

PERSPECTIVES

in genetic counseling

Volume 22 Number 3

Fall 2000

**national society
of genetic
counselors, inc.**

nsgc

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

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Women's Health Care Services,
providers of late abortion care for fetal
anomalies, George R. Tiller, MD,
Medical Director. 800-882-0488

☞ Look for our booth in Savannah

NSGC ROLLS OUT MARKETING PLAN

Bea Leopold, MA

In the last issue of PGC, we announced the retention of marketing consultants to develop a marketing plan. The mission of the plan is to "go public," with a focus on improving attitudes, awareness and understanding of genetic counseling. This article will describe that plan.

Our marketing plan was created by the marketing team of Peter Benkendorf and Russ Klettke, with NSGC guidance by Andy Faucett and Barbara Lerner, GeneAMP co-chairs, and Debra Lochner Doyle, Liz Stierman, Vivian Weinblatt and Bea Leopold, NSGC Board Members. The plan has four arms:

- National Media - geared to leverage media interest and increase media coverage of genetic counselors/ing through the development of a professional press kit and "hot" lists of contacts.
- Ambassador Program - to leverage the presence of NSGC members in the media, particularly the local media.
- Consumer Education Project - to

stimulate consumer interest in genetic counseling/ors, to increase the understanding of who might benefit from genetic counseling services and to research the potential for corporate partnership(s).

- Web Strategies - to enhance genetic counseling information on healthcare-related websites and assist consumers in their search for a genetic counselor.

The plan fits within our budget, drawn from GeneAMP and Strategic Planning dollars.

Indeed, this is a lot to bite off, but Russ and Peter are confident that we/they can accomplish this by year's end.

What a year we've had! Stay tuned as this exciting plan unfolds. ♦

ABGC ASSUMES CEU ADMINISTRATION

Sharon Robinson, MS

As of July 1, administrative responsibilities for processing applications for Category 1 Continuing Education Units (CEUs) for genetic counselors has been transferred from NSGC to ABGC. CEUs will continue to be granted by the American Counseling Association (ACA).

Submit all applications for programs to be considered for Category 1 CEUs directly to ABGC's Administrative Office.

☞ Guidelines ☎301-571-1825;
or visit www.faseb.org/genetics/abgc/abgcmenu.htm ♦

NOTE: NSGC requests that all members who expect to (ever) obtain CEUs email your Soc.Sec.# (or equivalent) to us c/o nsgcassist@aol.com. We assure you that we will not use your SS# for any reason, whatsoever, other than this stated CEU purpose. ♦

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NSGC AT WORK — FORGING AHEAD

Wendy R. Uhlmann, MS

As I write my last presidential column, it is clear that genetic testing and genetic discrimination issues have been a central focus this year. It has been an incredible experience to see these issues discussed at a national level and to represent NSGC.

WHITE HOUSE CEREMONY

NSGC was invited to attend the White House ceremony which announced the completion of a working draft of the human genome. Politicians, scientists and leaders of genetics and advocacy groups attended this historic event. Present in the East Room were four genetic counselors: Vivian Weinblatt, Diane Baker, Judith Benkendorf and myself.

GENETIC TESTING

The Secretary's Advisory Committee on Genetic Testing (SACGT) held meetings in June and August. At both meetings, I presented testimony on behalf of NSGC. NSGC

was publicly thanked for our comprehensive feedback and for proposing a sample algorithm for determining a level of genetic testing oversight. Our testimony was recorded in the Federal Register.

NSGC also submitted a comprehensive response to the CLIA (Clinical Laboratory Improvement Amendments) Notice of Intent regarding establishing a genetic testing specialty. The CDC Genetics Laboratory Forum is addressing laboratory issues related to genetic testing oversight; Andy Faucett represented NSGC at the June and September meetings.

DISCRIMINATION LEGISLATION

Past President Debra Lochner Doyle represented NSGC at a genetic discrimination event held at the U.S. Capitol on June 21. This event followed the introduction of HR2457 — the Slaughter-Daschle comprehensive genetic discrimination bill — to the House floor.

On July 20, a Senate hearing was held on Genetic Information in the Workplace. This hearing focused on genetic discrimination in employment and whether existing legislation sufficiently protects workers. Senator Thomas Daschle quoted from NSGC's letter of support for S1322, the Genetic Nondiscrimination in Health Insurance and Employment Act, which appears in the Congressional Record.

I represented NSGC at a September 5 meeting held with White House and congressional staffers and leaders of genetics and

advocacy groups regarding efforts needed to pass

S1322/HR2457. It was emphasized at this meeting that senators and representatives need to hear from both patients and professionals before October 1 about how this legislation is needed, including "real life stories" that document discrimination and/or experiences with patients who have declined genetic testing because of fears about how this information could be used.

PRACTICE RECOMMENDATIONS APPROVED AND PUBLISHED

"Genetic Counseling for Fragile X Syndrome: Recommendations of the NSGC" was published in the *Journal of Genetic Counseling*, August 2000. Congratulations to authors Nathalie McIntosh, Louise Gane, Allyn McConkie-Rosell and Robin Bennett.

APPOINTMENTS

- Melonie Michelson — NSGC's liaison to the National Council on Folic Acid.
- Robin Bennett — NSGC's liaison to the National Coalition for Health Professional Education in Genetics (NCHPEG). ♦

WEB FINDER

☞ SACGT :
www4.od.nih.gov/oba/sacgt.htm
☞ S1322 Senate Hearing:
www.senate.gov/~labor
☞ CLIA Notice of Intent
www.phppo.cdc.gov/DLS/pdf/genetics/noi-genetics.pdf ♦

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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 December 15
Submission deadline November 10

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TWO AAAS FELLOWSHIPS AWARDED TO GENETIC COUNSELORS

POLICYMAKING AND ADVOCACY FELLOWSHIP

Jessica Mandell, MS

Judith Benkendorf is forging a path in the U.S. government as the first genetic counselor to receive an American Association for the Advancement of Sciences (AAAS) Congressional Fellowship. Sponsored by the American Society of Human Genetics (ASHG) with support from the Department of Energy, Judith has worked for the House Commerce Committee Democratic Staff since January. Judith updates

us on her one-year venture into the land of politics.

How did you become interested in the AAAS fellowship?

After 20 years in genetic counseling, I was looking for a way to work on the national issues I grew passionate about.

How did you come to work for the House Commerce Committee?

The AAAS orientation program prepares us for identifying a place-

ment, but each congressional fellow must decide to work for: Democrats vs Republicans; House of Representatives vs Senate; and personal office vs committee staff. I knew I would work for the Democrats because of my strong convictions about

See p 6

GENETICS AND JOURNALISM FELLOWSHIP

Linda Cheng, MS

It is 6:30am, and I am escorted by a security guard into the control room of one of the nation's top morning TV programs, *Good Morning America* (GMA).

Standing before dozens of monitors and video switchers are some of TV's most powerful figures. Thirty minutes before sign on, the orchestra prepares for opening credits. Today, two groups will come together to announce that a working draft of the human genome has been sequenced.

Thanks to the American Association for the Advancement of Science (AAAS), I experienced the world of broadcast journalism for 10 weeks through the Mass Media Science and Engineering Fellowship Program. This program aims to strengthen the connection between scientists and journalists while increasing public understanding of science and technology. Twenty-five Masters and PhD candidates, from

See p 6

MEET YOUR BOARD OF DIRECTORS

We are pleased to announce the following elected, appointed and returning members who will serve as your Board, beginning November 2, at the NSGC Business Meeting in Savannah.

Officers/Executive Committee

Vivian Weinblatt, MS (3)* President
Katherine Schneider, MPH (2) President-elect
Cindy Soliday, MS (0) Secretary
Lisa Mullineaux, MS, MBA (2) Treasurer
Teresa Brady, MS (0) Treasurer-elect
Wendy Uhlmann, MS (4) Past President I
Debra Lochner Doyle, MS (5) Past President II

Committee Chairs

Liz Stierman, MS (6) Communications
Rob Pilarski, MS (1) Education
Kristine Courtney, MS (4) Finance
Kristin Niendorf, MS (3) Genetic Services
Nisha Isaac, MS (0) Membership
Jennifer Farmer, MS (1) Professional Issues
Karen Eanet, MS (1) Social Issues
Janice Berliner, MS (4) Editor, *Perspectives*

Regional Representatives

Alison Warner, MS (1) Region I
Julie Rutberg, MS (0) Region II
Angela Trepanier, MS (1) Region III
Dawn Allain, MS (0) Region IV
Catherine Wicklund, MS (1) Region V
Heather Brown, MS (0) Region VI

**(n) represents previous years served on Board before this term*

Thanks to the Nominating Committee for a job well done: Debra Lochner Doyle, Chair; Karen Treat (I); Jill Stopfer (II); Kelly Jackson (III); Julie Berger (IV); Katie Leonard (V) and Monica Alvarado (VI). ♦

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PSYCHIATRIC GENETICS EDUCATIONAL PROGRAM TARGETS GCs

Joseph D. McInerney, MA, MS

The National Coalition for Health Professional Education in Genetics (NCHPEG) has received a 20-month grant to develop an interactive CD-ROM on psychiatric genetics, to be distributed at no cost to all NSGC members. The grant, which totals approximately \$680,000, is provided by the Ethical, Legal and Social Implications branch of the Human Genome Program, in the U.S. Department of Energy's Office of Biological and Environmental Research Office of Science.

