PERSPECTIVES
in genetic counseling

Volume 26 Number 2 Summer 2004

national society
of genetic
counselors, inc.

nsgc

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

www.nsgc.org

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NSGC TO START FOUNDATION

Dawn Allain, MS and Bea Leopold, MA

The Board of Directors is pleased to announce its recent unanimous vote to start a Foundation of the National Society of Genetic Counselors. This action is the result of the work of the Foundation/Tax Exempt Donations (TED) Task Force and an independent feasibility study by Donor Strategies.

STUDY ACTIVITIES

Donor Strategies carried out the following activities to determine if NSGC should establish a 501c(3) association foundation:

- Assessed NSGC's governance structure, budget, membership, programs and services, non-dues revenue and past and present fund raising efforts.
- Drafted a prospectus based on the TED Task Force's work describing the proposed foundation and its mission and future plans.
- Conducted 26 informational interviews, which included NSGC members and non-members.
- Conducted two focus groups of NSGC Board members.
- Conducted research on foundations for potential funders and reviewed the report by **Kathleen Fergus,** Chair of the Development Subcommittee.
- Presented findings to NSGC's Board at their June meeting in Chicago.

Interviews were qualitative not quantitative. The consultants asked a range of questions pertaining to NSGC's image, reputation,

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DISCLOSING TEST RESULTS.......
PRACTICES IN CANCER GENETIC COUNSELING

Jennifer E. Axilbund, MS

It seems that many (if not most) cancer genetic counselors require that patients return to clinic to learn the results of their genetic tests. Provider perception is that patients benefit from in-person discussion of what often are complicated results. Until recently, we had such a policy here at The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins in Baltimore MD. Lately, though, patients have expressed that such a policy is inconvenient. Therefore, we revisited our requirement of a disclosure visit.

RESEARCH FROM THE FIELD

Little research is available on this topic. At the ISONG conference in November, 2003, a study was presented on the effects of phone vs. in-person disclosure for BRCA1 and BRCA2 testing, conducted by **Jean Jenkins, PhD** of the NIH. Results are not yet published. Other genetic counselors around the country have started or are contemplating similar studies.

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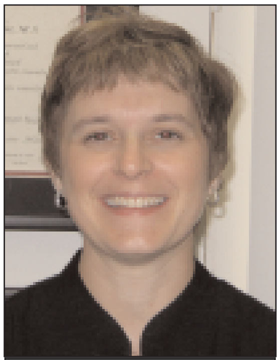
PRESIDENT'S BEAT

Time has flown so quickly! Since the last President's Beat, the Board of Directors has been busy tackling the strategic initiatives put forth in our 4th strategic plan. I encourage you to take a few moments to visit our website and familiarize yourself with this important document! Below are some of the initiatives we have begun.

TASK FORCES AT WORK

The Scope of Practice and Genetic Service Delivery Model Task Forces have been appointed and are off to work. The Genetic Counseling Definition Task Force is reviewing input received from NSGC members and outside organizations so a final definition can be voted on this summer. The Visibility Task Force has begun identifying methods to increase our exposure. The Social Issues Committee is establishing a Legislative Issues Task Force to identify national issues that NSGC needs to monitor or undertake to develop relationships with like-minded advocacy groups.


Dawn Allain, MS

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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 **September 15***
*Submission deadline **August 11***

BILLING & REIMBURSEMENT TOOLS

We are continuing to address billing and reimbursement for genetic counseling services. Data from a cost-benefit analysis for prenatal genetic counseling services will be presented during our Annual Education Conference. The Billing and Reimbursement Subcommittee is also completing work on a tool kit for use when dealing with payers in your practice setting.

FUNDS FOR LICENSURE

I am *thrilled* to announce that the Board of Directors approved the Licensure Grant Award Subcommittee protocol to disburse NSGC monies to states pursuing genetic counseling licensure. Three thousand dollars is available this year, with more expected next year. For those interested in applying for these funds, keep your email boxes open for an e-blast!

BEYOND THE STRATEGIC PLAN

We also have been undertaking activities beyond our Strategic Plan. I will represent NSGC at SACGHS' June meeting for a roundtable discussion regarding our efforts at genetics education and training of health care professionals, and **Kelly Ormond,** president-elect, will provide public testimony. The Board discussed whether NSGC needs to change its structure or function and decided that although a change will most likely occur, we first need to gather information about our current Board inefficiencies. We also voted to establish an NSGC foundation (see story on page 1).

PR SUCCESS

NSGC and STAR/Rosen continue to increase the public's knowledge of genetic counseling through magazine articles, newspaper stories and television (see our website for PR reports.) At the time of this writing, I am working with a producer from the TODAY show to develop a storyline on newborn screening, scheduled to air the last week of June! STAR/Rosen also is developing a marketing strategy targeting human resource benefit directors. Our first planned outreach to this group will occur at our Annual Education Conference.

As you can see, our cups are overflowing and our plates are full! I again encourage you to become involved in our organization. It will take all of us to accomplish these visionary *and* critical goals! ❖

Dawn C. Allain

Dawn Allain
2003-2004 President

GENETIC COUNSELING IN SOUTH AFRICA

CHALLENGES IN A REFORMED COUNTRY

Patricia Craig, MSc

South Africa recently celebrated its 10th year of democracy a credit to our Constitution, which enshrines basic rights previously denied to the majority of South Africans. The right to health care has become one such reality. The challenge to the field of genetics is how to position and deliver comprehensive services within a structure that has so many demands.

