PERSPECTIVES
in genetic counseling

Volume 25 Number 4 Winter 2003

national society
of genetic
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nsgc

the leading voice, authority and advocate for the genetic counseling profession

Table of Contents

Environmental Scan Update 1
New in '04 1
President's Beat 2
SACGHS Review 3
Joan Marks Award 3
Quality Genetic Testing 4
Voices of Our Community 4
On the Road in Japan 5
Shop Amazon 5
Media Watch 6
AEC '04 Update 7
Resources 8, 9
Research Network 10
Letters to the Editor 11, 12
In Memoriam 12

New For 2004

NSGC Member Benefits Go Virtual!

Look for these new NSGC benefits to give you added value for your membership dues. To take advantage of these new benefits, be sure to renew your dues on time! Your voice counts!

Publications Online

The Journal of Genetic Counseling will be exclusively online soon. Log on though the *Journal* logo on our homepage. Search for backfiles through Vol 6 (1997); expansion back to Vol 1 to follow. If your workplace library purchases an institutional subscription, log on through that service to promote subscription renewals. Sign up online for our continued *JGC*/CEU program.

Perspectives in Genetic Counseling will also be available online.

E-Blast System

Our customized **E-blast Notification System** will inform you when each issue of the *Journal* or *Perspectives* is online. The E-Blast subject line will read NSGC Info: [Specific Topic]. Keep your email current with our Executive Office. To make changes, visit:

☞ www.nsgc.org/members/membersprofile_forEO.asp.

Job Connection

JobConnection will go online in early January. View our database of job listings through our members' only section. The listserv announcements will continue to be broadcast on the 1st and 3rd Monday of each month.

Website

If you haven't had the chance to visit our website recently, be sure to take some time to surf our open and password protected areas just for the fun of it. New documents are being added regularly! ❖

☞ **www.nsgc.org**

Environmental Scan
A Counselor's Response

After a presentation of the scan at the Annual Education Conference, NSGC arranged small group sessions for members to explore issues with Melior Group's ***Maitlon Russell*** *and* ***Nicole Richardson.*** ***Terri Creeden,*** *who participated in a session with* ***Lori Correia*** *and* ***Cheryl Scacheri,*** *wrote the following letter to clarify specific concerns expressed by some members. For additional information see PGC 25:2 and PGC 25:3.*

– Bea Leopold, MA

Terri Creeden, MS, MPH

I just completed a call with the Melior Group, which was very beneficial to my understanding of the external/ internal scan process. I share my impressions for those who may have similar questions about the Environmental Scan.

At the Annual Education Conference, Maitlon Russell presented his research methodology and preliminary findings. There was some uncertainty about how the scan process was being conducted and that only 17 interviews were held with professionals about their views of genetic counseling. Interviewees were people who could be considered "friends" of the profession. It was not surprising that the research team found genetic counselors to be viewed positively. *...to page 7*

President's Beat

Although I have been your president for only a few months, it has been an exciting and rewarding experience! Once again, I thank you for giving me an opportunity to serve you.

Out and About

Since our Annual Education Conference, I have represented NSGC at several meetings. I attended a workshop with **Kelly Ormond** (president-elect) and **Karen Greendale** on Eugenics, Genes and Human Behavior at The Banbury Center at Cold Spring Harbor Laboratory. The meeting provided a wonderful opportunity to network and educate others about NSGC and the genetic counseling profession. In October, **Robin Bennett** and I represented NSGC at the second meeting of the Secretary's Advisory Committee on Genetics, Health and Society. (See the related article on page 3 of this issue.) While in Washington, I met with **Lindsay Middleton** and **Kathy Calzone,** the past president and president-elect of ISONG, to discuss future collaborations between our organizations. I also attended the ASHG Conference where I spoke to the leadership of ASHG, the Genetic Alliance, the American College of Medical Genetics (ACMG) and the Council of Medical Genetic Organizations (COMGO).

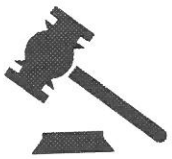
> ***"We must determine if this model will be effective as genomic medicine becomes more mainstream or whether it needs to change."***

Through my participation in these meetings, it has become clear to me that NSGC must take a critical look at the model we use to provide clinical genetic services. We must determine whether this model will be effective as genomic medicine becomes more mainstream or whether it needs to change. **Susan Manley,** Professional Issues Chair, and I have been discussing how NSGC can best address this issue. If you have thoughts on this topic, please contact us with your ideas.

Homefront

I also have initiated work on topics discussed during my presidential address. I have appointed **Bonnie LeRoy, Joe McInerney, Sheetal Parmar** and **Barbara Lerner** to a task force chaired by Kelly Ormond that will assess the structure and function of our Board. **Sandra Blum** and **Cindy Soliday** have agreed to co-chair the Visibility Task Force to develop logistical models to increase NSGC's visibility with governmental agencies, third-party payors, professional and consumer-based organizations, health care providers and the business community. I also have appointed **Amy Strauss Tranin** to be the NSGC liaison to ISONG.

Code Of Ethics



The BOD thanks everyone who commented on the proposed changes to our Code of Ethics (COE). An overwhelming majority support the changes, yet many members want the COE reviewed in its entirety to ensure the document is still current and true to our principles. To address this, I have established a working group, chaired by Robin Bennett, to review the COE and provide a written explanation regarding any proposed changes. Stay tuned for more information.

