current practice that allows for the development of an examination comprised of content reflective of that practice. By ascertaining the tasks performed by a professional, and the necessary knowledge and/or skills associated with these tasks, a PA allows for the construction of a relevant and valid certification examination. As states begin or continue to implement licensure, having an examination that is based on a practice analysis helps ensure that the examination is measuring and evaluating critical knowledge and skills related to competent practice. A PA also may provide guidance for the analysis and ongoing improvement of educational and training programs. A PA will assist ABGC, NSGC and other related organizations in their efforts to strengthen the future of the profession and will inform licensure, billing, reimbursement and scope of practice activities through evidence-based data.

You should have received an email invitation to complete the PA survey on March 10, 2008 from **ABGCja@goAMP.com**. This survey was developed and piloted with the assistance of an Advisory Committee comprised of genetic counselors with varied years of experience who practice in a variety of settings and geographical locations. **Please complete the survey by April 25, 2008. It will take about 30 minutes of your time.** If you did not receive the email invitation, please check your spam filter for the message. Should the message have been directed to your spam filter and you cannot retrieve it, or if you did not get the email invitation, please go to the ABGC website (**www.abgc.net**) and link to the survey from the home page. You also can send your email address to **Emma Nguyen** at **ABGCja@goAMP.com**, and she will resend you the survey invitation. Getting the email invitation directly from Emma Nguyen will enhance the response rate compared to accessing the survey from the website, but either method will work.

NSGC Professional Status Survey

The NSGC Professional Status Survey (PSS) has become the industry standard for genetic counseling professionals who are interested in establishing benchmarks for salaries and benefits, identifying issues facing the profession, gauging career satisfaction among the genetic counseling community and developing a detailed employment profile of the current NSGC membership.

NSGC will conduct the PSS again this summer and is pleased to announce that the 2008 survey will include changes based on membership feedback. **Maureen Smith** and **Mary Freivogel** are leading a workgroup that is implementing these changes. Some of the new features you will see in 2008 include additional questions and reporting regarding non-clinical roles and practice settings, part-time employment and salaries and the effect of licensure on salary.

In order for the PSS to be a valid measure of the current status of our profession, we need a strong response rate from genetic counselors working in all varieties of settings with a wide range of years of experience. For those in non-clinical settings, changes are being made to make it even easier for you to complete the entire survey.

The data from the PSS is extremely important to NSGC and ABGC and to you, our members, as we all continue to promote and strengthen our profession through advocacy, education and public policy. We encourage you to take the time to complete the PSS so that we can provide you with the data you need for professional advancement. To review information from a past PSS, click on: **http://www.nsgc.org/career/pss_index.cfm**. Please look for additional information about our 2008 survey to be distributed via Eblast and *Perspectives* in early summer.

Professional Development

The Abstracts Co-Chairs for the AEC have developed a set of articles to help genetic counselors who have an abstract accepted for presentation at a professional conference. This first article to details the ins and outs of creating a winning poster presentation. The second article will focus on oral presentations. Both articles will be available to download from the Abstracts page on the NSGC website.

Tips for Creating an Eye-Catching and Informative Poster

By Courtney Sebold, MS, CGC and Jehannine Austin, PhD, CGC

Congratulations! The abstract you submitted to the conference you want to attend has been accepted as a poster presentation. You now need to assemble your poster.

Poster presentations are an integral part of most scientific meetings. They provide attendees a chance to present their work as well as to exchange ideas with other scientists. As such, it is important that posters invite and foster discussions between the author and interested parties. The goal of this article is to give genetic counselors tips on creating a poster that is informative, eye-catching and professional. These guidelines can be applied for presentation at any conference and are not specific to the NSGC Annual Education Conference (AEC).

What size should my poster be?

The dimensions of the poster display area will vary among conferences. After an abstract is selected for a poster presentation, be sure to check the organization's "Instructions for Posters." The approximate dimensions of most poster display areas (including the NSGC AEC) are four feet high by four feet wide.

What technology do I need to make a poster?

There are two ways to make a poster using Microsoft PowerPoint. If you have access to a large-format color printer as well as the budget to do so, you can make your poster in PowerPoint as follows:

1. Create a new presentation by selecting "New" under the "File" menu.
2. To set the size of your poster, select "Page Setup" under the "File" menu.
3. Type in the desired height and width for your poster (e.g. if the poster display area is four feet square, type "48" inches in both the width and height boxes).

If the use of a large-format color printer is not feasible, you can make your poster in PowerPoint as follows:

1. Create a new presentation by selecting "New" under the "File" menu.

2. Make the sections of your poster as you would make slides for a talk.
3. Print out the 8.5 x 11 inch slides and affix them to colored posterboard. Leave a similarly sized margin of posterboard surrounding each of the panels.
4. Make sure the panels will all fit into the space allotted for posters. The panels should look neat and organized.

What font type and size should I use?

- Design the poster for viewing from at least three feet away. This means that the main title should have a font size of about 100 pt. Subheadings should be about 50 pt, and the main body of the text should be at least 25 pt.
- Use a font that is easy to read. Printed text is easier to read if it has serifs (short lines that extend from the bottom or top of a letter). Fonts like Times, Times New Roman and Librarian have serifs. Use one of these fonts for your poster.
- Use color effectively – make sure that there is substantial contrast between the background color and the font color. Black on white and yellow on blue are easy to read.

What sections should my poster include, and how should I arrange them?

- Your poster should include an Introduction, Methods, Results and Conclusion. Some authors choose to include a Summary, Future Work, Acknowledgements or References section.
- By convention, the introduction is located at the upper left with the conclusion at the lower right.
- Organize and define the flow of content by using columns or rows.
- Make your poster visually appealing by using graphs, charts, tables and/or pictures.
- Posters containing only or mostly text are very difficult to read. Use bullet points wherever possible.
- Keep the overall design of the poster as well as the diagrams and figures simple and easy to read. Some blank space between sections is desirable as this also makes the poster easier to read.
- Number all illustrations and figures in sequence. Place the figure legends or descriptions below each.

Anything else I should keep in mind?

- Make sure your poster can be easily mounted on the posterboard using push pins.
- The poster should be self-explanatory to allow viewing even when you are not present.
- Make about 50 copies (black and white is fine) of a letter paper size version of your poster that you can pin to your posterboard, so that people can take a copy away with them.
- Bring extra paper for you to use to help explain your poster to viewers.
- Bring business cards for people who might be interested in contacting you about your poster.
- Consider putting a sign-up sheet on your posterboard for those who want more information.

Summary

A well-designed poster reflects the professionalism of the author and encourages discussions and collaborations with other scientists. For additional tips and advice on creating poster presentations, visit the NIH Virtual Career Center at:
http://www.training.nih.gov/careers/careercenter/publish.html.

If you are interested in presenting a poster at NSGC's upcoming AEC, **the deadline to submit your abstracts is May 16th**. We look forward to reading all of your great posters.