BARRIERS TO ACCESS

We are a country of diversity, with 11 official languages and several ethnic and religious groups with varied beliefs about spirituality, ancestry, procreation, illness, health and inheritance. Many languages have no words to describe genetic concepts; we do not yet have any African-language speaking genetic counsellors. In many communities, there are myths and stigmas about birth defects which are not understood and are not being explored, by genetics health care professionals.

We also are a country with high rates of illiteracy, unemployment, poverty and AIDS/HIV and with huge rural and urban discrepancies related to healthcare resources and infrastructure. Affected individuals and families often are not afforded information and interventions to address even basic health issues. Members of rural communities may have to travel hundreds of kilometers to tertiary hospital settings, the only place where comprehensive genetic services are available.

FORMING A NEW MODEL

Historically we have used genetic counselling models from developed countries. The goal is to integrate these concepts into the Zulu philosophy of Ubuntu, which builds its foundations on the use of African cultural, linguistic, spiritual and human resources and recognizes an individual's humanity through other people.

There is a wealth of information available from anthropologists, sociologists, linguists, traditional healers and community-based health workers, as well as our clients, to help us meet the needs of the broader community in South Africa. Limited research has been conducted within the genetics field looking at the role of integrating indigenous customs, beliefs and practices. My own personal experiences and feedback from clients and colleagues will be translated into a PhD research proposal. ❖

> *"In a country with a population of 40 million people, it is impossible for the few registered genetic counselors to access all communities."*

THE STATE OF GENETIC SERVICES

Tina-Marié Wessels, MSc

South Africa has made immense progress since the 1970's, when genetic services were offered by a network of government sponsored genetic nurses and a few specialists in academic centers. The National Department of Health, together with a team of genetic health professionals, published "Policy Guidelines for the Management and Prevention of Genetic Disorders and Birth Defects and Disabilities" in 2001. This document addresses strategies for prevention, delivery of services, education and training, laboratory services and ethics in the provision of genetic services.

DIVISION OF SERVICES

Today in South Africa, genetic counselling services are offered in four centres. Two offer fully integrated services including laboratory and clinical support, and all offer outreach clinics. Twelve genetic counsellors are registered with the Health Professions Council of South Africa (HPCSA). Eight work in the four medical centres, and four work in private practices associated with commercial labs.

Both government and private health care facilities are available. Genetic counselling services at the four medical centres are mainly associated with government subsidized health care. While patients who utilize private health care can receive genetic counselling at these centres, most patients receive "genetic advice" from their general practitioners.

TRAINING: REALITY VS. NEEDS

Only the University of the Witwatersrand and the University of Cape Town offer a Master's degree training program in genetic counselling. Witwatersrand implemented its program in 1990, and the Cape Town program started in 2004. The two year MSc(Med)

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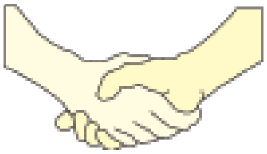
WHAT IS GENETIC COUNSELING ... TO AN AUDIOLOGIST?

Nancy Steinberg Warren, MS

In a genetic counselor's role as educator, most gratifying are the AHA! moments when you have facilitated a student's insight, perspective and direction. I have had the opportunity to teach several allied health graduate students enrolled in a first-year genetic counseling course called, "Introduction to Genetic Counseling" (IGC). The first and last assignments of the year are the same: write a reflective paper on the topic "What is Genetic Counseling?" and share how your personal perspectives have changed. This repetitive assignment might be loathsome to someone who is not studying to become a genetic counselor. However, the end of year paper I received from **Gina Montuoro, BS,** a doctoral student in audiology, underscores that we can have a tremendous impact on health care providers outside of our field. Excerpts from her paper follow.



"I remember convincing myself that I had a place in this class because I worked with infants and hearing loss, which occasionally involved genetics. We were always using the term genetic counseling in clinical situations, and I thought that maybe I should know what that was. As the class developed and we began various assignments I thought, "Hey this is good. This information is in the infants' medical charts." And that was ONLY the beginning. I will never be able to fully relay what this class has meant to me.

When I began pursuing my PhD I had difficulty focusing my passions within the field of audiology. Whenever I tried to narrow my interests it always felt like more emotion and less science than I was used to in my academic and clinical training. Through this course I discovered the skill of counseling within a medical profession. AHA! This is what was ALWAYS missing from my professional path. The skills and abilities to recognize that people seeking medical help – MY help – needed counseling specific to their medical needs!

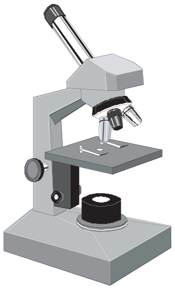
What an enormous difference this one realization has made in my life! I have narrowed down a focus for my dissertation based on genetic counseling ideas and literature. I have shared numerous articles from your field with my peers. I have encouraged students to learn skills that would be transferable and invaluable to their own field. I have investigated and made suggestions for remediation of the lack of this material in our own curriculum. But most important, I have greatly improved MY own skills in the clinic. I have heightened my awareness of cultural and religious diversity, psychosocial needs and assessments, support groups, attending skills and, of course, empathy, empathy, empathy! I cannot imagine practicing in my field without these skills! I DO NOT consider myself an expert, rather I will continue to learn on my own and with your profession's help! We are in allied health professions, and it is inevitable that we will benefit by learning a little about each other's practices and expanding on that knowledge in a way that benefits our clients.

These classes have completely changed my perspectives on what a genetic counselor is. I thought that genetic counselors tested families and told them whether or not their children would have birth defects. Period. Today, I am an advocate for the field. I value the importance of what you do and appreciate the difficulty in what you do. I know that if I had to make a referral to your clinic I could do it with appropriateness and confidence. I know that I can help my clients better now by truly understanding and LISTENING. Funny, isn't it? An audiologist can finally learn to listen, simply by taking a genetic counseling class. Thank you!"

