PERSPECTIVES *in genetic counseling*

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national society
of genetic
counselors, inc.

nsgc

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

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NSGC acknowledges Women's Health Care Services for a grant to support this newsletter.

GENETIC NONDISCRIMINATION ORDER SIGNED

Wendy R. Uhlmann, MS

The call from the White House came on Monday. In 24 hours, President Clinton would be issuing an Executive Order on genetic discrimination. Could NSGC attend? NSGC was also asked to endorse this executive order. Endorsers were required to have an existing position statement on genetic discrimination. NSGC had adopted one in 1991. Four organizations were listed as endorsers: American Medical Association, American College of Medical Genetics, Genetic Alliance (formerly Alliance of Genetic Support Groups) and NSGC.

The signing of this executive order took place on February 8 at the American Association for the Advancement of Science (AAAS). There were approximately 200 attendees, including several leaders in the genetics community, patient advocacy groups, three members of Congress [Representatives Louise Slaughter (D-NY), Fred Upton (R-MI) and Greg Ganske (R-IA)], members of government agencies who had worked on the bill and the press.

We were welcomed by Dr. Shirley Malcolm, Executive Director of AAAS, who then introduced Dr. Francis Collins. Dr. Collins and his staff were a driving force behind this executive

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CREATIVE JOB SEARCH

GENETIC COUNSELORS ON THE 'NET

Jessica Mandell, MS

In both our personal and professional lives, the Internet continuously impacts us. And genetic counseling, like many professions, now finds itself online, shaping a new arena of genetic services with expanded job opportunities. Here are some first-hand accounts from colleagues blazing a trail.

Jennifer Graham, MS, Genetic Counselor, Genetic Health, Inc. www.genetichealth.com

Genetic Health, Inc. was incorporated in early 1999 with the mission of providing on-line education, risk assessment, tailored results (including appropriate referrals) and membership services for individuals and families with a genetic predisposition to common adult-onset diseases. I became interested in alternative approaches to risk communication when I was employed by Ohio State University and developed a touch-screen kiosk to collect family medical histories specific to cancer. Appreciating the potential to provide genetics services over the Internet, I met with Scott Cole, founder and President of Genetic

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NSGC AT WORK: FORGING AHEAD

Wendy R. Uhlmann, MS

The first two months of the new century have proven to be active ones for NSGC. Highlights have included the Secretary's Advisory Committee on Genetic Testing (SACGT) Public Consultation meeting and NSGC's invitation to President Clinton's signing of an Executive Order on genetic discrimination. *(See page 1)*

SACGT PUBLIC CONSULTATION

This committee has been charged with developing standards for genetic testing. The Public Consultation meeting was their opportunity to hear input from the public on this complex issue. Public input was sought through a patient panel, small discussion groups, testimonies (which will be included in the Federal Register) and written submissions to the committee. NSGC provided testimony and submitted a formal written response. In addition, 53 genetic counselors sent individual responses, a significant number, which was noted by the SACGT. Several genetic counselors were involved in this meeting: Ann Happ Boldt (SACGT member), Sylvia Au, Barbara Bernhardt, Barbara Biesecker, Barbara Harrison, Nisha Isaac, Ilana Mittman, Diana Punales-Morejon, Stephanie Smith, Carmella Stadter, Lisa Steinberg and Vivian Ota Wang. The SACGT report and meeting summaries are available at their website.

☞ www4.od.nih.gov/oba/sacgt.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 **June 15***
*Submission deadline **May10***

CODE OF ETHICS EXPANDED USE

The Australasian Society of Genetic Counsellors requested permission to acknowledge NSGC as the basis for developing their Code of Ethics. The ASGC reviewed many codes of ethics from other professions. To quote their letter to NSGC, "The most useful was the code of ethics prepared by the NSGC. The ASGC would like to utilize the format of the NSGC code of ethics in its own code." It is quite an accomplishment that our Code of Ethics has such an impact on the other side of the globe!

TASK FORCE APPOINTED

A Diversity Task Force has been appointed and charged with developing strategies for encouraging individuals of differing physical abilities, gender and diverse racial, ethnic and cultural backgrounds to enter our field. Task Force members include: Ilana Mittman (Chair), Sylvia Au, Bruce Haas, Barbara Harrison, Rushina Patel, June Peters, Ericka Peasley, Lavanya Misra and Diana Punales-Morejon. Ilana Mittman is also asking national experts on diversity issues to serve as consultants to this Task Force.

SPECIAL PROJECTS FUND COMMITTEE APPOINTMENTS

New members appointed to this committee include Nathalie McIntosh (Chair), Michael Banke and Julie Bars Culver. Funding for projects has increased to $5000.

ACMG REIMBURSEMENT MANUAL

Jennifer Farmer, Chair of the Professional Issues Committee, has been asked to serve on a committee updating a manual designed to provide a comprehensive overview of billing and reimbursement for genetics services.

REPRESENTATION

Leslie Cohen, Region IV Representative, represented NSGC at the National Newborn Screening and Genetics Resource Center (NNSGRC) genetics planning committee meeting.

Kerry Silvey represented NSGC on the National Council of Folic Acid Communications Committee conference call.

COUNSELOR ON CAPITOL HILL

Judith Benkendorf is the first genetic counselor to be selected as ASHG/AAAS Fellow. She is working for Representative John Dingell (D-MI), minority chair of the Commerce Committee and will be addressing several legislative efforts, including the companion bill to S1981 Genetics & Public Health Services Act (*PGC* 21(4):12).

The NSGC Board of Directors appreciates the significant efforts of genetic counselors who are working to provide services to our members and increase our profession's visibility. ❖

Health, and was so intrigued that I accepted his job offer and moved to Northern California in October.

As one of two full-time genetic counselors at Genetic Health, I write educational content for the website, help develop pedigree drawing and risk assessment programs and will be working with academic institutions to test our content and tools prior to our public launch. As a founding team member of a start-up company, I am charged with developing new skills in business and marketing, creative design, writing for the web, logic and small business administration. I am also a genetic expert on the team and use my clinical knowledge and experience constantly.

Maureen E. Smith, MS
GeneSage, Director of Clinical Services, www.genesage.com

GeneSage is an Internet-based health company dedicated to improving lives by providing genetic information, services and products to consumers and those who care for them. My interaction with GeneSage began in 1997 when I was president of NSGC. At that time, the company's owner contacted me about his ideas to provide Internet resources in genetics. Then, two years later, I was recontacted by the company's owner to join GeneSage. I started working on a private practice and began looking into other industries related to health care and genetic technology.

I was attracted to GeneSage for a number of reasons. I would be able to expand my knowledge and responsibilities and increase my earning potential. GeneSage's philosophy of working with the genetics community to improve genetic health care appealed to me. I was also pleased with the company's commitment to the value of high quality genetic counseling and clinical genetic services. At GeneSage, I have enjoyed interaction with numerous professionals, including well-respected clinical genetics advisors and others with business expertise. who bring an exciting mix of professionalism, knowledge and interest in the future of health care.

My position allows me the utmost flexibility. I telecommute from Chicago to San Francisco and visit the company once a month for a whirlwind of meetings and planning sessions. As a member of the planning and management team, I participate in shaping and positioning business strategies and developing online products and services. I have also continued a small private practice in Chicago, which allows me to remain current on clinical issues and maintain my perspective on patient care.

