PERSPECTIVES
in genetic counseling

Volume 27 Number 2 Summer 2005

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nsgc

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

www.nsgc.org

Table of Contents

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A Billing and Reimbursement Timeline in NSGC's History

Susan Manley, MS

Membership surveys have consistently indicated the most important issue for NSGC to address is Billing and Reimbursement (B&R). In NSGC's 2004-2006 strategic plan, Improvement of Outlook for Billing and Reimbursement was a key strategic initiative. Here's a history of progress made and a look at exciting things to come!

GeneAMP Highlights

B&R has long been in the forefront of NSGC activities. In 1996, President **Ann Boldt** initiated GeneAMP – Genetic Applied Marketing Project – which funded opportunities for member-driven projects in five categories: Primary Care Providers, Managed Care Organizations, Medical Professional Organizations, Consumers and Employers and Legal. In the program's seven years, two projects specific to Managed Care Organizations raised awareness of B&R issues:

- "One Message for Managed Care," funded for $2300
- "Measurable Outcomes of GC: Counselor and Consumer Assessment," funded for $2500.

Task Force Initiatives

In 2001, NSGC decided to move toward professional marketing, and a strategic membership survey ...to page 3

Now Available: A New Option for Professional Liability Insurance

Deepti Babu, MS

NSGC has negotiated a new program for professional liability insurance available to members in good standing.

Liability Backgrounder

Professional liability insurance is meant to protect the insured against allegations regarding their professional services. Liability insurance for genetic counselors safeguards against assertions of negligence and liability incurred from defense and/or settlement of claims. As Executive Director **Bea Leopold** suggests, "Counselors and students can go to work knowing they will be protected with a professional liability policy in place."

Genetic counselors' liability coverage through employers may vary depending on circumstances. All employees named in a lawsuit may share the benefits in some group policies, ...to page 8

President's Beat

As summer arrives, bringing anticipation of vacations and a break from the office, I hope you can find time to renew your excitement about NSGC and the organization's activities. We continue to make great strides towards our strategic plan initiatives, and I encourage you to get involved in an area you feel passionate about.

B&R Achievements

NSGC has released a billing and reimbursement (B&R) "tool kit" on the website with helpful information and resources. NSGC, together with the American College of Medical Genetics, will present CPT codes specific for genetic counseling in early June. Many of you responded to our request for letters to SACHGS regarding their recent draft guidelines for reimbursement and coverage of genetic testing and services. View the webcast from the June 15-16 meeting when these guidelines were finalized. The B&R taskforce also has compiled an advisory committee of representatives from industry, health care and insurers that will meet this summer to develop a long-term plan.

Kelly Ormond, MS

Legislative Updates

NSGC has entered our third cycle for licensure state grants, with Florida, Illinois, Massachusetts, New York, Pennsylvania, Tennessee and Texas receiving grants. Licensure bills were introduced in Florida, Massachusetts, Oklahoma and Washington states this year. NSGC continues to play an active role in the Coalition for Genetic Fairness, promoting the Genetic Information Nondiscrimination Act of 2005 in the House of Representatives. The Social Issues Committee is monitoring other genetic counseling related legislation and developing a monthly legislative newsletter to help you learn about pending state and federal bills and how to get involved.

NSGC Builds Its Presence

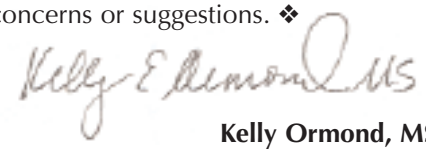
We have sent liaisons to many important meetings over the past several months. **Jennifer Sullivan** presented public comments at the Secretary's Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children, **Kristen Shannon** represented us at the Health Professionals Network meeting, **Nancy Warren** attended the Association of Schools of Allied Health meeting and **Wendy Uhlmann** represented us at the NHGRI Advisory Committee. **June Peters** and **Debra Eunpu** presented at the American Association for Marriage and Family Therapists meeting. In June, **Jennifer Hoksovec** will represent NSGC at the CDC's National Summit on Preconception Care, and **Kathy Schneider** will represent us at the Commission on Cancer meeting.

Upcoming Projects

NSGC's Board is currently evaluating its structure and effectiveness. It is about to complete the incorporation of a tax exempt "Genetic Counseling Foundation." The Foundation will support genetic counseling research, education and other activities that advance translation, understanding, application and delivery of genetic information. You will be hearing much more on this, and we hope everyone considers making a contribution.

Every Vote Counts

Finally, as we approach the upcoming NSGC election, I encourage you to make your voice heard by reviewing the candidates and submitting a vote. As genomics expands into all areas of medicine and biotechnology, NSGC needs visionary leaders who can help our organization continue to develop as the leading voice for our profession. In the meantime, I look forward to continuing to serve NSGC, and I encourage you to contact me or other members of the Board with questions, concerns or suggestions. ❖



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☞ www4.od.nih. gov/oba/sacghs.htm)

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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***

B&R History, *from page 1*

identified B&R as a key focus. Consequently, in 2002, President **Katherine Schneider** assembled a Task Force charged with recommending strategies to enhance B&R. This Task Force mapped out several steps, including the B&R tool kit now available on our website. Additionally, the Task Force recommended identifying and funding research studies on the value of genetic counseling and devising strategies for negotiating reimbursement with national third party (insurance) payors.