For Your Practice Special Series: Cases in Expanded Metabolic Screening

This is the fifth article in a six-part series presented by the Metabolism/Lysosomal Storage Disease SIG in response to the expanded newborn screening panel developed in 2005, by the American College of Medical Genetics' Newborn Screening Expert Group. This panel comprises 29 conditions to be tested by all state newborn screening programs, increasing the number of diseases on the test and requiring genetic counselors to determine the impact and recurrence risk of unfamiliar metabolic conditions. Perspectives is highlighting several lesser-known genetic conditions that are now included in newborn screening to help both metabolic and non-metabolic genetic counselors as they come face-to-face with these diseases.

CASE 5: Maternal carnitine uptake defect (CUD)/carnitine transporter defect (CTD)

By Peggy W. Rush, MS, CGC

Disease Review

Biochemistry: The deficiency of sodium ion-dependent high affinity carnitine transporter OCTN2 in muscle, heart, kidneys and lymphocytes leads to plasma carnitine deficiency. CUD/CTD is classified as a fatty acid oxidation disorder, although the defect is not in beta oxidation but in the transport of carnitine into certain cells.

Genetics: Autosomal recessive. The *SLC22A5* gene is located at 5q31.

Incidence: 1 in 30,000 to 1 in 100,000 in the Caucasian population.

Natural History: Classic presentation of CUD is hypoketotic hypoglycemia or cardiomyopathy. Muscle weakness or hypotonia often manifest. Supplemental carnitine is the primary treatment, as well as avoidance of fasting with frequent feedings relatively high in carbohydrates and the use of an emergency protocol when oral carnitine is not tolerated. Outcome is good with consistent carnitine supplementation.

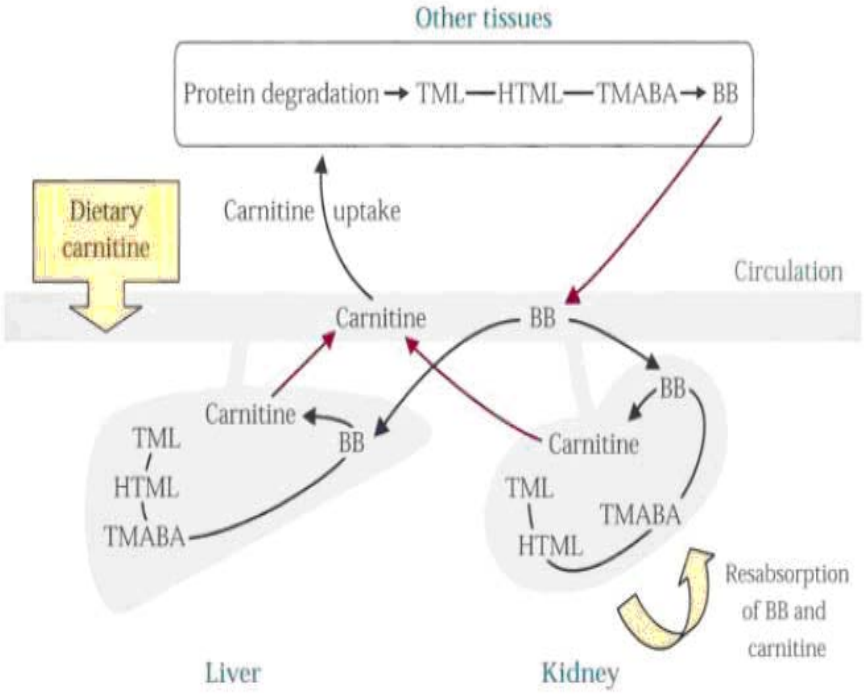


Figure 4 Schematic representation of carnitine homoeostasis in man

Carnitine is synthesized in the kidney, liver and brain (not shown). Other tissues depend on active uptake of carnitine from the circulation (uptake is indicated by black arrows; excretion by red arrows). Protein degradation yields TML, which can be converted into butyrobetaine (BB) in every tissue. However, only the liver, kidney and brain are able to convert BB into carnitine because BBD is expressed only in these tissues. BB is excreted from tissues which lack BBD, and transported via the circulation to liver and kidney, where it is converted into carnitine. The kidney efficiently reabsorbs carnitine and butyrobetaine, thereby minimizing urinary loss of both compounds.

Vaz FM and Wanders RJA. Carnitine biosynthesis in mammals. *Biochem J.* 361(Pt 3):417–429. 2002.

Genetic Counseling – Positive Newborn Screen Reflective of Maternal Disorder

Since the inception of expanded screening in Michigan, four women, all Caucasian, have been diagnosed with CUD/CTD following a positive newborn screen in an infant. As part of the confirmatory testing process following a newborn screen positive for CUD, both the infant and the mother are tested because the newborn screen could be reflective of CUD in either individual.

In each of the four diagnosed cases, the woman had low plasma free and total carnitine levels and either low or normal urine free and total carnitine levels. After supplementation with L-Carnitine, the plasma levels increased, although not necessarily to normal levels, and the urine levels increased dramatically. The follow-up test results on the infants were not consistent with the diagnosis of CUD.

To assess possible cardiomyopathy, two of the women underwent an echocardiogram. One was within normal limits, and the other showed right ventricular dilatation. We reviewed the women's physical histories, and three had participated in sports in school without difficulty; the fourth woman reported being "too slow or sluggish" to participate in sports. One woman was employed building

cabinets for recreational vehicles and lifted objects weighing 25-40 pounds multiple times per day without difficulty.

Regarding responses to fasting, three of the women reported needing to eat frequently to prevent symptoms such as fatigue, nausea, lightheadedness, vision and hearing problems or feeling "shaky." One reported occasional racing of her heart and needed rehydration in the emergency room on three occasions when she had a stomach virus. During these stomach illnesses, she reported being exhausted and unable to walk prior to rehydration. A change in energy level, fatigue and fasting intolerance were reported by some of the women after initiation of carnitine supplementation.

Genetic testing revealed that two of the women have double mutations in the *SLC22A5* gene. One woman has one mutation and will need measurement of carnitine transporter activity in cultured fibroblasts. The fourth woman has not had DNA analysis performed because of an upcoming change in her insurance company.

Each of the women was counseled about carnitine uptake defect and the treatment, management and inheritance pattern for this condition. They were asked to inform us of any future pregnancies so that the newborn screen result could be reviewed promptly. If a subsequent child had a newborn screen positive for CUD, confirmatory testing would need to be pursued, although the suspected accuracy of the newborn screen would be decreased in light of the mother's known diagnosis.

Teaching Lessons

1) Limited Knowledge of Natural History

Because there is little information in the literature on CUD in adults, genetic counseling of women diagnosed with this disorder following a positive newborn screen in an infant can be a challenge. While the women in our program have been happy to learn that their newborn does not have CUD, they wonder about the implications for their health, especially if they have been asymptomatic. Is this something for them to be concerned about or not? As states diagnose more women with CUD and report the findings in peer-reviewed journals, more information on the spectrum of the disorder will become available for counseling.