Non-Discrimination

We cannot forget the exciting and unanimous passage of the Genetic Non-Discrimination Act by the U.S. Senate. Thanks to **Karen Wolff** and to **Cheryl Scacheri,** Social Issues Chair, for keeping the membership apprised of this important legislation. I cannot emphasize enough how critical it is to contact your state representatives and encourage them to vote for this bill. A copy of my letter to **Speaker Hastert** can be found on the NSGC website. I encourage you to use it as a template for the letter you will write!

Environmental Scan

The data from our environmental scan will be available within the next few weeks. With this in mind, **Bea Leopold** and I are preparing for the Board's strategic planning meeting. Your Board is excited about this endeavor and looks forward to sharing the outcomes of this process with you! I also look forward to continuing the work we have started these last few months and representing NSGC as we move forward! ❖

Dawn C. Allain

Dawn Allain
2003-2004 President

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The opinions expressed herein are those of the authors and do not necessarily reflect those of the editorial staff or NSGC.

Next issue March 15
Submission deadline February 10

Secretary's Advisory Committee on Genetics, Health and Society

Dawn Allain, MS

The Secretary's Advisory Committee on Genetics, Health and Society convened for its second meeting October 22–23. **Barbara Willis Harrison** is the genetic counselor representative on this committee.

Genetic Testing: CLIA, FDA and FTC

The first day was devoted to presentations, testimony and discussion regarding the oversight of genetic technologies, laboratories and marketing, and the role of pharmacogenetic tests in therapeutics. **Joe Boone,** from the Office of the Centers for Disease Control and Prevention, discussed the current status of CLIA's plans to address genetic test laboratory issues. CLIA is scheduled to put out a Notice of Proposed Rule Making (NPRM) regarding oversight of genetic testing. The NPRM process requires that proposed regulations be in place so comments and information can be collected and an impact analysis performed. Once the NPRM is completed, CLIA can issue a Final Rule that will become a CLIA regulation.

The FDA discussed the impact of pharmacogenomics on the drug review process. The overall impression from the FDA is that although pharmacogenomic technology and biomarkers are new, the data review process by the FDA is sufficient for oversight. The FDA also addressed oversight of development, labeling, advertising and marketing of genetic tests. The speaker stated that the FDA is primarily concerned with device-specific issues and focuses on analytical and clinical performance. Therefore, genetic test oversight will fall under the purview of CLIA.

Matthew Daynard, the Senior Attorney in the Advertising Practices Division at the Bureau of Consumer Protection in the Federal Trade Commission (FTC), stated that the marketing of genetic tests that promise unfounded treatment claims would fall under the FTC. He encouraged reviewing the FTC website at www.ftc.gov. He is also interested in working with professional organizations to develop consumer-based fact sheets regarding genetic tests and proactive approaches to dealing with false or misleading advertising. NSGC has contacted Mr. Daynard offering assistance on these issues.

GC Training and Education

The second day of the meeting was devoted to presentations on how the U.K. and Australia are approaching issues involving genetic technologies and on genetic workforce, education and training issues. **Robin Bennett** presented a comprehensive report on "Genetic Counselor Training Program Capacities and Needs." This report was the culmination of research performed in collaboration with the NSGC Board of Directors, ABGC, ASHG, the Association of Genetic Counseling Training Program Directors and **Judith Cooksey** from the Unversity of Maryland. **Dawn Allain** provided testimony during public comments. Both Dawn and Robin's testimony will soon be available on the NSGC website. **Joann Boughman** from ASHG, **Sam Shekar** from HRSA, **Joe McInerney** from NCHPEG and Judith Cooksey discussed workforce training and education of genetic and non-genetic health care providers.

The most promising new information from this day's meeting was a letter from HRSA stating that genetic counseling educational programs are eligible for Federal support under the Allied Health Projects Program. The HRSA-04-027 Allied Health Projects RFA was posted on September 29 and specifically identifies genetic counseling as a funding priority. NSGC is strongly encouraging genetic counseling training programs to apply for these funds. ❖

☞ www4.od.nih.gov/oba/SACGHS/meetings/October2003/SACGHS_Oct_2003.HTM for webcast and transcripts of SACGHS meetings

Joan Marks and Genetic Counseling Recognized by ASHG

Jessica Mandell, MS

History was made at the American Society of Human Genetics meeting in Los Angeles in November when **Joan H. Marks, MS,** was awarded the 2003 American Society of Human Genetics Award for Excellence in Human Genetics Education. This is the first time any ASHG award has been granted to a professional in genetic counseling. Congratulations, Joan – this honor is certainly well deserved!

Many Came to Celebrate!

Sarah Lawrence College threw a high energy reception in Joan's honor on Wednesday, November 5, to kick off the meeting's celebration. The party was hosted by ASHG president **Michelle Myers**. Attendees included **Dr. Francis Collins, Dr. Arno Motulsky,** geneticist at the University of Washington in Seattle, **Dr. Kenneth Dumars,** former director of the Genetic Counseling Program at the University of California at Irvine, **Dr. Y. W. Kan,** hematologist at UCLA, several other geneticists, doctors and educators along with over 75 graduates of the SLC Genetic Counseling Program.

Award Ceremony

A full house of 3,000 conference participants witnessed the actual award ceremony on Saturday, November 8. In the words of Dr. Motulsky, who gave the introduction, "This award is a credit to Joan Marks and also an affirmation of all Master's level genetic counselors." ❖

A Team Effort for Quality Genetic Testing

Andy Faucett, MS

Jennifer Feiger's recent article, Protecting Patients While Managing Lab Errors, *PGC* 25:3, highlights the critical roles of the genetic counselor and the genetic laboratory in ensuring accurate genetic testing and patient protection. My interest in this area began by authoring a series of articles in *PGC* in 1990 and 1991 on choosing a genetic laboratory[1] and continues with my current participation in a Centers for Disease Control and Prevention (CDC) fellowship working with the individuals guiding oversight of clinical laboratories (CLIA). As such, I wanted to respond to the idea of team participation in appropriate patient care.