Postscript: Gina has developed and taught a course for audiology students, incorporating many of the skills that she learned in IGC. I challenge all genetic counselors to reach out to allied health care providers from diverse disciplines! ❖

RESEARCH NETWORK

NEW STUDY ON FRAGILE X SYNDROME



The NIH recently funded a research study focusing on how families with children who have fragile X (FXS) make adaptations. We are seeking African American mothers living with a biological child age 1 – 14 years who has FXS. Participation will include a family-friendly assessment. Thank you for helping us understand and support these families! ❖

☞ Jane Roberts, 800-351-4603;
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www.fpg.unc.edu/~fx

GIVING CANCER TEST RESULTS, *from page 1*

For more immediate information, a recent poll of the Familial Cancer SIG listserv assessed disclosure practices. As expected, cancer centers' policies are far from uniform. Many genetic counselors firmly supported in-person disclosures, citing numerous benefits. However, a growing number of counselors have tried phone disclosures, with largely positive experiences. The following is a summary of the CASIG responses.

TAILORED OPTIONS

Genetic counselors who initially enforced in-person disclosure now ask the patient how they would like to receive test results. Others do not expressly offer phone disclosure but will provide it at the patient's request. Still others cite the telephone as their preferred method. Everyone agreed that there are some patients for whom phone disclosure is not acceptable.

THE PROS OF PHONE DISCLOSURE

One advantage of phone disclosure is more clinic time to see new patients. Other pros include minimizing the patient's time away from work, especially if he/she has already been significantly absent due to treatment as a result of the side effects of chemotherapy. As pre-test counseling is traditionally extensive, most patients already understand the implications of testing, especially when reinforced by a summary letter. Most patients who receive a positive result choose to return to clinic, and disclosing to them over the phone provides time to formulate questions after the initial adjustment to the news. Patients with cancer often need some sense of control over their lives. If they feel it would be preferable to receive results in their home surrounded by family, then perhaps our "policies" are less beneficial than we had surmised.

AND THE CONS…

There are also disadvantages. Phone calls can be time-consuming and are often made after hours to accommodate patient schedules. No physician is present to address specific medical questions, and telephone time may not be billable. It also may be difficult to facilitate the emotional aspect of the conversation when relying on voice rather than visual cues. Further, patients who test positive may not return for follow-up discussion, resulting in unanswered questions or misinterpretation of information.

A TRIAL RUN

After considering the experiences of other cancer genetic centers, we recently implemented phone disclosures for the majority of our patients. Feedback thus far has been very positive, but only time will tell if this method is preferred. Until then, we will anxiously await the results of current and proposed research studies evaluating this issue. ❖

RESULTS DISCLOSURE:

REFLECTIONS IN TRADITIONAL GENETIC COUNSELING

Tillie Young, MS

Within the realm of offering carrier, prenatal and diagnostic genetic testing, there is a precedent for notifying patients of their test results in person and by phone. While genetic test results have become increasingly complicated and difficult to explain, testing itself has become more commonplace, and our caseloads subsequently have risen.

In prenatal genetic counseling, it is common for normal amniocentesis results to be disclosed by telephone but abnormal findings to necessitate a return visit. Receiving test results is a time of peak patient anxiety when details are difficult to absorb. When results are abnormal, we all are familiar with counseling "after the fact."

Each center, like each counselor, develops a unique style and format for conveying and documenting information exchanged. One large northeastern center provides all pre-CVS counseling by phone. Another requires every pre-amnio patient to be seen in person. Most consider fragile X testing to be complicated enough to require pre-test genetic counseling in person, though results are often conveyed by phone. For cystic fibrosis, where DNA carrier testing may not detect all mutations, results also are usually are given by phone.

Even our mentors might not be in agreement over phone or in-person genetic counseling. **Dr. Melissa Richter** saw the need for our specialty precisely because physicians lacked the time and interest for the interactive counseling process. **Dr. Seymour Kessler,** though, urged us to ask the patient, "What can I do for you?" and then do it.

It seems best to be flexible about reporting results. Keeping in mind the ethical principles of beneficence and recognition of autonomy, the use of the telephone can be a reasonable way to convey results, when agreeable to the patient and genetic counselor. Ongoing research to measure efficacy and patient satisfaction will be helpful. Will notification via the Internet be next? ❖

Career Watch

GENETICS EDUCATION PROGRAM GOES INTERNATIONAL

Claire Noll, MS

Julianne O'Daniel is a pediatric genetic counselor who graduated from the University of Pittsburgh. Now she oversees training in medical genetics, research, ethics and counseling for the genetic studies coordinators working at the Institute for Biomedical Sciences at Academia Sinica, the Taiwanese counterpart to the National Institute of Health. Read on to learn about this unique international opportunity that enhances awareness of the medical genetics field in Taiwan.

Q. Tell us about your job.

A. I am the Associate Director of the International Genetics Training Program at Duke University Medical Center (DUMC). This program is a specialized course developed as part of a training grant with the National Clinical Core for Genomic Medicine of Academia Sinica in Taipei, Taiwan. The head of this core, **Dr. Y.T. Chen,** is the Chief of the Division of Medical Genetics at DUMC. He has experience with and respect for the specialized skills of genetic counselors and suggested that the Taiwanese genetic studies coordinators be trained in a manner similar to genetic counselors. The basic structure of the program was developed by its director, **Dr. Allyn McConkie-Rosell.** I am responsible for planning the content and structure of the program, implementing the program, providing many of the lectures and evaluating the program to ensure it is meeting its objectives and everyone's expectations.