2) Lack of Compliance

Although the women in this case report symptoms of CUD, their physical effects are not unique to this condition and could have unrelated causes. Not all of the women have taken the carnitine at the prescribed dose. In addition, not all have reported changes in energy levels or stamina after starting carnitine supplementation. For those who did report increased energy levels and/or stamina, is this a reflection of treatment or of their infants sleeping longer and the mother getting more rest? Although one would expect the women to be compliant, especially if they have had symptoms that could be due to CUD, not all follow the medical recommendations.

3) Future Pregnancies

We expect the newborn screens of subsequent children born to women with CUD to be positive, not because the infant has the disorder but as a reflection of maternal disease. Being aware of this can reduce parental anxiety after learning of a positive newborn screen in a subsequent infant. Although recommendations will be made for caring for the child until the confirmatory test results are complete, we expect the emotional strain on the parents will be lessened knowing that the chance of the disorder in the child is low.

Legislation Report

The Road to Becoming a State Chapter of NSGC

Sponsored by the Genetic Counseling Access and Service Delivery Committee

In 2005, genetic counselors in Michigan and Texas approached NSGC about the possibility of offering states an opportunity to become NSGC State Chapters. Genetic counselors in both states were pursuing licensure and sought advice from lobbyists about how best to proceed. The advice given was that groups and organizations with a formal structure (vision, mission, elected officials, membership application and dues) are viewed more positively by legislators, state organizations and other professional groups. Having formal affiliation with a national organization gives even greater credibility when pursuing legislation such as licensure.

The following articles trace the efforts of these two states in organizing their genetic counselors and becoming the first state chapters of NSGC. States pursuing licensure may benefit most directly by becoming an NSGC State Chapter, though there may be longer-range professional benefits for other states depending on how a state organizes itself.

The Michigan Story
By Monica Marvin, MS, CGC, President, Michigan Association of Genetic Counselors, Inc.

For over 15 years, Michigan genetic counselors have been meeting as an informal group, known as the Michigan Association of Genetic Counselors (MAGC). In the "early days," meetings were held in the homes of genetic counselors across the state. This informal structure was sufficient in providing Michigan genetic counselors an opportunity for professional networking. As licensure emerged as a top priority for MAGC, the need to formalize the group became apparent.

The Organizational Process

Feedback from lobbyists and legislators in 2005 stressed that if MAGC was going to be taken seriously, we needed to organize and present ourselves as a legitimate, united, focused and financially sound group of professionals. A formal organization would allow counselors to establish credibility among statewide stakeholders in the healthcare field, the state legislature and the governor's office. Additionally, we were advised that formal affiliation with NSGC would give even greater credibility. As we started to look into becoming a formal organization within Michigan, we approached NSGC about whether it would consider having State Chapters.

Formalizing MAGC ultimately took over two years to accomplish. The process started in the Fall of 2005 with the drafting of vision and mission statements and the creation of a "transition team" charged with establishing a governance structure, drafting bylaws, developing a slate of candidates and conducting the first election. The first Board of Directors was elected in May 2006, and in July of that year, MAGC became a nonprofit corporation by filing its Articles of Incorporation with the state of Michigan. We also secured an Employer Identification Number with the IRS, and in February 2007, the first set of bylaws was ratified by the membership.

Legal Requirements

While a great deal had been accomplished, more work remained including obtaining tax-exempt status with the IRS and securing appropriate insurance coverage for our organization and its officers. We soon realized that there were many legal implications involved in filing these various documents, and MAGC sought formal legal counsel. The cost associated with obtaining legal advice had not been anticipated and ultimately proved to be a financial hardship for our organization. For this reason, in the Fall of 2006, MAGC applied for and was awarded an NSGC Licensure Rolling Grant of $500 to help offset the legal fees associated in becoming incorporated.

During this period, NSGC was looking into the possibility of State Chapter recognition. After a mutually agreeable affiliation agreement was developed by NSGC, and with the approval of our membership, MAGC became one of the first State Chapters of NSGC in January 2008.

Official and Active

MAGC is proud of its accomplishments over the past two years, and our activities keep progressing. The Education Committee has launched our website (www.magcinc.org), has planned and hosted two annual educational conferences and is planning for coordinated statewide efforts for DNA Day 2008. The Professional Issues Committee has been working hard on licensure efforts, including the development of multiple fact sheets and related supportive documents, collecting documentation of cases of harm in the state of Michigan, meeting with lobbyists and surveying key legislators regarding issues related to genetic services. The Genetic Services Committee completed a statewide survey of genetic services providers' current billing practices and is planning to launch a statewide professional status survey. Given its newly established recognition as a State Chapter of NSGC, MAGC is positioned to continue flourishing.

The Texas Story
By Kristine Courtney, MS, Treasurer, Texas Society of Genetic Counselors

Before the turn of the 21st century, Texas genetic counselors were not organized in any formal group. Networking occurred primarily at occasional "happy hours" held in either Houston or Dallas. As the job market for genetic counselors expanded in Texas, the number of counselors increased, the importance of state licensure was realized and the need for solidarity in the genetic counseling profession in Texas became apparent.

Initial Obstacles

In 2002, a small group of Texas counselors formed an ad hoc committee to explore the pursuit of state licensure. The Texas Genetic Counselor Licensure Working Group (TGCLWC) consisted of 13 members. For four years, the committee attempted to work with lobbyists and legislators through two legislative sessions to obtain licensure for the genetic counselors of Texas. In 2005, a bill was introduced, but it did not survive to a vote. The most significant stumbling block was the powerful Texas Medical Association (TMA), the voice of over 43,000 physicians within the state. Their major concern was that licensure would allow genetic counselors to practice outside of their jurisdiction. They also did not view the TGCLWG as a legitimate organization representative of Texas genetic counselors.

Putting it Together

To be considered a credible entity by the TMA, state legislators and other policymakers, the TGCLWG needed to become formally organized. In the Fall of 2005, the group met and voted to become the Texas Society of Genetic Counselors (TSGC). A Board of Directors was elected, and Articles of Incorporation were filed in August of 2006. The Articles were drafted based on the NSGC Articles, and a lawyer volunteered his time to edit the document so that it would be consistent with Texas law. With the lawyer's assistance, filing costs were about $25. Bylaws were written, also modeled along those in effect for NSGC. The small treasury of the TGCLWG was transferred to the new Society, and to encourage participation by Texas genetic counselors, dues were waived during the first year of the organization. Although licensure is a goal, the overall mission of the Society is

to promote the profession of genetic counseling in Texas and provide education, professional support and legitimacy to local genetic counselors.

Status Achieved

About the time that TSGC planned the somewhat daunting task of filing for 501(c)6 tax-exempt status, discussions were occurring within NSGC regarding having State Chapters. After several talks with the NSGC executive office, it seemed that becoming a State Chapter would allow TSGC to achieve tax-exempt status and acquire association insurance easily and with minimal expense. It also would afford our group the additional stature to support future legislative and advocacy efforts. In the Fall of 2007, when NSGC first offered the option of formal state chapterhood, TSGC members voted and agreed to apply. The NSGC Board approved the application, TSGC became one of the first State Chapters in January 2008. TSGC is planning its first educational conference for March 2008, and licensure efforts are planned for the 2009 legislative session.

How to Begin YOUR OWN Story

Interested in formalizing your state organization? The following list contains some of the important steps along the way.