The End Marks the Start

The article's concluding statement, "never assume a test is perfect," is central to understanding why both the genetic counselor and the laboratory play complementary and necessary roles in genetic testing. Errors occur in *all* labs. There are no data available to indicate that genetic labs are better or worse than other clinical labs. And there are no data available that compare large commercial labs, small specialty labs and academic labs, or show that one category is more or less accurate than the others.[2]

Without this data, it is important for the genetic counselor to inquire about the Quality Control (QC) and Quality Assessment (QA) processes in place before sending a sample to a given laboratory. In addition, the CLIA 88 Final Rule of 02/24/2003 states, "For each test system, the laboratory is responsible for having control procedures that monitor the accuracy and precision of the complete analytical process." All laboratories should have procedures in place to detect false positive and false negative results. All testing paradigms should include both positive and negative controls whenever possible. Most laboratory errors occur in the pre- or post-analytical phase of testing.

Quality Controls

In Feiger's case, both the counselor and the laboratory should have required a positive control sample before agreeing to the test because this was a new test for the lab. In talking with several molecular lab directors, gene nomenclature is a problem when more than one lab is involved, and this problem is unlikely to be resolved in the near future. Sequencing is very accurate, and this same characteristic makes it very inaccurate if the lab is sequencing the wrong section of a gene. I am personally concerned that because molecular testing is considered so accurate and because DNA doesn't change, lab errors could remain undetected. It is important for the genetic counselor and the lab to share clinical information upfront, and if a result doesn't "fit," to consider whether a test should be repeated.

Time Will Tell

It also is important that both the lab and genetic counselor not rush test results nor promise results on a particular date. Laboratory marketing departments often stress turn around times and try to link them with quality. "Average" turn-around times are advertised, but the actual range can be very wide. In Fieger's case, the lab's QA/QC system caught the error, and although the delay created scheduling issues for the genetic counselor and patients, the outcome was an accurate test result. In my 15 years as a genetic counselor, I have learned not to promise results on a given date because problems can and will arise, and you do not want to rush a result and compromise test accuracy. I have also determined, after several difficult cases, never to report preliminary results as part of my personal QA/QC.

Speaking Up

I encourage genetic counselors to take an active role in the oversight of genetic testing. It is important that we work with the laboratories that we use and learn more about their QA/QC processes. Together we can put systems in place to reduce errors and, more importantly, catch errors when they occur. ❖

[1] *PGC*, Vol 12:4 and Vol 13:1.

[2] Errors in Laboratory Medicine, Bonini P., *Clinical Chemistry* 2002; 48:5:691-698.

Voices of Our Community

The Future of the Genetic Counseling Profession: A Call to Action

Katherine Hunt, MS

This article is the first in a new series called "Voices of Our Community." Every few issues we hope to introduce a new idea or challenge facing our profession. In response, we encourage you to write back with suggestions or comments to be published in the following issue. We hope this open dialogue will help us learn what others are thinking and stimulate action and community connection.

Dr. Ross Maclean opened NSGC's recent Annual Education Conference in North Carolina with this idea: to ensure the future of genetic counseling, we must find a way to quantify the value of what we do each day as health care professionals. Dr. Maclean is the Associate Director of Outcomes Research for Bristol-Myers. His advice was that we must develop tools to measure our value in a format that is understood by and has meaning to our universities, hospitals, laboratories, other industries and employers.

Our own Industry SIG and Professional Issues Committee presented a complementary session on current health care trends, noting that as health care continues to move into a self-pay market, genetic counselors need to demonstrate their value, before delivery of service, to the consumers who will pay our fees. This is a reality our ...to page 10

On the Road

Bridging Two Worlds: Genetic Counseling In Japan

Chieko Tamura, ScM

I am the first genetic counselor in Japan formally trained in the U.S. I started my practice in Tokyo in April 2003. I am tremendously busy seeing clients, writing articles, giving presentations, educating medical professionals and helping establish a genetic counseling system. Let me introduce the current Japanese situation and how I came to this position.

Genetic Counseling Growth

Formal genetic counseling did not previously exist in Japan, though clinical geneticists have been discussing genetic issues with patients and families for over 30 years. Genetic science in Japan is well developed, as in the U.S. With the rapid emergence of molecular genetic technology, physicians are considering genetic testing in a wider variety of circumstances and now realize that a new form of patient-doctor communication is needed to discuss technical and probabilistic information, clients' self-determination and ELSI and psychological issues. Over the last several years, the Japanese government and genetics societies also have established ethical guidelines for genetic testing in both research and clinical settings. All state the importance of genetic counseling. To better facilitate the provision of genetic counseling services in Japan, clinical geneticists are learning advanced counseling skills and some are including nurses and psychologists in their sessions. In addition, two genetic counseling graduate programs started this year.

A Path to the U.S.

Before I began my genetic counseling training in the U.S., I studied pharmaceutical science and molecular biology and worked for a pharmaceutical company in Japan. In my spare time, I helped Japanese family support groups. Later, I became involved with a working committee that established ethical guidelines for genetic testing. My interest in genetic counseling led me to the NSGC meeting in Denver in 1998. At the conference, I was impressed to see so many motivated, knowledgeable and skillful American genetic counselors. I decided to quit my job and come to the U.S. to study genetic counseling.

Challenges

I had a great experience in the U.S., but there were many challenges.