Although the detailed content will emerge during the development process, the program is intended to address the following topics:

- Descriptions, incidence and natural histories of schizophrenia (SZ), schizoaffective disorders (SZA) and bipolar disorder (BPD)
- Current approaches to and limitations of diagnosis and treatment and the implications for genetic counseling
- Current explanations for the causes of the disorders
- The status of research into genetic contributions to SZ, SZA and BPD, including a review of research methodologies
- Current approaches to genetic counseling for SZ, SZA and BPD, the implications for genetic counseling of potential gene discovery and genetic testing and considerations for the development of standardized counseling protocols
- The potential involvement of primary-care practitioners and

mental-health professionals in providing referrals for psychiatric genetics services as well as the role of genetic counselors in educating those practitioners

- Ethical, legal and social issues that arise from continued research into the genetic basis of SZ, SZA and BPD and
- Ways in which these adult psychiatric disorders demonstrate the growing importance of common, complex diseases in genetic medicine.

Joe McInerney, Director of NCHPEG and NSGC charter member, will serve as principal investigator for the project. NSGC members will be involved in all phases of program development. Debra Collins, Karen Greendale and Vivian Ota Wang will serve on the advisory committee, and Beth Rosen, Psychiatric Disorders SIG chair, will be one of six authors who will write the program.

NCHPEG will test the program with at least 50 practicing counselors in various parts of the country and with students in at least 10 of the training programs here and abroad. Program Directors Deborah Eunpu, Beaver College, Barbara Biesecker, Johns Hopkins/NHGRI, Verle Headings and Barbara Harrison, Howard University and Lisa Steinberg, University of Maryland, have agreed to allow their programs to serve as test sites. Janet K. Williams has agreed to test the CD-ROM at University of Iowa's Genetic Advanced Practice Nursing and Mental Health Clinical Nurse Specialist Programs.

To volunteer to be one of the individuals field testing the program ©401-337-6728. ❖

GENES AND SOCIETY ARE FOCUS OF MEETING

Sarah Black

The American Society of Law, Medicine & Ethics (ASLME), the Whitehead Institute for Biomedical Research and The George Washington University Medical Center recently sponsored *Genes & Society: Impact of New Technologies on Law, Medicine & Policy* held on May 10-12 in Cambridge MA. Over 700 people attended.

The conference brought together physicians, attorneys, healthcare professionals, ethicists, biomedical scientists and business leaders to explore the dramatic changes that have occurred in genetics over the past two years.

Speakers included:

- Eric Lander, PhD, Genomics: Launching a Revolution in Medicine
- Mary-Claire King, PhD, Genomic Views of Human History
- Harold E. Varmus, MD, The Challenge of Making Laws on the Shifting Terrain of Science
- The Honorable Stephen G. Breyer, Genetic Advances and Legal Institutions.

ASLME is committed to providing forums for this type of interdisciplinary discussion. Also this fall, ASLME held its 2000 Annual Meeting, *Legal Challenges in Genetics & Reproductive Medicine*.

ASLME conferences:
www.aslme.org/conferences

May 10-12 conference audio:
www.aslme.org/news/index.html ❖



GENETIC ISSUES IN THE WORKPLACE

Katherine Hunt, MS

Genetic issues in the workplace was the theme of this year's *Genetics and Ethics* conference organized by the University of Colorado at the Given Institute in Aspen, July 21-23. The first day of the conference coincided with the Senate hearing on Genetic Discrimination in the Workplace, making it especially timely.

Faculty and attendees of the conference represented a variety of specialists: geneticists, genetic counselors, lawyers, occupational and internal medicine physicians and a biomedical ethicist. One participant was a woman who described losing her job shortly after starting treatment for alpha-1 antitrypsin deficiency. Hearing first hand that job discrimination is occurring and probably affects many who are afraid to speak out provided a wake-up call: *What can we do before this woman's story becomes commonplace?*

ANSWERS AND QUESTIONS

For many, federal legislation to prevent insurers and future employers from accessing genetic information is the answer. Having this legislation in place is certainly a first step towards protecting individuals from genetic discrimination. I, personally, do not believe such legislation will prevent genetic information from entering the workplace altogether.

How are we to prepare for the onslaught of genes, soon to be discovered, which confer genetic susceptibilities for certain diseases but only after specific environmental exposures? One example given was chronic beryllium disease (CBD), a systemic lung disorder. Some individuals with

CBD carry a specific HLA polymorphism, Glu69, which is a proven susceptibility marker. Studies have shown, however, that individuals with workplace exposure to beryllium have the same increased risk for CBD as those with the gene.

In another example, individuals homozygous for alpha-1 antitrypsin deficiency (AATD) have earlier onset and more severe symptoms when exposed to dust, fumes and tobacco smoke. Do companies whose employees encounter beryllium or dust and harmful fumes have an ethical responsibility to screen job applicants for susceptibility genes prior to hiring?

REAL-LIFE EXAMPLES

The last portion of the conference was spent in a mock exercise where conference participants acted as board members of a company considering adopting a policy of testing employees for AATD who work in mining operations with exposure to dust. Conference participants had appropriate suggestions and concerns before instituting such a policy, including hiring a full time genetic counselor to be involved in this process.

A real life pilot project is already underway at a beryllium plant in Tucson AZ. This company is offering screening for the Glu69 gene to all applicants with the assurance of no job discrimination or knowledge by the company of the results. And, thankfully, a genetic counselor is involved in this project.

Learning the outcome of this

project will be important in helping us anticipate the possible effects, good and bad, that genetics will play in the workplace. ♦



New Folic Acid Recommendations

Kerry Silvey, MA

We all know that daily intake of folic acid prior to and early in pregnancy decreases NTD risk. Evidence is emerging that it is difficult, if not impossible, to ingest enough folic acid through diet alone. There appear to be two reasons:

- the bioavailability of folic acid is higher in supplements than food sources and
- a significant proportion of the folic acid present in food is lost during food preparation.

The National Council on Folic Acid (NCFA) now recommends that all women of childbearing age take 400 micrograms of synthetic folic acid daily from fortified foods and/or supplements, in addition to consuming food folate from a varied diet. Among the 30+ members of the National Council on Folic Acid are the CDC, the Spina Bifida Association of America, the American Academy of Pediatrics, the American College of Obstetricians and Gynecologists and the March of Dimes. The NSGC has recently joined the coalition. Melonie Michelson is the new NSGC representative.

Some controversy continues over whether there is enough data documenting the safety and effectiveness of widespread ingestion of supplemental synthetic folic acid to recommend universal supplementation for women capable of becoming pregnant. However, the NCFA has reached a consensus and recommends supplementation as the wisest course. They will continue to monitor emerging research. ♦

POLICYMAKING AND ADVOCACY FELLOWSHIP, *from p. 3*

women's reproductive rights, and I decided to concentrate on the House since the previous ASHG fellows worked in the Senate. I next chose the House Commerce Committee, whose jurisdiction includes the public health service, biomedical programs and health protection, mental health and research, food and drugs and drug abuse. Working on a committee staff provides in-depth exposure to a range of issues with opportunities to work with many representatives' staffs, constituencies and agencies.

What specifically has been the focus of your work?

Highlights include staffing a landmark hearing on fetal tissue use in research; contributing to the funding reauthorization bill for the Substance Abuse and Mental Health Services Administration (SAMHSA), including writing a provision to fund services for adults with fetal alcohol syndrome; and working on "The Children's Health Act of 2000." The House-passed version of this bill includes new NIH funding for Fragile X research, expansion of the CDC's birth defects monitoring program and promotion of genetic counseling for pregnant mothers and infants with birth defects in the Healthy Start Program. Most rewarding for me has been ongoing work with Rep. Louise Slaughter's office to bring HR2457, genetic non-discrimination legislation, to the House floor for a vote.