Researching Reimbursement

In 2003, a study was conducted by the University of Washington entitled; Third-Party Reimbursement of Genetic Counselors: An Analysis of Costs and Outcomes. Data from this research was presented at the 2004 Annual Education Conference (AEC). The study proposed a model for cost-effectiveness in prenatal genetic counseling. While there remain gaps to be filled, we now use this data to approach third party payors.

Advisory Group to Commence

The researchers recommended that NSGC convene an advisory group to move the B&R initiative forward. As a result, we have established a Strategic and Analytic Billing and Reimbursement Advisory Group (SABRAG) of outside specialists. An initial meeting will take place this summer, with the goals of developing a strategic plan to begin negotiating for reimbursement of genetic counseling services and to advise us about further research to help make our data robust.

Steps Toward Improvement

Billing eligibility, licensure and appropriate billing codes go hand in hand in our quest for improved reimbursement. NSGC is taking steps to advance our B&R outlook by:

- Recommending mechanisms for genetic counseling billing at a national level and recognizing masters trained, certified genetic counselors as qualified genetics service providers through participating in the Secretary's Advisory Committee on Genetics, Health and Society (SACGHS) report on Coverage and Reimbursement for Genetic Services. Historically NSGC presidents have played an active role in all SACGHS meetings, delivering testimony and public comment (available at our website's Newsroom section).

- Forming a CPT working group, chaired by **Deb Lochner Doyle,** which submitted an application to the American Medical Association CPT Editorial Committee for a June 2005 review of billing codes available for genetic counselors.
- Assisting individual states pursuing licensure with $15,000 in NSGC-sponsored funds available in two grant cycles this year. Since 2004 when this grant program was initiated, we have funded nine states for a total of $16,300.
- Promoting genetic counselor eligibility for National Provider Identification (NPI) numbers in 2007, replacing the current UPIN system that gives identification numbers to health professionals for billing.
- Continue educating NSGC members regarding B&R issues by regional meeting presentations, AEC plenary and EBS sessions and *Perspectives* articles.

Future Directives

Watch for updates on the SABRAG Advisory Committee, new research projects and successes from other organizations working to improve the outlook for billing and reimbursement. Thanks to the countless genetic counselors who have assisted with these efforts, including the 2002 B&R Task Force, the current B&R Working Group, the B&R and Licensure Subcommittee and the CPT Working Group. ❖

☞ NSGC's B&R Primer: www.nsgc.org/members/tools/tools_primer_billing.asp

☞ Secretary's Advisory Committee on Genetics, Health and Society report on Coverage and Reimbursement for Genetic Services: www4.od.nih.gov/oba/sacghs/public_comments.htm

☞ www.nsgc.org/members/licensure/Licensure_Grant.asp

Achieving Genetic Counselor Licensure in Illinois: A Lesson on the Political Process

Judith Miller, MS

In Illinois, genetic counselors achieved licensure in 2004. The process was particularly political, however. I recently heard that in Illinois, legislative decisions are made in smoky rooms behind closed doors. I don't know if this is true, but our efforts certainly exposed the potential influence of legislators and special interest groups.

Here were the crucial factors for passing our Bill, Public Act 93-1041.

Genetic Task Force

A Licensure Committee was organized at a Genetic Task Force of Illinois (GTFI) meeting. Membership in GTFI is open to all genetics professionals in the state. Backing of the licensure effort by a state-wide genetics organization provided our effort with legitimacy and essential funding.

Communication and Networking

To start, we found it helpful to develop a proponent list, which included hospitals, large health conglomerates, support groups, physicians (geneticists and non-geneticists) and PhDs.

E-mail was the best way to contact colleagues to help with the bill. We had two lists, NSGC members in Illinois and GTFI members. When communicating with legislators, however, phone calls were better, especially before scheduled hearings and votes.

We had many meetings with a State Legislator interested in genetics who, most importantly, arranged a meeting with the Department of Professional Regulation (DPR). However, we weren't getting far in the Legislature, so we found a new legislative sponsor willing to make our act a priority. He advised us to hire a lobbyist.

The DPR enforces all licensure legislation. At a meeting with DPR representatives, we were told to use another Illinois Licensure Act as a template for our bill. In the end, DPR support was critical.

Compromise

The Illinois State Medical Society (ISMS), a powerful group, was our nemesis. Once they understood genetic counseling, they wanted licensure – with genetic counseling under the control of physicians. The ISMS informed us that we didn't "have a prayer" of passing our bill without a lobbyist. Our bill would have died if they had said no.

In the end, we had to accept several changes the ISMS made to our bill. We decided we were better having an imperfect bill than nothing at all and hoped future "adjustments" in the bill would be possible.

