PERSPECTIVES in genetic counseling

Volume 22 Number 2 Summer 2000

national society of genetic counselors, inc.

nsgc

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

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NSGC acknowledges Genetic Health for a generous grant to support this newsletter.

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NSGC HIRES MARKETING CONSULTANT

Bea Leopold, MA

The GeneAMP Committee and Board of Directors are pleased to announce that NSGC has hired the Chicago-based marketing firm of Wooster, Inc. to develop a marketing plan and assist us in making it happen!

Wooster is co-managed by Peter Benkendorf, brother of genetic counselor, Judith. His company competed with four other firms in the proposal process.
The proposal was action-driven and based on a June - July planning process, with a roll-out of the plan about August 1.

Wooster will partner with Klettke Public Relations, also Chicago-based, headed by Russ Klettke.

A kick-off conference call with GeneAMP Committee Members and Board representatives determined that NSGC's marketing vision will be to "go public," that is, to improve attitudes, awareness and understanding of genetic counseling.

"Increased attention to human genetics among consumers and the media creates a clear opportunity for NSGC. The key is to harness that attention. We're enthused about what can be accomplished," said Peter Benkendorf.

Look for more information in the September issue of *PGC* and at our Conference in Savannah. ❖

CREATIVE JOB SEARCH

MORE GENETIC COUNSELORS ON THE 'NET

Melissa Gabriel, MS and Allison Gregory, MS, Genetic Counselors, DNA Dynamics, Inc., www.dnaMD.com

It was exciting to read about the expanding roles of genetic counselors working for Internet-based genetics companies in the last issue of *PGC.* We would like to share our experiences at DNA Dynamics, Inc., a genetic resources company dedicated to creating, consolidating and distributing genetic products and services to health care professionals and consumers.

We joined DNA Dynamics last year. We were both impressed by the strong science and genetics backgrounds of those at the company. Even more inspiring was the strong belief among the company's founders that genetic education and services need to be more readily available to primary care physicians and the public. Having worked previously at a busy prenatal diagnosis clinic, we were intimately familiar with the need for physician and public education to maximize the benefits of genetic resources.

Since joining DNA Dynamics, we have had the

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NSGC at Work: Forging Ahead

Wendy R. Uhlmann, MS

Genetic testing and genetic discrimination are key national issues this year. NSGC is actively participating in these discussions.

Coalition for Genetic Fairness

Vivian Weinblatt, NSGC President-elect, represents NSGC on the Steering Committee of the Coalition for Genetic Fairness (CGF). A key goal of CGF is to encourage Congress to pass comprehensive legislation that bans genetic discrimination in insurance and employment. Recently, NSGC signed a letter that was sent to managed care conferees urging inclusion of genetic discrimination provisions in a forthcoming House and Senate bill.

SACGT

The Secretary's Advisory Committee on Genetic Testing (SACGT) will finalize their recommendations for oversight of genetic testing at their June meeting. Ann Boldt, a past president of NSGC, is a member of SACGT. NSGC provided formal written response and testimony.

Predictive Genetic Testing Symposium

Vivian Ota Wang, Pam Nutting and I presented at the Arizona State University/SmithKline Beecham symposium, "Legal Liabilities at the Frontier of Predictive Genetic Testing." Primary participants were legal and ethical experts including speakers from Canada and the UK. The conference also addressed the Environmental Genome Project which aims to identify genes affecting individuals' responses to environmental agents and genetic susceptibility to environmentally associated diseases. Conference proceedings will be published in *Jurimetrics.*

ACMG Meeting

In March, I represented NSGC at the American College of Medical Genetics meeting, their largest, with 594 attendees, including 163 genetic counselors. Several genetic counselors presented: Rebecca Rae Anderson, Katy Downs, Ellen Knell, Becky Butler, Barbara Karczeski, Nancy Hanson and Jennifer Stroop (moderator). In addition, several genetic counselors had posters. The program abstracts are in the Jan/Feb issue of *Genetics in Medicine.* Thanks to Robin Bennett and Debra Lochner Doyle for facilitating and presenting at the high school student outreach program. In addition to networking, I attended the ACMG Business Meeting and several committee meetings. There was interest both in NSGC activities and in having genetic counselor committee members.

Updates

- The Continuing Education Subcommittee (Chair, Barbara Lerner) conducted an online needs assessment survey of NSGC members which studied options, obstacles and preferences for obtaining CEUs. *See p. 6.*
- Ilana Mittman, Chair, Diversity Task Force, represented NSGC at the TEXGENE/Genetic Alliance conference, *Cultural Diversity in Genetics,* this Spring. NSGC also financially contributed to this conference. *See p. 7.*
- The Computer Users Group (Chair, Beth Billings) has announced a change in name to Online Communications Group.
- Karen Johnson was appointed to the Special Projects Fund Committee.
- The 2000 Professional Status Survey was mailed to Full Members last month. Help yourself and our profession by completing these important surveys. *See p. 12.* ❖

Websites to Visit

☞ SACGT report and summaries
www4.od.nih.gov/oba/sacgt.htm.

☞ Environmental Genome Project
www.niehs.nih.gov/envgenom/

☞ ACMG
www.faseb.org/genetics/acmg/acmgmenu.htm

☞ CEU survey results
www.bio.brandeis.edu/gc/lerner/

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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 10***

More GCs on the 'Net from p. 1

opportunity to broaden our experiences and skills. We have contributed significantly to the design of our website and its content, including genetic condition summaries, DNA testing information, genetics news and descriptions of genetics services. Our newsletters for health care professionals and consumers also may be requested on our website and will eventually appear online.

We have interacted with marketing professionals to develop materials describing our DNA testing products. These include identity, zygosity and paternity testing and home DNA storage kits. Also, DNA Dynamics has developed a strategic alliance with the DNA Diagnostic Laboratory at Baylor College of Medicine, through which we can provide DNA testing.

To educate our sales team about genetics and learn the needs of the market, we have also spent time in the field with our national sales force.

Finally, in keeping with our goal to better integrate genetics into primary care settings, DNA Dynamics is developing a model for telecounseling by interactive video. We are testing this model at a pilot site.

It is extremely rewarding to work in a setting where genetic services, including genetic counseling, are viewed as a valuable resource that is underutilized. Through outreach to the public and physicians, we hope to incorporate the field of genetics as part of primary care medicine, allowing the public to benefit from our rapid advances while supporting the clinical genetics community. ❖

More Creative Job Search

Birth Defect Registries

Melinda Clyne, MHS

The quality and quantity of birth defects surveillance programs has improved in recent years, attributable in large part to a financial commitment by our federal government through the Birth Defects Prevention Act. The National Birth Defects Prevention Network was formed in 1997, and in 1999, the Pew Environmental Health Commission evaluated each state's efforts.

A small percentage of birth defect registries currently employ genetic counselors, such as New York, Iowa, Indiana, Colorado, North Carolina, South Carolina and Puerto Rico. Other registries contract with genetic centers or have relationships with university medical centers.

Most positions that are held by counselors within birth defects registries have been created in the past two years. Position titles include Genetic Counselor, Project Specialist or Coordinator, Human Services Coordinator and Genetics Program Director. Job postings advertise specifically for a genetic counselor or an individual with similar skills. Certification is generally not required.

Counselors perform a variety of functions:

- identifying cases of prenatally and postnatally diagnosed birth defects
- reviewing registry data
- organizing and developing training seminars for primary care providers
- serving as a liaison between registry and research studies
- educating the public and health professionals regarding folic acid
- providing referral information for children with special needs and
- performing administrative tasks.

Counselors are also an integral part of federal grants administered by the Centers for Disease Control and Prevention in 1999 to 18 state surveillance programs. These grants require the development and implementation of an approach

- to prevent NTDs and
- to work with appropriate partners in the state on birth defects primary prevention programs.

Activities for counselors include direct patient counseling.

As we complete the Human Genome Project and move toward unraveling gene-gene and gene-environment interactions, the connection between public health, clinical genetics and human genome epidemiology grows tighter. For the genetic counselor, birth defects surveillance and prevention registries will likely continue to be an arena for new jobs and experiences. ❖

Resources

☞ National Birth Defects Prevention Network
www.schs.state.nc.us/NBDPN/

☞Pew Environmental Health Commission
www.pewenvirohealth.jhsph.edu

☞Centers for Disease Control and Prevention
www.cdc.gov/nceh/cddh/BD/bdpghome.htm

☞Public Health, Clinical Genetics and Human Genome Epidemiology
www.cdc.gov/genetics/hugenet/

HIGHLIGHTS OF BOARD OF DIRECTORS MEETING

Stefanie Uhrich, MS

The following represents highlights of NSGC's Board of Directors interim meeting, held in Chicago in early June.

STRATEGIC PLAN AND PARTNERING – *Bea Leopold, MA, Executive Director*

Our 2nd Strategic Plan is due for evaluation at the end of 2000. This new plan most likely will focus on marketing and issues of billing and reimbursement. Diversifying the profession also remains a priority.