Pamela Cohen, MS
GeneSage, Clinical Services Product Manager

I first learned of GeneSage through Dr. Philip Reilly, my mentor at Brandeis University and one of the co-founders of the company. Having always pursued non-traditional positions, I was excited by the opportunity to broaden the scope of my genetic counseling career. In addition, I agreed with the company's mission to provide high-quality genetic services and products online. Some of the benefits I enjoy while working at an Internet start-up company include having a significant impact on the company's direction and product development, working in an exciting, fast-paced and flexible environment, learning how a company is founded and expanded and interacting with a new group of colleagues in the business, health care delivery and computer fields.

Currently, I write content for the website, research product development and network with other professionals. I directly apply skills acquired from a previous job coordinating a public health genetics network and my experience managing a gene-mapping study.

Heather Brown, MS, GeneSage, Clinical Services Product Manager

Like many genetic counselors, I peruse the NSGC job listings, not to make a career move necessarily, but to imagine "What if?" Sometimes, my curiosity leads me in new directions, like my previous genetic counseling position in Hawaii and, now, to an Internet company. The prospect of participating in a new model for the delivery of genetic services was one of the reasons I was interested in GeneSage. In my position as Clinical Services Product Manager, I utilize my foundation in genetics in the creative process of developing new programs and products. Initially, I wondered if I would regret leaving direct patient care. Now I am excited by the opportunity to impact not only countless individuals, but the genetic counseling profession and the genetics community at large. ❖

If you are working for or involved with an Internet company focused on genetics, we'd love to print your story.

☞ Jessica Mandell, jmandell@mail.slc.edu

HIGHLIGHTS OF BOARD OF DIRECTORS MEETING

Leslie Cohen, MS, Region IV Representative and Stefanie Uhrich, Secretary

STATUS OF THE STRATEGIC PLAN

The Board of Directors' annual meeting in October began with an assessment of the status of the 1998-2000 strategic plan objectives. With the timeline for the strategic plan only halfway through, we have accomplished a great deal. Means to complete the remaining objectives, such as the billing, reimbursement and time surveys were discussed.

THE FUTURE OF THE EXECUTIVE OFFICE

As NSGC continues to grow and services expand, it is thought that in a few years, we will no longer be able to continue all of our administrative activities from a home office. Thus, a 10 member *ad hoc* committee has been appointed, chaired by Lisa Amacker North, to research the management of an association Executive Office. Lisa gave a report to the Board on efforts to date. *(See article, p. 6)*

DECISIONS, DECISIONS

Here are some of the meeting's noteworthy decisions:

- The Special Projects Fund will be increased to $5000 so that we can continue to support quality projects. Formal guidelines for the structure of the Special Projects Fund Committee, review of grant proposals and funding stipulations were also adopted.
- A standing Continuing Education Subcommittee has been created within the Education Committee which will work with the ABGC and the ACA to research, lobby and create alternative means of obtaining CEUs.

- A Professional Education subcommittee has also been formed within the Education Committee which will work with other professional organizations to pursue the inclusion of genetic counseling issues in training and continuing education programs for medical and allied health professionals.
- A policy was adopted regarding the promotion of organizations, products and/or other services during educational sessions (including workshops, symposia and plenary sessions) of national and regional education conferences.
- The Social Issues Committee will be streamlining the process by which position documents are approved. A formal process for reviewing drafts and briefs that are submitted to NSGC for review by other organizations was adopted.
- An approval process for Genetic Counseling Recommendations (formerly known as practice guidelines) was adopted.
- The Fragile X Syndrome Genetic Counseling Recommendations were approved.
- A new membership application form, which will require new members to sign a pledge to uphold the Code of Ethics, was approved. The creation of a standing Membership Application Subcommittee under the Membership Committee, which will review all applications requiring clarification, was approved.
- A task force will be appointed to explore the issue of lack of diversity within NSGC. The task force will be charged with exploring ways of encouraging minorities to join the profession.

[Ed. Note: This task force has been appointed. Ilana Mittman chairs the group. See page 2.] ❖

CF POSITION STATEMENT REVISION PASSES IN LANDSLIDE

Anne Spencer, MS

The membership voted in overwhelming support to revise the CF position statement, as stated in the ballot, which was mailed to all Full members in mid-November. Of the 437 ballots returned by the postmark deadline, 403 (92%) voted for and 34 (8%) voted against the revision. Seventeen ballots (16 for, 1 against) were disqualified because they were postmarked after the deadline.

The revised version will replace the previous version in all appropriate NSGC documents. Thank you to everyone who provided comments, voted and otherwise participated in this year long process. …And kudos to the seven of you careful readers who caught the misspelling of preconceptional in the ballot! We will fix it. ❖

HBO SPECIAL

CANCER: EVOLUTION TO REVOLUTION

Shelly Cummings, MS

On March 30, Home Box Office (HBO) will air “Cancer: Evolution to Revolution,” an informative and moving program on cancer and its effects on “real” people. As a public service, HBO is opening access to cable viewers who are not subscribed to HBO.

PERSONAL TOUCH

This emotional and educational documentary chronicles the personal experiences of several individuals as they react to their cancer diagnoses, and it walks the viewer through the thoughts, feelings and experiences of someone who is at risk for cancer but who has not yet been diagnosed.

INSIGHTFUL PERSONAL STORIES

The writer, producer and narrator, Joseph Lovett, brings to this documentary the dual perspective of a 20-year veteran medical and health journalist and a person with an extensive family history of cancer. Many dramatizations follow the trials and tribulations of courageous people as they face their treatment and frustrations with the medical community. It sends a strong message for patient awareness, proactivity and medical team playing. The stories include:

- Lilly Tartikoff, whose husband, Brandon Tartikoff, a renowned TV producer, died at a young age from cancer (HNPCC)
- Jessica, a 10-year-old with acute lymphoblastic leukemia (ALL)
- Gary, a 40+ year-old with hairy cell leukemia (HCL)
- Tricia, the narrator’s sister, died from ovarian cancer
- Vanessa, woman with breast cancer
- Arnold, a 40+ year-old man who ignored early symptoms of colon cancer. ❖

Throughout the documentary, numerous telephone numbers and web site addresses are listed.

The many national organizations, institutions and experts contributing to the production of this film are listed in the opening few minutes — and an impressive list of advisors are noted at its conclusion. NSGC’s website and phone number are listed as a resources.

Thumbs Up! …this $2^1/_2$ hour piece is extremely thorough and accurate in its collection and presentation of cancer-related information.”

VIEWER EDUCATION

In an interview, Dr. Richard Klausner, Director of the National Cancer Institute, endorses the “team player” approach to cancer treatment and encourages all individuals to be active in their care by asking questions. The film further discusses the clinical trial process and the benefits that clinical trials have provided to thousands of people with cancer.

Given the producer’s family history of colon cancer, a large portion of the film focuses on colon cancer prevention, screening, treatment and genetic testing. Dr. Bert Vogel-stein, Johns Hopkins Oncology Center, discusses the molecular defects that lead to colon cancer and highlights the mechanisms used to detect genetic mutations in colon cancer susceptibility genes.

Without revealing the rest of the film, I can tell you that this two-and-a–half hour piece is extremely thorough and accurate in its collection and presentation of cancer-related information. Some of the topics include support groups, insurance issues, genetic counseling — *with our very own Karen Johnson* — prevention, screening for many forms of cancer, chemoprevention and legislative involvement.