Q. How many students are in the program, and how long does their training last?

A. Typically we have three students for each program session. The duration of the program is approximately 20 weeks. So far 10 students have completed the course.

Students who completed the International Genetics Training Program in December, 2003. From left to right: Melody Lin, Ying-Ju Chen and Ruth Chen.

Q. Since that's shorter than a standard training program, how do you cover everything that's needed?

A. The goal is to expose the students to genetic counseling skills, not to train certified genetic counselors. The majority of the students have nursing backgrounds. Some have master's degrees in genetics or social work. I aim to give them the essential tools they need plus some extras to perk their interest in genetics.

Students start with a few weeks of lectures covering basic cyto- and molecular genetics, metabolism, population genetics, risk assessment, ethics and counseling skills. Then they begin several rotations. Their experiences include the Medical Genetics, Metabolic, Down Syndrome, Cancer and Prenatal clinics as well as clinical trials in gene therapy, single gene and complex disease research, molecular and cytogenetics laboratories, and pharmacogenomics.

Two to three weeks of lectures are focused on skills pertinent to a genetic counselor working in research, including topics in epidemiology, research ethics and IRBs, study design, clinical trials and patient/participant interactions. The students complete a research rotation through the Center for Human Genetics here at DUMC where they are exposed to various complex genetics studies and develop IRB protocols.

Q. What feedback have you received from program graduates?

A. They are clearly and understandably overwhelmed when they first get to DUMC, as they face a steep learning curve in a non-native language. Where they finish the course, however, the students feel comfortable with their new skills which they can immediately apply to their work in Taiwan.

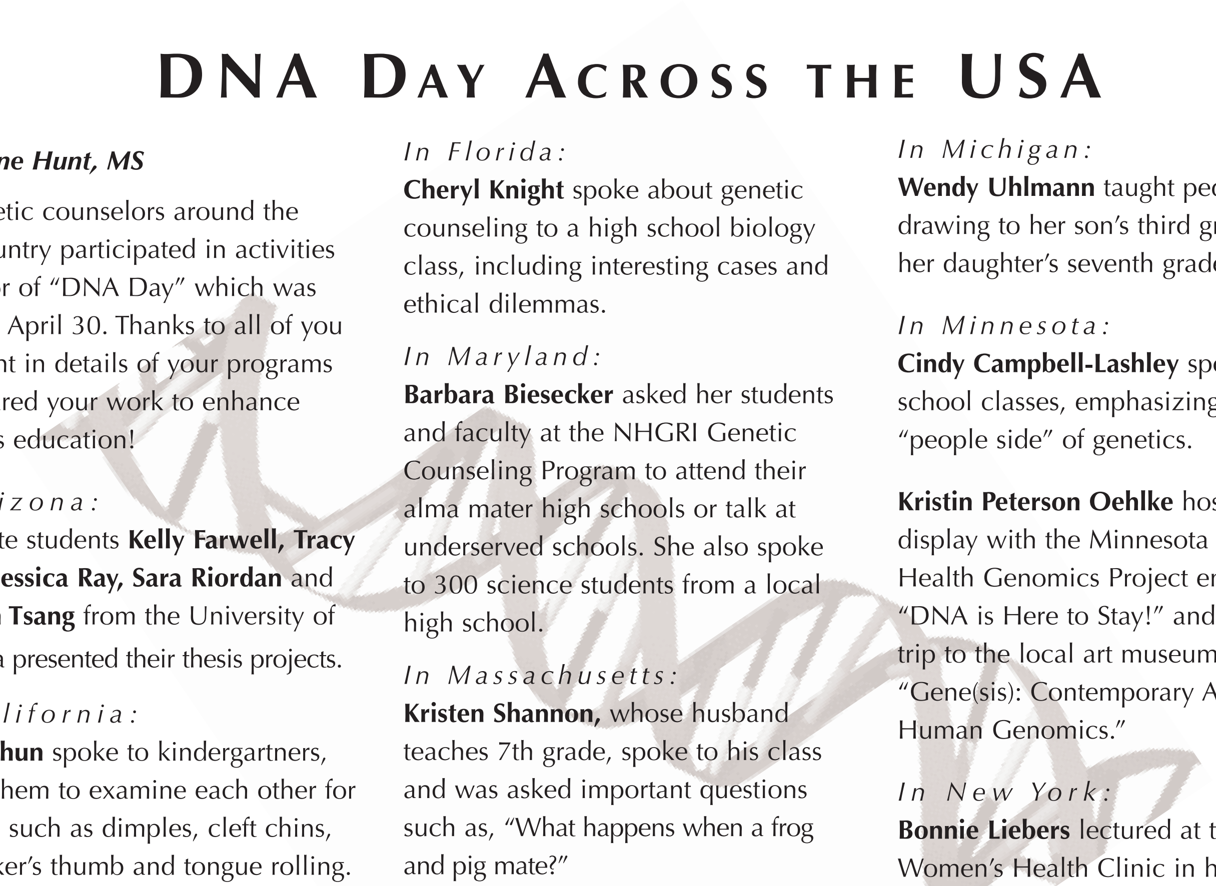
The students also have indicated that the program has increased their interest in their research work and in genetics as a whole. A few students have indicated that they would eventually like to work in a clinical genetics setting in Taiwan.