- It was difficult to understand American views on health, family, death, pregnancy and abortion.
- Western counseling theories were complex in terms of the language and styles of communication.
- The learning styles of graduate students in the U.S. are different; students in Japan are expected to follow the teacher, and assertiveness may not be welcomed.

I now work at one of the busiest genetics clinics in Japan, and many ideas that I learned in the U.S. work very well here. However, it is still unknown whether Western theories of psychosocial genetic counseling are applicable to Japanese clients in general. We also need more research into the needs and attitudes of Japanese people regarding genetic counseling. The idea that "knowledge is power" may not be as prominent in Japan. Self-esteem is not highly valued, and Japanese people sometimes act inferior to others to show respect. Thus, even if people are not heavily stigmatized, they may seem that way. Japanese legal systems, medical systems, health insurance and other social environments are also different.

When I was a genetic counseling student, I sometimes told patients that I was going back to become Japan's first genetic counselor. Many encouraged me and asked me to relate their views to Japanese patients with the same conditions. It helps Japanese patients and families when they realize that American patients feel the same way.

Becoming A Pioneer

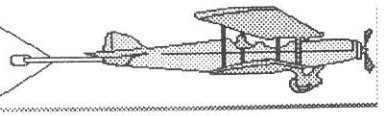
Being a pioneer is not easy, but it is certainly exciting. I am thankful to those in the U.S. who provided me with great experiences – my teachers, classmates, patients and fellow genetic counselors. I hope my contribution of bridging two countries will continue to help patients and genetic professionals. ❖

Shop Amazon!

Stefanie Uhrich, MS
NSGC Bookstore Coordinator

Here's a way to do your holiday shopping while helping NSGC at the same time. If you include Amazon.com in your holiday plans, NSGC will get a small percent of the proceeds, as long as you make purchases by entering through the NSGC.org website and clicking on "Bookstore." The site has many books that would make wonderful gifts. Books can be sorted alphabetically or by topic. If you don't see a specific book on the list, you can go to the Amazon website link at the bottom of our page and order from there. Remember to enter the NSGC Bookstore first for each order placed to ensure that we get credit for those purchases. Have a wonderful holiday and happy shopping! ❖

Media WATCH



Angela Geist, MS & Roxanne Ruzicka, MS

August '03 – Breastcancer.org Ask-the-Expert Online Conference, "Genetics and Breast Cancer – What's in a Gene?"

This conference focused on hereditary breast cancer and genetic testing. Hereditary breast cancer, information about genetic testing and concerns about insurance discrimination were discussed by the guest speaker, **Judy Garber, MD**. The importance of meeting with a genetic counselor before genetic testing was discussed, and the NSGC website was provided.

October '03 – *Better Homes and Gardens*, "Triple Screen"

This article inaccurately described the triple screen as "notoriously unreliable" and depicted the 3-D ultrasound as a level 2 ultrasound that can detect "many of the birth defects once found mainly through amniocentesis." Genetic counselor **Krista Redlinger-Grosse** was quoted discussing who should consider having the triple screen.

October 9 – *The Wall Street Journal*

An article titled, "A better test for Down syndrome," discussed the results of a study published in the *New England Journal of Medicine* about first trimester screening as a new and improved way to screen for Down syndrome and trisomy 18. The article mentioned how women with a screen-positive result could have CVS and find out results earlier, whereas other women would have to wait until 14 weeks gestation for amniocentesis. The possibility of false-positive and false-negative results was not detailed, and the article did not mention that first trimester screening does not screen for neural tube defects. The remaining information in the article was generally accurate.

October 11 – NPR, "Daughter of Family G"

A woman whose family had been diagnosed with HNPCC considered whether or not to pursue genetic testing. Her thoughts were described as she considered genetic testing, participated in a research protocol and received her results. Genetic counseling was not mentioned.

October 23 – NBC Nightly News

Tom Brokaw interviewed **Mary-Claire King, PhD,** about her research published in *Science* the next day. This project was the first large scale study to assess the impact of BRCA1 and BRCA2 mutations and environmental risk factors among Jewish women and their families with inherited breast and ovarian cancer. Over 30 genetic counselors and 100 Sarah Lawrence graduate students performed pre- and post-test genetic counseling for the study participants and their relatives. Information about this study also was covered by the *Washington Post, New York Times, Wall Street Journal, Jerusalem Post, USA Today, Reuters,* NPR and numerous TV stations.

October 23 – CSI

The inheritance and natural history of Tay Sachs disease were accurately portrayed during an episode in which a couple murdered their second child after they suspected he had the disease like their first child. The availability of prenatal testing for Tay Sachs disease was discussed.

October 24 – *Saline Reporter*, "Genetic Counseling for Breast Cancer Helps Women at Risk"

Kara Milliron described genetic counseling and her role as a patient advocate for individuals deciding whether or not to pursue genetic testing at the University of Michigan Breast and Ovarian Cancer Risk Evaluation Program.

October 28 – *The New York Times*, "A Deadly Disease of Infants Attracts New Research Money"

This article discussed new research funding for spinal muscular atrophy (SMA). It featured one family who had a child with SMA and discussed his symptoms and the genetic basis of the condition. The article pointed out that parents are shocked to find out they have an affected child because "no state requires prenatal screening for it," and that if the NIH's plan to finance research for this condition hastens the discovery of a treatment, "it can serve as a model for other hereditary forms of neuro-degenerative diseases like muscular dystrophy and Huntington's disease."