Lobbyist

We were extremely lucky to find a lobbyist experienced with licensure bills who guided us in working with the legislators and ISMS and who was willing to work for less than her usual fee. She introduced us to the right people, got us the right sponsors, acted as a liaison to the ISMS and monitored the ups and downs of our bill. Most importantly, because she was present, persistent and knew who to talk to, our bill passed during the last hours of the last day of the two month overtime session.

Documents

Here are some of the most helpful tools we created:

- Documentation that Illinois genetic counselors favor licensure. We surveyed genetic counselors, requesting a return e-mail stating they agreed with licensure and that our committee could represent them. Everyone we contacted agreed.
- Pertinent information on NSGC, the American Board of Genetic Counseling, the American College of Medical Genetics (ACMG) and the certification process. This sheet helped us keep our facts straight.
- Multiple "Talking Points" written to help genetic counselors garner support. Reimbursement was discussed only when talking to physicians and employers.
- "Fact Sheet on Genetic Counseling." This document was critical but gave the impression that genetic counselors only provide clinical services.
- "Harm to Patients Document." We were often asked about this topic. In all the examples of litigated cases we found, erroneous counseling was provided by a physician. We were told it was not wise to cite these cases and that they could be prevented by physician education. ❖

☞ The Illinois Genetic Counselor Licensure Act, Public Act 93-1041, can be found at www.ilga.gov/.

Career Watch

A Genetic Counselor's Most Valuable Skills

Terri Creeden, MS

Successful counselors communicate complex information, work with professionals and patients, understand research principles and coordinate clinical care. We multitask, navigate a complicated healthcare environment, act as liaisons, make difficult ethical decisions and comprehend and write technical information. Think you are in a narrow field with little growth opportunity? You couldn't be more wrong. The skills I gained in my six years as a prenatal counselor have served me well in what many would consider my following "non-traditional" roles.

From Job to Career

After achieving genetic counseling certification and questioning my career path, I entered a graduate program in Public Health, hoping to open more doors.

But you don't have to pursue another degree to gain new skills. I also became involved in teaching and research at a university, and I volunteered locally. Through this volunteer work, I landed my next job as Director of Professional Genetics Education at the March of Dimes. I managed grants, developed and evaluated genetics education programs and coordinated the program budgets.

I held this position for three years, but then a career change for my husband brought us to Switzerland. Not wanting to give up my career, I set up a consulting company, continuing my activities with the March of Dimes and working part-time for a pharmaceutical company. My work continues to center around genetics education, project management and communications.

Terri Creeden, MS

Staying Involved

Staying involved in NSGC has been important in my ability to transition my career. I could have drifted away from NSGC when I left clinical counseling, but at that time NSGC was showing greater appreciation for the dexterity of the genetic counseling degree in non-clinical settings. I joined the Industry SIG and found other counselors just like me: still passionate about their training but learning to apply it in new ways. Also, my work on a subcommittee turned into a current position on the NSGC Board of Directors, allowing me to stay connected and contribute a non-traditional and international perspective.

> ***"If you are considering a career change, I offer the following advice: get involved in NSGC and other groups that interest you and take a leadership role."***

Applying the Right Skills

I have found that "clinical" skills translate easily into new settings and make genetic counselors unique business candidates. To appreciate this, think beyond the tasks being asked of you in a new position, and focus on the abilities required to perform these tasks. Developing educational or promotional materials requires the ability to communicate information in simple terms and write scientific information for varied audiences. Project management is like managing a clinical case: the environment is time-sensitive, some tasks must be completed before others begin and other tasks can be completed in parallel. The manager must track multiple deadlines and act as a liaison between different departments, all while watching the "big picture." Naturally, a new setting requires some training, yet by identifying my limitations, seeking out information and applying this new knowledge, I was able to apply my current skills to be successful.

Some Advice

If you are considering a career change, I offer the following advice: get involved in NSGC and other groups that interest you and take a leadership role. Develop skills by taking on new responsibilities. Network, meet new people and stay connected with colleagues. Keep an open mind at all times. And of course, never underestimate the skills of a genetic counselor. ❖

☞ For additional materials on moving into a non-traditional career, visit the Industry SIG Web page in the members-only section of www.nsgc.org

What is Best for the Child?
Ethics Subcommittee Responds to Help Resolve Conflict

The Case...

The consulting genetic counselor was contacted by a woman diagnosed with attenuated familial adenomatous polyposis (AFAP). The client was the only known affected individual in her family, and she and her husband had one asymptomatic 12 year-old daughter. The client had undergone genetic testing, and a mutation was detected. The couple had not told their daughter about the diagnosis but wanted to test her without her knowledge.

The woman stated that waiting a month for her own test results had been extremely difficult, and she did not want to put her daughter through this anxiety. The couple's plan was to draw the daughter's blood in conjunction with an upcoming vaccine. If the test results were negative, they would disclose the mother's AFAP diagnosis and tell their daughter she was not at risk. If the results were positive, they would explain AFAP to their daughter and the medical recommendations to keep her healthy.