The concept of "partnering," where two or more parties such as a corporation and an association join together to promote themselves to others, was discussed. Opportunities for NSGC could include partnering with pharmaceuticals, major national consumer chains and other non-genetics associations.

NSGC has also been approached to partner with a genetics-related web company to facilitate online discussions for our members.

BILLING AND REIMBURSEMENT — *Leslie Cohen, MS and Jennifer Farmer, MS*

Three proposals to conduct a time study of genetic counseling services were submitted for review. Because the three have different spins, the Board discussed targeting our Requests for Proposals (RFP) to closer align with our intent. We also discussed the advantages and disadvantages of targeting other genetics groups, as the study will be expensive. The Board also determined that a time study might support genetic counseling needs in our own institutions regarding who we are, what we do and why it takes the time it does to successfully complete our work.

A conference call will be held with Debra Lochner Doyle, Jennifer Farmer, Leslie Cohen and Tanya Bardakjian as well as Mike Watson, Chair, ACMG Economics Committee. The purpose of the call is to target the RFP process and discuss common needs of NSGC and the College for possible partnering in this project.

A time study that is being conducted by GeneSage was discussed. The GeneSage study, not related to a study under consideration by NSGC, is attempting to understand the genetic counseling process on a business level to meet their company's mission.

POSITION STATEMENTS CONFUSION CLEARED — *Anne Spencer, MS, Chair, Social Issues Committee*

In a Herculean effort, the process for adopting position statements was streamlined, and all Position Statements, Resolutions, Position Papers and Points to Consider Documents have been combined.

In the future, they will appear in NSGC's membership directory and elsewhere, in the order of their adoption, and will be called Position Statements.

CERTIFICATION STATUS IN NSGC'S DIRECTORY – *Kristin Niendorf, MS, Chair, Membership Committee*

The issue of printing certification (CGC) status in our membership directory was discussed. As a result of the continuing controversy reported by the Regional Representatives and a survey of the Board and past presidents, consensus was not achieved. The issue will be presented as a "Point CounterPoint" article in an upcoming issue of *PGC.*

The majority vote was to include general information about ABGC certification and where one can obtain a list of diplomates. The next directory will be published in Spring 2001.

WEBSITE CHANGES — *Liz Stierman, MS, Chair, Communications Committee*

Design, content and input/maintenance were issues of focus in this discussion. We will redesign our website to bring NSGC more up to date with current trends in web design. In addition, we will augment the Web Submission Form to include tips for submitting information. Lastly, we look forward to a smoother process for updating the webpage.

Our new site will have media, consumer and member centers. We will announce the "unveiling." In the meantime, consider having your name in our RESOURCELINK. *See p. 12.* ❖

SURVEYS

Look for results of our recent surveys in the next issue of *PGC.*

Membership Committee

- Exit Interview Survey
- Job Search Survey

Professional Issues Committee

- Professional Status Survey

These surveys are one more reason to value your membership in NSGC. ❖

GENETIC COUNSELING IN SLOVENIA

Mateja Krajc, MD

Slovenia is a European country that lies between the Alps and the Mediterranean Sea. Slovenia's two million people speak Slovene, and 82% declare themselves Roman Catholic. Historically, the Slovenes belonged to several countries (most recently Yugoslavia), but they have kept their language, religion and culture.

CANCER COUNSELING

Until recently, medical doctors worked as genetic counselors in pediatric and OB departments of large public hospitals, and familial cancer risk counseling was conducted by medical and surgical oncologists. A multidisciplinary team operated for some time without BRCA1/2 gene mutation analysis. Recently, the University of Ljubljana's Departments of Oncology, Family Medicine and the Division of Medical Genetics initiated counseling for breast and ovarian cancer.

NEW SERVICES

Last fall, BRCA mutation screening became available to Slovenian families with a high incidence of breast and/or ovarian cancer via a pilot project with the Oncology Center, Vrije Universiteit Brussel in Belgium, where I am employed. This project investigates BRCA mutation testing in Slovenia by counseling high risk families with a clear dominant pattern of breast and ovarian cancer. Efforts have been made to increase awareness of the availability of testing.

The criteria for initiating a BRCA mutation screening program in Slovenia are more stringent than those in Belgium, where screening is warranted if there are two first-degree relatives with breast cancer, one diagnosed before age 50. If one of the symptomatic individuals has ovarian cancer, screening is initiated regardless of the age at diagnosis.

In Slovenia, where a large proportion of the population may originate from a common ethnic origin, the possibility of identifying a founder mutation is being considered. The identification of such a mutation could have important consequences for subsequent testing possibilities.

ETHICS REVIEW

The Central Ethical Commission of the Republic of Slovenia was consulted on issues relevant to high risk families. They addressed concerns generated before, during and after testing. Counseling sessions were taped with permission of patients and counselors, and verbal transcripts of these sessions were analyzed qualitatively. An analysis of the transcripts is being compared with other relevant literature.

At least one moral concern has been identified which the Slovene carriers of a BRCA gene mutation have in common with individuals in other countries — the sense of responsibility they feel toward their offspring. ❖

GENETICS AND INSURANCE IN THE UK

Caroline Benjamin, MS

Unlike the US, where health insurance dominates, life insurance prevails in the UK. Coverage relies on "mutuality" — claimants' disclosure of information combined with insurance companies' assessment of actuarial risks.

The UK government recently decided to allow insurance companies to use genetic testing to assess a person's risk of illness. While some fear such disclosure will create an uninsured segment of society, the government did not want insurers to perform testing without regulation. The Department of Health thus has commissioned an Independent Genetics and Insurance Committee to advise on the use of genetic tests by insurance. This September, the Committee will present a list of seven conditions considered valid to inform actuarial risks.

Under the new plan, insurers cannot force genetic tests but can suggest tests to those with a family disease history. They also may ask if a person has taken a test and demand to see the results. Insurers are limited in their use of testing information, as the test must be preapproved by the Committee, and coverage may be altered but not refused if the results support actuarial evidence.

As a genetic counselor in the UK, it is difficult to advise patients on testing and insurance. Many patients contact me "off the record" to discuss family histories, often opting for a full consult with the intention of keeping records from hospitals and doctors. There is also concern that testing may affect relatives' insurance, though the Association of British Insurers' code of conduct does not permit use of this information. As all testing is offered through National Health Service Units, results remain confidential and are disclosed to third parties only with clients' written permission. ❖

CEU Needs Assessment Survey

Barbara Lerner, MS

In 1999, the Education Committee created the Continuing Education Subcommittee to address recertification issues and help the American Board of Genetic Counseling (ABGC) and the American Counseling Association (ACA) expand CEU opportunities for counselors. Summarized below is the Subcommittee's first needs assessment survey. It is available in its entirety at www.bio.brandeis.edu/gc/lerner/.

Administration — NSGC members (n=1436) were notified of the survey in the Winter 2000 issue of *PGC* and on the listserv. The survey was available on the Internet and in hard copy.

Response Rate — Respondents (n=372) represented 25.9% of Full NSGC members and 26.4% of all certified genetic counselors (812 before 1996 and 598 in 1996 and 1999). Approximately 37% of the counselors who are required to recertify responded.

Certification Status — Respondents were split into two groups: Group A comprised 125 (33.6%) counselors certified before 1996; Group B comprised 100 (26.9%) certified in 1996, 121 (32.5%) certified in 1999, 23 (6.2%) who were not certified but plan to sit for the next exam and 2 (0.5%) who do not plan to get certified.

Plans to Recertify — Though recertification is not necessary for Group A, of that group, 83 (66.4%) planned to collect CEUs, 36 (28.8%) did not and 2 (1.3%) said this question did not apply. From Group B, only 10 (4.1%) said they did not plan to recertify.

Collecting CEUs at NSGC Conferences — Of respondents, 198 (53.2%) obtained CEUs at the last Annual Education Conference they attended while 169 (45.4%) did not, with no statistical difference between Groups A and B. Similar results reflected CEUs at regional meetings. Reasons for not obtaining CEUs included not attending the meetings since CEUs became required or not yet being certified.

Level of Difficulty Collecting CEUs — Of respondents, 240 (64.5%) expected difficulty obtaining CEUs, 81 (21.8%) did not and 39 (10.5%) were not planning to recertify. A significant difference existed between Groups A and B, with Group B expecting significantly more difficulty. Approximately 72% of respondents related this difficulty to financial constraints. Other reasons were lack of local programs and/or non-NSGC conferences offering CEUs.

Preferred Methods of Obtaining CEUs — Respondents favored expanded opportunities for obtaining Category 1 CEUs and selected several learning modalities for continuing education, in preferred order:

- NSGC-sponsored meetings
- other genetics related meetings
- Internet-based courses
- journal articles with test
- computerized learning modules
- videotapes with test
- audiotapes with test and
- teleconferencing lectures.