Q. Have any other countries expressed interest in starting a training program for their scientists?

A. Several South American scientists have expressed interest in a similar program. I believe that other countries have contacted some genetics centers in the U.S. It would be interesting to learn if other formal arrangements such as ours exist. ❖

☞ Julianne O'Daniel,
odani002@mc.duke.edu

DNA DAY ACROSS THE USA



Katherine Hunt, MS

Genetic counselors around the country participated in activities in honor of "DNA Day" which was held on April 30. Thanks to all of you who sent in details of your programs and shared your work to enhance genetics education!

In Arizona:
Graduate students **Kelly Farwell, Tracy Futch, Jessica Ray, Sara Riordan** and **Marilyn Tsang** from the University of Arizonia presented their thesis projects.

In California:
Nicki Chun spoke to kindergartners, asking them to examine each other for features such as dimples, cleft chins, hitchhiker's thumb and tongue rolling.

In Florida:
Cheryl Knight spoke about genetic counseling to a high school biology class, including interesting cases and ethical dilemmas.

In Maryland:
Barbara Biesecker asked her students and faculty at the NHGRI Genetic Counseling Program to attend their alma mater high schools or talk at underserved schools. She also spoke to 300 science students from a local high school.

In Massachusetts:
Kristen Shannon, whose husband teaches 7th grade, spoke to his class and was asked important questions such as, "What happens when a frog and pig mate?"

In Michigan:
Wendy Uhlmann taught pedigree drawing to her son's third grade and her daughter's seventh grade classes.

In Minnesota:
Cindy Campbell-Lashley spoke to high school classes, emphasizing the "people side" of genetics.

Kristin Peterson Oehlke hosted a display with the Minnesota Public Health Genomics Project entitled, "DNA is Here to Stay!" and led a field trip to the local art museum to view; "Gene(sis): Contemporary Art Explores Human Genomics."

In New York:
Bonnie Liebers lectured at the Women's Health Clinic in her hospital and at the Tumor Board.

In North Carolina:
Jennifer Sullivan, Blythe Crissman, Julianne O'Daniel and **Alexis Poss** asked students to draw a pedigree for the poem, "I am my own Grandpa."

In Oregon:
Cori Feist spoke to an English as a Second Language class, presenting topics on genetic counseling, testing and biotechnology.

In Pennsylvania:
Laura Dudlicek spoke to high school classes on "the genetics of myths and legends," exploring the theory of vampires having porphyria and relating holoprosencephaly to the mythical creature Cyclops.

Sheila Solomon hosted a table at Allegheny General Hospital with a DNA model and several brochures. ❖

AEC 2004 JUST A FEW MONTHS AWAY

By now you should have received your AEC 2004 Conference brochure. Register by July 16th to avoid late fees. After registering, you will receive a survey about DC touring options and wellness activities. Please reply promptly!

☞ **REGISTER ONLINE:** www.nsgc.org/conference/aec.asp

STRATEGIC PLANNING WANTS YOU

NSGC is ready to shape our own future! Attend the "Moderated Discussion Regarding NSGC Strategic Initiatives" on Saturday, October 9th, at 8:30 pm to ask questions and learn how you can contribute to the many projects in NSGC's three-year strategic plan.

BOOK SIGNING!

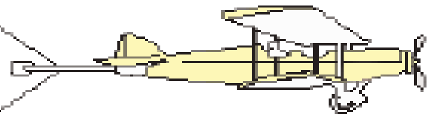
You may have noticed that **Rachel Simon,** author of the acclaimed novel, "Riding the Bus with My Sister," is a plenary speaker. This true story, which is being made into a CBS movie, recounts Rachel's relationship with her sister who has developmental disabilities. Order the book through the NSGC bookstore page under "Resources" or buy it at the conference, and have your book signed by the author.

NEUROGENETICS RESOURCE

The Neurogenetics Short Course planning committee invites those involved with neurogenetic studies to contribute to "The Summary of Neurogenetics Research Studies and Genetics Counselors' Roles." This resource will serve as a reference for ongoing studies. Submit your summary form before July 2nd by going to www.nsgc.org and clicking on the neurogenetics short course link.

☞ Erin Linnenbringer, erinlp@bu.edu. ❖

MEDIA WATCH



Angela Geist, MS, and Roxanne Ruzicka, MS

March 5 – ABC, "20/20"

This episode explored cousin matings and discussed the NSGC-funded research by **Robin Bennett** about the risk for genetic conditions in the offspring of consanguineous couples.

March 13 – NPR, "Genetic Testing, Part 2: Reading Genes for Disease"

This second of a two-part series on genetic testing features a couple that decides against prenatal genetic testing for cystic fibrosis even though the wife has the disease. The husband also decides not to have carrier testing. The first part of this series discussed a woman who sought genetic counseling for breast cancer.

April '04 – University of California, Berkeley, "Wellness Letter"

This issue presented an article on tracing your family tree called, "Family History 101: How Important Are Your Genes?" The article mentions the importance of genetic counselors and includes the NSGC as a resource.

April 1 – NBC, "ER"

A child with splenic sequestration was diagnosed with sickle cell anemia. The boy's father said the diagnosis must be wrong because he and his wife saw a genetic counselor who said that only his wife was a carrier. **Dr. Kovac** performed more testing and suspected non-paternity.

May '04 – Medinfosource.com

This online resource for consumers presented an article about a couple at risk for SMA who undergoes CVS. **Nancy Kramer** was interviewed and genetic counseling was discussed.

May 10 – *TIME Online Magazine*, "Savior Parents"

This story highlighted a woman whose child has a chromosome 18 deletion, a family whose child has progeria and a family with two children with ataxia telangiectasia to show how "rescuing an ailing child can become a crusade and a career." These parents devote their lives to providing for their children with "orphan" diseases that are not researched extensively. The Genetic Alliance is mentioned.