The last segment covers a large rally in Washington DC that focuses on the need for more research dollars in cancer. Even though this documentary deals only with cancer, the underlying message — that advances in medicine are occurring at an amazing pace and a team player approach to one’s health is vital in fighting diseases — can be extrapolated to all areas of medicine, particularly genetics.

The program ends with a moving rendition of one of my favorite hymns, “An Old Irish Blessing,” performed by a children’s choir. It features Jessica, a 10-year old with leukemia. This final scene is one of optimism, gratefulness and peace. Don’t we wish all of life’s scenarios could end this way? ❖

☞ For six months following the airing of this feature, HBO will provide information for consumers on cancer-related issues. This website, www.hbo.com, provides a hotlink to NSGC’s ResourceLink.

GROWTH AND EXPANSION IN NSGC'S EXECUTIVE OFFICE

Lisa Amacker North, MS

HISTORY

NSGC started as a volunteer run organization in 1979. Since 1986, Bea Leopold has been working with our organization, first helping with meeting planning and soon after as our part-time Executive Director. Initially, our Executive Office was run out of a spare bedroom in Bea's home.

Growth in membership and responsibility resulted in renovations, which greatly expanded NSGC-designated office space, including direct outside access.

Bea is currently managing three part-time employees, as well as other contractors as needed. NSGC expenses have grown from about $259,000 in 1995 to $593,000 in 1999. As NSGC has grown in membership, programs and complexity, so has our Executive Office.

THE FUTURE

Bea discussed the future of NSGC's Executive Office with President Wendy Uhlmann in terms of increasing demands that will soon outgrow available space in a home-based office. Wendy has appointed an *ad hoc* Executive Office Committee, of which I am the chair. Committee members are Ginny Corson, Cindy Soliday, Beth Billings, Judith Benkendorf, Angela Trepanier and Amy Cronister. Wendy Uhlmann and Bea Leopold serve as *ex officio* members.

The mission of this committee is to direct the growth of the Executive Office over the next five years.

The committee met for the first time at the 1999 Annual Education Conference in Oakland. Over the next year, we will research the management of an association executive office, using what is referred to as knowledge-based decision making. This involves:

- determining the needs, wants and preferences of our membership about our Executive Office. *(An initial survey will be sent on NSGC's general listserv this Spring.)*
- learning about the current dynamics of association management styles by surveying the executive offices of other associations, e.g., ACMG, Oncology Nursing Society (ONS), American College of Nurse-Midwives and others.
- visiting our current Executive Office to interview the staff and understand the current demands on NSGC's staff and office.

Later, in 2001, the committee will need to determine staffing needs and expenses of and location for a new Executive Office.

GIANT STEPS

Bea Leopold has been a critical and constant force in the growth of NSGC over the past nearly 13 years. We have grown from toddler to teenager to young adult under her guidance and leadership. However, every healthy young adult must grow into a new home …and so must NSGC. We look to our membership to help set the future direction of this organization's home.

☞ Lisa Amacker North, ✆704-355-3159; enorth@carolinas.org. ❖

'01 CONFERENCE DATES, SITE, THEME ANNOUNCED

Our 20th Annual Education Conference will be held November 3 - 6, 2001 in Washington DC. The theme is *Current Advances: Anticipating Change.* New and seasoned volunteers are welcome to join the planning team.

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WHAT'S AHEAD IN '00?

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

SAVE THESE DATES!
November 2 - 5: 19th Annual Education Conference, *Exploring the Counseling Role in Genetic Counseling* — Savannah, Georgia

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

PROGRAM: This conference will include a comprehensive review of counseling theory and technique, as well as an in depth exploration of clinical applications and genetic counseling research. Emphasis will be placed on the social and psychological aspects of the genetic counseling process and genetic disorders. The keynote address will be delivered by Annette Kennedy, PsyD, followed by a panel discussion on counseling theories and their clinical applications. Other related plenary topics include Death and Dying, Goals of Prenatal Counseling and Shame and Genetic Abortion. Remaining plenaries, workshops and practice-based symposia have been developed to address contemporary issues in clinical management and treatment of genetic diseases. Professional issues such as billing, fundraising and legislative education will also be explored.

ABSTRACTS: REMINDER: Abstracts submitted in hard copy must be postmarked by May 1. Enjoy a nearly three-week reprieve for electronic submissions — take until midnight, May 19. Visit www.nsgc.org, and then click cn conferences. We're ready when you are!

CEUS: 2.5 CEUS will be awarded for full attendance at this year's conference, and 1.15 CEUs will be awarded for the Short Course.

REGISTRATION: To accommodate the early Thursday start, registration will open on Wednesday, November 1 at 4:00pm.

SAVANNAH! Look forward to plenty of evening time for networking and exploring Savannah.

MORE INFO: Check out NSGC's website. Look for your brochure in the mail soon! ❖

SAVANNAH SPELLS EASY TRAVEL-ABILITY!

Andy Faucett, MS

Been wondering about the logistics of traveling to Savannah? Here are some facts.

Savannah is a major tourist destination and has amazingly easy access. Our international airport is *the* gateway for Savannah's historic district and the resorts and beaches, serving the major tourist sites of Hilton Head in South Carolina and St. Simons Island in Georgia. And here's a bonus — since Savannah is more of a tourist destination than a business destination, the fares are usually quite reasonable.

Currently, eight airlines serve Savannah with non-stop connections to 10 major US cities. Daily direct flights are available from Atlanta, Charlotte, Chicago (O'Hare), Cincinnati, Dallas, Houston, Newark, New York (LaGuardia) and Washington DC (Dulles). The major airlines are Delta and USAirways, and service is also available with AirTran, Continental Express and United Express.

If you plan to rent a car and spend a few days sight seeing before or after the meeting, [after you've seen Savannah, of course (!)], you have easy travel to Jacksonville, Florida and Charleston, South Carolina. Both of these cities are an easy-to-navigate two-hour drive. Jacksonville has a major airport and has direct flights to the west coast. It is also served by Southwest.

So come to Savannah! The meeting agenda looks great, and I promise you'll love the sightseeing opportunities here and in the surrounding area. ❖

BILLING, LICENSURE & REIMBURSEMENT: *SUCCESS!*

Tanya Bardakjian, MS

Welcome to *BL&R: Success!,* a new column dedicated to illustrating how our profession continues to meet the challenge of billing, licensure and reimbursement issues.

THE PROBLEM

The Genetics Division where I work has been under the Hospital Administration's scrutiny for a long time due to our large fiscal deficit. I imagine that this is a familiar scenario. This is a large community medical center in an urban area that provides a wide variety of genetic services: prenatal, pediatric, cancer and adult. Every year we are reminded that we operate at a large deficit and that our positions are tenuous. However, the hospital seems to be deeply committed to providing quality genetics services.

In the past, we have attempted to explain our difficulties in billing and reimbursement for genetic services, specifically for genetic counseling. Sadly, we have been largely ignored. Our income has steadily declined as our patient numbers and referrals have increased, yet no one in administration seemed to be interested in helping us address these problems.

MAKING AN EXAMPLE OF US

Several months ago, we were called to a meeting with senior administrators and the billing office, and we were told that the senior administrators had made the genetics billing problems and reimbursement issues a priority for the next fiscal year. They requested that we meet with the billing office, the managed care office and our department's administrators once every two months to find a solution!

