PERSPECTIVES in genetic counseling

Volume 21 Number 4 Winter 1999/2000

national society of genetic counselors, inc.

nsgc

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

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NSGC acknowledges — Athena Diagnostics — for a generous grant to support this newsletter.

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FETAL SURGERY: AN ETHICAL PERSPECTIVE

Katherine Hunt, MS

In utero surgery is a burgeoning new treatment for fetuses affected with major and, more recently, minor birth defects. As more centers offer fetal surgery, and with increasing attention being paid by the media to this technology, more patients will be requesting information about this procedure. While it sounds exciting to offer patients with fetal defects immediate treatment rather than waiting to perform surgery after the birth of the baby, we need to pay close attention to the ethical issues surrounding in utero surgery.

Craig Albanese, a surgeon from the Fetal Treatment Center at the University of California, San Francisco, was the featured speaker at this year's "Difficult

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LARGER GENETICS COMMUNITY

THE COALITION FOR GENETIC FAIRNESS

Vivian Weinblatt, MS

I represented NSGC at the organizational meeting of the Coalition for Genetic Fairness last November. The steering committee is currently comprised of representatives from a diverse group of organizations.

GOALS

As described by Susannah Baruch of the National Partnership, the long-term goal of the coalition is to see that federal legislation passes that bans genetic discrimination in both employment and insurance. However, it is the consensus of the group that this is not likely to happen in this Congress. Over the next six months, the group will be trying to reach consensus on principles for legislation in the next Congress that will hopefully get broad bi-partisan support.

In the short term, there are some genetic anti-discrimination provisions in the Senate. The House and Senate passed different versions of managed care reform and a conference committee has been appointed to work out the differences. However, given the largely Republican makeup of the conference committee, it is unlikely a bill will emerge from the conference that the President will sign — in other words, nothing is likely to become law next year. Therefore, now is an excellent time to educate the Congress about what we want to see in genetic discrimination legislation, using the Senate managed care bill as a vehicle for advocacy.

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Genetic provisions of the Managed Care Bill

☞ //thomas.loc.gov/cgibin/query/D?c106:3:./temp/~c106et1p7d:e165585

NSGC at Work: Forging Ahead

Wendy R. Uhlmann, MS

At our conferences each year, it is impressive to see our genetic counselor community reconstituted, to feel the energy generated when hundreds of counselors come together and to observe our community's continual growth. The quality of our conferences and the wealth of projects undertaken by NSGC members reflect positively on our profession. It is important to recognize that many genetic counselors involved in NSGC and other genetics professional organizations are doing this in addition to their full-time jobs. Realizing this, it is important to think about what *you* can contribute to these efforts. There are many ways of contributing to our professional growth that can take just a few hours to as much time as you have to offer. If what you are seeking does not currently exist, you have the ability to create it.

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•EDITOR: Janice Berliner • Janice_Berliner@siuh.edu

•STAFF: Susie Ball; Jennifer Claus; Shelly Cummings; Karen Eanet; Angela Geist; Lyn Smith Hammond; Katherine Hunt; Sarina Kopinsky; Jessica Mandell; Kathy Morris; Whitney Neufeld-Kaiser; Claire Noll; Melissa Patterson; Trisha Peters Brown; Karen Potter; Melisa Siegler, Roxanne Ruzicka; Kathryn Steinhaus French; Liz Stierman; Aimee Tucker; Cathy Wicklund and Beverly Yashar

•NSGC EXECUTIVE OFFICE: c/o Bea Leopold, Executive Director, 233 Canterbury Dr, Wallingford PA 19086-6617; ✆610-872-7608; Fax: 610-872-1192; NSGC@aol.com

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

Next issue ***March 15***
Submission deadline ***February 10***

Getting Involved

I encourage you to review our quarterly reports, posted on the listserv, and contact committee chairs about projects for the coming year. Some projects that could use your help include:

- Developing a strategic plan for our new Communications Committee, reviewing and producing publications, writing media releases, writing letters addressing articles/TV shows' portrayals of genetic counseling and expanding our webpage. *Contact Liz Stierman.*
- Exploring and developing alternative options to obtain CEUs, working to increase genetic counseling content in training of other health care professionals, developing educational tools and slides. *Contact Rob Pilarski.*
- Working on billing and reimbursement issues, time survey and Professional Status Survey. *Contact Jennifer Farmer.*
- Monitoring legislation and working on position documents. *Contact Anne Spencer.*
- Working on practice guidelines and standard family history forms. *Contact Robin Bennett.*
- Working on a poster to advertise the field of genetic counseling to prospective students, assessing job search strategies, and serving as a student mentor. *Contact Kristin Baker Niendorf.*
- Planning conferences and contributing articles to newsletters. *Contact your Regional Representative.*

To increase our visibility, it is important for our profession to have an active presence in genetics professional organizations. At the

recent meetings, I met with Uta Francke, MD (President, ASHG), Ronald Worton, PhD (President-Elect, ASHG) and with Rodney Howell, MD (President, ACMG) and Ed McCabe, MD, PhD (President-elect, ACMG). Both organizations were very receptive to having genetic counselor involvement. How can genetic counselors become involved?

Genetic Counselors Can…

- Join ASHG and ACMG
- Be appointed to ASHG and ACMG committees
- Be elected to the ASHG Board
- Be appointed to ASHG and ACMG Program Committees to plan annual conferences
- Attend ASHG and ACMG business meetings
- Submit proposals for conference workshops and symposia
- Submit abstracts to conferences and articles to journals

Several genetic counselors are already serving on Boards and committees within these organizations. To find out more about these organizations, visit their homepages at www.faseb.org/genetics/mainmenu.htm.

Every time you give a presentation or see a patient, you are representing genetic counselors and enhancing the visibility of our profession. Thanks to everyone's efforts, genetic counselors are entering the millennium with a well-established profession. As NSGC celebrates its 20th Anniversary year, there is much that our profession has accomplished and much to look forward to in the next century. ❖

Dilemmas" workshop at the NSGC Annual Education Conference in Oakland. He gave a dynamic presentation on the current status of fetal surgery and explained that it is no longer offered just for life threatening birth defects like congenital diaphragmatic hernia (CDH). With the use of operative fetoscopy, a minimally invasive fetal surgery using an endoscope under ultrasound guidance, more minor conditions are now being treated in utero. These include acardiac twins, amniotic band syndrome, fetal lower obstructive uropathy, twin-twin transfusion, chorioangiomas, myelomeningoceles and cleft lip. The endoscope allows such detailed surgeries because it provides higher resolution than ultrasound, magnifying the target area. Operative fetoscopy also has fewer risks for both fetus and mother than traditional open fetal surgery. Tocolysis, a major complication with open fetal surgery, is decreased with operative fetoscopy. There are some complications with fetoscopy, however, including pregnancy loss (approximately 3%), bleeding, premature rupture of membranes and uterine contractions.

Ethical Issues

The audience's discussion following Dr. Albanese's presentation pinpointed that fetoscopy may be ahead of its time from an ethical standpoint. Here we have a new, potentially safer procedure to offer a larger number of patients. But we have not completely resolved the ethical issues left over from traditional fetal surgery. One of these ethical considerations is which type of patient is seeking this service? According to Dr. Albanese, the majority of patients receiving fetal surgery at his center are well educated with a higher income level than the general population, partly because the surgery is very expensive and is still considered a research-based procedure.

A solution to equal access would be to offer fetal surgery on a clinical basis, enabling hospitals to advertise the service and seek Medicaid and insurance reimbursement. To justify this advertising, Dr. Albanese's center is currently investigating the safety and efficacy of fetoscopic surgery versus standard postnatal care for CDH. Patients referred for evaluation of CDH who meet the criteria for poor clinical outcome are offered entrance into the study and are randomized either into the treatment arm, receiving surgery, or into the standard postnatal care arm, receiving care at birth.

In Keeping with the Code of Ethics

While the study has been approved by the internal review boards and ethics committee at UCSF, Dr. Albanese and the audience found this randomization unsettling. Does the study contradict the NSGC Code of Ethics? We uphold the Code by "equally serving all who seek services" (section II number one), and we pledge to "recognize the competence of other health professionals and cooperate with them in providing the highest quality of service." Yet a patient referred to the CDH study may not be randomized to the surgery arm. Will we be held responsible if this patient continues the at-risk pregnancy and has a bad outcome because the baby only received traditional postnatal care?