November '03 – *Men's Journal*

The father of a boy with fragile X syndrome wrote this article on his emotional struggles in raising a child affected with this condition. The general features of fragile X, its inheritance, incidence, carrier frequency, carrier testing and prenatal diagnosis were discussed accurately. The father noted the lack of knowledge about fragile X on the part of professionals who dealt with the child (the final diagnosis was made by a neurologist). Genetic counselors were not mentioned.

November 4 – Law and Order: SVU

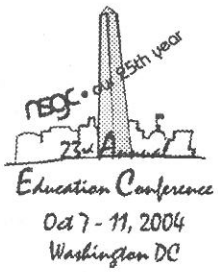
A pregnant woman who had one child with fetal alcohol syndrome was charged with "derivative neglect" because she was drinking during her current pregnancy. The woman saw a counselor (not clear if she was a genetic counselor) at a fetal alcohol syndrome center who explained that there are risks for fetal alcohol syndrome if a woman has more than seven alcoholic drinks per week or four or more drinks in one day. The symptoms of fetal alcohol syndrome were outlined, and it was pointed out that the first trimester was the most risky period for fetal damage from alcohol. ❖

2004 Conference Update

When: **October 7–11, 2004**

Where: **Hyatt Regency on Capitol Hill, Washington DC**

Overview: Planning is well underway for the 2004 Annual Education Conference (AEC). Our goal is to provide 25 hours (2.5 CEU's) of educational sessions with additional time for committee and SIG meetings, reunions and breathing room! Additional CEUs will be available with sponsored breakfasts and lunches.



Scheduling News: In setting the schedule for the conference, we've considered many factors, including comments on the 2003 AEC evaluations, flight times and the infamous DC rush hour traffic. The 2004 meeting will begin on Thursday evening, October 7, with two plenary sessions. Friday, Saturday and Sunday will be full days, and on Monday the conference will adjourn mid-day. This will allow attendees to either depart DC before rush hour or spend a few hours taking in the sights or dropping by their Representatives' offices. Stay tuned for more information on organized tours of the city after the conference.

Proposals Abound: The AEC planning committee has received a large number of proposals for educational breakout sessions (EBSs) and plenary sessions. As usual, NSGC members will receive a conference brochure in the mail in early spring. At that time, conference information will also be posted on the NSGC website and provided to other professional organizations such as ISONG and the Canadian Association of Genetic Counselors (CAGC).

Short Courses: There will be two concurrent short courses offered October 6-7, before the start of the AEC. **Susan Estabrooks Hahn** and **Emily Burkett** are co-chairing "Expanding Opportunities in Research," which is intended for genetic counselors with or without research experience. **Jennifer Farmer** and **Jill Goldman** are co-chairing, "A, B, C and D's of Neurogenetics: HD, AD, PD and Beyond," which will cover a wide range of neurological disorders including Alzheimer and Parkinson disease and the issues pertinent to genetic counselors.

Abstract Deadlines: Abstracts of interest to the genetic counseling profession and related fields are being accepted for consideration as platform or poster presentations from April 5 to June 4. Students, non-members and full members are encouraged to submit abstracts. Monetary awards will be presented for best full member and student member abstracts. Guidelines and instructions for submissions will be available in March on the NSGC website using a link to the Abstract Submission Form. **Janice Berliner** and **Nathalie McIntosh** are Abstract Co-Chairs.

Volunteer: Finally, it's not too late to volunteer your time and efforts to planning the AEC. Contact any of the conference chairs (see *PGC* 25:3) to learn how you can lend a hand to make this conference a huge success! ❖

Environmental Scan, *from page 1*

Project Goals

My first question was to clarify the goal of the research. Were we trying to find out if people like us, or were we trying to assess *why* and *how* people use our services and *how* these factors may change? I learned it was the latter. The question was not about patient satisfaction but rather the future of our services.

I also wanted to know if the research group was gathering the data NSGC needs to develop a strategic plan. We need to know the barriers/opportunities and strengths/weaknesses of our profession to decide if we are on target with future expectations and to make decisions accordingly. The research team believes that we are getting these answers.

It seems we also are asking the right people. To get at the future of genetic medicine and services, we need to talk to the people in the "know." The people interviewed were specialists who were suggested by the Board of Directors and NSGC members through a query on our listserv and SIG networks. To get people's opinions of us, it is not enough just to ask our "friends." This, however, was not the research question at hand. Those with concerns over the process may appreciate this clarification.

Filling the Gaps

Also, I gained a better understanding of why the reseachers stopped after 17 external interviews. If you are only talking to those who understand and direct policy and issues around genetic services, the same names will keep coming up. In addition, the same "issues" and "responses" will keep arising in each interview. According to Maitlon, "It was time to take the investigation to the next level, and then double back to fill in the gaps, when additional information, in this case the members' input, was gained."

In Conclusion

I now have a better understanding of the process and the knowledge we can obtain from our Environmental Scan. ❖

RESOURCES

BOOKS TEACH KIDS TO CARE

Review by: Jamilyn Daniels, MS

JayJo Books, LLC, was founded by **Kim Gosselin,** a mother of two children with special needs. The company produces a multitude of books designed to inform children about their own medical or psychological conditions and educate their classmates, friends, family and teachers.

"TAKING TO SCHOOL....."

I reviewed several titles in the "Taking to School" series, including Down Syndrome, Cystic Fibrosis, Tourette's Syndrome, Autism and Seizure Disorders. These books bring up the tough subject of being different. Descriptions of conditions and symptoms are tempered with requests for tolerance and friendship. In "Taking Autism to School," the voice is of Angel, whose friend Sam has autism. Angel mentions how she and Sam are alike and different. She explains that Sam needs routines and less stimulation than other children and that he may echo or repeat behaviors or speech. Angel implores, "I hope Sam can be your friend too!"