We were elated. Finally, we were a priority. After several meetings, much has been accomplished. The first priority was to update our voucher/billing sheets. (Previously we were using ICD-9 codes from 1990!) Our managed care office has begun to communicate with large HMOs to investigate and negotiate having genetic counseling services included in coverage packages. Several of the women in our billing and managed care offices received prenatal genetic counseling and found it invaluable. Now, they are fighting for us because they *understand what we do!*

Lastly, discussions and negotiations have resulted in other departments agreeing to pay us on a fee for service basis. For example, the department of surgery has agreed to pay us per patient seen by a genetic counselor for breast/ovarian cancer risk assessment and counseling.

SMALL STEPS, BIG RESULTS!

We are making small steps in the right direction. Through our hard work to increase referrals, patient numbers and services offered, we have made our division invaluable to our health care system. This has made the senior administrators committed to keeping us and has given us leverage to negotiate with other departments.

I encourage you to get involved with the billing and reimbursement process at your institution. Meet the people in your billing and managed care offices and share your concerns. They can be a tremendous resource. Do not give up; someone, someday will notice!

Have a success story to share or interested in volunteering? Contact the new subcommittee chairs.

☞ Tanya Bardakjian, ✆215-456-8726; aemcgenetics2@hotmail.com

☞ Carin Beltz, ✆317-841-5708; clbeltz@commhospindy.org

REIMBURSEMENT ISSUES TO BE ADDRESSED AT ANNUAL EDUCATION CONFERENCE

Our Annual Education Conference will provide two opportunities to explore reimbursement issues.

- *The ABC's of Billing and Reimbursement in the United States,* a workshop facilitated by Debra Lochner Doyle, MS, Mike Watson, PhD and David Flannery, MD will enhance participants' understanding of the fundamentals of billing and reimbursement and the varied relationships between third party payers and genetic counselors. This workshop will also help individuals develop strategies for negotiating the mazes of the health care insurance industry.
- The practice-based symposium, *Issues for the New Grad — Job Interviews and Reimbursement,* facilitated by Wendy Uhlmann, MS, Vivian Weinblatt, MS and Lisa Amacker North, MS will help students and new graduates learn about interview skills and reimbursement issues *before* accepting a new job.

GENETIC NONDISCRIMINATION ORDER SIGNED

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order. Dr. Collins spoke about uses of genetic information generated from the Human Genome Project and then introduced President Clinton.

President Clinton noted that this is the first executive order of the 21st century. "By signing this executive order, my goal is to set an example and pose a challenge for every employer in America, because I believe no employer should ever review your genetic records along with your resumé." The executive order prohibits the federal government, which is the nation's largest employer, from using genetic information in any decision to hire, promote or dismiss employees.

President Clinton urged Congress to enact legislation that would extend such protection to all Americans and formally endorsed the Genetic Nondiscrimination in Health Insurance & Employment Act of 1999, introduced by Senator Tom Daschle (D-SD) and Representative Louise Slaughter (D-NY). In addition, he briefly addressed the recent lapses in gene therapy clinical trials and requested expedient review of these guidelines.

President Clinton's administration has been notable for introducing several bills pertaining to genetic discrimination and privacy and addressing genetic issues in his State of the Union addresses.

It is a milestone for our profession that NSGC was asked to endorse this Executive Order and was present when it was issued. ❖

Executive Order 'Sitings'

☞ Full text of Executive Order on Genetic Nondiscrimination
www.whitehouse.gov

☞ Q & A about Executive Order
www.eeoc.gov

☞ Dr. Francis Collins' remarks
www.nhgri.nih.gov

LISTSERVINGS

Whitney Neufeld-Kaiser, MS

Many resources are discussed over the listserv. Here's a sample of some recently mentioned. *This list does not imply endorsement.*

CHILDREN'S BOOKS ON DEALING WITH DEATH AND DYING

- *How Do We Tell the Children?* Schaefer and Lyons (1993)
- *Parenting with Wit and Wisdom in Times of Chaos and Loss,* Coloroso
- *Lifetimes. A Beautiful Way to Explain Death to Children,* Mellonie and Ingpen (1983)
- *The Fall of Freddy the Leaf,* Buscaglia (1982)
- *Where's Jess?* Johnson and Johnson (1982)
- *Thumpy's Story: The Story of Grief and Loss Shared,* Dodge (1984)
- *Am I Still a Sister?* Sims (1986)

SPECIAL NEEDS ADOPTION AGENCY

- The Adoption Committee of the Greater Cincinnati Down Syndrome Association.
  ☞ www.altonweb.com/cs/downsyndrome/adopt.html

GENETIC FAMILY HISTORIES

- *How Healthy is Your Family Tree? A Complete Guide to Tracing Your Family's Medical and Behavioral History,* Krause
- *The Practical Guide to the Genetic Family History,* Bennett
- *Past Imperfect: How Tracing Your Family Medical History Can Save Your Life,* Daus

CANCER RESOURCES

- Finding a clinical trial for colon cancer: NCI has a search service (PDQ database) for ongoing clinical trials.
  ☞ 800-345-3300; pdqsearch@icicc.nci.nih.gov or http://cancernet.nci.nih.gov .
- Cancer risk information for individuals over 40 years of age for breast, colon, lung and prostate cancers.
  ☞ www.yourcancerrisk.harvard.edu ❖

MISCELLANEOUS RESOURCES

- Database of hemoglobin variants — A Syllabus of Human Hemoglobin Variants. Find out a little about the hematology of these variants, a lot about lab data and locate references.
  ☞ http//globin.cse.psu.edu/
- New low literacy family information booklet on ambiguous chromosome results (rearrangement, inversion or marker) from prenatal diagnosis. Available from the PacNoRGG in English and Spanish.
  ☞ http://mchneighborhood.ichp.edu/pacnorgg/
- Chromosome Deletion Outreach
  ☞ http://members.aol.com/cdousa/cdo.htm

MEDIA WATCH

Angela Geist, MS and
Roxanne Ruzicka, MS,

“ *Dateline NBC* chronicled the process through which a couple enrolled their son in a gene therapy trial after discovering that he had Canavan disease.

The child exhibited some improvement and his development appeared to plateau. The inheritance was briefly, but correctly, described. It was stated that carrier testing for Canavan disease was not routine at the time of this couple's pregnancy, but it is now routinely offered to individuals of Eastern European Jewish ancestry.

“ *48 Hours* followed a 13-year-old boy with Proteus syndrome as he traveled to Lourdes, France, a small town where miracles have reportedly happened. Proteus syndrome was described as a rare condition for which the cause is not known.

“ *Angel* ran an episode in which one of the regular characters had an amniocentesis. No genetic counseling was performed and informed consent was not obtained, but a 0.5% miscarriage risk from the procedure was mentioned.

“ *The Boston Globe* ran a six-part series, “Choosing Naia: A Family's Journey,” which chronicled the trials and triumphs of a couple who learned prenatally that their daughter had Down syndrome. Prenatal screening was referred to as “abortion screening,” and the triple screen was incorrectly described. Only after the amniocentesis had been performed and the possibility of Down syndrome had been raised, was the couple referred to a genetic counselor. Once there, they received a packet of information. After the diagnosis was confirmed, the couple searched for information as they visited various specialists. While the role of a genetic counselor was not portrayed in the most positive manner, the article did accurately portray the turmoil a couple faces when an abnormality is detected by prenatal testing.