Previous History

The client and her family were referred by a different genetic counselor that had met briefly with the couple. The couple had been hostile and insisted upon testing their daughter. The protocol of the original clinic required assent from a child old enough to be involved in the process. The counselor and parents could not find a way to test the daughter that felt comfortable to both parties. The oncologist involved in the case felt it would be better for the child to get tested and was willing to order the test without the child's knowledge.

The Response...

The Subcommittee recognized the counselor's discomfort in testing the 12 year-old without the child's assent. The Subcommittee also was concerned about the parents' ability to cope with the diagnosis in the mother and possibly in their daughter.

Significant discussion occurred regarding the age of onset of AFAP, average age to start screening and age-related management. Professional practice guidelines such as NSGC's "Prenatal and childhood testing for adult-onset disorders" and ASHG/ACMG's "Points to consider: ethical, legal, and psychosocial implications of genetic testing in children and adolescents" support the counselor's inclination to delay testing. Other suggestions included involving the hospital ethics committee, declining to be involved without informed assent and letting the oncologist order testing, and referring the family to a therapist.

Applying the Code

Many sections of the NSGC Code of Ethics (COE) can be applied to this case. The genetic counselor is supported if she decides to abstain from the case by sect. 1:5, which promotes personal physical and emotional health. Referring the patient back to the oncologist or to family therapy is supported by sect. 2:3.

NSGC's and ASHG/ACMG's practice guidelines mentioned previously suggested that genetic testing of minors should not be pursued unless there is a direct benefit to the patient, and the child should be involved in the decision about being tested. Given current information on AFAP, screening may not be needed at a young age, making direct benefit of testing a minor unclear. Therefore, pursuing informed assent of the child is warranted and supported by sect. 1:3.

If the daughter is considered the client, sect. 2:2 supports the need to enable clients to make informed, independent decisions. If the parents are the clients, sect. 2:2 suggests that each client's beliefs and inclinations should be respected, rendering testing of the daughter permissible.

In summary, there is support from the COE to deny or facilitate testing. The decision depends on the following:

1) Who is the client?
2 What can be done to satisfy concerns regarding testing?
3) What are the recommendations of the hospital ethics committee?

Conclusion

The consulting genetic counselor discussed the case with the oncologist, psychotherapist and family therapist at her center. It was agreed that standard of care was to obtain informed assent from the child. The parents were upset but chose to allow their daughter's assent. The counselor reviewed with the parents how they wanted information presented to their daughter and how test results would be given to the family. Follow-up visits would depend on the test results, and the family was referred to a therapist. ❖

NSGC Ethics Subcommittee

GENETIC COUNSELING TRAINING FROM AN IRISH PERSPECTIVE

Erica J. Ward, BSc, MSc

I am a second year genetic counseling student at the University of Michigan. What makes me a slight novelty is that I am from Ireland. My interest in this profession stems from an educational encounter with a genetic counselor in Ireland during my previous Masters program. This connection seems fated, given that the country has one genetic center, four counselors and no training program.

TRAVERSING THE SYSTEM

My desire to pursue a genetic counseling career led me to the U.S. where I began my journey through the American university system. I was lucky to be surrounded by people advising my every step; otherwise I fear I would have abandoned my dream within a few months. In Ireland, third level education is free, and there are no exams required to apply for graduate schools. Facing the strict U.S. requirements, I felt at a loss when writing essays, taking the GRE's, flying to interviews and determining the tuition for each university.

Erica Ward, BSc, MSc

A PRIVILEGED WORLD

In my two years of training at the University of Michigan, I have learned at an incredible pace the intricacies of a health care system that has more nuances than I thought possible. I have been allowed into a privileged world where diversity is embraced and encouraged, education is prized and friendships are strong. Each student is nurtured on an individual level, which, coming from a system that demanded academic autonomy, supplied me equally with challenges and rewards.

LOOKING BACK AND FORWARD

I look back on my training experience with a mix of emotions. The American system is superb in the education and diversity it offers, but I fear that the spiraling costs may limit access to many would-be international and American genetic counselors. I hope to bring my newfound skills back home some day and perhaps become the fifth genetic counselor in the Emerald Isle. ❖

GENETIC COUNSELING STUDENTS ARE ONLINE

Heather Peters, BS
Listserv Moderator

The NSGC student online discussion group is open, and all NSGC student members are urged to join! Come read what your peers are thinking, and exchange your ideas about graduate training, job search and difficult cases. Subscribers also can read the postings on the main Professional NSGC Listserv. We look forward to seeing you online!

To use the listserv:

1. Visit https://maillists.uci.edu/mailman/listinfo/nsgc-students.
2. Follow the instructions for subscribing to the listserv on the webpage. (Mark "yes" for the question, "Would you like to receive list mail batched in a daily digest?")
3. Write an email message to the listserv manager at nsgcstud@massun.ucicom.uci.edu. The message should include:
   - your first and last name
   - the name of the genetic counseling program you attend
   - the year you will graduate.
4. To send a message to the student listserv, simply post an email to nsgc-students@uci.edu, or reply to a listserv message.
5. Visit the main webpage any time to unsubscribe. ❖

LIABILITY INSURANCE, ***from page 1***

reducing coverage for each individual. An employer-based policy also may not cover services rendered outside of an individual's scope of employment.