Other methods included:

- hospital grand rounds/lectures
- journal clubs and case conferences
- presentations to students/professionals
- published articles in journals
- tumor boards
- video conferencing
- CMEs and
- a point system for counseling interesting cases.

The full report also lists the regularly attended meetings for which counselors desire to receive Category 1 CEUs.

Category 2 CEUs — Forty-six respondents have applied for Category 2 CEUs. In only two reported cases, CEUs were not granted because there was no continuing education governing body to oversee the accreditation of CEUs or CMEs.

Questions from Respondents — Counselors listed over 200 questions regarding the CEU program, detailed in the full report. Responses are pending.

Discussion — Genetic counselors agreed that continuing education is crucial to our professional development and that CEU requirements help support our credibility. However, there is considerable anxiety about our ability to meet the CEU requirements, particularly concerning appropriate educational opportunities and financial costs.

While this survey represents only a portion of NSGC members, it has helped identify preferences for obtaining CEUs and the need to educate counselors about the CEU process and how to be active in expanding CEU opportunities.

Since so many counselors expect difficulty recertifying, we also must find ways to lower the barrier to obtaining CEUs to support the future existence of certification within the profession. ❖

What's Ahead in '00?

Dawn Allain, MS & Kelly Ormond, MS
Conference Co-chairs

Register Now!
November 2 - 5: 19th Annual Education Conference, *Exploring the Counseling Role in Genetic Counseling* — Savannah GA

November 5 - 6: *Short Course — The Genetics of Infertility: Evaluation, Counseling and Intervention*

More Info: Check Out NSGC's Website!

Ethics Cases : The Ethics Subcommittee is looking for cases that deal with conflicts in professional relationships. These will be used at an Annual Education Conference 2000 workshop considering ethical dilemmas in the work place and in genetic counselor training. Cases need not have been submitted for consult.
☞ Stephanie Kieffer ✆780 407-7336; or anonymously by fax 780 407-6845;
skieffer@gpu.srv.ualberta.ca

Tour Savannah! Come early! Stay Late! Two two-hour trolley tours of Savannah will be offered on Wednesday, November 1 from 3:00-5:00pm and Sunday, November 5 from 1:00-3:00pm.

Experience our Hostess City and all its charm on this leisurely ride through one of the largest urban historic districts in the country, giving you a comprehensive overview of old Savannah. Ride along cobblestone-paved streets beneath moss-draped oaks, and experience the "Old South" with its stately mansions, beautiful squares and bustling riverfront. This professionally guided tour is a must for anyone coming to Savannah for the first time!

The cost for the tour is $12.00 per person. Tours leave from the Westin Savannah Harbor Resort…*on time!*

More information, including sign-up and pre-payment, will be mailed with your confirmation letter. *Please do not include payment with registration.*

☞ Kate Roth ✆912-350-3584;
Rothma1@memorialmed.com

Home to Vote! National Presidential elections are November 7. Plan your travel to get home in time to vote — or order your absentee ballot early! ❖

Cultural Diversity in Genetics

Ilana Mittman, MS

Consumers, genetic providers, anthropologists, social scientists and community activists gathered in Corpus Christi, Texas in May to discuss and learn about the delivery of genetic services to culturally diverse communities.

The conference partnership between the Genetic Alliance and TEXGENE was funded in part by the Genetic Services Branch of the Maternal and Child Health Bureau. NSGC also contributed financially to this conference.

Presentations provided an important overview of the components of culturally diverse populations:

- geography
- history
- vital statistics
- spirituality and
- identity.

One of the highlights was an inspiring and innovative presentation, "Positive Exposure: Illuminating the Richness of Difference," by a photographer and an epidemiologist. The striking beauty of pictures and stories of men, women and children with albinism from around the world stood in remarkable contrast to typical portrayals of people with genetic syndromes. The depiction poignantly illustrated the power of the media in shaping public opinion about aesthetics and social norms.

A delightful presentation by the Maui Native Hawaiian Health Care System included hula dancing and sweet treats! ❖

Regional Meetings Spell Success

Region I

Lori Ann Correia, MS

The Region I Conference, *Positioning Yourself for the New Millennium — Building Bridges,* was held at Brandeis University on May 5. Thanks to the planning committee for a job well done!

Dr. Bob Greenstein, Dawn St. Amand and Dale Lea spoke on billing and reimbursement. Mary McGrane, VP of Government Relations at Genzyme Genetics, and Massachusetts State Rep Jay Kaufman reviewed genetic and privacy legislation.

Participants relaxed in a stretch workshop by Susan Dibble, Dance Instructor at Brandeis. The class was so well received it has been requested for subsequent meetings. Kathy Schneider led a workshop on getting started in research. We had a lively discussion about job opportunities in grief counseling by Emily Lazar, who has started her own grief counseling practice.

Region II

Karen R. Eanet, MS

The Region II Conference, *Genetics in the 21st Century,* held on April 14, was a success, largely due to the efforts of Karen Johnson, the previous Region II Rep, and the planning committee. About 150 people attended, and one-third were students.

Dr. Francis Giardiello started with an overview of hereditary colon cancer. Kristyne Stone discussed genetic causes of infertility, and Katherine Oelrich reviewed Connexin 26 gene testing for hereditary deafness. Dr. Anne Maddalena talked about Factor V Leiden and pregnancy.

Four workshops featured student activities, student supervision, job searches and media relations.

Dr. Barbara Goodman reviewed multicolor FISH for chromosome analysis. Rosalie Goldberg discussed the search for the Noonan Syndrome gene. Sherry Campbell Grumet outlined prostate cancer risk assessment. Dr. Maimon Cohen gave us a glimpse into the future of clinical genetics.

Region IV

Leslie Cohen, MS

Over 80 counselors and students from the Midwest attended the Region IV conference in St. Louis, Missouri in April — the largest attendance in 10 years!

The conference began with Dr. Suzanne Mahon, who discussed the genetics of melanoma, and Dr. William Haire, who explained the intricacies of hereditary clotting disorders and the controversy regarding clinical testing. A workshop on licensure, billing and reimbursement included an expert in health care billing and coding who clarified the AMA's recommendations in creating codes for genetic services. Students attended a workshop on nontraditional roles.

Dr. Hilary Klein described the components of a mental status exam in psychiatric diagnoses. Also included were updates on support groups, the molecular genetics of NTDs, treatment for lysosomal storage diseases and imprinting, mosaicism and uniparental disomy.

Many felt this was the best regional conference in years, and I thank the organizers for their excellent choice of speakers and topics.

Region VI

Steven Keiles, MS

The Region VI Conference was held March 30 - April 2 in Monterey CA with the help of an outstanding planning committee, a beautiful location, great weather and over 150 counselors.

The conference started with a talk on hereditary hemorrhagic telangiectasia by Jamie McDonald, who related her personal story and professional experience. Norma Chow, Susan Donlon, Melody Kohan and Aparna Murali conducted a panel on cultural diversity to facilitate working with Asian, Hawaiian, Iranian and Indian patients. Dr. Vincent Felitti reviewed hemochromatosis. Writer, Diane Shader Smith, presented her moving story, including the termination of a fetus with CF, her daughter's CF, her son's Tourette's syndrome and her own breast cancer.

Workshops included advanced public speaking and Spanish for genetic counselors. Other topics were domestic violence, teratogen counseling and embryology.

We ended with networking and relaxing at our social event of wine, food and a make-your-own s'mores bonfire. ❖

SMART SEARCHING = SMOOTH SURFING

Kathleen Fergus, MS

If you have ever checked the web for Triple X syndrome and pulled up a variety of pornographic sites, then you are familiar with the capricious nature of Internet searching. With over 800 million webpages, Internet growth necessitates effective search techniques. Here are a few to help improve your searches.

There are two main ways to search the Internet — search engines and directories. Search engines build large indexes of sites that link to specific webpages and catalog them using computers and a variety of algorithms. Examples of search engines include Altavista, Google and Hotbot. Directories, on the other hand, are cataloged by humans. Examples include Yahoo and Ask Jeeves.

These two cataloging techniques have different strengths and weaknesses. Directories are a good place to start for general information. Ask Jeeves lets you ask a question in plain English and compares it to millions of pre-composed questions, giving you the search results for the questions that most closely match. Directories are less useful with precise or obscure information. When looking for specifics about rare genetic syndromes, search engines are the way to go.

A number of techniques can narrow or better define searches. Each search engine has techniques which are usually listed under a "help search" or "narrow your search" button. Techniques discussed here are for Altavista, one of the oldest search engines. Most search engines are based upon Altavista and use similar search parameters.

The simplest way to broaden a search is to use lowercase letters. This is the default for most search engines to pull up both lower and uppercase terms. If you use uppercase, the search engine will only pull up sites with the same uppercase terms. Another technique is to use the wild card symbol * (asterisk). Triple X syndrome, also referred to as Triplo X syndrome, would be searched as tripl* x syndrome, and the wild card symbol will search for both variations.