A formal reply outlining the specific skills and training genetic counselors have to address regarding the many difficult issues raised in the article was sent to the *Boston Globe* by Ali Warner, Region I Representative.

“ *Deuce Bigelow, Male Gigolo* was a box-office spoof which negatively portrayed individuals with Tourette syndrome as well as others with physical disabilities, but in the end showed that people who have differences should be treated with respect and kindness.

“ *CNN* presented a story about patient safety in gene therapy. Safety has been questioned since Jesse Gelsinger, an 18 year-old with ornithine transcarbamylase deficiency, died as a result of participating in a gene therapy study. An investigation following his death revealed that since 1993, only 39 of 691 adverse reactions in gene therapy experiments were immediately reported to National Institutes of Health officials. ❖ ”

LIAISON REPORT

by Rosalie Goldberg, MS

The National Advisory Council for Human Genome Research convened for its 28th meeting on February 28. Dr. Francis Collins presented the NHGRI Director's report highlighting both scientific and legislative issues.

ON THE LEGISLATIVE FRONT

On October 12, the President and First Lady hosted the 8th Millennium Evening, “Informatics Meets Genomics,” at the White House. Dr. Vinton Cerf, known as the “Father of the Internet,” and Dr. Eric Lander, Director of the Whitehead Institute/MIT Center for Genome Research, took the audience for an exhilarating ride through technologies that direct us toward the future.

President Clinton commented at his State of the Union Address that we are all, regardless of race, genetically 99.9% identical.

On February 8, President Clinton took historic action to ban genetic discrimination in the federal workplace. *(See p. 1)*

ON THE SCIENTIFIC FRONT

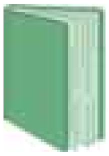
As of this writing, more than $2\frac{1}{2}$ *billion* base pairs of the human genome have been sequenced. Later this spring, the NHGRI is expected to announce the completion of a working draft of the entire genome, a seminal event in scientific history. ❖

View Full Text

☞ Full transcript and video of the White House Millennium Evening
www.nhgri.nih.gov/NEWS/news.html

RESOURCES • RESOURCES • RESOURCES

Unnatural Selection: The Promise and The Power of Human Gene Research



Author: Lois Wingerson
Publisher: Bantam, 1998
Length: 416pp
Cost: $24.95 HB; $13.95 PB
Reviewer: Melisa Siegler, MS

Lois Wingerson is a journalist, editor and writer for several lay and professional scientific publications. In the introduction, she states that one simple question drove her research for this book: "Can our society's ability to understand and resolve the consequences of new genetic research keep up? Can it even catch up with the headlong progress of the research itself?"

The book is intended for a wide audience and is written in a simplified, quick and easy-to-read style. The first few chapters focus on various genetic screening programs, including a fascinating portrait of screening for Tay-Sachs disease in an Orthodox Jewish community in New York City. Different types of screening (prenatal, pre-embryo, presymptomatic) for numerous disorders are highlighted, including cystic fibrosis, fragile X, Huntington disease, cancer, heart disease, Alzheimer's disease and many more. These early chapters include explanations of basic genetic principles and reasonably accurate descriptions of various diseases. Specific cases and family situations are used to illustrate screening dilemmas. Although these reports are often very poignant, they seem inflammatory at times, written with the purpose of soliciting an emotional response from the reader. Some of the language used is not particularly sensitive to individuals with disabilities.

Several genetic counselors and geneticists were consulted and quoted throughout the book. One chapter, aptly called "Identity Crisis," focuses entirely on genetic counselors. Although we may not all find the portrayal flattering, I find the depiction interesting, especially as it probably reflects the general lay perspective.

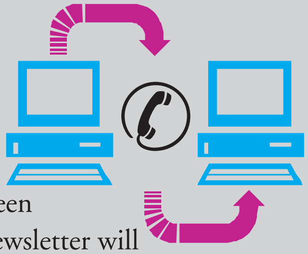
The middle chapters provide a fascinating historical account of the American and German eugenics movements of the early 19th century. The recent evolution and political origins of the Human Genome Project and ELSI are also explained.

The last several chapters explore the nature versus nurture debate, including an intriguing look at how the genome project could improve our understanding of evolution and migration patterns. Particularly interesting is a discussion of the impact (or lack thereof) that the genome project will have on individuals in various cultures worldwide.

This book helped me to understand several issues better, including the current political climate as it concerns genetic testing, oversight and managed care issues. Ms. Wingerson presents an unbiased look at gene research; she does not promote or condemn this research but encourages the public to consider the potential consequences. The issues raised in select chapters could be useful in discussions with lay groups or genetic counseling students.

Although I did not learn a lot of new factual information regarding genetics, I found it a very interesting analysis of the ethical dilemmas we regularly face and the historical events that brought us here. Already, since I've finished reading the book, it has positively influenced my interactions with patients and my professional activities. I would highly recommend the book for counselors with a special interest in history and those wishing to improve their understanding of governmental regulations. ❖

ONLINE SUPPORT GROUP FOR TETRA/PENTASOMY X



In an attempt to connect families worldwide, a support group for families of girls with tetra/pentasomy X has been established. An accompanying semi-annual newsletter will also be published to include those families without Internet access.

Interested families can susbcribe to this listserv by sending a blank email (send no information in the subject line or in the memo box) to: tetra-X-list-subscribe@egroups.com or contact kjenny@erols.com. Note: the egroups.com address listed above is case sensitive.

This support network will be monitored by Kim Jenny, a second year genetic counseling student at Beaver College. ❖

BULLETIN BOARD

PUBLIC HEALTH INTERFACE

Leslie Cohen, MS, represented NSGC at the initial meeting of the National Newborn Screening and Genetics Resource Center (NNSGRC) Genetics Planning Committee in January. NNSGRC is a cooperative agreement with the Maternal Child Health Bureau (MCHB) to provide a forum for interaction between MCHB and other organizations about newborn screening and genetic services. The purpose of the meeting was to create and prioritize activities, projects and goals for the center.

Goals already established include:

- Defining and evaluating current issues in genetics and public health.
- Integrating genetic services into local public health systems.
- Establishing consumer representation in all activities of NNSGRC.
- Providing technical assistance to states' genetic planning efforts. ❖

OI KITS AVAILABLE

Osteogenesis Imperfecta kits for healthcare providers are now available at no charge. Each kit contains a tabletop display with a brochure holder, brochures and information about Osteogenesis Imperfecta (OI). The 10-page educational brochure addresses some of the myths attached to OI and provides information on OI basics, genetic diagnosis and general guidelines for professionals.

☞ OI Foundation
✆800-981-2663;
bonelink@oif.org; www.oif.org ❖

PRENATAL INTERPHASE FISH ANALYSIS

A subcommittee of the American College of Medical Genetics has been charged with determining the types and frequency of false-positives associated with prenatal interphase FISH analysis. Both published and unpublished cases are of interest.

The group is particularly concerned that a significant number of false-positives are not being reported because they are individual cases and therefore not accepted for publication. Please send cases ASAP.

☞ Philip D. Buchanan, PhD
fax: 919-967-9519;
genecare@earthlink.net ❖

CHECK US OUT!

Lots of changes are happening on our website. We've added a new, improved Electronic Abstract Submissions page for our 19th Annual Education Conference, a form on which you can nominate members for the Natalie Weissberger Paul National Achievement Award and Regional Leadership Awards. In addition, coming soon, our Annual Education Conference Registration and Information brochure will be there to download if you misplace your copy.