- Define who you are and what your mission is. Even if the drive to formalize relates to licensure, your mission needs to be broader. This is a really important step! It may be helpful to have a "brainstorming" session with the counselors in your state so that the unique perspectives of counselors working at different institutions and in different settings are represented. In developing your mission statement, be careful not to imply that your organization was formed with a political agenda or that there is only one issue that is important to the organization. Once you have a mission statement established, refer back to it to remain focused.
- Define your membership. While Michigan and Texas both formed organizations with membership guidelines similar to NSGC, consider whether an organization consisting of different types of genetics professionals will be more effective in your state. Some states already have formalized genetics organizations that may make the need for a state chapter of NSGC less pressing. If you ultimately decide to become a State Chapter of NSGC, membership guidelines will be outlined by NSGC.
- Understand the process of formalizing an organization. Regardless of an organization's affiliation with NSGC, there are multiple tasks to accomplish to become a nonprofit corporation. You will need to learn the difference between articles of incorporation and bylaws, as well as important language to include in these documents. You also need to gain some familiarity with your state's nonprofit corporation legislation. Both Michigan and Texas sought legal advice from an attorney. In addition, the Michigan Department of Labor and Growth offered a workshop for individuals interested in starting a nonprofit corporation. Once you understand the process, you will need to file articles of incorporation with your state, establish bylaws, secure an Employee Identification number with the IRS, elect officers, establish your membership and collect dues.

- Develop a website and logo. A logo gives name recognition to your organization and a website helps communicate the big picture goals (vision and mission) and identifies the leaders (elected officials), the shorter-term goals and activities of your organization. Although these efforts may sound like a tremendous amount of time and cost, creating logos and websites can be affordable if there are hidden tallents in your membership.

How to Charter as a State Chapter of NSGC

There are many benefits for your organization to become an NSGC State Chapter, such as inclusion in NSGC's Federal group exemption as a 501(c)(6) organization. Aligning your state's organization with NSGC by chartering as a State Chapter will give your organization greater credibility as you pursue licensure with your state.

To charter as an NSGC State Chapter, a Chapter officer will need to complete and/or file certain documents with NSGC.

- Articles of Incorporation. All Chapters must be incorporated as not-for-profit corporations. In order to incorporate, a Chapter must file the necessary paperwork with the state in which they desire to incorporate. Please note, each state has its own requirements with respect to the formation of not-for-profit corporations. The requirements and forms necessary to incorporate in your state are usually available through your Secretary of State.

- Employer Identification Number. If the Chapter does not have an Employer Identification Number (EIN), it must apply for one. A chapter should complete a Form SS-4. If your state organization has not yet filed a Form SS-4, you may obtain this form from NSGC (as well as the IRS).

- Consent to be Included in Group Exemption Letter. All Chapters must obtain exemption for federal tax as a 501(c)(6) organization under the Internal Revenue Code. A state organization may apply for this on their own or can be included in NSGC's group exemption once becoming a State Chapter. To be covered under the group exemption, a Chapter officer must sign a consent form from NSGC, and the Chapter must establish the calendar year as their fiscal year.

- Chapter Agreement. All Chapters must sign a Chapter Agreement outlining the Chapter's relationship and responsibilities with respect to NSGC.

All of the above forms are available through the NSGC Executive Office. If you have questions or if your organization would like to take this important step, please contact Emily DiTommaso at editommaso@nsgc.org.

NSGC News

Call for Nominations for the Board of Directors

The Call for Nominations process is now open for the NSGC Board of Directors positions of President-Elect, Secretary/Treasurer-Elect and a minimum of three Directors-At-Large. The Call for Nominations is the most critical part of the election process, during which members are able to self-nominate or nominate others for consideration for leadership positions. Under our new governance structure, this is your opportunity to influence the direction of the organization.

Nomination "How Tos"

When considering people to nominate, please view the "Desired Leadership Criteria" on the NSGC website for characteristics that make a good leader. View the "Board of Directors Job Description" for more information on the responsibilities of and qualifications for the open positions.

Start thinking about those members that you know through your volunteer, professional or personal experiences and whether they might be a good leader for our organization, or use the NSGC "Who's Who Guide to Leadership" to identify those members who are active in the Society. You can nominate yourself or a colleague. If you are nominating a colleague, be sure to notify the colleague in advance to receive his/her consent to be nominated. You may nominate more than one member for each position and are encouraged to do so! Please note that, per the NSGC Bylaws, only Full Members are eligible to hold office.

Building a Strong 2009

Following the Call for Nominations, application materials will be distributed to nominated individuals and the Nominating Committee will thoroughly vet and evaluate all candidates nominated in order to provide a slate of candidates for the Board of Directors election. Your active participation in the process will enable NSGC to identify and grow new leaders with fresh perspectives to guide our organization. Your help also ensures that the best group of people will be representing NSGC for the 2009 year in volunteer positions, as those who are nominated but not placed on the slate will be encouraged to join other NSGC activities such as committees and task forces.

The Call for Nominations process will close on May 16, 2008 at 5:00pm CDT.

2008 JEMF Deadline Approaching!

"Genetic Counseling Education: Connecting the Global Community"

"Promoting Communication and Trust in Multicultural Genetic Counseling: Working with Interpreters"

"Investigating the Roles, Skills, and Training of the Research Genetic Counselor"

What do these projects have in common? All were funded by the Jane Engelberg Memorial Fellowship (JEMF) - a $50,000 one-year award to genetic counselors who are full members of NSGC and board-certified/active-candidates. May 2 is the deadline for submitting JEMF grant proposals. Complete information on JEMF proposals may be found below or by visiting **www.nsgc.org/members_only/jemf/index.cfm**.

Objective:	To promote the professional development of individual counselors and to improve the practice of genetic counseling by providing support for scholarly investigation of any aspect of the profession. Recipients may wish to explore new interests, enhance present skills, answer a specific research question or develop expertise in areas related to genetic counseling. Results must be of sufficiently broad interest and high caliber to warrant professional publication or presentation.
Award:	A one-year, $50,000 award to an individual genetic counselor (or more than one genetic counselor who will share the award).
Eligibility:	Board-certified (ABMG or ABGC) genetic counselor who is a Full Member in good standing of NSGC. Genetic counselors who have been granted active-candidate status by the ABGC also are eligible to apply.
Program Application & Guidelines:	Available at **www.nsgc.org**. Follow links to Members' Corner and "Funding Opportunities." Abstracts of previously funded projects are available at this site.
Deadline:	May 5, 2008
Questions?	Contact Michelle Fox, MS, CGC, Chair, JEMF Advisory Group, **MFox@mednet.ucla.edu**

Audrey Heimler Special Projects Award Deadline Approaching!

The Audrey Heimler Special Projects Award will provide funding to one or more genetic counselors for project(s) that focus on the future of the genetic counseling profession and/or the provision of genetic services. Projects will be reviewed on the basis of their merit and strength as well as on their vision of the future of the profession.