On the other side, how can we not refer patients to this study? We must follow the Code by "enabling our clients to make informed independent decisions, free of coercion, by providing or illuminating the necessary facts and clarifying the alternatives and anticipated consequences." Yet will our counseling really help patients understand the implications of the study in the midst of their hearing heartbreaking news about their affected fetuses? Can they comprehend the emotional consequences of pursuing a "cure" for their babies, only to be told that despite the severity of the disorder, they will not receive the new surgical technique and must wait until delivery for care?

On a Case by Case Basis

Dr. Albanese demonstrated how modern medical advances do not arrive at our door steps in one neat and compact package. We need to approach fetal surgery as if we were receiving a large box filled with many different packages of varied shapes and sizes and all marked fragile. Each potential surgical case referred to a fetal diagnostic center should be opened carefully. The contents should be explored individually and the patients treated thoughtfully. ❖

Resource for Fetal Surgery

This website features an online version of an educational videotape about fetal surgery for spina bifida in addition to patient education materials for a variety of malformations.

☞ www.chop.edu/clinical/surgery/fetalsurg/index.html ❖

CEU — Needs Assessment

Barbara Lerner, MS

The Continuing Education Unit Subcommittee of the NSGC Education Committee has been charged with exploring additional options for obtaining continuing education units (CEUs). Accumulation of CEUs is one of two pathways recognized by ABGC for recertification; the alternative — retake Boards every 10 years.

There was some discussion at the ABGC open mike and in committee in Oakland regarding perceived obstacles to achieving adequate numbers of CEUs. Issues include:

- Do counselors have access to adequate numbers of programs that provide category I CEUs?
- Will cost of travel, meeting registration and application for CEUs affect our members' abilities to pursue recertification?
- What alternative mechanisms for obtaining CEUs, other than national or regional meetings, would counselors be apt to pursue?

The subcommittee determined that an important step toward addressing these concerns is to query the membership about its needs and ideas. A short survey will be available online this Winter, and we encourage you to visit the survey website to make your needs regarding recertification known. A posting will be placed on the listserv as soon as the survey is ready. If you do not have access to NSGC's listserv, the committee will mail a hard copy of the survey to you.

Results will be tabulated, interpreted and reported to the ABGC Board and to the American Counseling Association (ACA). ACA is the CEU approval body. Our understanding is that the ACA is willing to explore alternative forms of education worthy of CEUs, including home study. More information on this subject and the survey results will be published in future issues of *PGC.*

For a hard copy of the needs assessment survey or the subcommittee's activities, contact Barbara Lerner, Subcommittee Chair, ✆781-736-3149; lerner@brandeis.edu. ❖

Erratum

Calculating CEUs: What Counts? was published in the Fall issue of *Perspectives in Genetic Counseling* prematurely. It was based on material that is being drafted by the American Board of Genetic Counseling in conjunction with the American Counseling Association and had not been authorized for publication. Please do not use the information in that piece until further notice. We regret that this occured and offer sincere apologies to Susan Schmerler for any embarrassment or inconvenience she may have experienced. ❖

CEU Issues Clarified

Bea Leopold interviews Lisa Findeisen, American Counseling Association (ACA) Professional Learning Specialist

Can you clarify the need for signing in 2x/day?
The reason for signing in more than once a day is to ensure that participants attend all parts of the conference. In that way, records are kept to show that credit given for courses attended was merited.

Are there CEU opportunities at which signing in 2x/day is not the protocol?
Partial credit for non-contiguous courses, such as NSGC's and ASHG's annual conferences, will be granted. In lieu of sign in sheets, each person requesting partial credit will be required to complete and sign a form indicating *each* session attended. Learning Institutes, that is, courses based on single or unified themes, and on which the thorough knowledge outcome is based on a continuum of the information presented, will require full participation. Partial credit for these courses will not be granted.

Explain the relationship between ACA and NBCC.
The American Counseling Association (ACA) is a non-profit association of professional counselors. The National Board for Certified Counselors (NBCC) is a *credentialing* board for certified counselors, created originally by ACA specifically to ensure an arms length between the organization *offering* educational courses and the organization *credentialing* individuals. NBCC has their own executive board; ACA cannot influence them in any way to affect the credentialing process. An analogy in the genetic counseling community would be the necessity to uphold the ethical arms length that separates NSGC and ABGC ❖

COALITION FOR GENETIC FAIRNESS, *fr p. 1*

The bill is S.1344, and the genetic discrimination provisions are in section 301-402.

FLAWS IN THE SENATE BILL

- It proposes no penalty for insurance companies found to be in violation of the genetic discrimination protections.
- Clarification of the term "predictive genetic information" is needed. The bill falls short of protecting individuals with a known diagnosis as opposed to those with a predisposition. Additionally, the protection does not seem to extend to those whose diagnosis was made clinically, in the absence of quantitative test results.
- The bill permits insurance companies to request genetic information but does not limit the reasons for which the information is available. The Coalition suggests that the fact that a genetic test was done should be disclosed, but that the *results* of the test be limited to a narrow set of circumstances. In other words, a patient's BRCA1 test results should be disclosed only if she is requesting treatment related to these results.
- The bill does not include protections against genetic discrimination in employment.

THE GOOD NEWS

On a brighter note, the bill does include protection for family history information. This is included in the definition of "genetic information." Family history information has never before been included in the definition of genetic information, despite the best efforts of the ELSI Working Group, among others.

The coalition has prepared a draft document responding to the Senate version of the bill and addressing the above concerns. I believe the draft is well written and is consistent with NSGC's mission. I additionally suggest that we appoint an NSGC liaison to this Coalition and inquire about membership (official or unofficial) on the steering committee. This is a unique opportunity to be included on the ground floor of an important legislative initiative. ❖

LIMITED OFFER — PRORATED CEUS FOR ATTENDANCE AT '99 ASHG MEETING

☞NOTE: This information does not apply to members who attended and paid for CEUs on site at American Society of Human Genetics, Oct 1999.

Wendy R. Uhlmann, MS and Pat A. Ward, MS

We are pleased to let you know that we have worked out a system with the American Counseling Association (ACA) to grant prorated Continuing Education Units (CEUs) to genetic counselors who attended *at least 50%* of the ASHG meeting, October 1999.

The following documentation must be postmarked by January 20, 2000 to the NSGC Executive Office. *Deadline extensions beyond January 20 will not be granted.*

1. A signed letter requesting partial CEU credits for the 1999 ASHG annual meeting, including the exact dates of attendance and the number of credits being requested, as calculated from the Continuing Education Credit Report Form (see #4 below).

2. A receipt of ASHG registration or confirmation of registration. To obtain a confirmation of registration, contact Jane Salomon: jsalomon@genetics.faseb.org

3. A copy of an airline, hotel, parking or other receipt for the dates of the conference. Persons living in the Bay Area may indicate in the letter that this documentation is missing. For registrants outside of the Bay area, if you no longer have this documentation and cannot obtain it by reasonable means from the airline or hotel, indicate this in your letter.

4. A completed Continuing Education Credit Report Form, indicating the portions of the conference attended.

   For a copy of the form by email (in MS Word 5.1) contact Lisa Brodeur, NSGC's CEU Administrator, nsgclistq@aol.com or fax: 610-447-8489. (*NOTE:* This is a shared line between fax and modem. Therefore, try again later if your initial request does not go through on your first try).

5. A check for $20, payable to NSGC.

This documentation, although it may seem cumbersome, is necessary because we are requesting ACA to grant prorated CEUs after the conference has been held and without the verification of attendance by daily sign-in logs.

We are pleased that ACA is willing to work with us to develop criteria for granting prorated CEUs for this meeting. ❖

New Foundation Devoted to Common, Complex Genetics Diseases

Joseph D. McInerney, MA, MS

The Foundation for Genetic Education & Counseling (FGEC), which began operation on June 1, was developed in response to the rapid growth of genetic medicine and its increasing importance in diagnosis, treatment and prevention of common, complex diseases. The foundation is the brainchild of Dr. Ann E. Pulver, director of the genetic epidemiology program in the Psychiatry Department at Johns Hopkins University School of Medicine and an experienced investigator into the genetic contributions to schizophrenia and bipolar disorder.