To narrow searches and prevent wading through extraneous pages, enclose your phrase in " " (quotation marks) e.g. "triple x syndrome." This results in pages only with the three terms next to each other. However, if you need something specific about Triple X syndrome, use a + (plus) symbol to narrow the number of pages retrieved. The + means that this term must be on the page; the + can be used in front of a phrase or word. Alternatively, using a - (minus) can allow you to get rid of pages with irrelevant information.

Search Engine Examples
(using Altavista)

TECHNIQUE	SEARCH TERMS	RESULTS
Capitalization	Triple X Syndrome	292,446
Lowercase	triple x syndrome	500,523
Phrase	"triple x syndrome"	56
Wild card	"tripl* x syndrome"	94
+ sign	+ "triple x syndrome" + support	35
- sign	+ "triple x syndrome" - support	63

Hopefully these tools will help refine your Internet searches. Since each search engine may have its own specific timesaving techniques, investigate your options. ❖

LIAISON REPORT

GROW II, THE SEQUEL

Lyn Hammond, MS

Genetic Resources on the Web (GROW) is an NIH-sponsored consortium of private and public web-based information sources. GROW II was held at the NIH in Washington DC in March.

Dr. Francis Collins opened the meeting by welcoming more than 50 attendees from 34 organizations. Each agency reviewed its current and planned relationships to the web. We discussed whether sites should maintain balanced content and points of view vs. stating sources of funding or biases, and when a site might require an internal search engine. We reviewed prototypes for a possible "GROW Search Engine."

On the second day, we focused on GROW's use of expert content providers and establishing and maintaining effective web links. Other issues: web-based content on human genetics, proprietary issues, conflicts of interest, criteria for quality assurance and cooperative efforts.

The GROW Working Group will investigate issues of technical access (e.g. use of the web by those with disabilities), socioeconomic access (e.g. use of the web by those with poor literacy skills) and confidentiality/privacy issues. ❖

MEDIA WATCH

Roxanne Ruzicka, MS &
Angela Geist, MS

"*State of the Union Address, 1/27/00* — In his national address, President Clinton stated, "We must act to prevent any genetic discrimination whatever by employers or insurers." He also recalled a scientist who said, "We are all, regardless of race, genetically 99.9% the same," and reminded the public that "we should do more than just tolerate our diversity, we should honor and celebrate it."

"*New York Times, 2/9/00* — Clinton issued an order prohibiting federal agencies from using genetic information in hiring, promoting or dismissing workers. He noted that while information about the human genome can transform disease treatment and prevention, we must not allow genetic discrimination against any individual or group. The article quoted Wendy Uhlmann, NSGC President, who hailed the President's action, stating, "All of us are predisposed to some type of illness, but most of us don't know what it is yet. The more protections we have in place, the better it will be for all of us."

"*Extra, 2/18/00* — A couple in Tennessee pursued plastic surgery for their baby girl with Down syndrome to make her facial appearance more "normal." The surgeon widened her eyes and created a more prominent nasal bridge. Two months after surgery, the parents reported fewer stares and comments from people regarding their daughter's appearance. They felt that by looking more "normal," their daughter would be treated better, which would improve her self-esteem and social development. The reporter stated that this surgery is usually covered by insurance, as Down syndrome is considered a disability.

"*Providence, 2/18/00* — A woman presented with a family history of breast cancer and was offered testing for the breast cancer gene. The woman was told she was at extremely high risk for breast cancer and that test results would help her prevent the disease. She was offered the names of genetic counselors since "they can be helpful." The results were available right away, and the patient was given results in an envelope as long as the patient promised not to open it when she was alone!

"*Extra, 5/4/00* — A segment on fetal surgery covered a fetus diagnosed with a spinal tumor at 16 weeks gestation at Children's Hospital of Philadelphia (CHOP). The tumor was removed, and the little girl is a healthy four year-old. The show correctly named the centers that perform fetal surgery: CHOP, UC San Francisco and Vanderbilt University.

"*ER, 5/4/00* — A child came into the ER with seizures and persistent hypoglycemia. A resident diagnosed the child with medium chain acyl-CoA dehydrogenase (MCAD) deficiency. Dr. Weaver suggested the family have a genetics consult. After discussing the cost/benefit analysis of newborn screening for rare genetic disorders with other doctors and listening to the anguish of the boy's parents, the resident started a petition to expand newborn screening in the hospital. ❖"

Billing Success…

Indiana Experience

Kirstin J. Schwandt, MS

Bloomington IN had no genetic counseling services before 1996 when I began a private practice, working from home and providing counseling in various physicians' offices. I spent a lot of time developing marketing tools and educating myself on insurance companies and CPT and ICD-9 codes.

In 1998, I joined a group of 14 physicians in an OB/GYN clinic. After the cost and difficulties of self-employment, I needed other health care providers' support. Creating a full-time genetic counseling position, however, depended on my ability to develop a billing system for my services.

Not a billing and coding expert, I used knowledge gained in my two years alone. I met often with the billing personnel and developed a "superbill," which listed only CPT and ICD-9 codes most applicable to genetic counseling. Insurance reimbursed for "consultation" but not "counseling," so we used consultation codes 99241-99244 in place of risk factor reduction or office visit codes. Since then, ICD-9 codes have grown.

Although my clinic has a current solution for billing, there are no guarantees. Patients ask, "Is this appointment covered?" or "Why didn't my insurance pay?" — questions without simple answers. The lack of adequate payment for counseling services cannot be underestimated.

No success is too small — we all learn and benefit from shared experiences. Share yours with us!

☞ Tanya Bardakjian, MS, Chair, BL&R Subcommittee, ✆215-456-8722; aemcgenetics2@hotmail.com ❖

RESOURCES • RESOURCES • RESOURCES

Genome: An Autobiography of a Species in 23 Chapters

author: Matt Ridley

publisher: HarperCollins, 1999. 344 pp.

cost: $26.00

reviewer: Claire Noll, MS

Matt Ridley attempts to write the story of human history from the vantage point of genes. He carefully chooses one gene from each chromosome and extrapolates from its function within the cell to its function at the organism or species level. He covers everything from the primordial soup to genetically engineered Brazil nuts, using wit, insight, personal opinions and a surprising amount of genetics.

Ridley is not a scientist, though this is his third book with a scientific theme. He's an editor, and this book is ultimately an annotated tour-guide of human genetics. Early chapters review basic concepts of speciation, dominant and recessive inheritance and pleiotropy. Later chapters include more esoteric topics such as genome evolution, balancing selection, gene processing and genetic engineering. The book succeeds because of Ridley's skill in guiding readers from the specific to the general.

Each concept is illustrated rather than defined, with references and light-hearted analogies. For instance, housekeeping genes are described as "tedious biochemical middle managers," and a promoter sequence is likened to a *Read Me* file.

Some topics are controversial. The chapter on speciation might offend readers who believe in creationism, as evolution is taken as given. The chapter on sexual selection covers research into sexual orientation. The book also mentions the DNA analysis of Thomas Jefferson's relatives, Monica Lewinsky's dress and recent cloning experiments.

Ridley is British and writes with a dry, understated humor. The chapters are short, the style straightforward and the arguments easy to follow. Ridley manipulates but notes that this is deliberate, and he also warns when the text delves into complicated science, such as a biochemical pathway. And to really make a point, HE PUTS IT IN CAPS and repeats it in several chapters. I also noted only one genetic howler — "Children are occasionally born with an extra chromosome 13 or 18, but they never survive more than a few days…."

While the book is thought provoking, it touches the surface of many facets of genetics while exploring none in great depth. Thus, it may best serve an audience already familiar with basic genetics, such as advanced high school or college science students. Genetic counselors may find it a good review of recent advances, including an ethical discussion of presymptomatic testing and some one-line explanations of concepts that might be handy in counseling sessions. I suspect that laboratory types might find it entertaining though superficial, while general readers might find the details too complicated. ❖

STUDENT RESOURCE: MENTOR MATCH

Troy A. Becker, MS

NSGC's Mentoring Program, sponsored by the Membership Committee, is entering its 5th year. The program's purpose is to allow professionals and students/recent graduates to exchange ideas and information about their interests or experiences in genetics and counseling. Mentors and students are asked to contact each other every four to six weeks for about six months.

For students, mentoring provides a resource outside their training program, a chance to discuss issues with experienced counselors and an opportunity to network. These interactions include providing a "real world" genetic counseling perspective, information about different employment situations, support in the job search and guidance in the transition from student to professional. For counselors, mentoring provides the opportunity to make contact with students.

The outcome and success of the match is linked closely to students' participation. Students who are more active in the program report having the best experience.

Interested? Mail the card enclosed in this issue back to us so we can set up your match!

☞ *Postmark deadline for postcards: Friday, July 28.* ❖

Bulletin Board

Professional Status Survey

Calling all Full Members! Your 2000 Professional Status Survey has been sent to you along with your new membership directory. Your participation is needed to ensure that this year's survey is a success and that we all benefit from the best and most accurate data. The more responses we receive, the stronger our results.