TIME FOR A CHANGE

NSGC has previously offered group liability insurance to members. Our recent carrier, American Counseling Association Insurance Trust, required American Counseling Association (ACA) membership for genetic counselors. NSGC members were unhappy, as ACA membership requires extra costs.

Following extensive research, NSGC has chosen Hays Companies, an international independent insurance carrier partnered with Lloyd's of London, as our new program administrator. The new program is pre-vetted by the American Society of Association Executives, and ACA membership is not required.

HOW TO APPLY

To be eligible for NSGC's liability insurance policy, you must be an NSGC member. Premium costs vary based on employment status and history. Students pay discounted rates. The Hays Companies' Internet site has the ability to provide quotes, risk management information and service your policy.

Although this program should help genetic counselors and students access coverage, NSGC members are not obligated to purchase a policy through Hays Companies. ❖

☞ Hays Companies, 202-263-4037; questions@hayscompanies.com; www.hayscompanies.com

☞ Future site for NSGC members: http://nsgc.haysaffinity.com

VOICES OF OUR COMMUNITY

Diversity Series, Issue Three

This series highlights our profession through essays by a breadth of genetic counselors. This personal account raises a voice less common among our ranks – that of the black male counselor – and calls for greater awareness by us all.

A VIEW FROM THE BLACK MALE PERSPECTIVE

Patrick Wilson, MS

Why genetics?, and more specifically, *Why genetic counseling?* These are questions I am often asked when people learn I am a genetic counselor. The genetics bug bit me when I was seven or eight and first heard of genetic engineering. Years later, I developed a separate interest in counseling and was frequently asked by others for my advice. I learned of genetic counseling from a physician who took interest in my career development. I was amazed a field existed that combined two interests that I enjoyed.

FINDING COMMON GROUND

Since graduating from Howard in 2001, I have worked in two general genetics clinics and one high-risk obstetric clinic. While each center has had its own niche population, the patients and families had a common concern: *Why am I or my loved one experiencing these symptoms, and what can be done to treat them?* I have learned that an honest discussion of the symptoms and diagnosis is best. My worst experiences were those in which I failed to acknowledge the needs of my patient; I saw a genetic condition rather than a person with such a condition. Thankfully, I have been blessed to have a second visit with those patients. I apologized for my shortcoming, and we were able to establish a new relationship.

REACHING THE BLACK COMMUNITY

One unexpected aspect of genetic counseling for me has been the small number of Black males in the profession. I know it is not a profession widely spoken of in the Black community, and I only heard of it from a White physician. For this reason, we need to make the profession more visible to the Black community. I have spoken to Black high school students about a career in genetic counseling. Hopefully, efforts like these will increase the number of Black individuals in the profession.

CULTURAL COMPETENCY

My biggest disappointment with the profession was when, as a student, I was approached by a conference attendee at an AEC meeting about the location of a slide projector. Even though I had on my convention badge, the woman seemed to assume I worked for the hotel. I was upset because I had heard so much about "cultural competency," and my first experience with my future colleagues was a negative one.

Since then, my interactions have been more pleasant. When I attend meetings with genetic counselors, I am greeted as an equal. I have been asked to sit on a national committee, the Visibility Task Force, and my views are given the same weight as those of my fellow committee members. Overall, in my genetic counseling career I have experienced personal and professional growth and satisfaction. More often than not, I am happy that I am a genetic counselor. ❖

☞ Hunt.Katherine@mayo.edu, *Voices* coordinator

NSGC Advises the Nation on Valuation and B&R

Susan Manley, MS

On February 28, NSGC reported to the Secretary's Advisory Committee on Genetics, Health and Society (SACGHS) regarding the capacity of the genetic counseling workforce and current limitations in billing and reimbursement. SACGHS was created in 2004 from the original Secretary's Advisory Committee on Genetic Testing to provide a forum for expert discussion on the complex issues raised by technological development in human genetics and to make recommendations to the Secretary of Health and Human Services on these issues. **Barbara Harrison** has been the genetic counseling representative on the committee.

A Rigorous Report

The meeting was a culmination of previous sessions assessing the genetic counseling profession. **Kelly Ormond** and **Andy Faucett** (who represented ABGC) presented data from a working group that outlined:

- the credentials of non-physician service providers
- the value and effectiveness of genetic counseling
- the importance of reimbursement of genetic counseling services.

The workgroup report highlighted our rigorous credentialing and certification process and current limitations to reimbursement. We concluded by asking SACGHS to:

- recommend reimbursement for non-physicians with recognized genetics expertise
- advocate for genetic counseling CPT codes to be created for non-physician providers
- help fund additional research to further examine the value and effectiveness of genetic counseling.