June '04 – *Redbook*

This article followed women who have had blood clots due to pregnancy, oral contraceptive use and hereditary risk factors (factor V Leiden and prothrombin mutations). The National Alliance for Thrombosis and Thrombophilia (NATT) is mentioned but not genetic counseling. ❖

NSGC WEBSITE WATCH

SEARCHING FOR WWW.NSGC.ORG

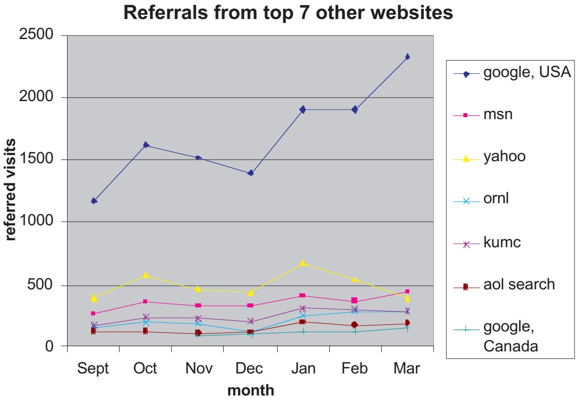
First in a Four Part Series

Aubrey R. Turner, MS

The NSGC website receives 20,000 – 30,000 visits each month. Where are all of these visitors coming from? How do they find www.nsgc.org? Most people find us via a direct link from another site or a search engine. One direct link, www.kumc.edu, sends an average of 250 visitors each month. One search engine, www.google.com, sends an average of 1700 U.S. visitors each month and another 100 from Canada.

The table below shows the recent traffic generated by the top referring sites. Note the increased referrals from Google, which may reflect the intensified marketing efforts of the StarRosen group. The top referral sources, however, only account for a fraction of our total visits. Each month, more than 650 different websites send people to us. With such a variety of monthly referrals, we end up with 30,000 visits. If these visits generate multiple clicks within the site, this translates into more than 500 thousand hits per month!

We tabulated the words and phrases people enter into search engines to find our website. Most visitors use terms like "genetic counselor," "genetic counseling," "genetic" and "genetics." The next time you are on the web, pick your favorite search engine, and see if you can find us online!



Next issue: "Searching for a Genetic Counselor." Once visitors are at the site, they most likely use the "find a counselor" feature. We'll look at these numbers and demystify the process of updating your membership information online. ❖

RESOURCES

GENOMIC MEDICINE: ARTICLES FROM THE *NEW ENGLAND JOURNAL OF MEDICINE*

Edited by: **Alan E. Guttmacher, MD, Francis S. Collins, MD, PhD,** and **Jeffrey M. Drazen, MD**
Published by: The Johns Hopkins University Press and the *New England Journal of Medicine*
Reviewed by: ***Scott Weissman, MS***

Genomic Medicine is a compilation of the genomic-based articles that appeared in the *New England Journal of Medicine* between 2002 and 2003. Many were written by distinguished authors, including **Henry Lynch, MD, Christopher Ellis, PhD,** and **Wylie Burke, MD, PhD.** The articles are comprehensive overviews of a variety of genetic dogmas.

The first few chapters focus on the basic principles of genetic testing and newborn and population screening, including informed consent, ethical issues in testing children and carrier screening. Genetic counseling is painted favorably.

Chapters 5, 6 and 7 review pharmacogenetics/genomics, including current applications of this emerging science, and discuss the implications of single nucleotide polymorphisms.

The next five chapters focus on adult conditions. **Henry Lynch** and **Albert de la Chapelle, MD, PhD,** offer a wonderful summary of hereditary colon cancers. **Richard Wooster, PhD,** and **Barbara Weber, MD,** present breast and ovarian cancer. They go beyond BRCA1 and BRCA2 and summarize low penetrance genes and whole genome approaches in analysis. **Louis Staudt, MD, PhD,** reviews the molecular diagnosis of hematologic cancers, spotlighting microarray technologies. The other two chapters offer somewhat basic but thorough reviews of Alzheimer, Parkinson and cardiovascular diseases.

The chapter on the ethical, legal and social implications of genomic medicine presents the realities (or non-realities) of workplace and insurance genetic discrimination. A comprehensive table lists each state and what type of legislation is active. The table is divided into heath insurance, life insurance, employment and confidentiality. As many patients ask about state laws protecting their family members, this table is a must for genetic counselors.

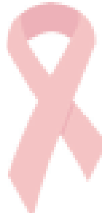
One criticism of the publication is that many authors pick the same genetic diseases (e.g., cystic fibrosis, hereditary hemochromatosis, sickle cell anemia, Tay-Sachs) to explain their points. On the plus side, the illustrations used in the publication are perfect for creating presentations or as adjunct genetic counseling tools, with appropriate copyright permission.

Genomic Medicine is well suited for physicians and genetic counselors. I would highly recommend this compilation of articles, each of which can be downloaded at no charge! ❖

WILL SOON BE AVAILABLE

Minutes from the NSGC Board of Directors meetings now are available on the NSGC Website. To see the minutes from June 2004, go to www.nsgc.org/members/bod_minutes/index.asp.

DEAR MOM, I AM SORY THAT YOU HAD TO GET BREST CANSER



By: **Mikayla A. Jackson**
Published by: Guardian/ Emerald Hill Books
$9.95 + shipping and handling
Reviewed by: ***Jill Yelland, MS***

Dear Mom is a touching paperback, written by seven year-old **Mikayla A. Jackson,** that traces the journey of a young mother and her family as they experience what it means to live with and survive breast cancer.