The back of each book contains tips for teachers on addressing the issues of children with the featured condition, a quiz for children to test their memory of the book and further resources.

BEST FOR OLDER KIDS

While these books may be too complex for small children, older children should understand most of the descriptions of symptoms. In "Taking Seizure Disorders to School," Jaime explains how seizures are like the electrical shock you get after rubbing your feet on carpeting and then touching something. In "Taking Cystic Fibrosis to School," Jessie describes the mucous that fills her lungs as "spider webs" that capture bacteria and lead to infections. Jessie also describes chest physiotherapy, nebulizers and a vibrating jacket named "Betty" that helps clear her lungs of mucous.

Throughout each book, the common theme is to promote understanding and acceptance of children with differences. If enough children read these books I

NATURE VS. NURTURE: GENES, EXPERIENCE, AND WHAT MAKES US HUMAN

by Matt Ridley
Harper Collins, 2003. 280 pages.
Review by: Judy Miller, MS

The topic of nature versus nurture used to intrigue me, but over the years I gradually resolved this dichotomy to my satisfaction. Initially, I was not interested in a book that re-examines this topic. Happily, **Matt Ridley** appears to have something truly new to say in his latest book.

A TRUE CONNECTION

The nature versus nurture debate has been waged with deep feeling, especially when considering certain traits such as race and IQ. Ridley argues that nature and nurture cannot be separated. The thesis of this book is that learning, intelligence, behavior and even culture – all ingredients of nurture – involve genes. According to Ridley, human nature is totally genetic and environmental because genes respond to experience.

The book describes the intricacies of gene expression including promoter and transcription factor functioning, tissue specific expression, expression limited to only a specific time in development and the switching on and off of genes. It is wonderful reading packed with fascinating facts about biology. Vision provides a good example of the interplay between experience and genes. Ridley explains mouse experiments showing that exposure to light switches on a key gene called BDNF in the visual cortex of the brain. The development of brain circuitry needed to see involves experience acting through genes.

A TREAT TO READ

In addition to the stories, experiments, analogies and metaphors presented with clarity and wit, Ridley relates the experiences of interesting scientists and philosophers. His descriptions of how genes act in the brain are a treat – consider reading the book only for this. He touches on the implications of the nature-nurture debate for human welfare and the topic of free will. He provides up-to-date references (many 2002) from a wide variety of disciplines. I recommend this book wholeheartedly for the clear descriptions and entertainment.

SCIENTIFIC MERIT

Ultimately, the book must be judged on its scientific merit. Although I don't feel qualified to evaluate all of the implications attributed to experiments or all conclusions, I had occasional concerns. For example, in the chapter on mental health, I question the validity of suggestions made for why genes for schizophrenia have been maintained. I am also uncertain about the many discussions of heritability.

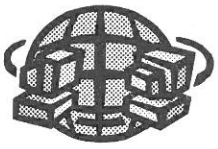
Matt Ridley has been a scientist (Oxford zoology PhD), journalist and science writer (author of *Genome: The Autobiography of a Species in 23 Chapters*). He acknowledges a long list of scientists with whom he consulted. This does not, of course, mean that the book has been peer-reviewed. So enjoy this book for its strengths – the stories, the history and thoughtful discussions. But use caution in accepting the big suggestions and conclusions. ❖

Resources

On the Net

Claire Noll, MS

To help answer the frequent listserv question, "Where can I find information on a specific condition in another language?" here are a few helpful Internet sites and services. For Spanish specific sources, see the NSGC website. This column will be updated periodically. New submissions are always welcome!



Multi-Language Sites

The University of Kansas Medical Center runs a website providing information on genetic and rare conditions and support groups in languages beyond English. The site is maintained by genetic counselor **Debra Collins** and the Medical Genetics Department.

☞ www.kumc.edu/gec/support/internat.html

The Pregnancy Foresight Project, provided by the Swedish Medical Center in Seattle, offers fact sheets on prenatal care, pregnancy and genetics in multiple languages.

☞ www.swedishmedical.org/PregnancyForesight/OtherPrint.html

The Guide to Internet Resources for Cancer is a non-profit service for cancer information on the Net. The site is run by CancerIndex.org, an epidemiological statistics researcher, and links to several sites in other languages and countries including an international Children's Cancer Web. Useful English pages also include a cancer glossary and genetics resources for health professionals.

☞ www.cancerindex.org/clinks13.htm

DiabetesMonitor.Com includes the page Diabetes on the Web: Websites Multilinguisticos, with links in Belgian, Bulgarian, Chinese, Danish, Dutch, French, German, Italian, Japanese, Korean, Norwegian, Portuguese, Russian, Spanish and Swedish.

☞ www.diabetesmonitor.com/other-10.htm

EthnoMed is a service providing medical information for immigrant populatations including Amharic, Cambodian, Chinese, Eritrean, Ethiopian, Mexican, Oromo, Somali, Tigrean and Vietnamese. Pages also include useful cultural information for health care providers. The site is sponsored by the Harborview Medical Center at the University of Washington in Seattle.

☞ www.ethnomed.org/

MultiLingual Health Education Net is a Canadian resource providing translated material in Chinese, Darshan, French, Farsi, Hindi, Italian, Japanese, Korean, Punjabi, Spanish and Vietnamese. Fact sheets address general pediatric and adult health issues but not prenatal or genetic issues.

☞ www.multilingual-health-education.net/

Translation Sites

Babel Fish is a service provided by Alta Vista that allows you to translate blocks of text or webpages into different languages. You choose what to translate, paste it onto the Babel Fish page and watch multilingual text appear!