The Foundation's Mission

Dr. Pulver, long concerned about the implications of her research for the patients and families participating in her studies, sees the foundation as a vehicle to develop educational and counseling programs in advance of gene discoveries. FGEC's mission, as defined by the foundation's board, is to promote genetic education for the general public and for health care professionals; to develop, evaluate and disseminate educational programs for individuals affected by common, complex diseases, and to provide information and resources that help to inform genetic counseling. The foundation will use its work on the genetics of mental illness as the basis for programs on other common diseases, in the context of the growing role of genetics in disease prevention and public health. The Genset Corporation, a Paris-based biotechnology firm that collaborates with Dr. Pulver, has provided the seed money for the foundation's operations.

The Foundation and NSGC

FGEC will not provide genetic counseling services but will work with other organizations to expand the reach of counseling and enhance its effectiveness.

Although the foundation and NSGC have no formal relationship, FGEC's mission clearly requires interactions with NSGC members on virtually all foundation programs. Members of NSGC's Psychiatric Disorders Special Interest Group already have reviewed a pending foundation publication on genetics and bipolar disorder.

In addition, the foundation now is seeking funding to develop an interactive CD-ROM on genetics and mental illness, for free distribution to all NSGC members, and to design counseling protocols for schizophrenia and bipolar disorder in anticipation of gene discovery. We are hopeful that NSGC members will be central participants in both projects, and we look forward to working with NSGC and its members in the long term to promote our mutual interests in genetic counseling. ❖

JEMF — Call for Applications

Joan Scott, MS

The Jane Engelberg Memorial Fellowship (JEMF) is open to genetic counselors who are full members in good standing of the National Society of Genetic Counselors (NSGC) and are certified in genetic counseling by the American Board of Medical Genetics or the American Board of Genetic Counseling. Individuals who have been granted active candidate status by the American Board of Genetic Counseling also are eligible to apply for a JEMF. The eighth fellowship award, an annual $50,000 grant of the Engelberg Foundation to the NSGC, will be awarded for 2000-2001 to one genetic counselor (or more than one genetic counselor who will share the award) for study, research, writing or exploration of new interests in order to enhance present skills, develop new skills, contribute to the body of knowledge in the field of genetic counseling or expand professional roles. Applicants must demonstrate that the work supported by the fellowship will produce results that will be of sufficiently broad interest to warrant professional publication and/or presentation and that enrich the base of knowledge in the professional community concerned with genetic counseling.

Applicants may elect to pursue fellowship work on a part-time or full-time basis for a maximum of one year. The award will be presented at NSGC's Annual Education Conference in 2000. Applications are due May 1, 2000. A Program Application and Guideline Booklet will be mailed in January to all NSGC full members and will be posted on our website.

☞ Audrey Heimler, P.O. Box 358, Morris, Connecticut 06763; Fax: 860-567-1340; AHeimler@aol.com. ❖

What's Ahead in '00?

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*

Overview: NSGC's 19th Annual Education Conference will explore the unique role of genetic counselors within the healthcare team. The emphasis of genetic counseling has evolved from providing medical information and genetic risk assessment to encompass psychological assessment, counseling and support. 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. An emphasis will be placed on the social and psychological aspects of the genetic counseling process and genetic disorders.

Call for Abstracts: Prepare Early! While submission of abstracts related to the conference theme is encouraged, research on other aspects of genetic counseling and related fields will also be considered. Monetary awards will be presented for best full member and student member abstracts. Abstracts submitted in hard copy must be postmarked by May 1. Enjoy a nearly 3-week reprieve for electronic submissions — take until midnight, May 19. The glitches that occurred last year, our first ever accepting electronic abstracts, have been debugged.
Visit www.nsgc.org, and then click cn conferences — *after February 1.*

☞ Hard copy instructions and form:
Stephanie Cohen, c/o Maternal Fetal Medicine and Genetics Center, St. Vincent Hospital Family Life Center, 2001 W. 86th Street, Indianapolis IN 46240-0970; ✆317-338-3487; sacohen@stvincent.org

Lyn Hammond, c/o Division of Genetics and Child Development, Medical Univ of South Carolina, 135 Rutledge Ave-Rm 395, Charleston SC 29425; ✆843-876-1504; hammondl@musc.edu ❖

Savannah! A Great Place to Meet *and* Visit

Andy Faucett, MS

Savannah was recently voted the second most hospitable city in America, and just last August, the *New York Times* travel section named Savannah one of the top 12 travel "hot spots." Fall and early Winter is a great time to visit — with its mild weather and smaller crowds. Why not plan to visit the city a few days before or after our Annual Education Conference to truly enjoy some "Southern Hospitality?"

Savannah was founded in 1733 as a planned city by General Oglethorpe. The original historic district is laid out in a pattern of parallel and perpendicular streets with 26 public squares. The majority of the historic district has been preserved. It is easy to cover the 2.5 miles of the historic district on foot.

The city boasts a thriving film industry, having hosted the filming of *Glory, Forrest Gump, Something to Talk About, Midnight in the Garden of Good and Evil, Forces of Nature, The General's Daughter* and recently *The Legend of Bagger Vance.*

Also available nearby are beaches, Hilton Head Island, nature preserves and other historic cities including Beaufort and Charleston, South Carolina.

NSGC's meeting will be held at the new Westin resort, which opened December 1999. Additional meeting space will be used in the new Georgia Maritime Convention Center, adjacent to the Westin.

Be sure to mark your calendars now in anticipation of a great meeting at a wonderful site! ❖

ResourceLink Survey Results

Lyn S. Hammond, MS

The ResourceLink is the part of NSGC's website that enables Internet users to locate genetic counselors by city or state. The Summer issue of *PGC* (21:2) included a ResourceLink Survey to assess utilization.

A total of 1679 surveys were mailed. Of the 184 members who responded, 156 were aware of the ResourceLink, including 124 who have been contacted as a result of this "service." For these participants, the frequency of contacts per month ranged from 0 - 10. About half of the ResourceLink participants had queries from students, some heard from lay persons and some were approached by peers. About 35% said the ResourceLink is easy to use and update, while 19% find the ResourceLink user unfriendly.

About 10% reported wanting more calls, while a few bemoaned too many contacts or found queries too broad or inappropriate. Very few people used the ResourceLink to make a referral or look for the name of another genetic counselor.

For those who do not participate in this handy genetic counselor locator, reasons given included:

- Ignorance of its existence or how to join.
- Too busy.
- No longer in the field or not involved with patient care.
- Unimpressed by the notion.
- Privacy issues.
- Others at the same site listed.
- No computer.

Sign On to ResourceLink

Want to become part of ResourceLink?

Simply log onto our website — www.nsgc.org — then click on ResourceLink. Click on the link, "Join the ResourceLink," to get to the form which asks you for your information.

It's that easy!

What's On the Web?

Shelly Cummings, MS

Gene Almanac

☞ //:vector.cshl.org/

Mendelian genetics gets multimedia treatment at this new Cold Spring Harbor lab online primer for high school students and laypeople. The site is bursting with video clips of scientists and historians, animations, archival photos, quizzes …*and more.* ❖

Glossary of Genetic Terms

☞ www.nhgri.nih.gov/DIR/VIP/Glossary

Also aimed at the public, a new genetics glossary from NIH defines nearly 200 terms, from adenovirus to yeast artificial chromosome, and includes illustrations and audio from experts such as Francis Collins. ❖

Human Genome at a Glance

☞ www.ncbi.nlm.nih.gov/genome/guide

From DNA sequences to new research on genetic diseases, details about the human genome are pouring into public databases.

The National Center for Biotechnology Information (NCBI) launched a Web site, called Human Genome Resources, that can help researchers monitor new data. The public site has links to important genomic databases and point-and-click paths to detailed maps and markers for all 23 pairs of human chromosomes. Type a gene name into LocusLink, and up pops a list of that gene's aliases, its location on the genome, ID numbers and links to its sequence in GenBank; or link to Medline abstracts and other resources. Ideal for the genetic counselor interested in research! ❖

TeleGenetics

☞ www.usuhs.mil/genetics/

This site provides current, basic and advanced information to a wide range of web watchers.

The site includes a dysmorphology link that outlines the morphological developmental abnormalities as seen in many syndromes of genetic or environmental origin.

Other interesting aspects include case studies for medical students, ethical cases and six different downloadable slide presentations covering inheritance patterns, congenital malformations, cancer syndromes and risk assessment.

The patient information section is very clear and emphasizes folic acid supplementation. In addition, there is a detailed genetics bibliography and educational resource section with many hotlinks. Valuable site and one worth watching as it expands! ❖

LISTSERV SURVEY REVEALS SENTIMENTS, RECOMMENDATIONS

Steven Keiles, MS

Of 1679 surveys mailed, 184 were returned, which may be low due to the incorrect fax number on the survey form. The vast majority of people responding were very satisfied with all types of listserv postings. A small percentage did not find them useful or were annoyed by them. The average ranking for usefulness was over 4 out of 5.