Enhancing Credibility and Eligibility

As a result of this presentation, we hope that SACGHS's final recommendations to the Secretary of Health and Human Services will include a statement that recognized qualified providers should be able to bill directly for genetic counseling services and that non-physician providers, such as genetic counselors, should be eligible for national provider identifiers. NSGC is working, through comments to the group, to modify the report to be as accurate and favorable as possible. Although it is unclear what the Secretary will do with this information, NSGC hopes to use these recommendations to our advantage as we continue to advance negotiations with third party payors. ❖

☞To find "Full Committee Discussion of Draft Coverage and Reimbursement Report," visit www4.od.nih.gov/oba/sacghs.htm. The main pages relevant to genetic counseling are 48-52; the beginning offers an excellent overview of the reimbursement.

Research Network

Turner Syndrome Study

The Children's Hospital and Regional Medical Center in Seattle is conducting a new research study on girls diagnosed prenatally with Turner syndrome. A significant amount of ascertainment bias is associated with Turner syndrome. We suspect that girls who are diagnosed prenatally, especially those picked up incidentally (e.g., through advanced maternal age or abnormal serum screen), may have significantly fewer phenotypic features as contrasted to those ascertained clinically[1].

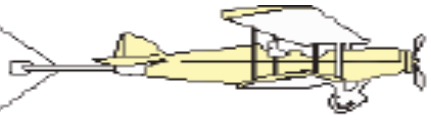
We are now beginning a prospective study of girls diagnosed prenatally who are not more than six months old. This is an information gathering study designed to solicit medical and growth data from participants' families and physicians. The initial recruiting period is three years, with three years of follow-up. Our study is supported by an educational grant from the Eli Lilly Corporation and has received approval from the Institutional Review Board at Children's Hospital and Regional Medical Center. ❖

To help in recruitment for this study, contact the PI or study coordinator.

☞ Principal Investigator: Daniel F. Gunther, MD, MA
Study Coordinator: Sue Kearns, RN, MN
206-987-1758; Sue.kearns@seattlechildrens.org

[1]Gunther DF, Eugster E, Zagar AJ, Bryant CG, Davenport ML, Quigley CA. 2004. Ascertainment bias in Turner syndrome: New Insights from girls diagnosed incidentally in prenatal life. *Pediatrics*. 114(3): 640-644.

MEDIA WATCH



Angela Geist, MS and Roxanne Ruzicka, MS

Winter '05 – *American Legacy Healthcare Advantage*, "Caution: Genetic Testing Ahead"

This article suggested that genetic testing may be used for possible discrimination. Consumers were urged to ask the reasons and risks behind genetic tests and were recommended to speak to "an expert, preferably a certified genetic counselor." **Tené Hamilton** was quoted.

January 30 – *The New York Times,* "Racing With Sam"

This article followed Sam, a boy with progeria, and his mother, a physician scientist who created the Progeria Research Foundation, a nonprofit organization promoting research into the cause and treatments of progeria. His mother also helped announce the discovery of the progeria gene. The article mentions **Diane Baker,** who provided genetic counseling to a progeria patient.

February 22 – The Today Show

Dawn Allain spoke to **Ann Curry** about screening newborns for genetic conditions and the federal advisory board that is recommending universal screening for 29 disorders. Dawn did a great job promoting genetic counselors and the NSGC.

March 8 – Good Morning America

In a segment on direct-to-consumer marketing for genetic testing, the head of DNA Direct illustrated how test kits work but did not clarify the process of follow-up (i.e., genetic counseling). A preventive medicine specialist from Yale provided the "con" arguments to this approach to genetic testing. An anonymous guest described her BRCA testing experience and how genetic counseling was instrumental in helping her deal with overwhelming and frightening information.

March 22 – *Biotech Week, Law & Health Weekly*, and *Life Science Weekly* "National society supports Senate's passage of genetic non-discrimination bill"

NSGC disseminated this press release, stating that this bill will help alleviate fears of genetic discrimination that prevent individuals and families from pursuing genetic testing and participation in research. **Kelly Ormond** explained how "this legislation is critical for society to be able to take full advantage of the technologies developed by the human genome project."

March 22 – *New York Times,* "Finding Medical Destiny on the Family Tree"

This article followed three sisters through genetic testing given their family history of breast and ovarian cancer. The article did not mention genetic counseling. **Dr. Judy Garber** was interviewed.

March 30 – ESPN.com and *ESPN magazine,* "Baby, You're the Greatest"

A sports writer had his one year-old son tested for a gene called ACTN3 by Genetic Technologies, a company in Australia that promotes "the world's first DNA test for sports performance." He also tested his son for APOE, "a gene associated with increased risk of brain damage and neurological deficits after head injuries suffered in contact sports."

April '05 – BabyZone.com, "Genetic Counseling and Testing"

In reference to prenatal diagnosis, this article discussed "how genetic counselors can help couples gain an understanding and receive emotional support dealing with the decisions they may have to face." NSGC and March of Dimes were mentioned.

April 10 – *Washington Post* website, "Hard Labor"

This article described managing a pregnancy diagnosed with a birth defect when the parents have opposite ideas. The article was followed by an online discussion with **Jill Fonda** and **Rhonda Schonberg**.

April 23 – *Reno Gazette Journal*

The Journal reported that genetic counselor **Robbin Palmer** accepted proclamations for National DNA Day from the Reno City Council and Washoe County Board of Commissioners.