Award:	Projects will be funded for one year, beginning January 1 of the year immediately following the year of application. Requests for renewals or extended study will be judged with other proposals in the year of application.
Eligibility:	Applicants must be Full Members in good standing of NSGC.
Deadline:	May 15, 2008
Program Application & Guidelines:	Available at **www.nsgc.org/members_only/funding/ahspa.cfm**

SIG Update

Cancer SIG, February 2008

By Joy Larsen Haidle, MS, CGC and Rebecca Nagy, MS, CGC, Cancer SIG Co-Chairs

This year, the Cancer SIG Co-Chairs have developed a strategic plan to maximize our volunteers' time by working on projects that will help the SIG reach three different overarching goals:

1. increase visibility
2. increase education to clients (patients and providers) and
3. increase access to care for appropriate patients.

Subcommittee projects to achieve these goals are outlined below.

Practice Issues

a) Explore practice models for cancer genetics to evolve for the billing era.
b) Develop a provider educational resource section on the NSGC website.

Education

a) Increase educational content for cancer at the AEC.
b) Serve as a liaison between the Cancer SIG and the journal *Community Oncology* for a new publication venue to educate oncology colleagues.

Research

a) Develop a fact sheet for patients and providers describing points of consideration for participation in genetics research.

Communications

a) Assist with liaison development.
b) Develop a database of international providers.
c) Update the Cancer Risk Brochure.

Right on Track

We are pleased to say that Cancer SIG members have been quite busy and are well on their way to completing some of the tasks above. Here are a few highlights.

1. Cancer SIG Co-Chairs wrote an editorial response regarding the *NEJM* paper, "Cumulative association of 5 genetic variants with prostate cancer," and NSGC's PR firm submitted it on January 22, 2008.
2. The Cancer SIG sponsored three successful Educational Break-Out Sessions (EBS) at the 2007 AEC.
3. Ten EBS topics as well as plenary ideas were submitted to the 2008 AEC planning committee on behalf of the Cancer SIG.
4. Cancer SIG Co-Chair, **Joy Larsen Haidle**, assisted the Occupational Information Network (O*NET) to update the data regarding the profession of genetic counseling for their occupational database.

5. The Cancer SIG is seeking to develop a resource section on the NSGC website for non-genetics cancer providers. This resource will encourage providers to access the NSGC website for information on cancer genetics and to locate a genetic counselor in their area. We hope this will enhance the visibility of the genetic counseling profession, increase access to care and provide an educational venue for our healthcare colleagues. A preliminary proposal was submitted to the NSGC Board of Directors.

New Publication Opportunity

Finally, in line with our Education Subcommittee goals above, the Cancer SIG is thrilled to announce that we have created a new publication venue with the journal, *Community Oncology*. This journal is widely read by the oncology field, from small offices with a single oncologist and nurse to large comprehensive cancer centers. Through negotiations over the last year, we have arranged for a standing section on genetics to appear in each month's issue. The journal will accept manuscripts from NSGC as well as other sources to fill these spots.

The Cancer SIG has already submitted articles to be spread over several issues. This gives us time to recruit your help! We are seeking volunteers to write articles about genetics-related issues that our oncology colleagues may face in their practices. These articles are intended to help providers survive in the rapidly expanding era of genetics and appreciate their level of responsibility in recognizing patients with an inherited predisposition for cancer. We are not trying to create a "how-to kit" but rather to share our expertise and offer insight into using genetic information in practice. Case examples to illustrate issues and apply genetic principles often are ideal teaching tools.

The Education Subcommittee of the Cancer SIG hopes to identify topics, authors and timelines to keep genetics submissions present in each issue of *Community Oncology*. If you'd like to be an author, we have a list of possible topics. We also are happy to hear any ideas for articles, even if you don't want to write.

This is a unique opportunity to gain experience in publishing and to educate a new population of readers. It also is a wonderful venue for genetic counselors to promote our profession. Please contact the Cancer SIG Co-Chairs or the Education Subcommittee if you are interested.

Education Co-Chairs: Katherine (Katie) Baker Lange, **bakerkm@parknicollet.com**; Debbie Pencarhina, **Deborah_F_Pencarinha@WELLMONT.ORG**

SIG Co-Chairs: Joy Larsen Haidle, **joy.larsen.haidle@NorthMemorial.com**; Rebecca Nagy, **Rebecca.Nagy@osumc.edu**

AEC Update

City of Angels

By Janice Berliner, MS, GCG and Stephanie Brewster, MS, 2008, AEC Co-Chairs

We look forward to welcoming you to the 27th NSGC Annual Education Conference (AEC) in Los Angeles, CA – the City of Angels. Soon you will receive your program brochure with all of the dates and deadlines for the AEC, to be held **October 24 – 28, 2008**. The short course entitled, "Taking Heredity to Heart: Cardiovascular Genetics, An Overview," is scheduled for **October 23 – 24.**

Your Feedback at Work

Based on conference evaluations from past years, we have made some exciting changes to the 2008 conference, sure to make it even more enjoyable.

- We have added a best poster award, to acknowledge the hard work of one outstanding research or clinical project. See the related article on creating a winning poster presentation in this issue of *Perspectives*.

- We have organized the schedule so that each day of the conference will have a combination of plenary talks and educational break-out sessions (EBS). Some exciting EBSs to expect include:

- an update on endocrine neoplasia syndromes
- emerging approaches to autism spectrum disorders
- a how-to guide for passing the board exams
- an assessment of patient educational materials and health literacy.

Plenary talks include:

- preimplantation genetic diagnosis: current status, value and the future
- a twins' perspective on living with cystic fibrosis
- translating research into clinical practice: what's new in BRCA1 and BRCA2
- incorporating genome-wide association studies in genetic counseling.

- In an effort to reduce costs and "go green," another change this year involves speaker handouts. Instead of being printed in the program book, handouts will be available online prior to the conference for self printing. We also will have computer terminals onsite for handout viewing.

Improved Accommodations

Thanks to Hyatt Hotels, the location of the AEC also has some added enhancements. The conference will be located at the Hyatt Regency Century Plaza, approximately 10 miles from LAX airport. In January 2007, the Hyatt completed a $40 million renovation including all guest rooms and meeting spaces. New amenities have been added such as an upscale Equinox Fitness Center, a full-service Starbuck's in the hotel lobby and the elite X-Bar, an indoor/outdoor lounge open daily from 4pm to 2am. The hotel is situated across the street from the Westfield Shopping Center with over 180 stores, a movie theater, six full service sit-down restaurants and a "fine dining" food court that includes outdoor seating.

Dates to Remember

The deadline for early registration for the short course and AEC is **August 29, 2008**. Be sure to sign up on time to avoid late fees.

Call for Abstracts

Abstracts for platform or poster presentations will be accepted from **March 21 – May 16, 2008 EST**. See the NSGC website on Abstract Submissions for more information.

The 27th NSGC AEC promises something for everyone. Mark your calendars to join us in Los Angeles, the City of Angels!

***Contact*:** Janice Berliner, **jberliner@sbhcs.com** or Stephanie Brewster, **stephanie.brewster@childrens.harvard.edu**

Resources

Ethical Challenges in Practice: What To Do?