KUDOS

- Enhanced communication, including notices of bereavement.
- Special features, such as digest and archive searches.

COMPLAINTS

- Commercial message postings.
- Personal message postings.
- Original messages repeated on the bottom of messages.
- Using listserv as directory, particularly when asking for counselors in a particular city.

RECOMMENDATIONS

- All listserv etiquette should be addressed by the administration and not by individual members.
- All responses should go back to the original poster who can then, in turn, summarize the responses and post the summary back to the entire group.
- "Thank you" messages need to be sent directly to the individual.
- A list of instructions on the main features of the listserv should be sent out in a mailing to the entire membership.
- Use more accurate subject lines when sending a message.
- Define abbreviations. ❖

LISTSERVINGS

Whitney Neufeld-Kaiser, MS

- PEER SUPPORT FOR 48,XXXX
  ☞Lois E. Lander, MS, Alliance of Genetic Support Groups; ✆202-966-5557 x211; llander@geneticalliance.org
- PEER SUPPORT FOR 47,XXX
  ☞ Melissa Aylstock, Executive Director, Klinefelter Syndrome & Associates; ✆916-773-1449; ks4zxxy@ix.netcom.com
- AMNIOCENTESIS/CVS VIDEOS
  ☞ Milner-Fenwick, ✆800-432-8433
- RESOURCE FOR PICTURES, DIAGRAMS & TABLES (*downloadable for slides)*
  ☞ This website also has an outline for a genetics course in medical school and has study questions. www.ucl.ac.uk/~ucbhjow/bmsi/bmsi-lectures.html.
- COMPUTER GENETIC COUNSELING
  ☞W. S. Rubinstein and G. McGee, "Computer-Based Genetic Counseling" (1999) *JAMA* 282 (18):1693-1790. //jama.ama-assn.org /issues/v282n18/full/jlt1110-2.html
- RESEARCH STUDIES ON PROSTATE CANCER
  ☞ Albert Einstein College of Medicine, Robert Burk's lab //leper1.ca.aecom.yu.edu/prostate/form Contact Bob Gern, gern@aecom.yu.edu, or Rochelle Vininsky, vininsky@aecom.yu.edu; ✆718-430-3739
  ☞ Hutchinson Cancer Center, Seattle, ✆800-777-3035
  ☞ Johns Hopkins, ✆410-614-4196
  ☞ Univ Michigan, Kathleen Cooney, MD or Kristen Brierley, ✆734-936-2031 or 800-723-9170.
- DOWN SYNDROME RESOURCES IN SPANISH:
  "Babies with Down Syndrome," Woodbine House
  ☞ www.woodbinehouse.com
  ☞ The PROUD website links to the "Health Care Guidelines for People with Down Syndrome," www.flash.net/~proud1/
- TOOLS FOR TEACHING OBSTETRICS FELLOWS
  1) J.L. Simpson and M. Golbus, *Genetics in Obstetrics and Gynecology* 2nd ed. (1992) W.B. Saunders

  2) S. Gabbe, J. Niebyl and J.L. Simpson, *Obstetrics: Normal and problem pregnancies* Churchill Livingstone

  3) Sample questions from past CREOGs (Council for Resident Education in Obstetrics and Gynecology)

  4) Questions based on ACOG forms (initial intake/genetic screening forms)

  5) Kershner et al, "Knowledge of Genetics Among Residents in Obstetrics and Gynecology" (1993) *AJHG* 53:1356-1358. One can also call to get a copy of their exam.

  6) "Clinical Objectives in Medical Genetics for Undergraduate Medical Students" (1998) *Genetics in Medicine* 1(1):54-55. This article lists objectives which would be a good jumping off point. ❖

Media Watch

Roxanne Ruzicka, MS, and Angela Geist, MS

“ Examining the Roots of Your Family Tree . *LA Times,* Aug 16, 1999

The writer discusses how her mother’s diagnosis of breast cancer encouraged her to delve into her family history and discover much about her own risks. She created a family tree and asked her mother for health information on family members, which encouraged her mother to divulge her own diagnosis of Marfan syndrome. She mentions that if interviewing family members does not provide complete information on family history, examining photographs and medical documents can also be helpful. the writer correctly mentions that the earlier the onset of serious disorders, the more likely they are to have a genetic basis. However, she also states that because no two of her family members had the same kind of cancer, the chance of a genetic link to the cancers is low, which may not be true. She suggested a referral to a genetic counselor for people with a family history of concerning health conditions and also provided contact information for the NSGC!

“ Will We Still Need to Have Sex? *Time,* Nov 8, 1999

This article proposes that in the future, a large proportion of human pregnancies may be conceived using in vitro fertilization or cloning and that sex for the purpose of procreation may become obsolete. It states that “many people born from in vitro techniques are themselves infertile; they inherit the infertility from their genetic parents.” Although the article suggests there will be an urge to “tinker with the genes of offspring,” it also concedes that human cloning and designer babies are “probably not imminent.”

“ *Bosom Buddies*. Rosie O’Donnell and Deborah Axelrod, MD, FACS

This recently published book tries to demystify breasts and breast cancer by answering commonly asked questions in a straightforward, although quite medical, manner. From the excerpt on the “Today Show” website, the book appears to be on a high reading level.

“ 20/20.

A family was featured in which a brown-eyed child was born to blue-eyed parents. An “expert” stated that this is not possible and there must be false paternity.

“ Sally Jesse Raphael. Nov 99

The show concerned DNA testing on a couple who had married and later discovered they are half-siblings. Sally and the paternity expert both encouraged the couple to see a genetic counselor because “they are the experts” and could discuss the implications of reproduction for this couple.

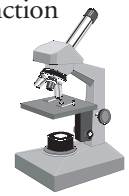
“ Providence (11/99)

A young man told his doctor that he had just received DNA testing results which were positive for Huntington disease. The family history fit autosomal dominant inheritance …father and grandfather were reported to be affected. The doctor later became suspicious and just added Huntington disease DNA testing onto the other bloodwork that she was ordering —without counseling or informed consent! To top that, the results were available the next day! ❖ ”

Research Network

Anophthalmia/Microphthalmia (A/M) Research

Albert Einstein’s Anophthalmia/Microphthalmia(A/M) Registry (Philadelphia) is collecting data on individuals with unilateral or bilateral A/M. In conjunction with the registry, we are coordinating a DNA research project collaborating with three different laboratories looking at 10 different genes involved in eye development.



Buccal cell and/or blood collection are involved in this project, which is being coordinated in the Genetics Division at AEMC.

☞ Mary Dwyer, MS;
✆215-456-8722;
schneida@aehn2.einstein.edu.

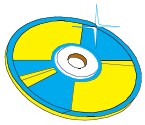
VCF Study

Investigators at The Rockefeller University in New York are conducting a research project that examines the performance of children with VCF on several measurements associated with increased risk for emotional and behavioral problems. Studies have shown that many children with VCF are at risk to develop emotional and behavioral problems. Initially participants would need to travel to New York. The study then requires yearly follow-up. There is no cost to participate, and all information is kept strictly confidential.

☞ Maude Blundell, MS, Genetic Counselor and Study Coordinator;
✆212-327-8335, or
888-920-9100, press 1;
blundem@rockvax.rockefeller.edu. ❖

RESOURCES • RESOURCES • RESOURCES

Counseling by Computer: Breast Cancer Risk and Genetic Testing
Publisher: University of Wisconsin-Madison, 1998, CD-ROM
Reviewer: Bonnie Baty, MS
Excerpt from a previously printed review in AJMG(1999) 86:93-4. Reprinted with permission.



The University of Wisconsin-Madison has developed an educational CD-ROM that walks a patient through a thorough explanation of breast cancer, breast cancer susceptibility genes and genetic testing. There are variable sections for individuals with little or no computer experience, outstanding computer graphics, a glossary, review questions and branches to explore topics in greater detail. The pacing is excellent and the level of detail appropriate. The scientific information is accurate, well presented and likely to remain current for some time. Most of the topics generally covered in cancer gene susceptibility education are included.