And, don't forget to check out ResourceLink …and sign on right online, while you're there! ❖

DEADLINES DEADLINES, DEADLINES

April 7 *Call for Nominations, NSGC's 2000/2001 Board of Directors*
☞ Find Information: Early March membership mailing
☞ Send Nominations: Karen Treat, Karen.Treat@genzyme.com

April 15 *Call for Nominations, Natalie Weissberger Paul & Regional Leadership Awards*
☞ Find Information: Early March membership mailing *or* www.nsgc.org Click on Deadlines
☞ Send Nominations: Jennifer Farmer, FarmerJ@uphs.upenn.edu

May 1 *Call for Proposals, Jane Engelberg Memorial Fellowship*
☞ Find Information: January mailing to Full members *or* www.nsgc.org Click on Deadlines

May 1 *Hard Copy Abstract Submissions, 19th Annual Education Conference*
☞ Find Instructions: Stephanie Cohen, sacohen@stvincent.org

May 15 *Special Projects Fund proposals*
☞ Find Information: Early March membership mailing *or* www.nsgc.org Click on Deadlines

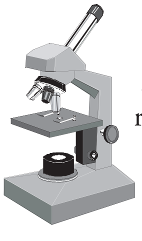
May 19 *Electronic Abstract Submissions, 19th Annual Education Conference*
☞ Find Instructions: www.nsgc.org Click on Conferences

RESEARCH NETWORK

DEVELOPMENTAL GENOME ANATOMY PROJECT

Researchers at Harvard Medical School are interested in identifying genes involved in human development that are disrupted or dysregulated by chromosomal rearrangements. This effort is being called DGAP (Developmental Genome Anatomy Project).

We are collecting blood or cultured cells (such as amniotic fluid cells or fibroblasts) from individuals who have both balanced chromosomal rearrangements (reciprocal translocations or inversions) and congenital abnormalities. We have estimated that in the US, this type of rearrangement occurs with a frequency of 150 cases annually.



While DGAP is primarily a research effort, it is likely that the results will also help to clarify certain diagnostic issues, especially within the prenatal counseling setting as increasing numbers of breakpoints and genes are characterized.

To be eligible, individuals are required to have:

- a *de novo* balanced reciprocal translocation or inversion *and* at least one major malformation *or*
- a familial, balanced reciprocal translocation/inversion that segregates with the malformation(s).

A DGAP database of submitted cases will ultimately be disseminated on a website. It will have a search tool to query by human gene or phenotype and the relationship to specific chromosome bands.

☞ Janine Lewis, MS
✆617-724-2365;
jlewis@helix.mgh.harvard.edu

☞ Azra Ligon, PhD
✆617-732-7984;
aligon@rics.bwh.harvard.edu ❖

MEETING MANAGER

April 6 - 9	*Dying, Death & Bereavement in the New Millennium — Lessons from the Past, Visions for the Future,* Association for Death Education & Counseling, Charlotte NC ☞ ✆960-586-7503; info@aedc.org
April 14	*Genetics in the 21st Century,,* NSGC Region II, Maritime Institute of Technology, Linthicum Heights MD ☞ Karen Eanet, Representative to Region II, ✆410-828-3131; keanet@gbmc.org
April 15	*First Trimester Prenatal Screening and Ultrasound Diagnosis,* GeneCare Medical Genetics and Carolina Perinatal Assoc. ☞ www.genecare.com
May 5	*Positioning Yourself for the New Millennium — Building Bridges,* NSGC Region I, Brandeis University, Waltham MA ☞ Lori Ann Correia, MS ✆617-525-5846; lcorreia@rics.bwh.harvard.edu or Kathryn Spitzer Kim, MS ✆781-736-3108; kkim@IMAP.FACULTY.BRANDEIS.EDU
May 19-21	*MPS Society Internat'l Symposium,* Minneapolis MN ☞ Mary Harings, Morquio's Support Group ✆520-408-4932; Sackrison@aol.com; www.lumiarte.com/morquio/
June 27	*The National Council on Folic Acid Annual Meeting 2000,* Milwaukee WI. Held in conjunction with the Spina Bifida Association of America's 2000 Annual Conference.
Oct 2-3	*ISONG 2000: Caring for People's Genetic Health through Managing Genetic Information,* Philadelphia PA. Molecular Technology Short Course offered October 1, 2000. ☞ Eileen Rawnsley ✆603-643-5706; erawn@valley.net; //nursing.creighton.edu/isong

EYE MOVEMENT DISORDERS GENETIC RESEARCH

The Engle Laboratory at Children's Hospital, Boston is interested in enrolling families in their studies of congenital ptosis, congenital fibrosis of the extraocular muscles (CFEOM) and Duane syndrome (including those with radial ray anomalies).

The laboratory has identified three chromosomal regions associated with CFEOM and one associated with congenital ptosis.

There is no cost to participate and all information is kept strictly confidential. Participation entails:

- giving a sample of blood
- completing a questionnaire and
- undergoing an eye examination *or* releasing eye examination records.

☞ Nathalie McIntosh, MSc
✆617-355-7311;
mcintosh@rascal.med.harvard.edu ❖

EMPLOYMENT OPPORTUNITIES

PHOENIX AZ: Immediate opening for two BC/BE Genetic Counselors in Phoenix and Fort Worth. High motivation, bilingual (Span) req (Phoenix), desired (FW). Join expanding perinatal practice. Some satellite travel req.
☞ Human Resources, Pediatrix Medical Group, 2119 W Orangewood Ave, Orange CA 92868; Fax 714-385-5743; anita_downs@pediatrix.com EOE/AA

BIRMINGHAM AL: Immediate opening for BC/BE Genetic Counselor . Self-motivation & good commun & org skills req. Join expanding Human Genetics Dept: partic in PN, peds & preconception GC; some tchg.
☞ CV & ltr of interest to Paula Cosper, PhD, University of Alabama School of Medicine, 1530 3rd Ave South, CCB 336, Human Genetics, Birmingham AL 35294; ✆205-934-4983; Fax 205-975-6389 EOE/AA

HUNTSVILLE AL: Immediate opening for BC/BE Genetic Counselor. Highly motivated individual needed to help develop & implement new GC prog: provide direct genetic risk assessment & follow-up.
☞ Helen Gammons, HealthGroup of Alabama, 188 Sparkman Dr - 1st Floor, Huntsville AL 35805; ✆256-882-6359; Fax 256-883-0849; heleng@CHP.hgala.org EOE/AA

LITTLE ROCK AR: Immediate opening for Cancer Genetic Counselor. High motivation, independent, adaptable, ability to work in fast paced, high growth program req. Join multidisc team at major tertiary cancer ctr: cancer risk assessment, GC & testing; staff, student & public educ; clin research.
☞ Becky Butler, LCSW, Cancer Genetics Program - Slot 506, Arkansas Cancer Research Ctr, Univ of Arkansas for Medical Sciences, 4301West Markham, Little Rock AR 72205-7199; ✆800-358-7229; Fax 501-296-1701; Butlerbeckyb@exchange.uams.edu EOE/AA