What was one of your greatest accomplishments?

One of my favorite experiences was working with the staffs of Reps. Diana DeGette and Henry

Waxman to develop "The Human Subject Research Protections Act of 2000." We then organized a press conference introducing the bill and walked it over to the Capitol where I put it in the box and watched it get assigned its official number, HR4605.

What's the most significant thing you've learned?

Congressional staff members are key to the policy process, and every

action is a blend of policy, politics and procedure.

How has this fellowship affected you personally?

My next challenge is figuring out what to do after the fellowship ends. I will always be a genetic counselor at heart, but I know now I desire a position oriented toward policy and advocacy. ♦

GENETICS AND JOURNALISM FELLOWSHIP, *from p. 3*

astrophysicists to zoologists, were selected to intern as reporters, researchers and production assistants in media organizations nationwide.

I was assigned to the Science Unit at *GMA* and found the job an exciting challenge, as I had no previous journalism experience. *GMA* runs two hours of live programming every weekday with a strong commitment to covering science. This summer, we covered topics from lightning to retinal surgery, cabin air quality and high-tech swimsuits.

The highlight of the fellowship was co-producing two segments on the Human Genome Project. My role included: obtaining graphics and animation of genetic concepts, compiling a research packet, arranging to film at a sequencing lab, interviewing guests, providing background information to Diane Sawyer, attending executive meetings on story content, assisting script development and acting as the on-site producer in the control room during the live broadcasts.

While I was thrilled with my journalism experience, my passion and persistence did not revolutionize TV science programming as I had hoped. The segments that *GMA* aired were not much different than what other media venues publicized. Educational components I designed were cut, and questions about genetically engineered babies and profit prevailed. I sought out the show's executives during program development, and they demonstrated genuine interest in learning the science behind the announcement. They did not, however, include much of the information we discussed in the aired segments. Fortunately, Dr. Collins and Dr. Ventner voiced some of these key issues in interviews.

During my work, I did receive enormous support from genetic counselors I contacted for information and suggestions. I also was able to edit out inaccuracies in scripts, including removing the term "mapped." I have learned from this experience that changing the way science is reported can happen in small steps. I hope to continue to use my genetic counseling and media skills to enhance public understanding of genetics through multimedia education.

☞ Information about the Mass Media Science and Engineering Fellowship Program, //ehrweb.aaas.org/ehr/MassMedia ♦



DINING AROUND IN SAVANNAH!

Richard Allen

There are three things you need to know about eating out in Savannah.

1 — Barbecue means pork. Usually pulled or chopped pork. You often can get chicken and sometimes beef. But, you have to ask.

2 — Tea is sweet. As in *very*. The sugar is poured in while the tea is hot so more is diluted in. Unsweetened tea is available but, again, you have to ask.

3 — Reservations are available and restaurants fill up fast. Especially if you want to go somewhere nice. Unless noted, all take reservations, which I highly recommend.

Savannah is a popular tourist spot and has plenty of very good restaurants, many within walking distance of the riverfront. My Historic District favorites:

- Elizabeth on 37th – Honored as the best chef in the Southeast by the James Beard Foundation, regional food becomes elegant. You'll need a car or a cab. 912-236-5547
- Sapphire Grill – Stylish, trendy and delicious. American food done fancy, e.g., lamb lollipops. Service can be maddeningly slow. 912-443-9962
- Bistro Savannah – Eclectic, with Cajun, Oriental and Indian touches, along with a great veal and wild mushroom meatloaf. 912-233-6266
- Café Metropole – Converted bus station is Savannah's French bistro, with fresh bread made on the premises. Everything from pizza and mussels to fish in parchment and stuffed game hens. 912-236-0110
- Garibaldi's – Main menu reads like an Italian café, but blackboard fare drifts to veal chops, lots of seafood, lamb. Noisy. 912-232-7118
- The Olde Pink House – 1771 building was a red brick bank, covered with plaster. The red seeped through and, voila, pink. Great seafood, pork, lamb, etc. After dinner, head to the basement for a drink and romantic music by Gail Thurmond. 912-232-4286
- Il Pasticcio – Italian with an attitude, this excellent Italian restaurant offers a variety of dishes. Great place to people watch, since its huge windows open on the main downtown shopping area. 912-231-8888
- Casbah – This Moroccan restaurant offers up tender lamb, shrimp or game hens with your fingers...and belly-dancing. Lots of fun and the food is very good. 912-234-6168
- AquaStar – This is one of those rarities, an excellent hotel restaurant. Lots of seafood and the best view in town...right at the conference site, the Westin. 912-201-2000
- Lady & Sons. Does not take reservations, but may for large groups. Southern country cooking at its best, with buffet and menu service. Buffet usually includes fried chicken, fish, one or two other meat dishes, loads of veggies and salad. Servers bring garlic cheese biscuits, hoe cakes and a little bowl of dessert. 912-233-2600.

Richard Allen is the restaurant critic for *The Savannah Morning News*. His reviews can be found online at savannahnow.com. Click on Diversions. ♦

SEEKING JOURNAL OF GENETIC COUNSELING EDITOR-IN-CHIEF

Robert Resta, MA

The NSGC is seeking a new Editor-in-Chief for Journal of Genetic Counseling, starting in 2001. The first year will be a transition year, with the new Editor expected to assume full responsibilities by the end of 2001. Responsibilities:

- Solicit, review and edit manuscripts
- Work with the editorial board, publisher, authors, reviewers and readers to maintain the quality and integrity of the journal
- Prepare each issue of the journal (6 issues per year) and
- Manage the journal's budget and overall administration.

This volunteer position is expected to take about 10-15 hours per week. Qualifications include good standing as a full NSGC member, at least five years of genetic counseling experience, excellent interpersonal skills, research and publication experience, writing and editing abilities, creativity, intestinal fortitude and the courage of your convictions.

Interested applicants are encouraged to submit any inquiries, a CV and a brief cover letter explaining the reason for your interest in the position and your vision of the journal's future to:

✉ Robert Resta, Perinatal Medicine, Swedish Medical Center, 747 Broadway, Seattle WA 98122-4307; ☎206-386-2101; fax: 206-386-2552; robert.resta@mail.swedish.org
Applications will be accepted until October 20. ♦



Childhood Cancer Survivors: A Practical Guide to Your Future

Authors: Nancy Keene, Wendy Hobbie, Kathy Ruccione

Publisher: O'Reilly & Associates, 101 Morris Street, Sebastopol CA 95472

Cost: \$27.95 (paper) • 482pp.

Reviewer: June Peters, MS

Surviving childhood cancer was practically unheard of before the medical advances of the last two decades. Currently, one of every 750 twenty-year olds in the U.S. is a childhood cancer survivor, and by 2010, this figure will rise to one in 250. Prenatal, pediatric, internal medicine and cancer genetics practices will be impacted by this rise.

Childhood Cancer Survivors: A Practical Guide to Your Future, is an excellent reference for patients, families and health care professionals seeking experience with and medical knowledge about cancer survivorship. The book offers technical information in readable language with stories and advice from survivors and their parents. The authors deal candidly with the stages of survivorship, including the realities of late effects on a variety of organ systems and the frustration that many patients and parents feel when their symptoms are not taken seriously.

The book is organized into several sections. The early chapters describe the survivorship journey after the end of treatment, and emotional reactions during survivorship are detailed. A key medical chapter is organized by

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disease, type of treatment and long term effects, such as what retinoblastoma survivors can expect if they did or did not have radiation therapy, and includes a table of follow-up tests recommended for survivors of specific diseases and treatments. Remaining chapters are organized by body system, e.g., brain and nerves, hormones and immune system. The last chapter covers second cancers due to genetic predisposition, lifestyle and previous treatment effects.

Useful appendices include:

- Personal vignettes designated as "survival sketches"
- Comprehensive Resources, including a website that serves as a medical literature review. NSGC and the Genetic Alliance are listed, as well as other organizations for cancer services, support, information and referrals.

The authors' credentials are impressive. Nancy Keene, author of *Childhood Leukemia*, was motivated as the parent of a two-year old with acute leukemia to become an author and advocate for survivors. Wendy Hobbie is a nurse practitioner who developed a comprehensive care program at Children's Hospital of Philadelphia. Kathy Ruccione is a pediatric oncology nurse and a parent of a son with multiple congenital anomalies and deafness. Her personal experiences in the midst of her nursing career led her to recognize the ways people cope with life-changing and lifelong threats to health and wellbeing, whether from genetic disease or cancer.