In general, the CD is an outstanding educational tool. However, I had some concerns about its proposed use. In a cover letter accompanying the CD, it was stated that the computer program can be used by primary care practitioners, since genetic counselors and geneticists are not widely available to patients. A press release stated that the CD could replace the information from a health professional. These statements are of concern for several reasons. First, risk assessment is mostly ignored. Second, the CD does not provide the general practitioner with answers to patient questions. The idea that patients would be offered testing without any health professional involvement is clearly inappropriate. Third, the complex and often emotion-laden decision-making in the context of a personal and/or family history of cancer(s) makes the availability of counseling an important part of the process.

In summary, this interactive computer program is an excellent educational tool best used by practitioners who have in-depth training in cancer genetics. In the current practice climate of testing high-risk individuals, it is not appropriate for use by practitioners who do not have such training. ❖

Sturge-Weber Syndrome

Editors: John B. Bodensteiner, MD and E.S. Roach, MD
Publisher: Sturge-Weber Foundation, PO Box 418, Mt. Freedom NJ 07970-0418. www.sturge-weber.com $49.95
ISBN: 0-9670484-0-0
Reviewer: Nancy S. Cangany, MS

The last book to be dedicated to the diagnosis and treatment of Sturge-Weber syndrome (SWS) was published in 1960. This new offering seeks to encompass the technological advances made in medical imaging and medical, surgical, dermatological and pharmacological treatment of this condition.

The book is divided into chapters addressing various aspects of the condition: Port-wine stains, ophthalmological, neurological, neurosurgical, imaging and psychosocial issues. The forward, authored by Richard Alan Lewis, MD, MS, ophthalmologist and Chairman of the Sturge-Weber Foundation Advisory Board, provides some historical background for this condition and the physicians whose names it bears. The introduction and overview are thorough and succinct and raise a number of questions in hopes of inspiring ongoing research into the pathology and treatment of SWS. I would recommend this section to anyone needing a synopsis of SWS.

Each of the chapters is contributed by experts in the field and is well annotated. There is some redundancy in the chapters on neurologic manifestations and neurosurgical aspects, but this allows each chapter to be read independently. There are a number of color plates depicting the dermatologic and ophthalmologic manifestations of the condition. Illustrations and photographs of various imaging technologies are used liberally and effectively throughout. The section on psychosocial issues is nicely done and spans from neonatal to adult concerns. These issues include not only those of the obvious physical appearance but also the disability, dependence and restrictions that may accompany living with seizures.

As a genetic counselor, I feel one of the best aspects of the book is the appendix of resources, which lists over nine pages of organizations, web sites, support groups and examples of other areas of assistance. Finally, there is an informative section on the Sturge-Weber Foundation. ❖

In the News!

NSGC Gives Input to Genetics Legislation

Wendy Uhlmann, MS

Sen. Edward Kennedy introduced a bill to establish "The Genetics and Public Health Services Act" on November 19. The NSGC Board wrote a letter of support, which was printed in the Congressional Record.

The bill creates a new federal-state matching block grant program to "develop systems to promote access to quality genetic services" and "develop strategies for using emerging genetic information and technology to improve the public health." Access the bill summary, Senator Kennedy's introductory statement and letters of support to the Nov. 19th Congressional Record, p. 15096 at //thomas.loc.gov/home/thomas2.html. The full bill text can be accessed by searching for bill number S. 1981 in the 106th Congress.

NSGC has been asked to:

- Provide feedback, including any suggestions for improvements.
- Provide a concise definition of "genetic services."
- Compile educational resources and data about availability of and need for local and state genetic services.
- Locate patients as spokespersons.

Congresswoman Louise Slaughter will likely be introducing this proposal into the House of Representatives towards the end of January.

☞ Contact: Anne Spencer, Chair Social Issues Committee, spencera@slrmc.org by January 10. ❖

Bulletin Board

New Rep for Region II

Karen Eanet, Genetic Counselor at the Harvey Institute of Human Genetics, Greater Baltimore Medical Center, has been appointed by President Wendy Uhlmann to complete the Region II Representative post being vacated by Karen Johnson. Karen will be relocating to the University of Michigan, Ann Arbor, in Region IV. The term will begin January and continue through the next election term, November 2. ❖

Call for Mentors

We now have the opportunity to educate and encourage Native Americans to consider genetic counseling as a career. Genetic Education for Native Americans (GENA) provides mentors in the genetics field for Native American undergraduates within a program of Native American Cancer Initiatives. NSGC is working with GENA to offer the expertise of our members as mentors. Genetics education modules are currently under construction by GENA to educate students about genetics issues. Later, students will be assigned placements with mentors, primarily in research settings. Monetary support may be available.

☞ Kristin Niendorf, Membership Chair, kniendorf@yahoo.com ❖

Funding for Qualitative Research

ELSI study sections are supportive of qualitative research. Purely quantitative studies are often criticized for lacking a qualitative component. In addition, genetic counseling is a respected, and often expected, component of these studies. Interested in qualitative research? Consider pursuing grants through the ELSI program.
☞ www.ornl.gov/hgmis/resource/elsi.html ❖

Meeting Manager

February 26	*Are Your Patients at Risk? Genetic Technologies and Risk Management in the New Millennium,* City of Hope, Duarte CA ☞ www.cityofhope.org/ccgp
March 9 - 12	*Clinical Genetics Meeting 2000,* ACMG, Palm Springs CA ☞ ✆301-571-1887; acmg@faseb.org
March 20 - 25	*Formatting our Future — Our Responsibility, The Potential,* American Counseling Association Annual Conference, Washington DC ☞ www.counseling.org
March 23 - 26	*PREVENTION 2000,* 17th Annual National Preventive Medicine Mtg, Atlanta GA ☞ www.prevention-meeting.org
Mar 30 - Apr 2	*The Many Faces of Genetics,* NSGC Region VI, Asilomar Conference Center, Pacific Grove CA ☞ Steve Keiles, steven.b.keiles@kp.org; Sue Demsey, sue.a.demsey@kp.org
April 14	*Genetics in the 21st Century*, NSGC Region II, Maritime Institute of Technology, Linthicum MD ☞ Karen Eanet, keanet@gbmc.org

Committee and SIG Updates

Ethics Consults

Bev Yashar, MS, PhD

The Ethics Subcommittee, a confidential resource for all NSGC members, helps members make informed decisions by interpreting our Code of Ethics and providing additional information on related issues. Appropriate topics include relationships between counselors and their clients, colleagues, society and themselves. The process may be initiated by mail, phone, fax or email to any subcommittee member.

The 1999/2000 Subcommittee includes: Stephanie Kieffer, Chair, Kevin FitzGerald, Logan Karns, Karen Lewis, Dorene Markel, Dan Riconda, Kathy Valverde and Beverly Yashar. ❖

SIG Chairs — Year 2000

NSGC's Special Interest Groups were formed to create a group of members within NSGC who share common professional interests. Members may enlist in any SIG at any time by sending $20 to NSGC. To learn more about SIG activities, contact any of the following chair/co-chairs. The Board liaison to SIGs is Maureen Smith, maureens@21stcentury.net.

ART/Infertility	Noelle Agan^ . . . . . .nagan@bcm.tmc.edu
	Kristyne Stone^ . . . . . .KMStone@jhmi.edu
Clinical Supervisors	Liz Stierman . . . . . .LStierman@aol.com
	Sue Demsey^ . . . . . .sue.a.demsey@kp.org
Connective Tissue	Michelle Moore^ . . . . . .mmoore@pop.jhmi.edu
Diversity	Nisha Isaacs^ . . . . . .nisaac@geneticalliance.org
DNA Diagnostic Labs	Cathi Franklin . . . . .Cathi.R.Franklin@questdiagnostics.com
	Trisha Brown^ . . . . . .brownt@labcorp.com
Familial Cancer	Shelly Cummings . .scumming@medicine.bsd.uchicago.edu
	Jill Brensinger^ . . . . . .brensji@jhmi.edu
GC Training Program Directors	Diane Baker^ . . . . . .bakerdl@umich.edu
Legal	Carrie Croxall^ . . . . . .Fax: 310-541-7485
	Joan Kegerize^ . . . . . .jokegeri@earthlink.net
Neurogenetics	Karen Krajewski . . . . . .ac5339@wayne.edu
	Anne Yesley^ . . . . . .ayesley@athenadiagnostics.com
Pediatrics	Julie Rutberg . . . . . .jrutberg@welch.jhu.edu
Prenatal	Melissa Kershner . . . . . .kershnm@slhn.org
	Renee Laux . . . . . .lauxra@mfm.evms.edu
Private Practice	Susan Donlon . . . . . .donlon@lava.net
Psychiatric Disorders	Beth Rosen . . . . . .BRosen@shriver.org
Psychotherapy & Expanded Skills	Vivian Ota Wang . . . . . .otawang@asu.edu
Public Health	Sylvia Au . . . . . .sau@hgea.org
Research	Robin Grubs^ . . . . . .RGrubs@helix.hgen.pitt.edu
	Emily Hanson^ . . . . . .hansone@ohsu.edu
— and new in 2000!	
Support Groups	Lois Lander^ . . . . . .llander@geneticalliance.org
	Gail Anderson Stapleton^ . . . . . .Ggcgville@aol.com

^ Indicates new leadership

New SIG Starts in '00

Gail Anderson Stapleton and Lois Lander have initiated a Special Interest Group (SIG) with a focus on Support Groups.