☞ www.babelfish.altavista.com/trans late.dyn

Your Dictionary.com includes a multilingual translation service for words to and from English and other languages. ❖

☞ www.yourdictionary.com/

Billing and Reimbursement Resource Online

Barbara J. Pettersen, MS

A new document titled, "Primer on Billing and Reimbursement for Genetic Counselors," co-sponsored by the Genetic Services Committee and the Billing and Reimbursement Subcommittee of the Professional Issues Committee, is now posted on the NSGC website for use by NSGC members. This document contains the most up-to-date information to help genetic counselors understand the complexities of billing for genetic counseling services. It contains definitions, current billing methods and resources. A list of CPT and ICD-9 billing codes compiled from entries solicited from the NSGC membership can be found in the Appendix. This is not a legal document and does not endorse particular billing and/or reimbursement strategies. To view the document go to the Members' area of www.nsgc.org, and click on "Tools for your practice."

Thanks to the Genetic Services Committee and Billing and Reimbursement Subcommitee for their review and contributions, especially **Debra Lochner Doyle, Leslie Cohen, Kristen Shannon, Diana Chambers, Robbin Palmer, Vickie Venne, Jill Yelland** and **Lance Grau.** ❖

☞ **Barbara Pettersen, MS,** Chair, Genetics Services Committee, barbpett@bendcable.com

☞ **Leslie Cohen, MS,** Chair, Billing and Reimbursement Subcommittee, leslie.cohen@uhhs.com

Voices of Our Community,

from page 4

profession must take seriously.

Reality Check

Recognizing this reality, while perhaps disappointing, is not difficult. Formulating a plan to stay alive and thrive *is* difficult. Justifying our worth in a monetary manner is inherently contradictory to how we work. Many of us likely were drawn to this profession knowing that success is not measured by the bottom line. The information, validation, comfort and support we provide our patients cannot be monetarily quantified. Yet I'm hearing that unless genetic counselors find a way to make money, we could be squeezed out of the health care arena – not because our job is unimportant or unworthy but because the bottom line directs administrative support, and in this respect, we have little to contribute to the pot.

Call to Action

After months of discussing this issue with colleagues, and sadly watching friends leave the profession, I believe now is the time to follow the advice of Dr. Maclean and act through our SIGs and committees. Together we can create and standardize questionnaires for each of our specialties to measure the outcomes that have meaning to our employers. Through these questionnaires we can quantify what we already know – that we are valuable and necessary professionals in the health care field. Accomplishing this immense task will take time and work from every one of us. It is no longer enough to sit back and hear what others are doing in this effort. If we believe in what we do, we must all work together to guarantee our survival. ❖

☞ Email responses or ideas for "Voices of Our Community" to khunt@azcc.arizona.edu

Research Network

Cancer, Longevity, Ancestry and Lifestyle (CLAL): A case-control study of prostate cancer among Ashkenazi Jewish men

This study seeks to identify specific alleles associated with prostate cancer by comparing Ashkenazi Jewish men with prostate cancer and an Ashkenazi Jewish control group. Due to the relatively homogeneous nature of the population, the goal is to compare the alleles at polymorphic loci throughout the genome in men with and without prostate cancer. Each participant will complete a detailed questionnaire and provide DNA from blood samples and/or mouthwash samples. Best referrals are men diagnosed with prostate cancer at a young age, with a family history or with a Gleason score of 7 or more. There is no cost to participate, and travel is not necessary. ❖

☞ **Peggy Cottrell, MS;** 718-430-3739; pcottrel@aecom.yu.edu

Enhanced Screening Program (ESP): Use of breast MRI to screen high-risk women

This study is investigating the effectiveness of an intensive screening program, including mammogram, breast ultrasound, MRI and clinical breast exams, for the detection of breast cancer in high-risk women. Eligible women must have strong family histories, resulting in at least a 20% likelihood to carry a BRCA1 or BRCA2 mutation, and be either unaffected with breast cancer themselves or have Stage 0 or Stage 1 cancer not treated with mastectomy. Participants will receive genetic counseling, genetic testing and an annual MRI at no cost. Women who have tested positive for a BRCA mutation and have not had a mastectomy are eligible for screening. Travel is required to White Plains Hospital in New York. ❖

☞ **Peggy Cottrell, MS;** 718-430-3739; pcottrel@aecom.yu.edu

The Colon Cancer Sibling Pair Study

This study is designed to elucidate both environmental and genetic factors leading to the development of colon cancer. Eligible families must include at least two living siblings with a confirmed diagnosis of adenocarcinoma (invasive or in situ) of the colon, rectum or rectosigmoid junction, or adenomatous polyps with high-grade dysplasia. The study is specifically targeting families that do not have FAP, HNPCC or other known colon cancer predisposition syndromes.

Participants will be asked to release their medical records and tumor blocks, submit a blood sample and complete questionnaires. MSI will be performed on the tumor blocks, and if genetic testing is indicated, MLH1 and MSH2 genes will be sequenced. If genetic testing reveals a disease-causing mutation, participants will receive clinical results.

The study is sponsored by the National Cancer Institute and is conducted through a collaboration with several Cancer Genetics Network Centers. ❖

☞ **Angela Schwab, MS;** 801-585-5938; Angela.schwab@hci.utah.edu

Letters to the Editor

Ed Note: These letters represent the ideas and feelings of the authors, only. They do not reflect policies or practices of NSGC or ABGC.

Is Certification Really that Important?