Do you ever find yourself wishing you had another opinion about how to handle a challenging situation with a patient, co-worker or student? The Ethics Advisory Group (EAG) of NSGC can be a resource for you.

The charge of the EAG is to provide confidential ethics consultations on professional issues for members of NSGC. The EAG, previously a Subcommittee of the Professional Issues Committee, is comprised of six genetic counselors with an interest and training in deliberation about ethical issues. An advisory bioethicist also participates in discussions to assist NSGC members.

How to Request a Consultation

NSGC members can contact any member of the EAG by telephone or email to initiate a consult when ethical concerns arise. The EAG member will ask for a brief written description of the ethical scenario which will be shared with the entire advisory group. You may request a formal consultation, which results in a written response in two to three weeks, or an informal response by telephone or email within a few days to a week. EAG responses are based on interpretations of the NSGC Code of Ethics as well as practice guidelines, information in the medical literature and other professional organization publications.

Confidentiality

Confidentiality is of paramount importance throughout the ethics consultation process. Identifying information about the scenario is only shared with the members of the EAG. Scenarios that are of significant interest and have broad applicability to the profession may be considered for publication or presentation with written permission of the submitting NSGC member.

Use in Practice

The recommendations of the EAG do not constitute required action or standard of practice, nor do they substitute for legal advice. The opinions are meant to help members see these challenges from an outside perspective and think about the situations in the most thorough and ethical manner possible. Members have the autonomy to make ultimate decisions about how best to apply the suggested course of action. Consultation with the EAG can serve as a supplement to other resources relevant to the particular situation such as peer supervision, hospital or institutional ethics committees and/or legal council.

For More Information

EAG members and their contact information are below. For a further description of the consultation process, go to the Members Only section of the NSGC website and click on Committee Activities.

Cate Walsh Vockley, Chair (2005 -2008)
(412) 692-7349
catherine.walshvockley@chp.edu

Karin Dent (2006-2009)
(801) 581-8943
karin.dent@hsc.utah.edu

Sonja Eubanks (2006-2009)
(336) 256-1174
Sonja_Eubanks@uncg.edu

Bonnie LeRoy (2005-2008)
(612) 624-7193
leroy001@umn.edu

Nancy Warren (2006-2009)
(513) 636-4475
Nancy.Warren@chmcc.org

Janet Williams (2007-2010)
(801) 507-3833
janet.williams@imail.org

Dianne Bartels, MA, PhD, Bioethics Consultant
Associate Director, Center for Bioethics
University of Minnesota
(612) 624-9672
barte001@umn.edu

New Online Forum and Publications from the National Marfan Foundation

The National Marfan Foundation (NMF) is creating an e-list forum for genetic counselors and nurses who work with the Marfan syndrome and related disorders community or are interested in learning more about these disorders and networking with other genetic counselors and nurses. Members of the e-list forum will have the ability to share questions, comments, thoughts and ideas. To join this forum, email **jbuffone@marfan.org**. Please indicate that you would like to be part of the Marfan forum and include your name, address and email address.

The NMF is pleased to announce several new publications that are available free of charge at, **www.marfan.org**.

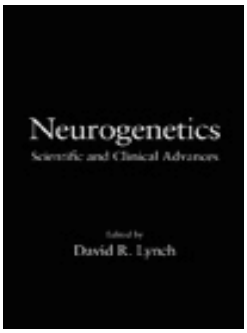
- Marfan Syndrome A to Z, for children ages 4-8 years old
- Marfan Syndrome: A Guide for Teens, for teens age 12 and up
- The Heart of the Matter Fact Sheet Series, includes fact sheets on diagnosis as well as all of the different body systems affected by Marfan syndrome

The National Marfan Foundation, founded in 1981, is a non-profit organization dedicated to individuals and families affected by Marfan syndrome and related disorders.

Contact: Information Resource Center, 1-800-8-MARFAN ext. 26, or **www.marfan.org**

Book Reviews

Neurogenetics: Scientific and Clinical Advances



Edited by: David R. Lynch
Published by: Taylor & Francis, NY, 2006, pp.755

Reviewed by: Jill Goldman, MS, CGC

The idea of reading a 755 page book on neurogenetics at first sounded overwhelming and tedious. Much to my surprise, *Neurogenetics: Scientific and Clinical Advances* provided a fascinating look at the complexity of this field. The book covers clinical and molecular aspects of diseases, concentrating heavily on genetic testing and the surrounding ethical issues. The book is directed at non-genetic neurologists but can be understood and used by anyone seeing neurogenetics patients.

Focus on Genetics and Counseling

The book is divided into three sections. The first provides a synopsis of neurogenetics in a clinical setting. It includes assessment of family history, principles of genetics and genetic testing, genetic counseling, gene therapy and ethical dilemmas. This emphasis on genetics is not found in other neurogenetics books, and the chapters on genetic counseling and ethics are written by genetic counselors, **Robin Bennett** and **Wendy Uhlmann**. The second section describes clinical features and genetics of 18 adult and pediatric neurogenetic conditions. The last section discusses five adult multifactorial neurological diseases including Parkinson disease, Alzheimer disease and ALS.

Comprehensive Overviews

The book is particularly pertinent to clinicians and genetic counselors seeking an overview of neurogenetic diseases. The first chapter, "Neurogenetics in the Clinic" written by **Dr. Thomas Bird**, is an excellent summary of how to tackle a potentially genetic neurological condition. Dr. Bird stresses the importance of a targeted family history and correct diagnosis in providing accurate recurrence risk assessment and genetic counseling. Robin Bennett's chapter on genetic counseling helps provide a thorough summary of the profession.

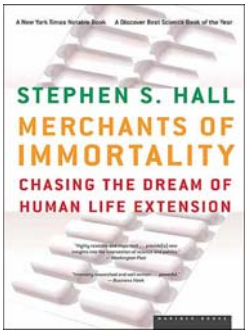
Dr. Martha Nance's chapter is an outstanding review of the complexities of genetic testing in neurological conditions. It includes heterogeneity, variable expression and penetrance, the need for different types of genetic assays and interpretation of genetic tests. This section ends with Wendy Uhlmann's chapter on ethical dilemmas where she presents various scenarios using the NSGC Code of Ethics, NSGC/ASHG position statements and practice guidelines and recommendations from the guidelines for genetic testing of Huntington disease.

Heavy on Science

The bulk of the book is written clearly and comprehensibly so clinicians from varied professional backgrounds can use the material. Several chapters, though, including the chapter on gene therapy, demand a more scientific background. The specific disease chapters summarize the most important clinical features, diagnoses, potential treatments, genetic mechanisms and testing complexities for each disease, but at times contain more molecular information than most genetic counselors or neurologists need to know. The chapters do contain helpful tables and figures.

I highly recommend *Neurogenetics: Scientific and Clinical Advances* to anyone who sees neurogenetics patients. Although primarily for neurologists, the book is relevant to genetic counselors at all stages of their careers and would be a good reference for students and fellows studying for board exams. When purchasing such an expensive volume, one must consider whether the information will remain current, which is a problem in any field changing as fast as genetics. The sections on Parkinson disease and frontotemporal dementia are already out-dated with the new discoveries of the *LRRK1* and Progranulin genes, respectively. However, the book does contain a wealth of basic medical information that will never be out of date.