Childhood Cancer Survivors fills a significant gap in currently available survivorship information, which often features the treatment processes and is scant on what

happens after all treatment ends. In a second edition, I would like to see more coverage of genetic conditions predisposing to multiple primary neoplasms in children and adults, e.g., LiFraumeni, FAP or MEN.

Overall, this book appears to be a one-of-a-kind resource for survivors of childhood cancers, their families and the medical professionals who treat them. It would make a handy reference for most genetic counselors, not solely those involved in cancer genetics. ♦

Wrestling with the Future: Our Genes and Our Choices

Publisher: The Committee on Medical Ethics of the Episcopal Diocese of Washington, Morehouse Publishing, PO Box 1321, Harrisburg, PA 17105

Cost: \$10.95

Reviewer: Beverly Yashar, MS, PhD

Wrestling with the Future asks the disarmingly simple question, "Should I undergo genetic testing?" As genetic counselors, we know there is no right or wrong answer, rather the best response is found when an individual considers his or her concerns, beliefs and circumstances during decision-making.

This book is written as a working resource that looks at the personal, ethical and theological issues at stake in genetic testing. Be forewarned that the viewpoint of the Anglican Church is an integral component of the discussion and may make this an inappropriate resource for some counselors and their clients. However, this book does an excellent job of considering the variety of contexts in which a genetic question can be asked and answered. The basic mind set of the Anglican Church toward genetic testing is highly consistent with the

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non-directive stance of genetic counseling.

This book begins with a knowledgeable introduction to the basics of genetics and gene testing and then considers the morality of genetic testing within the context of Anglican traditional beliefs. It presents four broad scenarios in which testing may be requested:

- Testing of adults
- Testing of young children and adolescents
- Testing as part of the decision to have children and
- Testing in a prenatal setting.

Each section is organized around a few broad questions discussed in a series of smaller “talking points.” Each chapter contains useful questions that readers are encouraged to ask themselves and their genetic counselor, physician, social worker or religious leader. Finally, each section ends with a number of relevant scenarios and provides points for discussion.

One of the dominant principles

cited throughout the book is the value of using genetic testing to lessen human suffering by decreasing the occurrence of genetic disease. However, the book does not present a *carte blanche* attitude towards testing; it considers the pros and cons within the context of a number of diverse Christian theological viewpoints. There are no simplistic answers in this book. Instead, it outlines paths for information gathering and resolution. This book is valuable in helping genetic counselors understand the diversity of Christian beliefs and integrate them into contemporary genetic counseling and testing. ♦

My Journey With Jake: A Memoir Of Parenting And Disability

Author: Miriam Edelson

Publisher: Between the Lines, 2000

Cost: \$24.95 (Canadian) • 208 pp

Reviewer: Cheryl Shuman, MS

Miriam Edelson's story is one that is all too familiar to genetic counselors: the indescribable joy of a first pregnancy; the disappointment and anxiety of a complicated delivery and neonatal period; the exhausting adjustment to caring for a new baby; the mounting terror when things really begin to go wrong; the unbelievably insensitive delivery of a grim diagnosis; and finally the overwhelming difficulties of raising a medically fragile child — difficulties that are compounded by the diminishing services provided by federally-funded agencies. This is a story well worth reading by health care providers and students, members of social service agencies and policy-makers and families of children with disabilities.

At the age of four and a half

months, Miriam and Jim's first child, Jake, is diagnosed with lissencephaly. Though there had been some realization of an underlying problem because of Jake's failure to thrive and increasing seizure activity, the shock and subsequent adaptation to the actual diagnosis were “text-book.” Moreover, the delivery of the diagnosis in the emergency room of an esteemed pediatric hospital while surrounded by “five eager medical students” typifies everything we learned not to do when giving bad news. Miriam goes on to write about her quest for information and the painful recognition that she and Jim would be unable to provide the medical care and stimulation needed to give Jake the best possible quality of life.

Ultimately, they find a wonderfully caring and respectful group home, and Jake has miraculously survived to beyond the age of ten years. Though many of her interactions with health care professionals were suboptimal, Miriam acknowledges the very positive interactions with her genetic counselor, Jennifer Fitzpatrick.

As a trade union activist, Miriam has the ability to advocate on behalf of her son and all children with disabilities. She reveals the inadequacies in the Canadian system's provision of care for children with disabilities, and in doing so, provides insight useful for the international community. Miriam Edelson writes with clarity and poignancy, making this a “good read” on many levels. ♦

NEWLY-PUBLISHED BOOKS BY MEMBERS



Psyche and Helix. Essays on Psychological Aspects of Genetic Counseling, Seymour Kessler, edited by Robert G. Resta. Wiley-Liss, 2000. A book of Seymour Kessler's essays on the psychological aspects of GC.



Psychosocial Genetic Counseling, John Weil. Oxford University Press, 2000. “Drawing on direct clinical experience and the growing body of relevant literature, [this book] provides a comprehensive, integrated approach to understanding these issues and their applications to genetic counseling.” (Quote is taken from book jacket.) ♦





EVALUATING MEDICAL INFORMATION ON THE WEB

This is part one of a two-part series of how to evaluate medical and health websites. This article covers site design; part two will cover how to evaluate the content of a website.

Kathleen Fergus, MS

As more and more people search the internet for health and medical information, consumers need to be taught how to judge the information that is found. The good news is that most websites are designed with the best of intentions; the bad news is that there are some sites that are deliberately misleading and potentially dangerous. Luckily, there are some objective criteria that can help differentiate between the two.

Before even evaluating a website, there are some aspects of website design that can provide a hint as to the reliability of the information within the site.

WHO AND WHY

There should be an easily found statement of purpose covering questions such as why this website was developed. Is it a review of information or a statement of opinion? Is it designed to sell something? This statement should also include information about the author's credentials and if and how the information in the website is reviewed.

WHEN

Another basic criterion is a date of creation. This allows you to determine if this website is current. Ideally, a website should have two more dates — a date of revision and a date of last review. Having all three dates will show how timely and thorough the website is.

WHAT

A statement about the creation of the website is critical. Can the information provided be backed up with scientific fact? Did the author(s) use a scientific review board? Is there a bibliography or citation? The presence of any or all of these attributes adds to the credibility of the website.

WHERE

The website's URL, or Unique Resource Locator, typically starts with www. There are seven possible types of sites, all identified by a three letter suffix:

- .com — Commercial, mainly USA
- .net — Networks
- .org — Non-profit organizations
- .edu — limited to four-year colleges and universities
- .gov — Restricted to U.S. federal government agencies
- .mil — Restricted to U.S. federal government military entities
- .int — International organizations.

Make sure that the suffix matches the site description (a government site should not have a .com ending).

CONTACT INFORMATION

There should be an email address provided for feedback and a statement as to what kind of response a person can anticipate. Most credible websites state that they do not provide medical care but will try to find other available resources to answer questions. Be leery of any site that states it will provide medical care via e-mail.

LINKS

Any good impartial website should provide links to others with related information. If there is no way to get to other websites, you have to ask why the website doesn't want you to leave.

By using this simple set of site design criteria, you can get a feeling for the reliability of the information within a site. ♦

RESEARCH NETWORK

Tuberous Sclerosis Complex Research

The Northrup Research Laboratory at The University of Texas Houston Medical School is accepting blood samples from persons with a definite or probable diagnosis of tuberous sclerosis complex (TSC) for inclusion in our research. In conjunction with our study researching genotype/phenotype correlations, both the TSC1 and TSC2 genes will be sequenced for causative mutations. Original detection of the causative mutation will be done at no cost to the family, thanks to funding from the National Tuberous Sclerosis Association. Families identified to have a mutation can elect to have these findings confirmed clinically, via an arrangement with Baylor DNA Diagnostic Laboratories, at a cost of \$400. Further testing of other family members can also be arranged.



Aimee J. Tucker, MS
©713-500-5766;
Aimee.J.Tucker@uth.tmc.edu ♦

Media WATCH



Angela Geist, MS

Scientific American (July). A 3-part series discussed where we go from here now that the draft of the human genome has been completed. The new fields of pharmacogenomics, bioinformatics and proteomics were discussed. Wendy Uhlmann was quoted regarding the limitations of testing for certain disorders, such as Huntington's disease, since the age of onset, severity or progression of the disease cannot be predicted even when testing is informative.