Please take the time to complete this survey thoughtfully and accurately.

Deadline: All surveys must be postmarked by June 28.

☞ If you did not receive your copy, contact NSGC's Executive Office, nsgc@aol.com.

☞ If you've misplaced your return envelope, mail your survey to: Jennifer Farmer, Chair, Professional Issues Committee, 29 Bryn Mawr Ave., Newtown Square PA 19073.

☞ For specific questions about completing the survey, contact Jennifer Farmer, ✆610-325-3473; farmer@netaxs.com ❖

Elections — Your Vote Counts!

Full Members are invited to cast their votes about the future leadership of the profession. This year, you will be electing President-elect, Secretary, Treasurer-elect and Representatives to Regions II, IV and VI.

Ballots will be mailed on June 26 with a return date of July 31. Announcements of new leadership will be printed in the fall issue of *PGC.* ❖

Mail Call!

Confused about reporting your address change? Here's a roadmap.

- NSGC prints labels for all NSGC mail, usually one day before the mail preparation begins. All of our mail is sent first class.
- NSGC supplies labels for the *Journal of Genetic Counseling* publishers, KU/Human Sciences Press. *Journal* labels are requested about three weeks before mail prep begins. The *Journal* is sent book rate, which means your *Journal* may take up to three weeks to arrive. Your mail *will not be forwarded* in the event that you relocate.
- ResourceLink, our website referral to genetic counselors, has a new system to ensure timeliness and accuracy. However, it is not linked to our main database. All additions, changes and deletions will be reported to our web genie on the 15th of each month so edits can be completed by the 25th. You can add, change or delete your listing right online.

It is critical that we have correct address information immediately after or just before your relocation. Be sure to notify NSGC promptly!

☞ Fax the last page of your membership directory to ✆610-565-6220 or single line changes to nsgcassist@aol.com.

☞ Make ResourceLink changes online: www.nsgc.org click on ResourceLink, then click on the link, Join the ResourceLink. If you wish to be removed, or are reporting changes, indicate those instructions in the memo box. ❖

Discrimination, Privacy Issues Study

The Genetic Alliance is studying and documenting incidents of genetic discrimination and privacy abuse. Deadline for participation is July 15.

☞ Lois Lander or Liz Kramer, ✆800-336-GENE; info@geneticalliance.org; www.geneticalliance.org ❖

Meeting Manager

July 19-23	*The Seventh International Fragile X Conference,* Sheraton Universal Hotel, Los Angeles CA
Aug 10-13	5p- Annual Conference, *Miami 2000*, Miami FL 5p- Society, 7108 Katella Ave PMB-502, Stanton CA 90680
Sept 19-20	*Genetics in Public Health,* Ann Arbor MI ☞ ✆301-984-9450; registernow@mindspring.com, subject line: Genetics Conference
Sept 22-24	*Twelfth National Perinatal Bereavement Conference, A Path To Healing*. Cincinnati OH ☞ Alana Roush, ✆513-569-6402
Oct 16 - 18	*NIH Consensus Development Conference, Screening and Development for PKU,* NIH, Bethesda MD ☞ ✆301-592-3320, pku@prospectassoc.com; consensus.nih.gov
Nov 16-18	*Ethics and Genetics: Advanced European Bioethics Course,* Nijmegen, The Netherlands ☞ N. Steinkamp, n.steinkamp@efg.kun.nl.

Research Network

CLAL Research Study

Cancer, Longevity, Ancestry and Lifestyle (CLAL) is a prostate cancer research study at the Albert Einstein College of Medicine in collaboration with the National Human Genome Research Institute at the National Institutes of Health. This is a case-controlled study of Ashkenazi Jewish men with and without prostate cancer. The goal is to identify genetic and/or environmental differences between the two groups of men. Participation in this study requires giving informed consent, filling out a questionnaire, providing a buccal (inner cheek) or blood sample and providing a pathology report for men diagnosed with prostate cancer.

☞ Rochelle Vininsky, MS,
✆718-430-3738;
toll free ✆877-444-2525;
vininsky@aecom.yu.edu

Online registration for study:
www.ca.aecom.yu.edu/burk ❖

Brain, Tissue Banks for Developmental Disorders

The University of Maryland's Brain and Tissue Bank for Developmental Disorders, funded by the National Institute of Child Health and Development, collects, stores and distributes brain and other tissues to qualified researchers. The Bank is currently accepting tissues from deceased fetuses, babies, children and young adults with a multitude of developmental disorders. Brochures, registration forms and a video are available.

☞ ✆800-847-1539;
www.som1.umaryland.edu/btbank/

The University of Miami has a similar program.
☞ ✆800-592-7246 ❖

SIG Update

Working with Support Groups

Gail Stapleton, MS and Lois Lander, MS, Co-chairs, Support Groups SIG

When professionals and consumers work together, they have the best chance of creating a successful support group. Professionals contribute information, resources and potential members. Patients have the passion and drive necessary to get a new group off the ground.

Give and Take

Some patients and families are wary at first of professional involvement, and professionals may be overbearing or stifle consumer attempts to be autonomous. When the two groups share trust and respect, however, the relationship can be productive, and everyone benefits.

Genetic counselors have much to offer support groups. We can provide:

- links to local, state and national resources
- access to public health and political arenas
- discussion about discrimination
- explanations about informed consent and confidentiality and
- raised awareness about cultural differences.

SIG Activities

The Support Group SIG is a new addition to the NSGC. We have developed a listserv and recently presented a talk at the Region IV meeting in St. Louis. Currently, we are working on resources that will help guide genetic counselors working with support groups.

☞ Gail Stapleton ✆864-455-5388
gstapleton@ghs.org, or
Lois Lander ✆202-966-5557
llander@geneticalliance.org ❖

Tips for Organizing a Support Group

Arranging Meetings

- generate publicity
- manage logistics, e.g. convenient time and place
- consider weekends to accommodate working members
- provide refreshments and babysitting
- plan for wheelchair accessibility and parking
- provide for both speakers and time for member sharing

Alternative GC Roles

- group leader
- advisory board member
- clinical consultant

Facilitating a Group

- identify group's focus
- be flexible
- allow group to specify its needs
- create a safe atmosphere
- stress confidentiality
- monitor accuracy of information
- encourage members to share
- be supportive and nonjudgmental
- enhance coping and self-esteem
- be prepared for confrontations and dominating members ❖

EMPLOYMENT OPPORTUNITIES

■ **ANAHEIM CA:** Immediate opening for PT (50%) BC/BE Genetic Counselor. Potential for expansion. Self motiv, multidisc team player, excellent commun skills & limited trav req. Exp pref, will consider new grads. Bilingual Eng/Span & computer exp pref. Join large, active multidisc team: partic in all aspects of PN GC: XAFP scrng, AMA, fam & preg hx, terat, multiple SAB. May also incl preconcep GC, NB scrng, cancer GC & prof educ.
☞ Send CV & 3 ltrs rec to ID #OCX0000392 c/o Mindy Cameron, Kaiser Permanente, 1188 N. Euclid, #220, Anaheim CA 92801; ✆714-279-6067, Fax: 714-279-6069; Joan Wetzel, joan.m.wetzel@kp.org

■ **DUARTE CA:** Immed opening for BC/BE Genetic Counselor or RN w/ MS spec in genetics. Exp in cancer genetics strongly pref. Span a plus for clin outrch svcs/resrch. Join LA-area growing, multifac prog: cancer risk assmt & GC in on-site & sat clins; clin rsrch, grant writing, prof educ & CME educ activ.
☞ Ltr w/ CV & ref to: Kathleen Blazer, MS, City of Hope Natl. Medical Ctr, Clinical Cancer Genetics, Duarte CA 91010; Fax: 626-930-5495; kblazer@coh.org

■ **LOS ANGELES/ORANGE COS. CA:** Immed opening for FT & PT BC/BE Genetic Counselors. Work i'pendently & on team: PN & preconcep pts.
☞ Kristen Jadul, Genzyme Genetics, 15 Pleasant St Connector, PO Box 9322, Framingham MA 01701; Fax: 508-872-2460; kristen.jadul@genzyme.com

■ **MADERA CA:** Immed opening for BC/BE Genetics Counselor. Exp pref, new grads enc to apply. Join dynamic team at tertiary genetic ctr svg wide geographic & diverse pts: PN, peds, adult & cancer GC.
☞ Susan Wisniewski, Manager, Dept Genetic Medicine, Valley Children's Hospital, 9300 Valley Children's Place - GE 06, Madera CA 93638-8762; www.valleychildrens.org. EOE

■ **MOUNTAIN VIEW (SAN JOSE AREA) CA:** Immed opening for BC/BE Genetic Counselor. Abil to work i'pendently req. Join 2 GCs in priv PN prac svg diverse pts. Spanish, Cantonese or Vietnamese a plus.
☞ Katherine Young, Peninsula Prenatal Diagnostics, 1580 W El Camino Real, Mountain View CA 94040; ✆650-938-6066; Fax: 650-964-1522