April 25 – *The Washington Post,* "Pa. Cousins Try to Overcome Taboo of 'I Do'"

The Journal of Genetic Counseling article by **Robin Bennett** et al. discussing the risks to offspring of consanguineous couples was referenced regarding the social implications of first cousins pursuing marriage.

April 25 – *Newsweek* magazine, "Heredity and Health: Tracking Family History"

This article discussed being knowledgeable about family history so available preventive measures can be taken. **Anu Chittenden** was quoted describing what information a person should know about relatives. ❖

RESOURCES

MISSING GENETIC PIECES: STRATEGIES FOR LIVING WITH VCFS, THE CHROMOSOME 22Q11 DELETION

Author: **Sherry Baker-Gomez**
Publisher: Desert Pearl, Glendale AZ, 2004
Reviewed by: ***Courtney Sebold, MS***

Written by the mother of a boy with a 22q11 deletion, "Missing Genetic Pieces" is meant to fill a void in lay literature on VCFS. The author compiled and published this book on her own, attesting to her dedication to the families of people with VCFS.

The book's main strength lies in select excerpts from families who have "been there, done that." In addition, there are chapters focused on topics not often covered in the medical setting, including "Negotiation," "Finances and Trusts," "Advocacy" and "Marriages, relationships, and VCFS."

Sprinkled throughout the book are essays from experts speech pathology, audiology, dentistry and other fields. The sections on medical issues include figures explaining complex heart and palate problems. The book, however, is disorganized, particularly related to medical and developmental issues. The book also may be intimidating; it is over 500 pages long, and the family excerpts describe more negative than positive experiences.

While this book helps raise awareness of VCFS, genetic counselors should consider the needs of their patients before recommending it. ❖

PHARMACOGENOMICS: THE SEARCH FOR INDIVIDUALIZED THERAPIES

Edited by: **Julio Licinio** and **Ma-Li Wong**
Publisher: Wiley-VCH, Weinheim (German), 2002, 558 pp., $94.00

Reviewed by: ***Elizabeth A. Balkite, MS***

Licinio and **Wong** bring considerable expertise to their goal "to bring together in one volume the current level of development in pharmacogenomics." They convey a sense of the promise and complexity of pharmacogenomics, including its variety of approaches and applications and related social and ethical issues. The authors make clear that pharmacogenomics, with its roots in the Human Genome Project and advances in bioinformatics and biotechnology, heralds a fundamental shift away from the reductionist approach of 20th century medicine and towards one that acknowledges the complexity of living systems. They acknowledge that the field is in its infancy.

COMPREHENSIVE CONTENT

The book is comprehensive, with initial chapters addressing genomics, single nucleotide polymorphisms (SNPs), clinical and basic pharmacogenomic research, platform technologies in genomics, proteomics and bioinformatics and the role of pharmacogenomics in drug discovery and development. About two-thirds of the book is devoted to state-of-the-art reviews of historical, current and future pharmacogenomic research related to specific therapeutic areas. There are excellent chapters on the pharmacogenomics of alcoholism, tobacco addiction and the opioid systems, as well as reports of cutting edge work involving human P-glycoprotein, other drug transporters and vascular proteomics.

SERVES AS REFERENCE

Most health care professionals will find this more of a reference book. Each chapter contains an abstract, conclusion, tables, figures, illustrations and a glossary. There is redundancy in content among chapters, but it is interesting to see the different authors' interpretations giving a sense of the field's complexity and how quickly it is evolving. One chapter summarizes some of the ethical and social issues related to pharmacogenomics.

Genetic counseling and nursing program directors, pharmacy and medical school instructors and public health educators will find this book a valuable resource for teaching. Health care professionals working with patients receiving pharmacotherapy for chronic conditions (such as cancer and psychiatric disorders) may find it provides helpful information explaining varying responses to therapy. It may raise more questions than answers about the risks and benefits of therapies when counseling patients.

Pharmacogenomics: The Search for Individualized Therapies is a good, current resource in a complex area of genomic science. It makes the reader realize that the integration of pharmacogenomics into healthcare will be almost as complex as the science itself. ❖

Bulletin Board

A New Year of Mentor Match

Troy Becker, MS
Membership Committee Chair

The Mentor Program just completed its 9th year and is planning the 2005 match. The program allows professionals and students/recent graduates to exchange ideas and information about interests or experiences. The program begins in October and runs over six months.

For practicing genetic counselors, the Mentor Program offers an opportunity for contact with students. For students, the program provides an experienced resource outside of their training program. Mentor interactions can offer a "real world" genetic counseling perspective, information about different employment situations, support in the job search process and guidance in the transition from student to professional. The success of the Mentor Program is linked to the student's participation, and students who are more actively involved have the best experience.