The application to initiate the SIG includes the following explanation of the group's intent.

How does the purpose of the group meet NSGC's mission?

"By providing important education and information for people interested in genetic conditions; providing guidance to support groups, themselves, allowing [NSGC members] to become more involved and more visible to patients and their families."

Other members signing the application form are: Kelly Connerton-Moyer, Jennifer Keenan, Kate Dietrich, Donna Russo, Karen Powers, Sylvie Parkin, Allyson Norris Meyer and Alexis Poss. ❖

AEC Subcommittee Call for Proposals

Short courses offer intensive study in specific areas of genetics. Put that great idea to work! Applications for short courses given in 2001 are being accepted through March 31.

☞ Cindy Soliday, Chair, Annual Education Conference Subcommittee, ✆408-972-3332; Cindy.E.Soliday@kp.org. ❖

EMPLOYMENT OPPORTUNITIES

LITTLE ROCK AR: Immediate opening for BC/BE Genetic Counselor. Join expanding statewide PN genetics svc: individual GC for wide variety of indications; case mgmt & follow-up; involvement w/ Terat Info Svc, telemedicine clin, triple screen program, medical student & community educ, Fetal Boards conf, rsrch.
☞ Barbara Karczeski, MS, Univ Arkansas for Medical Sciences, 4301 W. Markham-Slot 506, Little Rock AR 72205; ✆501-296-1700 or 800-358-7229; karczeskibarbaraa@exchange.uams.edu. EOE/AA

BERKELEY CA: Immediate opening for BC/BE, FT (PT negotiable) Genetic Counselor. Excellent org, ntwkg, commun & computer skills req. Manage public health genetics network to promote genetic svcs in tri-state region. Oppty to travel. Flex schedule. Competitive salary, excellent benefits.
☞ Pamela Cohen, MS, Pacific Regional Genetics Network, 2151 Berkeley Way- Annex 4, Berkeley CA 94704; ✆510-540-2852; Fax 510-540-3293; pcohen@dhs.ca.gov. EOE/AA

OAKLAND CA: Immediate opening for PT Genetic Counselor/Hemoglobinopathy Screening Coordinator. Req: 1 yr clin genetic exp w/ all facets of GC & PNDx, demonstrated hx of excellent svc skills exhibited by courtesy, cooperative spirit, tact when interacting w/ employees, members & visitors. Strongly pref: admin &/or prog planning exp, analytical &/or computer exp & organizational skills. .5 FTE: Reg'l Hemoglobinopathy Screening Prog Coordinator for Northern CA Kaiser Region, acting as Prog Admin, Case Mngr & Consultant to med staff & educ svcs. .3FTE: counsel pts in genetics, w/ primary focus on peds & adult pts.
☞ Ellen Bloch, Kaiser Permanente Medical Ctr, 280 West MacArthur Blvd, Oakland CA 94611; ✆510-596-6298; Fax 510-596-6754. EOE/AA

OAKLAND CA: Immediate opening for BC/BE, FT Genetic Counselor. Spanish pref. Join 4 GCs & 2 Med Geneticists at Children's Hosp svg diverse pt population: PN & ped GC, in-hosp consults, multi-disc subspecialty clins.
☞ Cheri Loustalet, MS or Liane Abrams, MS, Children's Hospital-Oakland, 747 52nd St, Medical Genetic Dept, Oakland CA 94609; ✆510-428-3550; Fax 510-450-5874. EOE/AA

ORANGE (SO. CALIF) CA: Immediate opening for BC/BE Genetic Counselor. Computer skills pref. Possible setting incl locations in Orange Co, S. CA (10 mins from Disneyland). Join comprehensive PNDx Ctr: amnio, CVS, AFP & terat + variety of genetic subspecialty clins & molecular genetics.
☞ Khalil N. Zadeh, PhD, Genetics Center 1201 W. La Veta Ave Ste 402, Orange CA 92868; ✆714-288-8520; ✆714-288-8525; nzadeh@aol.com; www.geneticscenter.com. EOE/AA

SAN JOSE CA: Immediate opening for BC Genetic Counselor/Reg'l Cancer Genetics Prog Coordinator. Exp in cancer genetics strongly pref. Primary respon: ongoing educ & liaison w/ non-genetics providers at 26 hospitals & clins; add'l respon: continued prog devel & expansion, clin resource for 55 reg'l genetics providers; partic in BRCA Task Force & other reg'l & interreg'l cancer genetics & rsrch projects, maintain stats for cancer GC & testing, some direct GC.
☞ JoAnn Bergoffen, MD, Chief of Genetics, Kaiser Permanente, 260 International Circle, San Jose CA 95119; ✆408-972-3300; Fax 408-972-3298. EOE/AA

MODESTO CA: Immediate opening for BC/BE, PT (24-30 hrs wk) Genetic Counselor. Bilingual (Span) pref. Abil to work independently & as a member of our Western reg'l team of 12+ GCs, 1 hr from Bay Area in private hosp setting.
☞ 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

SAN MATEO CA: Immediate opening for Genetic Counselor at start-up company focused on providing educ info & svcs re: genetics on the internet. Seeking creative, dynamic individual w/ min. 5 yrs clin exp, excellent writing & health commun skills. Competitive compensation & benefits; oppty to play signif role in bldg exciting new business.
☞ Human Resources, GENETIC HEALTH, 1720 S Amphlett Blvd Ste 130, San Mateo CA 94402; ✆650-655-7255; Fax: 650-655-7299; hr@genetichealth.com. EOE/AA

NEW HAVEN CT: Summer '00 opening for 3-month pd summer Cancer Genetic Counseling Internship at Yale Cancer Center. Available to candidates who have completed at least 1 yr grad work in GC from ABGC-accredited prog. Internship divided between clin cancer genetics & rsrch proj sponsored by member of Cancer Genetics Prog.
☞ Deadline for apps: 2/15/00. Send resumé, 2 ltrs rec & a 300-400 word personal stmt describing interest to: Ellen T. Matloff, MS, Director, Cancer Genetic Counseling, Yale Cancer Center, Box 208028, New Haven CT 06520-8028; ellen.matloff@yale.edu. EOE/AA

DELAWARE: Immediate opening for BC/BE Genetic Counselor. Interest in PNDx, knowl of genetics, impact on MFM.
☞ Send resumes: Attn: Dept. PROFJT, Christiana Care, PO Box 3238, Scranton PA 18505-0238; Fax 888-908-8585; christianacare@alexus.com. EOE/M/F/D/V

DOVER DE: Immediate opening for Genetic Counselor, Delaware Health and Social Services, Div Public Health. 25% Preconception & PN GC. Also, manage Birth Defects Prog, incl prof & commun educ, outrch and implement Regulations. Work w/ Newborn Scrng Prog & consult for abnorm dx. Salary: $36,542 - 45,677.
☞ Request Recruitment Doc #DO-H13C & application: ✆302-577-4690. Add'l info: JoAnn Baker, MSN, FNP, Director, Women's & Reproductive Health, ✆302-739-3111l jobaker@state.de.us. EOE/AA

ATLANTA GA: Immediate opening for FT, BC/BE Genetic Counselor. Enthusiastic, dedicated, team-oriented individual w/ exp in OB or peds pref. Travel; excellent verbal & written skills req. Must be computer-friendly.
☞ Send cover ltr & resume: Mitzi Janas, GeneCare, PO Box 4270, Chapel Hill NC 27515-4270; mjanas@genecare.com. EOE/AA