■ **OAKLAND CA:** Immed opening for .8 FTE, BC/BE Genetic Counselor. Join team svg diverse pts: PN & ped, hosp consults, multidisc subspec clins.
☞ Cheri Loustalet, MS or Liane Abrams, MS, Medical Genetics Dept, Children's Hospital-Oakland, 747 52nd St, Oakland CA 94609; ✆510-428-3550; Fax: 510-450-5874. EOE/AA

■ **SACRAMENTO CA:** Immed opening for BC/BE Genetic Counselor. Join estab, c'hensive HMO. Provide broad range of PN, CA, peds, adult GC.
☞ Jacqui Wright, Kaiser Permanente, 1650 Response Rd, Genetics Dept, Sacramento CA 95815;-✆916-614-4798; Fax: 916-614-4768; jacqui.wright@kp.org. EOE/AA

■ **SAN FRANCISCO CA:** Immed opening for BC/BE Genetic Counselor. Self-motiv, i'pendence req. Work in multidisc clin setting in academic med ctr: eval & GC svcs for neurodegenerative disorders, prof & public educ, coord & partic in clin rsrch fam studies of atypical dementias. Write educ materials, facil monthly caregiver supt grp.
☞ Jennie Feiger, MA, MS, UCSF Memory & Aging Center, 350 Parnassus Ave, Ste 800, San Francisco CA 94117; ✆415-476-8820; Fax: 415-476-4800. EOE/AA

■ **SAN FRANCISCO CA:** Immed opening for BC/BE Genetic Counselor. Abil to work i'pendently, excellent commun & org skills req. Exp pref. Span or Cantonese a plus. Dynamic, diverse & growing PNDx & new cancer risk GC prog.
☞ Susan Millar, Manager, California Pacific Medical Ctr, Prenatal Diagnosis Ctr, 3700 California St, #G330, San Francisco CA 94118; ✆415-750-6400; Fax: 415-387-5876

■ **SAN FRANCISCO CA:** Immed opening for BC/BE Genetic Counselor. Bilingual Span; 2 yrs exp pref. 2nd position may become avail w/out Span req. Join estab c'hensive prog in HMO setting. Broad range svcs: PN, ped, adult, cancer.
☞ Chris Harlove, MS, Kaiser Permanente, Genetics Dept, 2350 Geary Blvd - 3rd fl, San Francisco CA 94115; ✆415-202-3323; Fax: 415-202-2999. EOE/AA

■ **SAN JOSE & MODESTA CA:** Immed opening for FT BC/BE Genetic Counselor. Bilingual (Span/Eng) pref. Work i'pendently & on large team: PN GC to diverse populations in busy c'hensive med ctrs.
☞ Kristen Jadul, Genzyme Genetics, 15 Pleasant St Connector, PO Box 9322, Framingham MA 01701-9322; Fax: 508-872-2460; kristen.jadul@genzyme.com

■ **SAN JOSE & MODESTA CA:** *See Genzyme, LA/Orange Cos. CA*

■ **SAN JOSE CA:** Immed opening for PT (14 hrs/wk) BC/BE Genetic Counselor. Bilingual (Span/Eng) pref. Work i'pendently & on large team: PN GC to diverse pts.
☞ Kristen Jadul, Genzyme Genetics, 15 Pleasant St Connector, PO Box 9322, Framingham MA 01701-9322; Fax: 508-872-2460; kristen.jadul@genzyme.com

■ **SAN JOSE & MOUNTAIN VIEW CA:** Immed opening for BC/BE Genetic Counselor. Join large team to provide range of PN svcs. Possible oppty to provide GC for adult-onset disorders.
☞ Fax to: Kim Rittenhouse, MS, PhD, Perinatal Practice Management, Samaritan Dr, San Jose CA 95124; ✆408-358-7127; Fax: 408-358-8264

■ **SAN JOSE CA:** Immed opening for BC/BE Genetic Counselor. Abil to work i'pendently, excellent commun skills, admin exp desired. Join Kaiser w/ dual responsibilities as Reg'l PN CF Scrng Coord & Clin GC. Coord respon: day to day operations & tracking, coord w/ molec & clin labs, OB educ, qual assurance & prog rept for N. CA Kaiser reg'l CF, Tay-Sachs & Canavans screening prog. Genr'l svc: GC for PN, ped & adult cases.
☞ Karen Wcislo, MS, Kaiser Permanente, Genetics Dept, 260 International Circle, San Jose CA 95119; ✆408-972-3306; Fax: 408-972-3306. EOE/AA

■ **STANFORD CA:** Immed opening for PT (50%) BC/BE Genetic Counselor. Potential for expansion. Energetic, work well i'pendently on large, multidisc team. MS, MA or MPH req. GC: AMA, XAFP, U/S anomalies, DNA dx, fam hx & terat. Some travel to new East Bay sats.
☞ Robbie Tung, MS, Coordinator, GC Clinic Lucile Packard Children's Hospital at Stanford, Dept OB Genetics, HF306C Genetics, Stanford CA 94035; ✆650-723-5198; Fax: 650-725-2878

■ **COLORADO SPRINGS CO:** Immed opening for BC/BE Genetic Counselor. Join c'hensive multidisc PNDx ctr. All aspects of PNDx; amnio, CVS, AFP, terat, U/S, fam hx. Oppty to expand cancer risk assessment prog.
☞ Fax CV & 3 ltrs ref: Elena Strait, MS, Memorial Hospital, 1400 E. Boulder, Maternal Fetal Medicine Ctr, Colorado Springs CO 80909; ✆719-365-5960; Fax: 719-365-5977. EOE/AA

■ **MIAMI FL:** Immed opening for BC Genetic Associate. Min 3 yrs exp in field, incl exp in genetics rsrch. Respon: pt contact, recruit, review med records & fam hx, assist in coord fam studies, informed consent process & collect & org fam data for publication.
☞ Dr. H. A. Lubs or Dr. Lisa Baumbach, University of Miami School of Medicine, PO Box 016820-D820, Miami FL 33101; (HAL): ✆305-243-6383; Fax: 305-243-3919; hlubs@peds.med.miami.edu; (LB): ✆305-243-3997; Fax: 305-243-4570; lbaumbac@med.miami.edu

■ **MIAMI FL:** *See Genzyme, LA/Orange Cos. CA*

■ **MIAMI FL:** Immed opening for BC/BE Genetic Counselor. Bilingual (Eng/Span) & 2+ yrs exp req. Abil to work i'pendently & on team. PN GC in 3-co. area: GC for variety of PN & preconcep pts.
☞ Kristen Jadul, Genzyme Genetics, 15Pleasant St Connector, Framingham MA 01701-9322; Fax: 508-872-2460; kristen.jadul@genzyme.com

■ **ORLANDO FL:** Immed opening for BC/BE Genetic Counselor. Exp pref. Respon: Join multidisc team: GC Peds & PN pts, clin coord, prof & commun educ, outrch clin respon.
☞ Send ltrs rec c/o Dan Riconda, MS or John McReynolds, MD, Arnold Palmer Hospital, 92 W. Miller St, Orlando FL 32806-2036; ✆407-649-6910 x1050 (DR); ✆407-650-7301 (JM); Fax: 407-872-7739; driconda@orhs.org

■ **ATLANTA GA:** *See Genzyme, LA/Orange Cos. CA*

■ **ATLANTA/DECATUR GA:** Immed opening for BC/BE Genetic Counselor. New grads may apply. Interest or exp in PN GC & lab operations exp req as well as org & flex'bilty skills, abil to handle variety of respon; c'hensive pt follow-up, back-up for other Emory couns & oversight of lab phone triage. Join large GC team in an acad setting: 1/2 PN GC in Atlanta & sat affiliates & priv perinat groups; the other 1/2 phone triage for all aspects of Emory Genetics Laboratory (cyto, serum scrng, molec & biochem genetics).
☞ Cathy Tesla, MS, Emory Genetics Laboratory, 2711 Irvin Way, Ste 111, Decatur GA 30030; ✆404-297-1521; Fax: 404-297-1512; clt@rw.ped.emory.edu. EOE/AA

■ **ATLANTA/DECATUR GA:** Immed opening for BC/BE Genetic Counselor, Triage. 1 yr exp or completion of internship in GC; new grads welcome to apply. Phone triage for all aspects of Emory Genetics Laboratory (cyto, serum scrng, molec & biochem genetics); coord & explain lab & other dx tsts to docs & pts primarily via phone. Facil informed decision making about tstg. Effectively utilizes commun resources & provide med, educ & psychosocial supt to ind/fam.
☞ Cathy Tesla, MS, Emory Genetics Laboratory, 2711 Irvin Way, Ste 111, Decatur GA 30030; ✆404-297-1521; Fax: 404-297-1512; clt@rw.ped.emory.edu. EOE/AA