I would like to bring into the open some of the problems that uncertified genetic counselors face, some myths related to board certification and some suggestions for addressing these problems.

Myth #1 – Board certification equals competence in genetic counseling.

Many of us know board certified genetic counselors whose competence we question. There are also many excellent genetic counselors who have Master's degrees but are not certified for a number of reasons including:

- Poor exam taking due to learning disabilities and trouble memorizing
- Financial constraints regarding travel, review course and exam fees
- Life circumstances such as illness, having a baby, caring for family members and moving
- Lack of actual degree required to qualify to take the boards (people with degrees in closely related fields are not considered eligible).

Myth #2 – Board certification is not a requirement to practice genetic counseling.

Judging by job postings on the listserv, about 98% of jobs list BE/BC as a requirement. It is almost impossible to get hired despite the fact that most uncertified counselors have the same genetic counseling training as their certified counterparts. The current system renders the Master's degree in genetic counseling useless for anything except taking the board exam.

Additionally, as states pursue licensure, some are considering using board certification as a requirement. If states refuse genetic counseling without a license, by definition this policy discriminates against new graduates and those who cannot take or pass the exam and increases stress to pass the exam. This remains a sticking point in the licensure process, and many uncertified genetic counselors are opposed to licensure.

NSGC Issues

Uncertified genetic counselors are not eligible for some awards, leadership positions or inclusion in some studies. Do we believe that people who don't pass or take the boards are not leadership material? That they can/should not do research or projects? They pay the same dues as the rest of the genetic counselors and should have the same opportunities.I urge the genetics community to stop sweeping the problem with uncertified genetic counselors under the rug.

Board Issues

I urge genetic counselors to prompt the ABGC to make these changes:

- Allow "special consideration" for individuals who do not qualify to take the board exam by the usual method, e.g. having a different degree
- Allow the exam to be taken more than twice without renewal of cases in a 10 year period
- Offer the exam more than once every three years
- Consider changing to a pass/fail rather than percentile system so poor exam takers have a fair chance.

If boards are the be-all and end-all of a person's genetic counseling career, we must ensure that they are fair and that competent individuals are not being excluded from practicing.

There is stigma associated with being uncertified which is why you rarely hear uncertified genetic counselors speaking out and why this letter is anonymous. There are more uncertified genetic couselors than you probably realize. According to the Executive Office, 374 out of 1705 full members were uncertified as of the 1999 boards. Please ask yourself, when hiring genetic counselors, whether you require BE/BC, or will someone with a Master's degree with experience and good references be able to do the job just as well. ❖

Are Certification Requirements Fair?

Gael Bretz, MS

Earlier this summer I queried the listserv on behalf of a genetic counseling student in the United Kingdom who was interested in her employment prospects in the United States. I received 17 responses, mostly from non-BE/BC genetic counselors. These included, "...it's almost impossible to get a job in the U.S. without at least being board eligible...," "In four years I have not been able to find a full time position...," and "...she should think twice before coming here. The U.S. employers and GCs are not accepting of non-boarded counselors." A few boarded GCs said, "I'm sure there must be some place...willing to take her on," and, "The prospects are severely limited for her." Many respondents asked that I not post their replies on the listserv, suggesting a measure of stigmatization for non-BE/BC individuals.

Supporting Data

The most recent published information regarding non-BE/BC NSGC members comes from the 2000 Professional Status Survey, which states that 4% (39) had no exam plans or were not eligible to take the certification exam, and 122 members had plans to take the 2002 exam. With what I believe is a 30% failure rate for the exam, this might mean an estimated 36 persons who found their eligibility at risk, with some portion of them losing their eligibility altogether.

In discussing these issues with colleagues several questions arose. Has it become increasingly more difficult to attain the requirements for BE/BC? In the UK a new MSc graduate works as a student for 27 ...to page 12

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LETTERS TO THE EDITOR,
from page 11

months in a paid postition, logging cases for registration. Would it be more realistic to allow U.S. GCs to log cases at their place of employment? With the dramatic increase in genetic knowledge, is the scope of the general exam too broad? With the vast majority of employers requiring BE/BC, is there a discrimination factor involved? How do uncertified individuals "prove" themselves to prospective employers and other genetic counselors without these credentials? Does the NSGC, as the leading voice of our industry in the U.S., have a responsibility towards these individuals? What does the future hold for those who have not achieved board certification?

I have worked with both certified and non-certified genetic counselors and can find only this single factor that separates them in their abilities and skills. I would encourage those concerned, or even curious, about this issue to add their voices. ❖

CLASSIFIED

LOOKING FOR THE **CLASSIFIEDS?**
THEY'LL BE ONLINE STARTING EARLY JANUARY!
GO TO:
www.nsgc.org

IN MEMORIAM

Melissa Valentine Hill Davis, MS.....
passed away from cancer on November 20. Melissa joined Prenatal Diagnosis of Northern California in July 2003, shortly after receiving her Master's in Genetic Counseling from the University of California, Irvine. Melissa was an outdoor enthusiast who enjoyed hiking, camping, cycling, deep sea diving and kayaking. She also belly-danced, was a member of the Sierra Club and Easter Seals and was a Big Sister. Melissa loved being a genetic counselor. She will be remember for her kindness, her relaxed enthusiasm and the courage and sense of humor she showed while facing her illness.

Dorothy Wertz, PhD.....
died on April 29 at age 65 while scuba diving in Cancun. Dr. Wertz conducted research on ethical issues in genetics, co-founded the ethical newsletter "Geneletter" and was a staunch supporter of genetic counselors. Her warmth and outspokenness made her a true leader in the field of genetics. ❖