GARY IN: Immediate opening for PT BC/BE Genetic Counselor. All aspects of PN & genr'l GC: outreach clins; educ; newsletter & advisory board partic; tchg med students.
☞ Janice Zunich, MD, Indiana University School of Medicine, NW Ctr for Medical Education, 3400 Broadway, Gary IN 46408; ✆219-980-6560. EOE/AA

BALTIMORE MD: Immediate opening for BC/BE Genetic Counselor. Excellent org & commun skills req. Join Johns Hopkins Cancer Risk Assessment Program & Mid-Atlantic Cancer Genetics Network: All aspects of GC/case mgmt for family hx of cancer, collab & independent clin rsrch, tchg & student supervision.
☞ Send CV to Jill Brensinger, MS, The Johns Hopkins Hospital, 550 N. Broadway Suite 108, Baltimore MD 21205; ✆410-614-4038; Fax 410-614-9544; brensji@jhmi.edu. EOE/AA

BOSTON MA: Immediate opening for Data Coordinator/Genetic Counselor. MS in GC req. Primary respon: enroll study subjects into the FASTER (First and Second Trimester Evaluation of Risk for Aneuploidy) clin trial, admin aspects of trial, incl ensuring pts return for follow-up tstg, ensuring completion of all req data entry forms, meeting w/ pts to discuss meaning of a positive screen & obtaining complete follow-up on fetal karyotype & pregnancy outcome.
☞ Resumé by fax to: Dr. Diana Bianchi, c/o Fax 617-636-1489. Dr. Diana Bianchi, Maternal Fetal Medicine Div of OB/GYN, New England Medical Center, 750 Washington St, Boston MA 02111. EOE/AA

BOSTON MA: Winter 99-00 opening for FT Project Coordinator/Genetic Counselor. MS or PhD trained candidates w/ clin &/or rsrch exp strongly pref. Manage overall rsrch & design; provide GC for new multi-ctr, NIH-funded project "Genetic Risk Assessment & Counseling for Alzheimer's Disease" using susceptibility genotyping w/ APOE. Funded through '02.
☞ Robert C. Green, MD, Boston Univ School of Medicine, 715 Albany St L-320, Genetics Program & Alzheimer's Disease Ctr, Boston MA 02118; ✆617-638-5362; Fax 617-638-4275; rcgreen@bu.edu. EOE/AA

COLUMBIA MO: Immediate opening for 1-2 FT BC/BE Genetic Counselor(s). Join busy, full svc in academic setting w/ 4 GCs & 3 MD geneticists. Coord metab clin, 1 outrch clin/mo, attend genrl genetics clins, in-house consult rotation. 2nd position: coord Missouri Teratogen Info Svc, a moderate-sized TIS w/ an active rsrch prog: GC, clin rsrch, PR & admin duties. Opptys for prof growth, rsrch & prog devel in a vigorous, friendly prog located in a diverse college town.
☞ Judith Miles, MD, PhD, Div Medical Genetics, Dept Child Health, Univ Missouri Hospitals & Clinics, Columbia MO 65212; ✆573-882-6991; milesjh@missouri.edu. EOE/AA

See next page

EMPLOYMENT OPPORTUNITIES

KANSAS CITY MO: Immediate opening for BC/BE Genetic Counselor w/ 1/2 peds & 1/2 PN respon. Join 2 GCs in tertiary care peds facility: genrl peds genetics, hemophilia, CL/P, hemoglob, NTD, 2 reg'l outreach clins & off-site PND clins. Prof & commun edu.
☞ Michael Begleiter, MS, The Children's Mercy Hospitals & Clinics, 2401 Gillham Rd, Sec Medical Genetics & Molecular Medicine, Kansas City MO 64108; ✆816-234-3290; Fax 816-346-1378; EOE/AA

HANOVER NH/EASTERN VT: Immediate opening for BC/BE Cancer Genetic Counselor. FT/PT negotiable. Join Norris Cotton Cancer Ctr, Dartmouth-Hitchcock Med Ctr, an NCI-designated cancer ctr serving New Hampshire & eastern VT. Collab w/ multi-disc team: rsrch & GC for adults re: cancer predisposition.
☞ Bradley Arrick, MD, PhD, Director, Familial Cancer Program, Dartmouth Medical School, Kellogg Box 0128, Hanover NH 03755; Bradley.Arrick@dartmouth.edu. EOE/AA

ESPANOLA NM: Immediate opening for FT BC/BE Genetic Counselor. Bilingual (English/Spanish) pref. Exp pref but not req. Self-motiv, abil to work independently, good commun & org skills req. All aspects of PNDx incl 3-D U/S.
☞ Send CV: Robin E. McBride, MS Genetic Centers of America, 11125 Rockville Pike Ste 302, Rockville MD 20852; ✆301-770-5300; Fax 301-770-2005; geneticcon@aol.com. EOE/AA

NEW BRUNSWICK NJ: Immediate opening for FT BC/BE PN General Genetic Counselor. Masters, Span pref. Work w/ group of 2 MD geneticists; 4 GCs, (3 PN, 1 ped); 2 nurses (1 ped, 1 OB) & metab nutritionist at private hosp w/ med school affil & high volume PN pts. GC for terat, AMA, U/S abnorm, fam hx, preconception. Satellite clins w/ MFM attendings weekly. S'vise students/residents. Tchg & rsrch opptys, spec clins avail.
☞ Send CV w/ 3 ltrs of rec: Donna Chavez, MS or Rosemarie Peschek, Div Genetics, St. Peter's University Hospital, 254 Easton Ave, New Brunswick NJ 08903; ✆732-745-6659; Fax 732-249-2687. EOE/AA

LIVINGSTON NJ: Immediate opening for FT BC/BE Genetic Counselor. Unique oppty to provide GC for pts partic in repro endocrin & infertility prog, incl in vitro fertilization & pre-implant dx.
☞ Santiago Munne, PhD, The Institute for Reproductive Medicine & Science of Saint Barnabas, 101 Old Short Hills Rd Ste 501, West Orange NJ 07052; ✆973-322-6247; Fax 973-243-6235; santi.munne@embyros.net. EOE/AA

BRONX NY: Immediate opening for BC/BE Genetic Counselor w/ fluency in Spanish pref. Ability to work w/ team req. Diverse GC oppty in genrl genetic svcs: PN, peds & adult clins. Unique oppty to provide GC for a culturally diverse population. Salary negotiable w/ exp.
☞ Hody L. Tannenbaum, MS, Pediatrics-Genetics, Lincoln Hospital, 234 E. 149th St Ste 4-20, Bronx NY 10451; ✆718-579-5295; Fax 718-579-4640. EOE/AA

MANHASSET NY: Immediate opening for BE/BE Cancer Genetic Counselor. Exp pref; computer skills req. Comprehensive cancer consult; commun & prof educ. Work independently; w/ medical geneticists supervision.
☞ Gittel Silverberg, MS, North Shore Health System, 300 Community Dr, Manhasset NY 11030; ✆516-365-3996; Fax 516-365-4597. EOE/AA

NEW YORK NY: Immediate opening for FT, BC/BE Genetic Counselor. High motiv, computer & excellent commun skills req.
Work w/ Chair, Dept Human Genetics, on rsrch proj involving gene discovery & treatment of genetic diseases. Tchg in ABGC-training prog.
☞ Fax CV & ltr of interest outlining strengths c/o R.J. Desnick, PhD, MD, Mt Sinai School of Medicine, Dept Human Genetics, One Gustave L. Levy Pl-Box 1498, New York NY 10029-6574; ✆212-659-6700; Fax 212-360-1809. EOE/AA

NEW YORK NY: Immediate opening for FT Genetic Counselor. Prof growth opptys through interaction w/ Residency & Human Genetics Programs at NYU School Med. Diverse population incl Southeast Asian & Financial District communities. Join Dept OB/GYN, w/ active MFM practice & busy PNDx unit: all aspects of PNDx; thalassemia scrng & monthly peds genetcs clin & outreach progs.
☞ Dr. Iffath Abbasi Hoskins, Residency Prog Director & Chief, Human Genetics Program, NYU Downtown Hospital, 170 William St, New York NY 10038; ✆212-312-5880; Fax 212-312-5878. EOE/AA

NEW YORK NY: Immediate opening for 2 BC/BE Genetic Counselors. Exp pref. PN GC/case mngmt; some peds. Diverse pt population. Great opty for committed individuals who desire teamwork & independence.
☞ Kwame Anyane Yeboa, MD, Director, Div Genetics, Roosevelt Hospital, 1000 10th Ave #11A, New York NY 10019; ✆212-523-3112 or ✆212-523-3454. EOE/AA