■ **CHICAGO IL:** Immed opening for BC/BE Genetic Counselors w/ min 2 yrs exp. Provide PN GC for amnio & CVS; coord preimplant genetic dx prog & genrl genetics clin. Appt to med school faculty & particip in GC Graduate Trng Prog.
☞ Eugene Pergament, MD, PhD, Northwestern University Med School, 333 E. Superior St, OB/GYN, Repro Genetics, Chicago IL 60611. EOE/AA

■ **IOWA CITY IA:** Immed opening for Program Associate I. Master's in nursing, PH, human genetics, GC or related field. Desirable: BS in nursing & state license or BC GC. Genetic eval & GC svcs in cancer risk and genrl genetics clins: conduct clin, educ, admin, liaison & rsrch.
☞ Attn. #54, Janine McBride-Rahn, University of Iowa, Dept Pediatrics, 200 Hawkins Dr, Iowa City IA 52242-1083. EOE/AA/W/M

See next page

Employment Opportunities

■ **Iowa City IA:** Immed opening for 3 Genetic Counselors: #1 temp 4 mo, 1st stage devel of formal statewide terat prog; #2 genrl genetics in outrch clin; #3 genrl genetics & hered eye diseases.
☞ Carol Johnson, Program Assistant, Univ of Iowa Hospitals & Clinics, 200 Hawkins Dr, 2612 JCP, Div Med Genetics, Iowa City IA 52242; ✆319-356-2674; Fax: 319-356-3347; carol-Johnson@uiowa.edu. EOE/AA

■ **Baltimore MD**: Immed opening for BC/BE Genetic Counselor in DNADx lab at acad inst. Primary respon to i'face w/ referring sources re: lab tsts & results; if interested, other activ may incl: devel of trng progs or pt, prof lit on lab tests, database & website dev and more.
☞ Corinne Boehm, MS, Johns Hopkins Hospital, 600 N. Wolfe St, CMSC 1004, Baltimore MD 21287; ✆410-955-0483; Fax: 410-955-0484

■ **Boston MA:** June opening for PT BC/BE Genetic Counselor. Exp pref. 20 clin, 10 rsrch hr/wk w/ poten for + hrs at busy, hi-risk PNDx unit: AMA, +serum scrn, U/S, terat, hx of birth defects/genetic disease. On-site cyto & fetal path svcs; commun outrch & educ; preg termination supt grp; prof educ.
☞ CV & 3 ltrs ref: Amy Bosco, MS, Brigham & Women's Hospital, Antenatal Diagnostic Ctr, 75 Francis St, Boston MA 02115; ✆617-732-4208; Fax: 617-264-6310

■ **Boston MA:** Immed opening for PT (32 hrs/wk) Genetic Counselor. Exp pref; i'pendence req. Join team in busy, acad, hi-risk PN genetics prog. Oppty for tchg, cancer GC & partic in rsrch.
☞ Heather Ferguson, MS, Beth Israel Deaconess Medical Center, 330 Brookline Ave, Boston MA 02215; ✆617-667-7110; Fax: 617-667-1551. EOE/AA

■ **Boston MA:** Immed opening for BC/BE Genetic Counselor. Exp pref, not req. Famil w/ databases a plus. Work i'pendently as Genetic Studies Coordinator w/ active rsrch in Molec Neurogenetics. GC in Dystonia Clin as resource to rsrchrs using MGH Genomics Core Facility in fam studies design, informed consent, IRB appvl, pt enrollment, specimen collec & data storage. Tchg & rsrch oppty.
☞ Cheryl Pizzano, Massachusetts General Hospital, Molecular Neurogenetics Unit, Bldg 149 - 13th St, Charlestown MA 02129; ✆617-726-5094; pizzano@helix.mgh.harvard.edu

■ **Rochester MN:** Immed opening for BC/BE Genetic Counselor. Join expndg clin genetics prac. I'pendent work atmosphere: PN, adult, cancer & others. Opptys for rsrch & educ roles. Large tertiary/ref ctr.
☞ Cynthia L. Scott, Mayo Clinic Staffing Ctr, 200 1st St. SW -OE 1-22, Rochester MN 55905; ✆507-284-0030; Fax: 507-284-1445; cscott@mayo.edu. EOE/AA

■ **Las Vegas NV:** Immed opening for BC/BE Genetic Counselor. Rapidly growing MFM prac: range of GC issues: terat, fetal anom, AFP scrng, preconcep GC, PNDx (amnio, CVS).
☞ Brian Iriye, MD, Las Vegas Perinatal Associates, 400 Shadow Ln, Ste 206, Las Vegas NV 89106; ✆702-382-3200; Fax: 702-382-3575; biriye@lvpa.com. EOE/AA

■ **Hackensack NJ:** August 2000 opening for temp (min 6 mo) BC/BE Genetic Counselor. Req: multitask abil, work i'pendently, excellent verbal & written comm skills. Some trav to sat clin;. Span a plus, exp pref, not req. Join busy c'hensive genetics dept: PN, peds, cancer.
☞ CV & 3 ltrs rec: Sivya Twersky, MS, Hackensack Medical Center, 30 Prospect Ave, IMUS-Rm 258, Hackensack NJ 07601; ✆201-996-5264; Fax: 201-996-0827; stwerky@humed.com

■ **New Brunswick NJ:** Immed opening for BC/BE Genetic Counselor. Span pref. Hi-vol, varied pt PN pts: AMA, U/S, terat, preconcep, etc. on large, multidisc team at priv hosp w/ med school affil. Sat clins; s'vise students, residents. Tchg & rsrch opptys, specialty clins avail.
☞ Donna Chavez, MS, Inst Reproductive & Peri-natal Genetics, St. Peter's Medical Ctr, 254 Easton Ave, MOB-4, Room 2190; New Brunswick NJ 08903-0591; ✆732-745-6659; Fax: 732-249-2687.

■ **New Brunswick NJ:** Immed opening for BC/BE Coordinator for NJ Fetal Abnormality Registry. Ped & PN clin exp & Span pref. Some trav to ≥1 NJFAR sites. Newly-devel prog: collect info on dx, mgmt & outcomes for preg w/ fetal abnorm identified before birth; i'view & hx taking, record reviews, prepare reports, devel nltrs, s'vision. Tchg, rsrch & pub opptys. Grant-funded position: CDC & Preven & NJ Dept of Health & Sr. Svcs.
☞ CV & 2 ltrs ref: John C. Smulian, MD, MPH, Director NJFAR & Perinatal Research, UMDNJ-RWJ Medical School at Saint Peter's Univ Hospital, 254 Easton Ave, MOB-4th Fl, MFM, New Brunswick NJ 08903-0591; ✆732-745-8549. EOE/AA

■ **New York NY:** Immed opening for Sr. Genetic Counselor. MS in Human Genetics, min 2 yrs exp, excellent s'visory skills & strong knowledge of med genetics. Provide work direction, genrl educ & in-svc instruc; monitor GCs, assistants & grad students.
☞ Human Resources, New York Presbyterian Hospital, 525 East 68th St, Box #238, New York NY 10021; Fax: 212-746-8235

■ **New York NY:** Immed opening for BC/BE Genetic Counselor. Span pref. Join c'hensive genetics svc in tertiary care ctr affil w/ NY Medical College. All aspects of PN & Peds genetics. Coord amnio prog. Oppty to work w/ multidisc OBS & Peds teams. Diverse cultural caseloads. Prof & commun tchg opptys.
☞ Karen L. David, MD, Director, Clin Genetics, Metropolitan Hospital Center, Dept Peds-Genetics, 1901 First Ave - Rm 523, New York NY 10029; ✆212-423-6452; Fax: 212-423-6183; aakd97@pol.net

■ **Charlotte NC:** Immed opening for BC/BE Genetic Counselor. I'pendent work style and team player skills req. Join busy PN grp; prof educ. Denise Howard, MS, Carolinas Medical Ctr, Women's Institute, PO Box 32861, Charlotte NC 28232; ✆704-355-6089; dtilley@carolinas.org

■ **Greenville NC:** Immed opening for BC/BE Genetic Counselor in busy med genetics unit. Wide range of pts: peds, PN & adult. Fac appt.
☞ O.J. Hood, MD, The Brody School of Medicine at East Carolina Univ, Rm 3E140, Greenville NC 27858-4354; ✆252-816-2525. EOE/AA/D/IRCA

■ **Wilmington NC:** Immed opening for BC/BE Genetic Counselor. Some trav req. Self-motiv, org, creative & team player. Join Public Health Genetics Network svg 13 counties. Coord w/ ECUMS clins; fam pedigrees, provide GC & commun educ.
☞ Elizabeth G. Moore, Genetic Health Care Program, 1916MSC, Div Public Health, Raleigh NC 27699-1916; ✆919-715-3420. EOE/AA

■ **Cincinnati OH:** Immed opening for BC/BE Genetic Counselor. Excellent commun, org & follow thru skills req. All aspects of M/F dx preconcep GC, srv as resource & educ for pts & staff.
☞ Heidi Luggen, Human Resources, TriHealth, Good Samaritan Hospital, 375 Dixmyth Ave, Cincinnati OH 45220; Fax: 513-872-3672. EOE/AA

■ **Columbus OH:** Immed opening for BC/BE Genetic Counselor. Exp pref. Join expanding acad peds grp. Assist in genrl genetics clinic, coord outrch clins, cover spec clins; tchg activ avail. Complete cyto, biochem & molec lab svcs onsite.