PASADENA CA: Immediate opening for FT or PT Genetic Counselor. Spanish speaking, enthusiam, self-motivated, positive personality pref; willingness to work as team member important. Familiarity w/ CA Expanded AFP prog desired. PN in private practice w/ perinatalogist. Diverse ethnic population. Some work-related travel.
☞ Bharat D. Shah, MD, 50 Alessandro Place Ste 150, Pasadena CA 91105; ✆626-449-8706; Fax 626-449-3464 EOE/AA

SAN FRANCISCO CA: Immediate opening for FT BC/BE Genetic Counselor. Possible add'l opening for PT, temp. Bilingual pref. Join established comprehensive prog in HMO setting. Provide broad range of genetic svcs: PN, CA, peds, adult.
☞ Kristina Keilman, MS, Genetics Dept, Kaiser Permanente, 2350 Geary 3rd Floor, San Francisco CA 94115; ✆415-202-2995; Fax 415-202-2999; kristina.keilman@kp.org EOE/AA

SAN FRANCISCO CA: Immediate opening for BC, Internet-savvy Genetic Counselors. Min 2 yrs clin exp w/ strong oral & written commun skills. Ability to interact w/ variety of medical/business professionals and strong interest in energetic environment & nontraditional GC role. Develop & support online genetic services.
☞ Maureen E. Smith, MS, GeneSage, 589 Howard St, San Francisco CA 60605; ✆312-554-1552; Fax 415-371-9501; MSmith@GeneSage.com EOE/AA

SAN FRANCISCO CA: Immediate opening for BC/BE Cancer Genetic Counselor. Exp in cancer genetics pref; strong initiative, excellent verbal & written communication skills & ability to work independently req. Coordinate all clin & research activities in hereditary colorectal cancer prog & registry. Oppty to combine clinical, research & community/professional education activities.
☞ CV & 2 ltrs of rec to Peggy Conrad, MS or Beth Crawford, MS, UCSF Colorectal Cancer Prog/ UCSF Cancer Risk Program, 1600 Divisadero St, Box 1693, San Francisco CA 94115; ✆415-885-7481 (PC); 415-885-7779 (BC); Fax 415-885-3787; peggy.conrad@ucsfstanford.org EOE/AA

SAN JOSE CA: Immediate opening for permanent & April -Aug opening for maternity leave coverage for BC/BE Genetic Counselors. Exp pref. Join active team in estab, comprehensive genetics program in large HMO. Broad range of services: PN, peds, adult, cancer, specialty clinics.
☞ Cindy Soliday, MS, Genetics Dept, Kaiser Permanente, 5755 Cottle Road, San Jose CA 95123; ✆408-972-3332; Fax 408-972-3298 EOE/AA

SOUTHERN CA: Immediate opening for BC/BE Genetic Counselor. Computer skills pref. Possible setting incl locations in Orange County, Southern CA (10 mins from Disneyland). Join Comprehensive PNDx Ctr: amnio, CVS, AFP & teratogen GC plus wide variety of other genetic subspecialty clins & molecular genetics.
☞ Khalil N. Zadeh, PhD, Genetics Center, 1201 W. La Veta Ave - Ste 402, Orange CA 92868; ✆714-288-8520; 888-4GENETIC; Fax 714-288-8525; nzadeh@aol.com; www.geneticscenter.com EOE/AA

PENSACOLA FL: Summer '00 opening for BC/BE Genetic Counselor. Exp pref. Ability to work independently, good commun & org skills req. Join perinatologist in hosp setting to provide primarily PN w/ some adult GC.
☞ Deanna Steele, MS, Center for High-Risk Pregnancy, 1717 North "E" St, Baptist Medical Towers - Ste 425, Pensacola FL 32501; ✆850-469-7000; Fax 850-469-7064 EOE/AA

CHICAGO IL: Immediate opening for BC/BE Genetic Counselor. Work w/ 2 clin geneticists/pediatricians in a variety of clin progs (genrl, PKU, etc) & Ctr for Jewish Genetic Disorders. Conduct community education re: Jewish genetics diseases, coord community-based Tay-Sachs disease carrier screenings, work w/ hosp-based Gaucher disease prog. Develop website on Jewish genetic disorders, maintain clin databases. Oppty to work w/ 3 other couns in a hosp/univ-based prog w/ full range of clin svcs.
☞ Joel Charrow, MD, Head, Section of Clinical Genetics, Children's Memorial Hospital-59, 2300 Children's Plaza, Chicago IL 60614; ✆773-880-4462; Fax 773-929-9565. EOE/AA

BALTIMORE MD: Immediate opening for BC/BE Genetic Counselor. Join univ-based team to provide svcs for peds & adult pts at hosp & satellite clinics; involvement w/ research & teaching.
☞ CV & 2 ltrs of rec req to Michelle Moore, MS, Johns Hopkins Hospital, 600 N. Wolfe St, Blalock 1008, Baltimore MD 21287-4922; ✆410-955-3071; Fax 410-614-9246 EOE/AA

ROCKVILLE MD: Immediate opening for PT, BC/BE Genetic Counselor. Local travel involved. Excellent i'personal & org skills req. Work w/ 1 other GC in busy private PNDx/perinatology practice w/BC geneticist, svg diverse pt population.
☞ Jill Fonda, MS, Ctr for Maternal-Fetal Medicine & Reproductive Genetics, 9707 Medical Center Drive - Suite #230, Rockville MD 20850; ✆301-279-6060; Fax 301-279-6345; jfonda@adventisthealthcare.com EOE/AA

ROCKVILLE MD: Immediate opening for Genetic Counselor to work with Mark H. Greene, MD, Chief, NCI, NIH, Clinical Genetics Branch. Degree in genetics or one of the basic

See next page

biological sciences req. Serve as head of Branch/Div GC counseling research progs responsible for planning, designing, implementing & directing research protocols to develop & evaluate delivery of GC svcs. Engage in interdisc studies of families & populations at high risk to define genetic mechanisms & gene/ environment interactions in cancer risk; provide consultation to Div & nat'l leaders on GC issues.
☞ Sara Sutphin, NIH, NCI, Clinical Genetics Branch, Rockville MD 20852; ✆301-594-7512; Sutphins@mail.nih.gov EOE/AA

BOSTON MA: Immediate opening for Genetic Associate w/ MS in GC or related field. Exp pref, not req. Join busy PNDx & molec DNA diagnostic progs. Involvement in MSAFP. Newly available: PN GC in high-risk OB clin, partic in medical genetics clin. Rsrch oppty available.
☞ Aubrey Milunsky, MD, Center for Human Genetics, Boston University School of Medicine, 715 Albany St, Boston MA 02118; ✆617-638-7083; Fax 617-638-7092; amilunsk@bu.edu EOE/AA

FRAMINGHAM MA: Immediate opening for BC/BE Genetic Counselor w/ up to 2 yrs exp & current, working knowledge of molecular tstg req. Strong communication skills & ability to multi-task essential. Answer inquiries from health professionals re: molecular testing, assist in review & reporting of results.
☞ Kristen Jadul, Genzyme Genetics, 15 Pleasant St Connector, PO Box 9322, Framingham MA 01701-9322; Fax 508-872-2460; kristen.jadul@genzyme.com EOE/AA

DEARBORN MI: Immediate opening for PT, BC/BE Genetic Counselor. Exp pref, not req. Join busy PN ctr: coord maternal serum triple screen prog & PN GC. Oppty for involvement in cancer GC; assist in genetic rotations for OB residents & med students.
☞ Julie Zenger Hain, PhD, Clinical Cytogenetics Dept, Oakwood Hospital & Medical Center-Dearborn, 18181 Oakwood Blvd - Ste 102-G, Dearborn MI 48124; ✆313-593-8483; Fax 313-436-2004; zengerj@oakwood.org EOE/AA