STATEN ISLAND NY: Immediate opening for FT, BC/BE Genetic Counselor. All aspects PN/Peds; Cyto, molec & biochem labs. Spec clins, supt groups, rsrch.
☞ Attn: Personnel (Ref.#874), NYS Inst for Basic Research In Developmental Disabilities, Comprehensive Genetic Disease Program, 1050 Forest Hill Rd, Staten Island NY 10314; ✆718-494-5240; Fax 718-494-1072; ssbsi@webspan.net. EOE/AA

WEST ISLIP NY: Immediate opening for BC/BE PN Genetic Counselor. Excellent commun, org & follow-thru skills req. Abil to work independently; Span a plus. Join Perinatologist in busy expndg MFM hosp.
☞ Send CV: Dr. Mastrogiannis Attn: Kristi Page, MS, Maternal Fetal Medicine, 1111 Montauk Hwy, Ste 2-4, West Islip NY 11795; ✆516-376-4242; Fax 516-376-4245. EOE/AA

RALEIGH NC: Immediate opening for BC/BE Genetic Counselor w/ strong admin skills.Coord CDC-funded "Enhanced Birth Defects Surveillance & Intervention Project." Close collab w/ UNC Birth Defects Ctr, Office for Health Statistics, March of Dimes & all NC Med Genetics Ctrs. Goal: to identify newborns w/ NTD & link families w/ GC & early intervention svcs. Educate women about folic acid.
☞ Elizabeth G. Moore, Director, Div Public Health, Children & Youth Branch, 1916 Mail Service Ctr, Raleigh NC 27694-1916; ✆919-715-3420; Fax 919-715-9633. EOE/AA

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national society
of genetic
counselors, inc.

nsgc 233 Canterbury Drive
Wallingford PA 19086-6617

➢ Re-Member NSGC!
Membership Dues '00 Deadline
Friday, January 7

Employment Opportunities, from p. 15

Akron/Mansfield OH: Immediate opening for BC/BE Genetic Counselor. Exp pref; but new grads encouraged. Abil to work independently, strong org skills req. Join staff of 2 medical geneticists & 4 GCs at home-basd Akron office; coord satellite genetics svcs in Mansfield OH. Provide general & PN GC svcs, prof & public educ. Oppty for prog devel & rsrch. Competitive salary & benefits.
☞ John R. Waterson, MD, PhD, Children's Hospital Medical Center of Akron, Genetic Center, One Perkins Sq, Akron OH 44308; ✆330-543-8792; Fax 330-543-3677; jwaterson@CHMCA.org. EOE/AA

Oklahoma City OK: Immediate opening for BC/BE Genetic Counselor. Join growing clin prog, directed by Dr John J. Mulivhill. See a wide variety of pts from all areas of GC: peds, metabolic disorders, adult, cancer & presymptomatic testing for adult-onset disorders. Excellent oppty for rsrch & tchg.
☞ Send ltr of interest, CV & 2 prof ref c/o Susan Hassed MS, Asst Prof Pediatrics, Children's Hospital of Oklahoma, Rm 2B 2418, 940 NE 13th St, Oklahoma City OK 73104; ✆405-271-8685; Fax 405-271-8697; susan-hassed@ouhsc.edu. EOE/AA

Portland OR: Immediate opening for BC/BE Genetic Counselor. Exp working w/ team & trng in cancer genetics/oncology pref. Must be creative, flexible & have good org/commun skills & desire to work on interdisc team. Prim respons: cancer GC & tstg w/ 2-pronged approach to prevention & detection; prog devel, mrktg, pt educ, assist w/ cancer risk assessmt & commun cancer prevention detection progs. Signif role in growth & development of Cancer Genetics prog.
☞ Legacy Employment Services, 1120 NW 20th Ste 111, Portland OR 97209; ✆503-415-5660; Fax 503-415-5200; To apply online: www.legacyhealth.org. EOE/AA

Philadelphia PA: Immediate opening for BC/BE Genetic Counselor. Exp in cancer pref but not req. Good writing skills, public spkg ability, interpersonal skills & ability to work independently pref. Oppty to work in cancer risk assessment progs for breast, ovarian, GI & prostate cancers as part of a multidisc team providing genetic risk assessment, educ & GC. Strong emphasis on rsrch.
☞ Josephine Costalas, MS, c/o Human Resources, Fox Chase Cancer Center, 7701 Burholme Ave, Philadelphia PA 19111; ✆800-325-4145; Fax 215-728-4061; J_Costalas@fccc.edu. EOE/AA

Philadelphia PA: Immediate opening for BC/BE Genetic Counselor. Exp in cancer genetics pref; high motiv, excellent org & public spkg skills, abil to work independently req. Join multidisc team in center city Phila: coord newly-estab, high-risk cancer eval prog to provide risk assmt, educ & GC; assist in rsrch, assist in devel mktg & educ materials. Oppty for prof & commun tchg; s'vision of GC & med students.
☞ Bruce M. Boman, MD, PhD, Thomas Jefferson University, 1025 Walnut Street Ste 1014, Philadelphia PA 19107; ✆215-955-4652; bruce.boman@mail.tju.edu. EOE/AA

Greenwood SC: Immediate opening for BC Genetic Counseling Associate. Min 2 yrs exp in clin genetics & GC, prior exp in program devel & prof genetic educ desirable. Position req: active demonstration of ongoing personal devel & prof growth; work independently & on team; highly developed i'personal & commun skills w/ all levels of faculty & staff. Prim respons: Coord educ activ & GC opptys.
☞ Roger Stevenson, MD, Director, Greenwood Genetic Center, One Gregor Mendel Circle, Greenwood SC 29646;✆864-941-8146; Fax 864-941-8114; res@ggc.org. EOE/AA

Houston & Dallas TX: Immediate opening for 2 FT BC/BE Genetic Counselors. TX Spanish pref - Houston site. Motiv, self-starters req. Join a team of GCs, medical geneticist & cytogeneticist in large priv lab. PN consults for diverse indications; serve as resource for referring MDs nationwide. Generous compensation pkg.
☞ Cathy Blanchard, Human Resources, Laboratories for Genetic Services, 7400 Fannin - #1200, Houston TX 77054; ✆713-798-9500 x114; Fax 713-798-9595; cblanchard@lgsgenetics.com. EOE/AA

Salt Lake City UT: Immediate opening for BC/BE Genetic Counselor w/ MS in GC from accredited prog. Salary range $34,120-$54,594, commens w/ bkgrnd & exp. Join medical genetics team to partic in genr'l genetics clin w/ opptys for growth & specialization.
☞ Apply w/ ltr, resumé & 3 prof names, addresses & phone #s to: Chair Search Committee, Human Resources (KP-3764), c/o Kenya Fail, University of Utah, 1901 East South Campus Dr, Rm 101, Salt Lake City UT 84112. For info on position contact: Bonnie Baty, MS, ✆801-581-6914; Fax 801-585-7252; bonnie.baty@hsc.utah.edu. EOE/AA

Salt Lake City UT: Immediate opening for BC/BE Genetic Counselor. Spanish helpful. Join busy perinatal team providing GC for U/S abnorm, amnio, CVS, PUBS, teratogens & PGD for IVF Ctr. Partic in FASTER providing GC for 3 yr trial comparing 1st trimester aneuploid screening to "Quad test." Work w/ local MS scrng prog.
☞ Send CV & 2 ltrs of rec: Christine E. Miller, MS, University of Utah, Dept OB/GYN, 50 North Medical Dr, Rm 2B200, Salt Lake City UT 84132; ✆801-581-7825; Fax 801-585-2478; Christine.E.Miller@hsc.utah.edu. EOE/AA

Salt Lake City UT: Immediate opening for Regional Genetic Counselor. Present educ seminars about Myriad's genetic tstg svcs; help estab new cancer risk progs by assessing needs, providing trng; provide educ/sales support for Reg'l Managers. Estab relationships w/ commun/advocacy groups; attend/present at educ/scientific meetings; consult w/ health care prof to eval pedigrees for genetic susceptibility to breast/ovarian cancer. Reg'l consultant re: genetic susceptibility to breast/ovarian cancer.
☞ Connie Minen, Administrative Assistant, Myriad Genetic Laboratories, 320 Wakara Way, Salt Lake City UT 84108; ✆801-584-1162; Fax 801-584-3515; cminen@myriad.com. EOE/AA