The story is told through the eyes of a child, with many words spelled as they sound to her, like "cemotheripe" and "canser." The text is simple for young readers. Mikayla provided the illustrations for the book. Adorable pencil drawings reflect the different experiences of her mother and family, such as her mother's gradual hair loss and the whole family's participation in *Race For The Cure*. Additional pages are devoted to the dedication and foreword (the latter is written by Mikayla's mother), an inspiring poem by Mikayla's aunt and a series of photographs of Mikayla's family as they celebrate the happy ending of her mother's journey with breast cancer.

Mikayla was inspired to write this story after she realized that other young children might share her worries and questions. A one dollar donation from each book will be contributed to the Susan G. Komen Breast Cancer Foundation. ❖

To order contact:

☞ Karla Randle-Jackson;
901-754-4456;
dearmom030902@aol.com;
www.emeraldhillbooks.com

BULLETIN BOARD

OKLAHOMA LAUNCHES GENETIC COUNSELING PROGRAM

Susan Hassed, MS

The University of Oklahoma Health Sciences Center announces the launch of the Master of Science in Genetic Counseling (MSGC) program, the 28th genetic counseling graduate program in the U.S. and Canada.

The MSGC program obtained accreditation from the American Board of Genetic Counseling last summer and enrolled its first class of three students. These students have completed their first two semesters of didactic work and will begin clinical and laboratory rotations this summer.

THE CORE CURRICULUM

The MSGC program is comprised of two semesters of classroom study, four clinical placements, two placements in either a research or clinical lab and a research thesis. Courses are taught by faculty members, professionals in the community, researchers from the Oklahoma Medical Research Foundation and patients and families.

INNOVATIONS IN TRAINING

The program combines a research focus with psychosocial theory and practical experience. The goal of the program is to educate students to provide the best possible genetic counseling for patients and families and to serve as educators, researchers and administrators, or anywhere their knowledge and interests take them. ❖

☞ Susan Hassed, Director, 405-271-8685; www.OUHSC.edu; Susan-Hassed@ouhsc.edu

SOCIAL ISSUES COMMITTEE UPDATE

The Social Issues Committee (SIC) invites you to participate in several exciting projects:

GENETIC DISCRIMINATION

A campaign has begun to educate NSGC members and the public about the myths and realities of genetic discrimination. We plan to publish a review of the history of eugenics, genetic discrimination, current research and legislation.

☞ **Sarah Burton,** sarahmsgc@hotmail.com

☞ www.nsgc.org/members/com_sub_activities/genetic_discrimination.asp

SNPS AND PGD

Two authoring committees are being formed to draft NSGC's position statements on:

- using single nucleotide polymorphisms to predict risk for common disorders and non-health-related traits (e.g. propensity to get wrinkles); and
- issues surrounding preimplantation genetic diagnosis (PGD) including sex selection and non-disease traits.

☞ **Cheryl Scacheri,** cheryl@genedx.com

SPEAK UP, SPEAK OUT

Do you live in or visit the Washington DC area? The Legislative Subcommittee is looking for people to attend meetings on genetics-related issues, such as the Allied Health Professions Reinvestment Act, SACGHS and genetic nondiscrimination. If you are attending the AEC this October and would like to meet with Members of Congress, the SIC will have online materials with lobbying tips.

☞ **Karen Wolff,** kwolff@gbmc.org

A JOB WELL DONE

Thanks to the NSGC members who commented on our soon-to-be-released position statement on somatic cell nuclear transfer or "cloning." Thanks to **Nancy Kramer** for leading the authoring committee! ❖

MENTOR MATCH

Troy Becker, MS

The Mentor Program, sponsored by the Membership Committee, is planning the 2004 match. The program's purpose is to allow professionals and students/recent graduates to exchange ideas and information about current interests and experiences. The program typically runs six months and begins in October. Mentors and students are urged to be in contact monthly.

For practicing genetic counselors, the mentoring program offers contact with students. For students, the program provides an opportunity to have a resource outside their training program, to discuss issues and concerns with an experienced counselor and to facilitate networking.

Sign up by sending your name to **Troy Becker** before July 23. Include your mailing address for August, when you will be notified of your match. Mentors must have graduated prior to July 2002; students who graduate after January 2004 are eligible. Those who participated previously need to sign up again. We look forward to another successful year of this NSGC program! ❖

☞ Troy Becker, BeckerT@allkids.org

VOICES OF OUR COMMUNITY

A CHARACTERIZATION OF THE "TYPICAL" GENETIC COUNSELOR

Katherine Hunt, MS

When you think about your colleagues, those you work with day in and day out, what adjectives come to your mind? Hard-working? Dedicated? Smart? Maybe even quirky or nerdy? Our profession is filled with talented individuals, but have you really spent time appreciating the ways in which our genetic counseling colleagues shape our lives? A genetic counseling student at the University of Minnesota is writing her thesis project on "The Characterization of the Typical Genetic Counseling Graduate Student." This got me thinking about the "typical" genetic counselor. My hypothesis might go something like this:

I'm not sure how we all start out in genetic counseling training, but there are a few things I'd like to tell you about some of my genetic counseling colleagues in Albuquerque NM, and what a student can expect to encounter several years into the profession. The "typical" genetic counselor colleagues I've worked with have been pioneers as well as professional and tireless caretakers. My good friend, **Jo Cope,** embodies these qualities. Now retired, she is remembered for paving the road for the profession of genetic counseling in our state.

A typical genetic counselor, in my experience, is innovative, determined and witty. My friend, **Lori Ballinger,** can be described with these adjectives. Her loyalty is unfailing. And having someone around who can make you laugh is important, because on those really tough days, laughter is the best medicine.