Time (July 3). A series of articles discussed the Human Genome Project. The first article discussed the race between Celera Genomics and NIH to sequence the human genome as well as the feud between J. Craig Venter and Francis Collins, the leaders of the two organizations. The next article reviewed the advances in medicine developed as a result of sequencing the human genome, such as determining which treatment will be most effective on a particular type of cancer based on which genes are active. Proteomics was described in one article, and another article outlined some of the issues that have been raised by the Human Genome Project including privacy, patenting and germline modification. The series ended with a piece by James Watson, who gave an overview of the journey from the discovery of the double helix in 1953 to the sequencing of the human genome in 2000.

Money (May-June). "The Future in Your Genes" discussed the possibility of discrimination after undergoing genetic testing. Two genetic counselors were quoted, and the article encouraged the reader to review his or her family history with a genetic counselor.

The New York Times (July 21). "Boom in Gene Testing Raises Questions on Sharing Results" quoted several genetic counselors as they described the sensitive issue of discussing genetic testing results with at-risk family members.

San Francisco Chronicle (May 1). "Genetic Weapon in Cancer War" described the inheritance of nonpolyposis colon cancer and included quotes from individuals with hereditary cancer mutations and their genetic counselors. An overview of the advantages, disadvantages and limitations of genetic testing for cancer, including the potential for insurance and/or employment discrimination issues was provided. A question and answer column directed patients towards genetic counseling to help with the decision as to whether to have a genetic test, and a resources column included the NSGC, GeneTests™ and local genetic service facilities.

Newsweek (July 16). "Stop Blaming Your Genes" discussed a study in the *New England Journal of Medicine*, revealing that environmental factors were more important than genetic factors in determining an individual's cancer risk.

Newsweek (July 23). "The Happy Family We Set Out To Be" was a mother's story about trying to make a "happy family" for her two autistic children. She told of meeting with genetic counselors who told her that her twins would not be autistic since they had never seen a family with more than one case of autism. Both were later diagnosed with autism. ♦

Celebrate Ourselves

RESTA TO SPEAK IN LONDON

Bob Resta has been invited to speak at "A Century of Mendelism," a conference sponsored by the Galton Institute in London this Fall. His talk, "The Galton Lecture 2000: Genetic Counselling - Its Scope and Limitations," is a command performance addressing this group.

AAAS FELLOW SELECTED

Diane Baker has been awarded the American Association for the Advancement of Science (AAAS) Congressional Fellowship, sponsored by ASHG. She will be responsible for providing genetic expertise on "the Hill" during her one-year tenure, to begin in January.

CDC NAMES NSGC MEMBER AS FELLOW

The Association of Teachers of Preventive Medicine (ATPM), in collaboration with the CDC, has selected Andy Faucett as one of six Career Development Awardees in Genetics and Disease Prevention. ATPM provides national representation for teachers, researchers, practitioners of preventive medicine and medical school departments of preventive medicine.

Andy will serve in the Public Health Practice Program Office and has been charged with helping to build a program to support genetics in public health.

He began July 1 and will serve for up to three years. ♦





CALL FOR PAPERS & PRESENTATIONS

The 25th National Conference on Perinatal Social Work, 2001: *A Perinatal Odyssey — Integrating Clinical Social Work Practice and Technology*, is accepting abstracts and workshop ideas through November 1.

✉ Ella Goldweber, LCSW, UCSD Medical Center, Social Work Dept, 200 West Arbor Dr, San Diego CA 92103-8918; 619-432-6094.

AEC '01 TOPIC, CALL FOR WORKSHOPS, PBS ANNOUNCED

Current Advances - Anticipating Change, NSGC's 20th Annual Education Conference, will address recent and anticipated advances in genetics and prepare genetic counselors for the impact of changes in roles, patient care, education, legislation and research. The conference will be held Nov 4 - 7, in Washington DC.

Proposals for workshops and practice-based symposia (PBS) are being accepted through October 30. All proposals will be considered; preference will be given to topics that fit the conference theme. Contact Workshop or PBS Committee Co-chairs for information, guidelines, forms or to learn about serving on either of these committees.

WORKSHOPS

- ✉ Dawn St. Amand
801-883-3261; fax: 801-584-3515;
dstamand@myriad.com
- ✉ Jennifer Bojanowski
510-428-3168; fax: 510-428-3382;
jenboj@hotmail.com

Perspectives in Genetic Counseling
22:3 — Fall 2000

BULLETIN BOARD

PRACTICE-BASED SYMPOSIA

- ✉ Kathryn Murray
541-349-7600;
fax: 541-686-8330;
kmurray@peacehealth.org
- ✉ Julie Rutberg
410-502-7161; fax: 410-502-9148; jrutberg@jhmi.edu

EDUCATIONAL MODULES IN CLINICAL TERATOLOGY

Clinical Teratology Educational Modules have been created as part of an NSGC Special Projects Fund and GLARGG Special Education Fund. Modules will be distributed to all the graduate program directors and will be available to the general membership.

Modules are available with or without slides: \$35 including shipping with slides, \$25 without. A module will be available for viewing at the NSGC Resource Room in Savannah.

- ✉ GLARGG, 347 Waisman Center, 1500 Highland Ave, Madison WI 53705-2280. Make checks payable to "GLARGG."

VCF HANDBOOK AVAILABLE

The "Faces of Sunshine" handbook regarding velocardiofacial syndrome (VCF) for parents and professionals is now available for \$10.00/booklet. A video tape of the same name is also available for teaching purposes at \$20.00.

- ✉ Donna M. McDonald-McGinn, MS, Clinical Genetics Center Program Director, 22q and You Center, The Children's Hospital of Philadelphia, 34th and Civic Center Boulevard, Philadelphia PA 19104. Make checks payable to: The Clinical Genetics Educational Fund #12690.

Note: The announcement of the two preceding publications does not imply endorsement by NSGC. ♦



MEETING MANAGER

- Oct 12 American Bar Association Workshop, *Medical Information and Privacy*, Washington DC. Wendy Uhlmann will be a panelist.
✉ www.abanet.org/adminlaw/home.html
- Nov 10-11 Montefiore Medical Center & Albert Einstein College of Medicine, in conjunction with March of Dimes Birth Defects Fdt, *Confronting Preterm Birth in the 21st Century: From Molecular Intervention to Community Action*, The New York Academy of Medicine, New York NY.
✉ Karla. Damus, damus@necom.yu.edu; or Ann Umemoto, aumemoto@modimes.org
- Nov 16-18 National Perinatal Assn Annual Clinical Conference, *Evolution of Perinatal Health and Healing: Complementary Care and Nontraditional Practices*, Charlotte NC.
✉ www.nationalperinatal.org
- Mar 22-23, 01 Sarah Lawrence College Masters Programs of Health Advocacy and Human Genetics, *Genetics and Advocacy: Exploring the Scientific and Human Issues Surrounding Breast and Ovarian Cancers*, Bronxville NY
✉ Charlene Schulz 718-885-3292; charlenejs@aol.com ♦

COMMITTEE AND SIG UPDATES

MINORITY MENTORSHIP

Nancy Hsu, MS

At the 18th Annual Education Conference in Oakland, the Diversity SIG reintroduced the Minority Mentorship Project (MMP) as a strategy to provide support for minority genetic counseling students. The MMP is currently in its fourth month.

Students and mentors were recruited from genetic counseling programs and the Diversity SIG. Matches were made according to students' interests and geographical preferences. Approximately one-third of the Diversity SIG membership is taking an active part in this project. Twelve student-mentor pairs are in communication and are contracted to three contacts over a period of four to six months.

The term "minority" does not merely apply to different ancestries and ethnic backgrounds. Indeed, students and mentors are of African, Chinese, Japanese, Asian Indian, Vietnamese, North African, Israeli, Hispanic, Puerto Rican and Italian descents. In addition, there are participants of various religious preferences, genders, sexual orientations and disabilities.

The MMP represents an elaborate quilt of diversity. The dual purpose of the MMP is to provide tailored mentorship for minority students and to encourage continued diversity within the genetic counseling profession. This follows the mission statement of the Diversity SIG. More specifically, the MMP strives to guide and mentor in graduate training experiences, job searches, career opportunities, leadership skills, grant writing skills, advocacy, public speaking and involvement in professional committees and organizations.

Feedback has been received from both students and mentors. Students feel the MMP has been a productive way to network and to gain others' perspectives. Mentors hope to serve as unique resources based on personal experiences and interests.