To join the Mentor Program, email your name and the postal address where you will be receiving mail in August. The deadline to enroll is Friday, July 22. Mentors must have graduated before July 2003; eligible students must have graduated after January 2005. Those who previously participated will not be automatically re-entered in the program, so sign up again if you want to participate as either a mentor or student. ❖

☞ BeckerT@allkids.org

Arthur M. Sackler Colloquia of the National Academy of Sciences

"The Tapestry of Life: Lateral Transfers of Heritable Elements"

When: December 12-13, 2005

Where: Beckman Center, Irvine CA

Meeting Overview

What Darwin saw as a tree of life descending in a linear fashion is now more accurately seen as a tapestry of life, a network with important lateral transfers of heritable elements among parallel lines of descent. These transfers range from small insertion sequences to whole genes, gene islands and portions of genomes which may be combined in symbiogenesis. The purpose of the colloquium is to bring together researchers, empirical and theoretical, working at all levels on genomics, comparative genomics and metagenomics to identify features of lateral gene transfer and to examine their implications for science and for human concerns.

Registration Information

Registration is $350, including meals, reception and banquet. An early registration fee of $250 is available before August 1. A reduced registration fee of $100 is offered to graduate students and postdocs. ❖

☞ www.nas.edu/sackler/tapestry

NSGC 2005 Annual Education Conference

When: November 10 - 11, Short Course;
November 12 – 15, AEC

Where: The Westin Century Plaza Hotel & Spa,
Los Angeles, CA
www.westincenturyplaza.com

A Few Quick Reminders

- Register before August 15th to avoid late fees!
- Make your hotel reservations early. Room rates cannot be guaranteed after Thursday, October 20th!
  Call 310-277-2000 or 800-228-3000 and mention the NSGC conference for our discounted rate.
- Get involved in NSGC! Check your conference schedule and plan on attending a committee meeting, SIG meeting or the 2006 Annual Education Conference Planning Committee Meeting. ❖

Letters to the Editor

Reponse to Print Version of JOGC

This letter is a response from the *Journal of Genetic Counseling* to **Ms. Keep** and **Ms. Dorsainville** regarding their Letter to the Editor, "NSGC Should Print *JGC*" (*PGC,* 27:1 – Spring 2005).

The discontinuation of the print version of the *JOGC* to NSGC members did not occur hastily or without consideration of membership response. We anticipated and are aware that some NSGC members are upset because they no longer receive six print issues of the *JOGC* each year as a membership benefit. The *JOGC* continues to be available in print with institutional subscription as well as via the newly available year-end bound volume.

The provision of electronic issues to NSGC members was the only way to continue publishing the *JOGC* and offer it as a membership benefit. The alterative was to discontinue the publication of the *JOGC,* a choice that would have completely removed the *JOGC* from the medical literature.

We are disappointed to learn that Ms. Keep and Ms. Dorsainville will no longer consider submitting work to the *JOGC*. Our primary goal is to provide a publication forum to encourage the endeavors of all medical professionals engaged in genetic counseling. As such, the choice to not submit any manuscript to a forum that has the ability to readily reach so many health professionals is a loss for us all.

We hope the NSGC membership is as excited as we are about the great strides the *JOGC* has taken in the past few years, such as inclusion in MEDLINE and an increase in the number of articles published in each issue. We continue to do our best to balance the needs of the membership with the reality of publishing a scholarly and exciting professional journal. We sincerely hope readers will find items of value, use and inspiration in every issue. ❖

Allyn McConkie-Rosell, PhD,
Editor in Chief
Jennifer Sullivan, MS,
Associate Editor
Journal of Genetic Counseling

A New Breed of Genetic Testing: Who Needs Genetic Counselors?

Predictive genetic testing for patients with no family history of breast cancer – it seems paradoxical. Yet such a test on the clinical horizon may cause us to re-think the role of genetic counselors in health care.

The test, called *Oncovue*, calculates a woman's risk of developing breast cancer using SNPs from multiple genes involved in cancerous pathways along with standard demographic variables. It is like a Gail model that incorporates DNA results.

Oncovue has four characteristics that question the role of genetic counselors in implementing the test:

- The test is aimed at premenopausal women with no personal or family history of breast cancer.
- The results of one woman are not used to predict the genetic risks of her relatives. There is no need to explain inheritance or assess risk by pedigree analysis.
- The psychological impact is likely to differ from single gene testing. The results may evoke personal issues for a woman facing her own risk of cancer, but there are no genetic implications for her family.
- A key component of genetic counseling involves educating patients. But *Oncovue* does not require a detailed explanation of genetics and genetic testing.

The skills genetic counselors possess could be useful for incorporating *Oncovue-like* tests into clinical practice. Genetic counselors can help women decide if they are appropriate candidates based on family history. We could help assess the value of predictive testing and educate the medical community on the clinical utility of such testing.

But *Oncovue* is not automatically in our domain. Because the test is geared to the general public, group education sessions or interactive computer programs could be more cost effective and may do the job as well as, or better than, genetic counselors.

Conditions like cardiovascular disease and Alzheimer disease will fit this model. Will genetic counselors have a role? Should we position ourselves to incorporate such testing into our practice? These questions are sure to be asked by physicians, insurance providers, hospital administrators, laboratories and patients. We had better have answers soon. ❖

Robert G. Resta, MS