The typical genetic counselor is courageous and confident. I have a friend, **Kathy Baldwin,** who maintained her board certification while taking time off from her career to raise her children and then returned when they were older. Kathy has taught me the art of patience and perseverance.

Work can be fun as well. The typical genetic counselor is friendly, welcoming, kind and empathetic. **Joanne Milisa** brings to the profession warmth, acceptance and understanding. We all feel as if we have a home when we are around Joanne.

Genetic counselors are adventurers, such as **Margaret Lilley,** who traveled from Canada to spend a few years working in New Mexico. They also are intelligent and independent, adjectives that describe my friend, **Alison Anderson.**

It goes without saying, genetic counselors are an over-qualified group. I give you my experience working with these women in New Mexico for five years. I now live in another city and look forward to learning the qualities of my new genetic counselor colleagues. Suffice it to say, I believe a study on the "typical" genetic counseling student will conclude that these individuals are exceptional people just waiting to touch your life. ❖

SOUTH AFRICA, *from page 3*

in genetic counselling is offered to students with a BSc Honours degree in biological or social sciences. There are currently seven genetic counsellors in training.

In a country with a population of approximately 40 million people, it is impossible for the few registered genetic counsellors to access all communities. More trained genetic counsellors are required if the goal of providing comprehensive genetic services in South Africa is to be realized. Academic centres are being encouraged to offer formalized training for genetic counsellors and to form working partnerships with the government and other organizations. ❖

FOUNDATION, *from page 1*

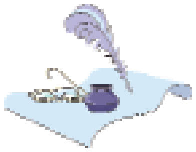
strengths and challenges. These areas will have a direct impact on the potential of establishing a foundation.

Twenty-two of 26 interviewees favored creating a foundation and noted research, education, expert panels and trend analysis as focus areas.

LEGAL ISSUES

The Board met with our legal council, **Paula Goedert,** who addressed setting up the foundation as a legal 501(c)3 charitable foundation. She also addressed facilitating outreach for charitable contributions and how to avoid common pitfalls.

Look for information about our next steps toward our foundation goal in future issues of *PGC*, on the listserv and at our Annual Education Conference in Washington this fall. ❖



LETTERS TO THE EDITOR

"TRADITIONAL" VS. "NON-TRADITIONAL" CAREERS IN GENETIC COUNSELING: DIFFERENT ROLES, SIMILAR GOALS

Genetic counselors in "non-traditional" roles often feel as though they are "different." Many of their colleagues view them as different because their everyday activities diverge from those of a clinical genetic counselor. However, clinical and non-clinical roles in genetic counseling are more alike than some might think.

THE FOCUS IS THE PATIENT

As a group, genetic counselors share similar training, skills, knowledge and ethics. Whether they counsel patients, work in a research or in a public health setting or work for a laboratory, biotechnology or pharmaceutical company, they all strive for the same ultimate goal: to inform people about genetics so that every patient who could benefit from genetic services obtains them. To reach this goal, members of the genetic counseling community must cooperate and embrace the various ways in which members choose to utilize their talents and skills.

While clinical genetic counselors are usually the ones on the "front line" with patients, they cannot assist a patient unless that patient reaches their clinic. How does that patient learn about genetic counseling? Perhaps it's due to a clinical genetic counselor's presentation at grand rounds, which educated the patient's physicians, or their presentation to a support group. Or perhaps the patient discovered genetics after seeing a magazine advertisement designed by a genetic counselor working for a commercial laboratory. Maybe the patient was referred following participation in a pharmaceutical clinical trial. Maybe a public health campaign caught the patient's attention. Does it matter how the patient became interested in genetic counseling? No. The important thing is that this patient will now be offered the genetic services needed.

WORKING TOGETHER

As stated in the NSGC Code of Ethics, "the primary concern of genetic counselors is the interests of their clients." In concordance with this idea, the more genetic counselors in clinical settings and those in commercial organizations separate themselves, the less united they will be in reaching their professional goal. By working together, they can reach a wider audience with a message about the importance of genetic counseling. As a result, more patients will become aware of genetic counseling and have the opportunity to make informed decisions about the health of themselves and their families. By examining the motivations behind what ALL genetic counselors do each day, it becomes evident that the similarities of what we do outweigh the differences. ❖

Mary Freivogel, MS, and
Dawn St. Amand, MS

CHANGING GENETIC LANGUAGE

Languages, like genes, slowly evolve over time. The addition of new words (humongous came into the English language about 1968) or loss of old words (who uses mimsy nowadays?) changes a language. Some words take on a special meaning when used among professional colleagues (for genetic counselors AMA means "advanced maternal age" not "against medical advice").

I have noticed a new word trying to establish itself in the vocabulary of genetic counselors: preconceptional. Like the phrase "genetics counselor," this word irks me. It not only sounds bad but is grammatically incorrect. I would argue against allowing this word to get a foothold in our professional communications.

Here's my thinking. Whenever I've seen preconceptional used, it has been as an adjective for counseling. It is used to mean counseling that is done prior to conception. According to my dictionary, the suffix –al is used to form adjectives that will mean of, like, suitable for. Adding –al to preconception does not convey the intended meaning of genetic counselors who are referring to preconception counseling. That being the case, why use a word that is inadequate and incorrect when there is a perfectly suitable one, preconception, already in our vocabulary that says exactly what we mean?

Our written words represent us to the public and to other professions. In general we have no control of how others misuse genetic terms, but we should promote clear and accurate communication among ourselves. ❖

Susan Schmerler, MS