✉ Nancy Hsu 206-386-2101;
nancy.hsu@mail.swedish.org

Social Issues Committee

WORKS IN PROGRESS

Anne Spencer, MS

The Social Issues Committee has recommended that NSGC adopt a new process for creating position papers.

Maximizing member input and speeding up the approval process are the two main goals. Before a position paper is approved, the Board of Directors will elicit comments by circulating it to the membership by email and making it available on our website. Members without access to electronic communication can monitor the progress of documents through a "Works in Progress" column in *PGC* and can obtain a copy of a draft document by notifying the appropriate contact person. This column will also be used to recruit people to collaborate on new papers. Keep your eyes open for related items of interest.

Currently the Social Issues Committee is actively working on a position statement on the Use of Biotechnology. The Research Subcommittee is drafting a paper reviewing research in genetic counseling.

✉ Anne Spencer, Chair
©208-381-3088;
spencera@slrmc.org (until Nov 2)
✉ Karen Eanet ©410-828-3131;
keanet@gbmc.org (after Nov 2). ♦

NEW SIG WITH INDUSTRY FOCUS

*Heather Brown, MS, and
Kathleen Fergus, MS*

Heather Brown and Kathleen Fergus have initiated NSGC's newest addition to our SIG roster, the Industry SIG.

The Industry SIG is open to NSGC members who work in industries involved in delivery of varied genetic services. This SIG will facilitate communication among genetic counselors to promote genetic counseling and increase their knowledge of business affairs.

The group plans to participate in NSGC's 20th Annual Education Conference in Washington DC, maintain a specialized listserv and advise NSGC on business and partnership proposals from commercial entities.

In addition to the co-chairs, individuals who have committed to membership in the SIG are Beth Balkite, Trisha Brown, Pam Cohen, Melissa Gabriel, Allison Gregory, Joan Scott, Maureen Smith and Amy Vance.

The group will convene in Savannah for their first official meeting. Look for the Industry SIG checkbox on your 2001 membership dues invoice to join!

✉ Kathleen Fergus
©415-540-2852; KFergus@dhs.ca.gov
✉ Heather Brown
©415-371-9500;
hbrown@genesage.com ♦

EMPLOYMENT OPPORTUNITIES

■ **LITTLE ROCK AR:** Immediate opening for BC/BE Genetic Counselor. Join statewide PN genetics/dx svc: wide variety of indications; case mgmt & follow-up; TIS, telemed clin, triple scrn prog, med & u/s stud educ, commun educ, Fetal Bds conf & rsrch.

☞ Shannon Barringer, MS, U Arkansas for Medical Sciences, 4301 W. Markham - Slot 506, Little Rock AR 72205; ☎501-296-1700; 800-358-7229; BarringerShannonN@exchange.uams.edu. EOE/AA

■ **LOS ANGELES CA:** Immediate opening for 2 energetic BC/BE PN Genetic Counselors. Exp & fluency in Span pref. Trav to satellite sites may be req. Join active acad PN svc: full range of PNDx procedures & svcs.

☞ Bill Herbert, MS, Cedars-Sinai Medical Center, 444 S. San Vicente Blvd Ste 1001, Los Angeles CA 90048; ☎310-423-9935; Fax: 310-423-9939; Bill.herbert@cshs.org. EOE/AA

■ **OAKLAND CA:** Immediate opening for Genetic Counselor/Craniofacial Clinic Coordinator. Min 1 yr recent ped/perinatal clin exp req. Clin/prog plng background, computer skills, exclnt org, team spirit & interest in case mgmt strongly pref. Coord Craniofacial Clin svgs adults & children in N. CA Kaiser Reg: new referral mgmt, multidisc clin prep, pt eval & case mgmt.

☞ Pat McMahon, RN, MS, Kaiser Permanente Med Ctr, 280 West MacArthur Blvd, Genetics Dept, Oakland CA 94611; ☎510-596-7834; Fax: 510-596-6367. EOE/AA

■ **SACRAMENTO CA:** Immediate opening for BC/BE Genetic Counselor. Travel to satellite clins in Stockton & Modesto. Spanish a plus. Work w/ 3 GCs & Repro Geneticist in busy private PNDx prac. PN GC for all aspects of PNDx: AMA, abnorm u/s, +Exp AFP, + fam hx, terat exposures. Oppty to partic in 2 multi-ctr NIH trials: 1st trimestr scrng & ran-domized study of transabdom CVS & early amnio.

☞ Diana Stultz, Practice Manager, PNDx of Northern California Medical Group, 1315 Alhambra Blvd #210, Sacramento CA 95816; ☎916-736-6708; Fax: 916-731-5569; ADMPNDx@aol.com. EOE/AA

■ **SAN DIEGO CA:** Immediate opening for PT, BC/BE Genetic Counselor. Abil to work i'pendently & take initiative req. Join multidisc BR & GYN ONC teams to provide genetic risk asmt & GC.

☞ Linda Wasserman, MD, PhD, UCSD, Clinical Cancer Genetics Program, Cancer Ctr, 9500 Gilman Dr, San Diego CA 92093-0639; ☎858-534-8955; Fax: 858-534-0269; lwasserman@ucsd.edu. EOE/AA

■ **SAN JOSE CA:** Immediate opening for BC/BE Genetic Counselor. Exp pref. Join active team in estab, c'hensive genetics program in large HMO. Broad range of svcs: PN, ped, adult, cancer.

☞ Cindy Soliday, MS, Kaiser Permanente, Dept Genetics, 5755 Cottle Road, San Jose CA 95123; ☎408-972-3332; Fax: 408-972-3298. EOE/AA

■ **WALNUT CREEK CA:** Immediate opening for BC/BE Genetic Counselor. I'pendent work style pref. Provide GC in state approved PNDx ctr: AMA, MSM scrng, fam hx, terat exposure & U/S abnorm.

☞ CV, brief cover ltr & 2 ltrs of rec: Attn: Human Resources Dept, Perinatal Practice Mgmt, 43 West Del Mar Blvd, Pasadena CA 91105; Fax: 626-795-9045; HR@ppmus.com. EOE/AA

■ **FARMINGTON CT:** Immediate opening for BE PN Genetic Counselor. Exp pref in PN/Perinatal clin svc. Begin @7-9 FTE w/ potential for FT w/in yr. PN GC in busy hosp-based w/ 3 GCs & wide array of clin prog; med & GC elective rotations.

☞ Robert Greenstein, MD, Director, Dept Peds, Div Human Genetics, University of Connecticut Health Center, Farmington CT 06032-6310; rgreens@cmckids.org. EOE/AA

■ **AUGUSTA GA:** Immediate opening for BC/BE Genetic Counselor. Join Ped clin genetics prac at acad med ctr. General genetics clin duties & craniofacial, CL/P, telemed & hemophilia clins. Limited outrch & adult clin respon. Some state NB scrng follow-up. Tchg & GC stud s'vision.

☞ CV & ref: David B. Flannery, MD, Medical College of Georgia, 1446 Harper St, Bldg CK 287, Augusta GA 30912; ☎706-721-2809; dflanner@mail.mcg.edu. EOE/AA

■ **HONOLULU HI:** Immediate opening for Genetic Counselor. Exp pref, not req. Looking for highly motivated, flexible, team player who enjoys working in a multicult setting. Join 3MFM's, 1 MFM Geneticist & 2 BC GCs. Dynamic ctr provides svcs to Hawaii & Pacific Basin. All aspects of PN couns w/ opptys for cancer GC.

☞ Tammy Stumbaugh, MS, Kapiolani Medical Ctr for Women & Children, Fetal Dx Center, Ste 540, Honolulu HI 96826; ☎808-983-6893; Fax: 808-983-8989; tammys@kapiolani.org. EOE/AA

■ **CHICAGO IL:** Immediate opening for BC/BE Genetic Counselor. Work w/ 2 clin geneticists/pediatricians & 3 GCs in acad children's hosp: genrl genetics, metab disorders, NF, skeletal dysplasias, PKU, neurogenetics, ophthalmogenetics & Gaucher disease. Dx lab, educ prog & clin rsrch prog.

☞ Joel Charrow, MD, Children's Memorial Hospital, Clin Genetics, 2300 Children's Plaza, Chicago IL 60614; ☎773-880-4462; jcharrow@northwestern.edu. EOE/AA

■ **CHICAGO IL:** Immediate opening for PT (60%) BC/BE Genetic Counselor. Exlnt commun skills a must. Exp pref. Join 1 GC & 6 MDs in bustling acad MFM suburban prac w/ interesting pt pop. Clin geneticist & med school on site. Tchg opptys.