See next page

national society of genetic counselors, inc.

nsgc

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☞ Dr. Gail Herman, Children's Hospital Research Foundation, 700 Children's Drive, Room W403, Columbus OH 43205; Fax:614-722-27166; HermanG@pediatrics.ohio-state.edu. EOE/AA

■ **Portland OR:** Immed opening for BC/BE Genetic Counselor. Join multidisc team in lrg, stable MCO: provide GC for wide variety of genetic conditions, partic in PNDx prog. Full-svc cyto lab.
☞ Laura Russell, Kaiser Permanente, 500 NE Multnomah, Portland OR 97232; ✆503-813-3762; Laura.Russell@kp.org

■ **Philadelphia PA:** Immed opening for FT &/or PT BC/BE Genetic Counselor. Excellent verbal, written, org & i'personal skills req. Abil to work i'pendently & on team. Exp pref, not req. Join a multispec NIH funded study on genetics of congenital heart disease: recruitment, GC for study results, data recruit & org. Opptys for own related rsrch & interaction w/ varied clin genetic staff.
☞ Elizabeth Goldmuntz, MD, The Children's Hospital of Philadelphia, Div of Cardiology, 3516 Civic Center Blvd, Rm 7002 ARC Bldg, Philadelphia PA 19104; ✆215-590-5820; Fax: 215-590-5454; goldmuntz@email.chop.edu. EOE/AA

■ **Providence RI:** Immed opening for Genetic Counselor. Abil to work i'pendently. Exp pref. Join busy PNDx ctr.
☞ Debbie Owens, RNC, MS, Prof Coordinator, Women & Infants Hospital, 79 Plain St, Providence RI 02903; ✆401-453-7510; Fax: 401-453-7517; dowens@wihri.org

■ **Columbia SC:** Immed opening for BC/BE Genetic Counselor in hi-risk preg mgmt svc; CVS, amnio, U/S, terat. Oppty for proj in clin svc, educ, rsrch, GC tchg. Exclnt org and i'personal skills req.
☞ Send CV & 3 ltrs rec: Janice G. Edwards, MS, CoDirector, Genetic Counseling Program, Dept. Ob/Gyn, University of South Carolina School of Medicine, Two Medical Park, Suite 103, Columbia SC 29203; ✆803-779-4928 x227; Fax: 803-434-4596; jedwards@richmed.medpark.sc.edu

■ **Dallas TX:** *See Genzyme, LA/Orange Cos. CA*

■ **Dallas TX:** Immed opening for BC/BE Genetic Counselor. Min 1 yr exp pref; Span helpful. Motiv, enthus personality pref. Join team at peds tchg hosp: outpt genrl genetics & metab clin; DS clin, inpt consults; oppty to facil supt grps, tchg & public educ.
☞ Gail Brookshire, Children's Med Center-Dallas, 1935 Motor St, Dallas TX 75235; ✆214-456-2357; Fax: 214-456-2567; Gbrook@childmed.dallas.tx.us. EOE/AA

Employment Opportunities

■ **San Antonio TX:** Immed opening for Genetic Counselor. Provide GC svcs to large Hispanic population. GC svcs: advanced stage colorectal & other cancers. Studies incl natl colon cancer sib pair & diet & nutrition effects on penetrance of BRCA1/2, APC & HNPCC mutations.
☞ J. Milburn Jessup, MD, University of TX Health Science Ctr at San Antonio, Surgical Oncology, 7703 Floyd Curl Dr, San Antonio TX 78229-3900; ✆210-567-5750; Fax: 210-567-6862; jessup@uthscsa.edu or us020723@mindspring.com

■ **Salt Lake City UT:** Immed opening for BC/BE Genetic Counselor. Join dynamic univ-based DNA dx lab. Exp pref, not req. Commun daily w/ prof, pts & public. Excellent org skills, abil to work i'pendently req. Assist in updating lit; coord QA/QC prog, accred process & new tst dev. Provide PR; maintain close contact w/ univ-based cancer genetics, PN & ped prof. Rsrch & educ opptys.
☞ Phyllis Penaranda, Univ Utah DNA Diagnostic Laboratory, 729 Arapeen Dr, Rm 149, Salt Lake City UT 84108; Fax: 801-585-3876

■ **Charlottesville VA:** Immed opening for non-tenure track BC/BE Cancer Genetic Counselor in Div Hem/Onc. Exp pref. Abil to multi-task & work i'pendently & computer skills important. Join multidisc clin/research Cancer Genetics Prog teams: eval & GC pts re: hereditary cancer predisposition; coord clin. Resrch & tchg as time permits.
☞ Susan M. Jones, MS, University of Virginia Cancer Genetics Program, Cancer Center, Div Hematology/Oncology, Charlottesville VA 22908; ✆804-243-6446; Fax: 804-243-5860; smj8d@virginia.edu. EOE/AA

■ **Seattle WA:** Immed opening for highly motiv BC/BE Genetic Counselors. Join large multi-state healthcare co.
☞ Human Resources, Obstetrix Medical Group, 2119 W. Orangewood Ave, Orange CA 92868; Fax: 714-385-5743; anita_downs@pediatrix.com. EOE

■ **Morgantown WV:** Immed opening for Genetic Counselor. Exclnt commun & org skills, abil to work i'pendently req. Join team in busy office setting; collab w/ peds/dysmorph expected.
☞ Mark Gibson, West Virginia Univ, OB/GYN, PO Box 9186, Morgantown WV 26506-9186; ✆304-293-5631; Fax: 304-293-4291. EOE/AA

■ **Madison WI:** Immed opening for Program Director. MS in Medical Genetics or related field, ABGC cert & min 7 yrs exp in GC profession req. Handle overall prog direction, coord among various prog elements & participants; oversight of curric content for GC trng prog. Provide all instruction w/in prog either directly or by recruiting fac & clin educators. Expected to provide ldrshp in prog direction & new prog initiatives. Complete job description: www.ohr.wisc.edu//pvl/pv37407.html.
☞ CV & ltr of interest stating qualifications, 1 pg sumry of perception of future of GC & GC training progs to: Search Committee, Genetic Counseling Program Director, Univ Wisconsin - Madison, 118 Genetics, 445 Henry Mall, Madison WI 53706-1574

■ **Marshfield WI:** Immed opening for Genetic Counselor. Organize Genetics Clin, genetic services in Specialty Clins & other sat clins. Provide GC to pts & fams. Provide supt & coord for genetic dx & GC svc. Serve as genetics educator & resource for health care prof & genrl public. Coord & partic in clin rsrch activ. Be leader in devel & implement of performance & quality improvement measures w/in the dept & GC field.
☞ Medical Genetic Services-1A4, Marshfield Clinic, 1000 North Oak Ave, Marshfield WI 54449; Fax: 715-389-4399.

■ **Milwaukee WI:** Immed opening for Genetic Associate. 1-2 yrs exp req. Provide GC in peds clin.
☞ Human Resources, Children's Health System, 9000 W Wisconsin Ave Box 1997-MS 951, Milwaukee WI 53201; ✆414-266-6138; Fax: 715-389-4399; online app: www.chw.org

In Canada

■ **Toronto ON:** Immed opening for Genetic Counselor. Exp, BC status, Canadian citizenship pref. Excellent in'personal & orgl skills req. Join active univ-based Genetic Metab team w/ wide variety of pts referrals; primarily peds but includes PN, adult & specialty clins. Involve w/ GC training prog tchg & rsrch.
☞ Nancy Taylor, Hospital for Sick Children, Div Clin & Metabolic Genetics, 555 University Ave, Toronto Ont, Canada M5G 1X8; ✆416-813-6386; Fax: 416-813-5345; nancy.taylor@sickkids.on.com

■ **Toronto ON:** Immed opening for Genetic Counselor. Exp, BC status, Canadian citizenship pref. Excellent in'personal & org skills req. Join active univ-based Pediatric Cancer Genetics multidisc team; variety of pt ref for familial CA; 1 genrl gneetics clin; rsrch; tchg.
☞ CV & 3 ltrs rec: Nancy Taylor, Hospital for Sick Children, Div Clin & Metabolic Genetics, 555 University Ave, Toronto Ont, Canada M5G1X8; ✆416-813-6386; Fax: 416-813-5345; nancy.taylor@sickkids.on.com