Merchants of Immortality: Chasing the Dream of Human Life Extension



Author: Stephen S. Hall
Publisher: Mariner Books/Houghton Mifflin Company, NY, pp. 439, $14.00

Reviewed by: Jason Cowan, MS

In his dedication to *Merchants of Immortality: Chasing the Dream of Human Life Extension*, Stephen Hall, a contributing author and editor at *The New York Times*, expresses the wish that his children "live the experiment well." Hall's dedication is revealing; it expresses the relative youth of molecular genetic aging research ("molecular gerontology") and touches on the engine that has driven this research forward - the desire for therapeutic advances that will greatly prolong, if not indefinitely extend, the human lifespan. It also raises the questions of how this research will contribute to our scientific knowledge and whether potential real-world applications will be of greater benefit or greater harm to future generations. From these thoughts, *Merchants of Immortality* traces the interconnected scientific, political, ethical and commercial paths of molecular gerontology, from its genesis in cellular replication and shortening telomeres to current debates regarding stem cells and cloning.

A Cast of Characters

Hall begins with **Leonard Hayflick**, who discovered in the early 1960s that cells possess an intrinsic biological mechanism preventing indefinite self-renewal (the Hayflick limit). However, it is **Dr. Michael West**, the charming and forward-thinking entrepreneur and founder of Geron, who is the book's leading man. Indeed, *Merchants* becomes as much about West - impresario, salesman and scientist - as about the growth and commercialization of a science. The book is more intent on providing insight into the scientific, public and political climate in which molecular gerontologists have devoted their efforts than on presenting the biological foundations of the field. (A great bulk of the narrative encompasses the years leading up to and following the restrictive effects of American legislature on scientific progress in stem cell research.) West, ambitious and omnipresent, serves as an ideal vehicle for traversing this landscape.

Surprisingly Readable

Revealing Hall's journalistic roots, the tone of the book remains detached, reserving the final chapter for expression of the author's personal beliefs. What makes *Merchants* so readable, however, is a consistent humanity in Hall's approach. Passive, but always present, Hall is a character in his own narrative to whom the reader continually relates. His writing is marked by deft turn of phrase and a lyrical quality most evident in his accounts of the achievements, dress, demeanor and personality of every important researcher, politician and bureaucrat. Equally delightful is the dry wit brought to the subject, such as a description of corporate feelings toward an experiment in which the lifespan of *C. elegans* was lengthened through gonadal excision ("a tactic, alas, with limited commercial potential"). These facets help lighten the book's complex scientific, political and ethical subject matter.

The book is not perfect; it is now slightly outdated, the narrative ends abruptly and an appendix identifying the web of scientists, politicians and businessmen would have been helpful. Still, I have yet to find a similar account as accessible and comprehensive.

Clear Past, Unknown Future

Merchants of Immortality traces history - where molecular gerontologists have been, what they accomplished and the issues they faced along the way. As for the future, Hall makes his point clear: as scientific advancements in molecular gerontology continue and the American political landscape shifts into new administrations, it is difficult to predict how quickly and in what manner the field will grow. May we *all* live the experiment well.

Research Network

HBOC Counseling and Testing for African Families

Hereditary breast cancer genetic counseling and testing is being offered through a research study at the Mount Sinai School of Medicine in New York to women of African descent (American, Caribbean, etc.) whose family history is suggestive of an inherited breast/ovarian cancer syndrome. Andrea Forman, MS, CGC, Heiddis Valdimarsdottir, PhD, and other researchers at Mount Sinai are working on this randomized clinical trial to examine the impact of different genetic counseling formats on decision-making about BRCA1 and BRCA2 genetic testing, decisional satisfaction, quality of life and behavioral outcomes (such as cancer surveillance and prevention options). The study offers genetic counseling and the option of genetic testing at no cost. Participants cannot have undergone genetic counseling for hereditary breast cancer prior to participation. This study is approved by the Mount Sinai Institutional Review Board (GCO No.00-0730(001)-Project 2 through 14/08).

Contact: Ms. Elizabeth Carroll or Ms. Eileen Farrell, 212-659-8213, **HBOC.research@mssm.edu**

Fragile X Mutation Study

Patients and families with mutations in the *FMR1* gene are invited to participate in a collaborative research project on intermediate and pre-mutation fragile X alleles conducted by the Institute for Basic Research (IBR) and Genzyme Genetics.

The specific aims of the study are:

1) to conduct an epidemiological study of allele stability by examining repeat size distributions in families and
2) to examine factors that may influence repeat instability.

The index case in each family must carry an *FMR1* allele with 45 to 200 repeats. The referring provider is responsible for offering participation to patients. Initial enrollment involves the index

case, one or both parent(s) and siblings if available. Blood draw kits and shipping supplies are provided at no cost; the family is responsible for blood draw fees.

Molecular testing is performed at IBR, and initial results may take one to two months. Results will be sent to the referring physician/genetic counselor. Other at-risk family members then are eligible for participation. Prenatal samples will not be accepted, but a sample from a baby may be submitted postnatally. Pregnant patients may enroll, but all prenatal testing must be handled separately. Due to shipping constraints, international participants may be considered on an individual basis.

Contact: Marcia Jodah, MS, CGC, (813) 250-0588, **marcia.jodah@genzyme.com**

Consortium Established to Find Lung Cancer Genes

Researchers at Wayne State University School of Medicine and several other academic institutions have formed the Genetic Epidemiology of Lung Cancer Consortium (GELCC) to study the role that genes play in hereditary lung cancer. Eligible families must live in the USA and have at least three blood relatives with a diagnosis of lung cancer (living or deceased). Participants must provide information about their medical and family history and lifestyle, donate a blood or mouthwash sample and, for those with cancer, allow researchers to review pathology reports and access surgical samples. There is no travel required or cost to participate.

Contact: Alicia Salkowski, MS, CGC, 313-578-4311, **salkowsk@karmanos.org**, **www.genetics.wayne.edu/lung**

Public Eye

Media Watch

By Roxanne Ruzicka Maas, MS, CGC

November 16, 2007 – *The New York Times*, "Company Offers Genome Assessments"
"The revolution in human genomics, though barely understood by professionals, is about to hit the street…." This article reviewed several companies' plans to launch a new service of personalized genome assessment. **Angela Trepanier** and **Elizabeth Balkite** were quoted in the article expressing their concerns that consumers understand the limitations of this testing and not misinterpret results. The article reported that NSGC has prepared consumer guidelines that apply to the new genotyping services.

December 16, 2007 – *The Dallas Morning News*, "Jobs" section
Judy Hawkins was featured in an article promoting the genetic counseling profession titled, "Head for science; Heart to help - Need grows for genetic counselors to aid patients who are at risk." Also quoted was **Claire Singletary**, Director of the University of Texas-Houston training program, and **Robin Grubs**, President of the ABGC, who said, "We don't tell patients what to do. What we do is provide patients with options and then help people make decisions that are congruent with their beliefs."