☞ Kelly Moyer, MS, Loyola University Medical Ctr, 2160 S. First Ave, Genetic Prog, Rm 1046 - Bldg 103, Maywood IL 60153; ☎708-216-8167; Fax: 708-216-5669. EOE/AA

■ **FORT WAYNE IN:** Immediate opening for BC/BE Genetic Counselor. Conduct client GC re genetic risks, estab pt stats re: dx, answer inquiries.

☞ Hallie Custer, Human Resources, Parkview Hospital, 2200 Randallia Dr, Fort Wayne IN 46805; ☎219-484-6636 x 22318; Hallie.Custer@parkview.com. EOE/AA

■ **BALTIMORE MD:** Immediate opening for BC/BE Genetic Counselor. Join univ-based team to provide svcs for ped & adult pts at hosp & satellite clins; involv w/ rsrch & tchg.

☞ CV & 2 ltrs of rec: Melissa Patterson, MS, Johns Hopkins Hospital, 600 N. Wolfe St, Blalock 1008, Baltimore MD 21287-4922; ☎410-955-3071; Fax: 410-614-9246. EOE/AA

■ **BOSTON MA:** Immediate opening for Genetic Counselor. PN GC, working w/ perinatologists & med geneticists at primary tchg hosp for Tufts U Med School. Travel to satellite clins.

☞ Dr. Diana Bianchi, Chief Perinatal Genetics, New England Medical Center, Box 394, 750 Washington St, Boston MA 02111; Fax: 617-636-1469. EOE/AA

■ **BOSTON MA:** Immediate opening for Genetic Associate. MS in GC or related field; some exp pref, not req. Busy PNDx prog, molec DNA dx prog, involv in MSAFP; rsrch oppty avail. Newly available, position for 3rd GC: PN GC in high-risk OB clin; partic in med genetics clin.

☞ Aubrey Milunsky, MD, DSc, Boston University School of Medicine, Ctr for Human Genetics, 715 Albany St, Boston MA 02118; ☎617-638-7083; Fax: 617-638-7092; amilunsk@bu.edu. EOE/AA

■ **BOSTON MA:** Immediate opening for BC/BE Genetic Counselor (80%-possible FT). Join busy Perinatal Dx Unit providing GC for AMA, abnorm MS scrns & u/s findings, terat, fam hx & +CF NB scrns. S'vise GC stud, involv w/ med students, residents & genetic fellows. Diverse pt pop.

☞ CV & cover ltr: Marisa Likhite, Massachusetts General Hospital, Perinatal Diagnostic Unit-Blake 1053, 55 Fruit St, Boston MA 02114; ☎617-724-9004; Fax: 617-724-9069; mlikhite@partners.org. EOE/AA

■ **DETROIT MI:** Immediate opening for BE/BC Genetic Counselor. Join busy PN prac: amnio, CVS, dx & 3D U/S, ample oppty for terat, ethnic scrng, rsrch, pubctn, fetal ther prog & tching.

☞ Adel Gilbert, MS, Hutzel Hospital, Div Repro Genetics, 4707 St. Antoine Blvd, Detroit MI 48201; ☎313-745-7068; Fax: 313-993-0153; gilbert@med.wayne.edu. EOE/AA

■ **GRAND RAPIDS/KALAMAZOO MI:** Immediate opening for BC/BE Genetic Counselor. Abil to work i'pendently & on team; willing to travel req. 3/4 PN genetics in perinatal setting, 1/4 peds.

☞ CV & 2-3 ref s contact: Helga Toriello, PhD, Spectrum Health, Genetic Services, 21 Michigan St NE - Ste 465, Grand Rapids MI 49503; ☎616-391-2700; Fax: 616-391-3114. EOE/AA

■ **ROCHESTER MN:** Immediate opening for BC/BE Genetic Counselor. Exp as molec genetics lab liaison a plus. Must be able to work i'pendently as well as on team. Join team in Div Lab Genetics: pre/post-test conslts, tech supt & GC expertise to referring physicians & healthcare prof. Primary assignment: molec genetics lab w/ some cross-coverage of other (cyto, biochem) labs as needed. Opptys for involv in educ, rsrch & clin also exist.

☞ Cover ltr, CV & contact information for ≥3 refs: Carrie Miesbauer, Mayo Clinic Staffing Ctr, 200 1st St. SW-OE 1-22, RE:00-2469, Rochester MN 55905; ☎507-538-1183; Fax: 507-284-1445; careers@mayo.edu; www.mayo.edu. EOE/AA

EMPLOYMENT OPPORTUNITIES



■ **ST. LOUIS MO:** Immediate opening for Genetic Counselor. MS or RN req, exp in preconcep & PN pref. Verbal & written commun skills essential. Computer skills req. Enthusiastic, dedicated, team-oriented ind for PT/FT position in private office.

☞ GeneCare Medical Genetics Center, PO Box 4270, Chapel Hill NC 27515-4270; No phone calls. EOE/AA

■ **COLUMBIA MO:** Immediate opening for BC/BE Sr. Genetic Counselor. 2+ yrs exp req. Join busy, full svc, academic Div Med Genetics w/ 4 GCs & 3 MD geneticists: direct PNDx & GC Svcs, PN GC, genrl genetics clins & in-house consult rotations. Optyts for prof growth, rsrch & prog develop in vigorous, friendly program located in a diverse college town.

☞ Judith Miles, MD, PhD, Univ Missouri Hospitals and Clinics, Div Medical Genetics, Dept Child Health, Columbia MO 65212; ☎573-882-6991; milesjh@missouri.edu. EOE/AA

■ **LAS VEGAS NV:** Immediate opening for BC/BE Genetic Counselor. Bilingual (Eng/Span) a plus. Handle wide range of PNDx issues in busy, expanding perinatal practice in Las Vegas.

☞ Attn: Human Resources Dept., Obstetrix Medical Group, 2119 W. Orangewood Ave, Orange CA 92868; Fax: 714-634-1762; anita_downs@pediatrx.com. EOE/AA

■ **NEW YORK NY:** Immediate opening for BC/BE, PT (21 hrs/wk) maternity leave cvg for PN/peds genetics practice, Oct-Feb, with potential to evolve into a FT, permanent position. Work w/ Chinese-speaking GC asst to provide genetic svc to newly-immigrated Chinese women

as part of diverse pt pop; likely to incl cancer genetics. Abil to work i'pendently a must.

☞ Elinor Langfelder Schwind, MS, Saint Vincent's Hospital and Medical Center, 36 7th Ave Ste 509, New York NY 10011; ☎212-604-8896; Fax: 212-604-3899; eschwind@saintvincentsnyc.org. EOE/AA

■ **LEBANON NH:** Immediate opening for PT Temp BC/BE Genetic Counselor. GC or related training, eg, nursing or equiv exp req. Serve on MFM team: PN & preconcep GC, oord scrng & dx tstg, follow-up GC svcs. GC jointly w/ MFM physician or medical geneticist in difficult scrng issues & dx of fetal abnorm. Liaison to subspec svcs & referring clinicians.

☞ CV & ltr of interest: Dorothy Williams, Human Resources, Dartmouth Hitchcock Medical Ctr, 1 Medical Center Dr, Lebanon NH 03756; Fax: 603-650-8919. EOE/AA

■ **LIVINGSTON NJ:** Immediate opening for BC/BE Genetic Counselor. Highly motivated, i'pendent ind desired. Min 1-2 yrs exp pref. Join busy MFM prac. Individual GC for wide variety of indications, case mgmt & follow-up.

☞ Send resume to Karen Callahan, Human Resources, St. Barnabas Medical Center, Old Short Hills Rd, Livingston NJ 07039; ☎973-322-4247; Fax: 973-322-2309; alt. contact: Elena Ashkinadze ☎973-322-2187. EOE/AA

■ **NEW BRUNSWICK NJ:** Immediate opening for BC/BE Genetic Counselor. Span spkg pref. High vol, varied PN pts. Large multidisc team at tertiary level priv hosp w/ med school affil. Satellite & spec clin, student/resid s'vision. Tchg, rsrch, lect opptys.

☞ Donna Chavez, MS, St. Peter's University Hospital, Institute for Reproductive & Perinatal Genetics, 254 Easton Ave, New Brunswick NJ 08903-0591; ☎732-745-6659; Fax: 732-249-2687. EOE/AA

■ **PATERSON NJ:** Immediate opening for BC/BE Genetic Counselor. Exp pref, bilingual (Spa) desired. Strong verbal & written skills nec. Self-motiv, energetic GC with interest in tchg. Join genrl genetics team based in urban tertiary-care hosp providing broad range of svcs.