DETROIT MI: Immediate opening for BC/BE Genetic Counselor. Initiative, excellent i'personal, written and verbal skills req. Provide GC in busy outpt pediatric genetics and hemophilia clinic. Oppty to teach med students, residents, GC students & community.
☞ Erawati V. Bawle, MD, Div Genetics, Children's Hospital of Michigan, 3901 Beaubien, Detroit MI 48201; ✆313-745-4513; Fax 313-745-4827; ebawle@med.wayne.edu EOE/AA

HACKENSACK NJ: Immediate opening for BC/BE Genetic Counselor. Some travel to satellite location; Spanish a plus. Self motivation, ability to work independently, excellent verbal & written commun & org skills req. Join 5 GCs in busy comprehensive genetics dept. High vol PN pts. Research & tchg opptys.
☞ Sivya Twersky, MS, Genetics Svc, IMUS Pediatric Ctr, Hackensack Univ Medical Ctr, 30 Prospect Ave - Rm 258, Hackensack NJ 07601; ✆201-996-5264; Fax 201-996-0827; stwersky@humed.com EOE/AA

NEW YORK NY: Immediate opening for two Genetic Counselors. Exp pref, not req. Highly motivated, abil to work independently, excellent commun & org skills req. FT position: PN, ped GC. PT position: cancer GC to affiliated cancer GC prog. Opptys for tchg & clin rsrch.
☞ Randi Zinberg, MS or Karen Brown, MS, Dept Human Genetics, Mount Sinai School of Medicine, 100th St & Madison - Box 1497, New York NY 10029; ✆212-241-6947; Fax 212-860-3316 EOE/AA

WINSTON-SALEM NC: Two openings for BC/BE Genetic Counselors, one immediately, one for Summer '00 at large academic med institution. Rotating position covers PN, ped clins & maternal serum screening prog coordination. Opptys available for clin research. Partic in prof, med school & GC training prog education req.
☞ CV & 3 ltrs of rec to Peggy Berry, MS, Dept Pediatrics, Sec Genetics, Wake Forest University School of Medicine, Medical Center Blvd, Winston-Salem NC 27157; ✆336-716-2213; Fax 336-716-7575; mnberry@wfubmc.edu EOE/AA

CLEVELAND OH: Immediate opening for PT BC/BE Genetic Counselor to conduct research in Alzheimer's disease. Exp w/ research operations desirable; team player and interest in ethics desirable. Work in collab with Boston and New York centers to identify and assess individuals at risk for AD: conduct educational sessions and GC w/ longitudinal follow-up for three yrs.
☞ Peter J. Whitehouse, MD, PhD, Case Western Reserve University, Fairhill Center for Aging, 12200 Fairhill Rd - #323C, Cleveland OH 44120; ✆216-844-6448; Fax 216-844-6466; pjw3@po.cwru.edu EOE/AA

PORTLAND OR: Immediate opening for Oregon State Genetics Coordinator. BC/BE GC or nurse w/ genetics exp req. Excellent written & verbal communication, consensus building, facilitation, program management, grant writing skills req. Integrate genetics services into OR public health progs: develop & implement statewide

See next page

national society
of genetic
counselors, inc.

nsgc
233 CANTERBURY DRIVE
WALLINGFORD PA 19086-6617

EMPLOYMENT OPPORTUNITIES, from p. 15

public health genetics plan, facilitate collab between genetics providers, policy makers, consumers, payers & others. Job Announcement Info: www.oregonjobs.org/jobsdocsnofrm/LE000248.html
☞ Jill Skrezyna, MPH, Oregon Health Division, Ctr for Child & Family Health, 800 NE Oregon St #21 - Ste 825, Portland OR 97232; ✆503-731-8606; Fax 541-346-2624; or Kerry Silvey ksilvey@oregon.uoregon.edu EOE/AA

PROVIDENCE RI: Immediate opening for BC/BE Genetic Counselor w/ ability to work independently in busy cancer clinic; exp in cancer GC pref. Position is halftime (permanent) in oncology division as a cancer GC, halftime (temporary) as part of a 2-3 yr grant for the NIH FASTER trial.
☞ Debbie Owens RNC, MS, Professional Coordinator, Prenatal Diagnosis Center, Women & Infants Hospital, 79 Plain Street Providence RI 02903; ✆401-453-7510; Fax 401-453-7517; dowens@wihri.org.

RAPID CITY/SIOUX FALLS SD: Immediate opening for BC Genetic Counselor/Research Associate. MS in GC, human genetics or related subject req. Significant related exp pref *or* equiv comb of educ & exp will be considered. Assist in operation of statewide Birth Defects Genetics Clinic: serve as info resource, assist in research projects, develop educ materials & workshops on birth defects & genetics.
☞ Virginia P. Johnson, MD, Dept OB/GYN, USD School of Medicine, 414 E. Clark St, Vermillion SD 57069; ✆605-677-5623; Fax 605-677-5778; vjohnson@usd.edu EOE/AA

CORPUS CHRISTI TX: Immediate opening for BC/BE Genetic Counselor. Spanish a plus; some travel to satellite locations. Join busy expanding PN ctr serving entire S. TX area. Main office site includes state-of-the-art cytogenetics & triple screen dx lab. On-site U/S dept in each office. Team includes one geneticist, one cytogeneticist & one GC. Referrals: AMA, abnormal triple marker screen, U/S, teratogen & abnormal fam hxs.
☞ Lisa Kelley, MS, Center for Genetic Services, 7121 S. Padre Island Dr - Ste 202, Corpus Christi TX 78412; ✆361-985-6600; Fax 361-985-6603; Bay1@Davlin.net EOE/AA

FORT WORTH TX: *See Phoenix AZ*
☞ Genetic Counselors, Obstetrix Medical Group, 1325 Pennsylvania Ave Ste 690, Fort Worth TX 76104-2133; ✆817-878-5298.

TIDEWATER VA: May '00 opening for Genetic Counselor, Dynamic, self-motivated, organized individual w/ 2-3 yrs clin GC exp req. Join fast paced ped/adult prog. Opptys for GC, pt mgmt, teaching & partic in clinical research protocol.
☞ V.K. Proud, MD, Div Medical Genetics, Children's Hospital of the King's Daughters, Eastern Virginia Medical School, 601 Children's Lane, Norfolk VA 23507; ✆757-668-9723; Fax 757-668-9724; vproud@chkd.com EOE/AA

MILWAUKEE WI: Spring/Summer '00 opening for BC/BE Genetic Counselor. Previous GC exp req. Exceptional commun skills are req. Join a reg'l healthcare provider system in developing & providing GC svcs in oncology & perinatology, assist in training residents & other students, potential for partic in rsrch activities. Excellent prog development & direct pt contact oppty.
☞ Kristin Niendorf, MS, Cancer Counseling Center, St. Luke's Medical Center, 2900 W. Oklahoma Ave, Milwaukee WI 53209; ✆414-649-5786; kniendorf@yahoo.com EOE/AA

JOBCONNECTION HOTLINE

✆	610-872-7608, press 2
Fax	610-565-6220
EMail	nsgcassist@aol.com