December 21, 2007 – *Baltimore Sun*, "Genetic Counselor Shows Patients the Options"
This article highlighted **Jessica Scott** and her career as a genetic counselor. Jessica summed up her job quite well: "I help patients think about things they may not have thought about, so they are empowered to make informed choices." One of her patients commented, "What Jessica gives patients isn't just knowledge, but power."

December, 26, 2007 – *The Denver Post*, "Aurora Man's Survival Mystifying"
This article told the story of Roger, one of the few people who has been diagnosed as an adult with DiGeorge syndrome. **Donna McDonald-McGinn** was interviewed for the story and commented on how improvements in pediatric care, especially cardiac surgery, mean more children are surviving longer with DiGeorge. The article discussed the cause of DiGeorge and the various symptoms that are a part of the condition.

January 2008 – *Investment Advisor* magazine, "Something Old and New"
Direct-to-consumer genetic testing hit the realm of financial planning in this investment article. Sending off your DNA to explore your past and future was suggested as a potential "service that a wealth manager can offer — recommending reputable labs that will guarantee privacy for the testing part of the process, and then managing the health-related information about clients and their families on an ongoing basis, maybe by keeping a genetic counselor on retainer. The article also pointed out the need for help in interpreting genetic test results: "Like investing at uncertain times, interpreting the information on those 23 pairs of chromosomes we all carry, and then deciding what, if any, action to take based on that information could be beyond the ken of the average client."

January 9, 2008 – *US News and World Report*, "Why Not to Buy a Scan of Your Genome"
Researcher and professor, **David Hunter**, explained that although DNA scans have led to a blizzard of new discoveries that may have relevance in the future, direct-to-consumer gene scanning is not yet useful for making personal health decisions. He described the information gleaned from this research as "preliminary, premature and sketchy." In regards to what people can do with a family history of a potentially genetic condition (besides gene scanning), Hunter recommended discussing the condition with a physician, "to see if it deserves referral to a genetic counselor and a work-up. If people have very specific family histories that they're worried about, it's totally appropriate to be referred to a genetic counselor."

February 12, 2008 – NBC Nightly News, "The Downside of DNA Testing"
NBC Nightly News ran a series on genetic testing called, "Who We Are: The Truth About DNA." **Ellen Matloff** was interviewed and shown performing genetic counseling. She discussed how genetic testing results are not often "yes" or "no" answers and stressed the importance of informed consent and of patients understanding the implications of test results for themselves and their families. **Dr. Gregory Critchfield** of Myriad Genetics spoke about the importance of genetic counseling in explaining test results to patients.

March, 2008 - *Healthy Beginnings* magazine, "Newsbriefs" section
Robbin Palmer was highlighted for being selected by the Advocates Partnership Program 2008 to attend the American College of Medical Genetics Annual Clinical Genetics meeting in Phoenix, AZ, March 12-16. The Partnership Program is sponsored by the American College of Medical Genetics and the Genetic Alliance. Robbin's private practice, Northern Nevada Genetic Counseling, was also noted: "NNGC helps you understand your hereditary risks, identify options for managing your risks and explore ways to decrease your risks. Specializing in hereditary cancer risk assessment. For more information, go to **http://www.genesrus.net**."

*Send media items to Roxanne at **rruzicak@gmail.com**.*

Bulletin Board

Nominations for ABGC Board of Directors

The American Board of Genetic Counseling (ABGC) is seeking genetic counselors, board certified for five or more years and in good standing with ABGC (i.e. up to date with their certification maintenance fee), to serve on the ABGC Board of Directors.

Nominations are being accepted through Monday, April 25, 2008, from which a slate of four candidates will be chosen by the Nominating Committee. Elections will take place from mid-July to mid-August 2008 for two positions whose five-year terms will begin January 1, 2009.

- To make a nomination, send the name of a potential candidate to **Sheila O'Neal**, ABGC Executive Director, **soneal@goamp.com**.
- Contact **Barb Pettersen**, BarbPett@bendcable.com, or another Board member with questions about serving on the ABGC Board of Directors (**www.abgc.net/english/View.asp?x=1466**).

2008 ABGC Nominating Committee

Daniel Riconda, Chair; Barb Pettersen, Board Representative; Wendy Kohlmann, Anne Matthews, Michelle Moore

In Memoriam

My Friend, Kathi L. Marymee

By Ilana Mittman, MS, CGC

The genetic counseling profession will deeply miss Kathi L. Marymee, who died March 12, 2008 at the age of 52.

Kathi L. Marymee was born in Castro Valley, CA in 1956 to her parents Peggy and Frank, and was one of four children. She grew up in Hayward, CA where she attended high school and earned both her undergraduate and graduate degrees from UC-Berkeley. She received her master's degree in Genetic Counseling in 1984 and immediately became the Coordinator of Genetic Clinics at the Crippled Children's Division in Eugene, OR.

Five years later she moved to Portland where she served as Project Coordinator and Research Associate for the Medical Genetics Department at the Oregon Health Sciences University. In 1990, Kathi married Scott Hall and moved to Kennewick, WA where she served as a genetic counselor for the Columbia-Basin Genetic Counseling Women and Children's Clinic. In 1992, Kathi gave birth to her daughter, Lauren, and in 1995 moved with her family to Sandpoint, ID and then to Spokane, WA in 2003. During that time she worked as Senior Genetic Counselor for the Inland Northwest Genetics Clinic and a Resources Liaison for Gene-Tests at the University of Washington Medical School.

One and a half years ago, Kathi received the diagnosis of advanced stage colon cancer following a routine exam. Kathi refused to let the disease determine her life, and she continued her activities amid a fierce battle with cancer. She maintained her sense of humor and resolved to keep up her daily routine, working two jobs even during the most difficult parts of her treatment. When asked how she coped through it all, Kathi often answered, "What am I supposed to do, get in bed and pull

the blankets up?" Before she left for the hospital on the day she died, Kathi checked into her computer to perform one last work-related task.

Kathi was a devoted mother and wife who placed her family above all. She was determined to fight for her life, and when her doctors exhausted their treatment plan, she decided to try a clinical trial at the NIH. She set off for Washington, D.C. in what proved to be the last full week of her life, eager to mix "pleasure with business" and take her daughter, who has just turned 16, around the nation's capitol. Kathi worked hard not let her pain and fatigue keep her from enjoying her trip with her daughter: going out for meals, sightseeing and shopping.

Kathi died on her 52nd birthday. In Judaism, the righteous ones are privileged to die on their birthday, completing a wholesome cycle of living. Kathi was not Jewish, but righteous she was. She carried her life with dignity, bravery and selflessness.

Kathi is survived by her husband, Scott, her daughter, Lauren, her two sisters and a brother, and her parents. Kathi also is survived by scores of friends and colleagues who will forever cherish her memory. May we remember her life and be inspired by her courage.

A college trust fund for Kathi's daughter has been arranged. Donations can be made to Lauren Hall's College Fund, care of Scott Hall, 2515 E. 35th Avenue, Spokane, WA 99223.