☞ Susan Schmerler, MS, St. Joseph's Hospital, Section Genetics, 703 Main St, Paterson NJ 07503; Schmerler@sjhmc.org. EOE/AA

■ **ALBUQUERQUE NM:** Immediate opening for BC/BE Genetic Counselor. Join office/hosp-based Perinatal prac. Work closely w/ BC MFM physicians & BC clin genetisist spec in PNDx, GC & fetal therapy progs.

☞ CV & 3 ltrs rec: Anna Bryarly, Practice Administrator, Perinatal Associates of New Mexico, 201 Cedar SE, #405, Albuquerque NM 87106; ☎505-764-9535; Fax: 505-845-9646; abpanm@msn.com. EOE/AA

■ **ELMHURST NY:** Immediate opening for PN Genetic Counselor. Exlnt commun & org skills. Abil to work i'pendently & on team req. Knowledge of 2nd language pref (Span, Hindu, Urdu, etc). Assist in PN scrng prog.

☞ Sonia M. Castro, MS, Elmhurst Hospital Center, 79-01 Broadway, OBS/GYN H1-94, Elmhurst NY 11373; ☎718-334-5510; Fax: 718-334-5759; Sonia@Walrus.com. EOE/AA

■ **NEW HYDE PARK NY:** Immediate opening for Genetic Counselor. BC/BE highly desirable. MS req; exp pref. GC for genrl genetics clin, spec & PN clins.

☞ Send CV & salary history: Human Resources, Long Island Jewish Medical Center, 410 Lakeville Rd, New Hyde Park NY 11040; amcgoldr@lij.edu. EOE/AA

■ **NEW YORK NY:** Immediate opening for BC/BE Genetic Counselor. Exp in cancer GC pref. Join world-renowned leader in cancer care & rsrch: all aspects of GC/case mgmt for pts & families, partic in rsrch protocols in genetic epidemiology.

☞ CV & ref: Dr. Kenneth Offit, Dept Human Genetics, Memorial Sloan-Kettering Cancer Center, 1275 York Ave, Box 192, New York NY 10021. EOE/AA

■ **WEST ISLIP NY:** Immediate opening for BC/BE Prenatal Genetic Counselor. Exlnt commun, org skills nec. Abil to work i'pendently. Spanish a plus. Join perinatologist in busy expndg MFM prac.


☞ Dr. Mastrogianis, Attn: Jenna Antonelli, MS, L.I. Maternal Fetal Medicine, 1111 Montauk Hwy, Ste 2-4, West Islip NY 11795; ☎631-376-4242; Fax: 631-376-4245. EOE/AA

■ **RESEARCH TRIANGLE PARK NC:** Immediate opening for BC Genetic Counselor. Min 5 yrs exp req. Need motivated, creative GC w/ good org & commun skills to join 3 GCs in busy commercial lab. Coord pre- & post-analytical phase of specimen tstg, report results, act as client liaison, provide client & in house educ through lectures & written materials, PN phone GC.


☞ Trisha Brown, MS, LabCorp; ☎877-396-3438; Fax: 530-885-0388; brownt@labcorp.com. EOE/AA

See next page

Women's Health Care Services



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Informal contact and program information: www.drtillet.com

**Tues, November 7
Don't Forget to Vote!**

EMPLOYMENT OPPORTUNITIES, from p. 15

■ **RALEIGH NC:** Immediate opening for BC/BE Genetic Counselor. Some travel req. Self-motivated, org, creative, team player req. Join Public Health Genetics Network svgs 13 counties in Eastern NC. Coord w/ East Carolina Univ School of Medicine genetic satellite clins; prepare fam pedigrees, provide GC & commun educ.
✉ Elizabeth G. Moore, Director, Genetic Health Care Program, 1916 Mail Service Ctr, Raleigh NC 27699-1916; ☎919-715-3420. EOE/AA

■ **PORTLAND OR:** Immediate opening for PT, Temp (min 4 mo) BC/BE Genetic Counselor. Coord pre-clin prep & post-clin follow-up & GC.
✉ Karen Kovak or Karen Guthreau, Oregon Health Sciences University (OHSU) Genetics & Birth Defects Clinic, Portland OR 97207; ☎503-494-5606; 800-452-3563 x5606 or Karen Guthreau ☎503-494-2785; 800-452-3563 x2785. EOE/AA

■ **PORTLAND OR:** Immediate opening for BC/BE Genetic Counselor. Exp pref. Solid commun & public speaking skills nec. Join Med Genetics prog: GC, direct pt care & pt care coord.
✉ Legacy Employment Services, Legacy Health System, 1120 NW 20th, Ste 111, Portland OR 97209; ☎503-415-5660; Fax: 503-415-5200; www.legacyhealth.org. EOE/AA

■ **PHILADELPHIA PA:** Immediate opening for PT BC/BE Genetic Counselor. Local travel & evening lectures req. Strong initiative, exlnt commun skills & abil to work w/ different depts essential. Join busy Div Genetics w/ 1 geneticist & 3 GC to soord Ashkenazi Jewish Genetic Disease Screening Initiative. Outreach educ (prof & at risk ind) & GC. Cover PN, peds & cancer GC when necessary.
✉ Tanya Bardajkian, MS, Genetics Division, Albert Einstein Medical Center, 5501 Old York Rd, Philadelphia PA 19141; ☎215-456-8722; Fax: 215-456-2356; schneida@aeahn2.einstein.edu. EOE/AA

■ **NASHVILLE TN:** Immediate opening for BC/BE Genetic Counselor. Join active genetics team at univ med ctr. Genrl genetics (peds/adults), PN, metab, cancer, hem, HD, outreach, teaching. Oppty for resrch.
✉ Vickie Hannig, Vanderbilt School of Medicine, DD 2205 MCN, Nashville TN 37232; ☎615-322-7601; Fax: 615 343-9951; vickie.hannig@mcm.vanderbilt.edu. EOE/AA

■ **AUSTIN TX:** Immediate opening for BC/BE Genetic Counselor. Exp pref, not req. Join multidisc team in large priv corp to provide PN svcs to diverse pts.
✉ Lisa Kelley, MS, Center for Genetic Services, 7121 SPID, Ste 202, Corpus Christi TX 78412; ☎361-985-6600; Fax: 361-985-6603. EOE/AA

■ **HOUSTON TX:** Immediate opening for BC/BE Genetic Counselor. Exp pref. Spanish a +. Exlnt commun skills, highly motivated, abil to work i'pendently & enjoy a fast-paced high-growth environment, limited travel req. Flex & adapt in meeting client needs emphasized. Join busy rapidly growing ctr w/ 1 geneticist, 1 GC, a full svc cyto lab & an active PN screening prog: GC & case mgmt for PN, ped & cancer risk asmt pts. Assist in coord PN scrng prog. Tchg oppty: lectures for nurses, genetic lab trainees & commun groups.
✉ CV & salary hx: Katherine Thompson, MD, Center for Medical Genetics, P.A., 7400 Fannin St, Ste 1150, Houston TX 77054; ☎713 790-1990; Fax: 713-790-1903. EOE/AA

■ **SEATTLE WA:** Immediate opening for Genetic Counselor w/ MS in genetics or eqv 2 yrs exp w/ adults, infants, adolescent. Computer & exlnt commun skills req. Friendly, supportive environ in HMO setting.
✉ Dodie Williams, Human Resources, Group Health Coop, 521 Wall St, Seattle WA 98121; ☎800-848-4259 x2737; Williams.da@ghc.org. EOE/AA

■ **MADISON WI:** Immediate opening for PT/FT (50-100%) BC(pref)/BE Genetic Counselor. GC & genrl case mgmt in Biochemical Genetics Clin. Involw w/ State newborn scrng follow-up. Tchg & GC student s'vision; oppty for clin rsrch & pub.

✉ Send CV and ref: Jon Wolff, MD, UW Biochemical Genetics Program, Rm 361 Waisman Ctr, 1500 Highland Ave, Madison WI 53705; Fax: 608-263-0530; mlrasmus@facstaff.wisc.edu; Full job description: www.ohr.wisc.edu//pvl/pvl37853.html. EOE/AA

IN CANADA

■ **TORONTO ON:** Immediate opening for 2 Genetic Counselors (1 FT; 1 PT). Must work i'pendently & have exlnt commun & org skills. Join busy satellite PN clin. PN GC w/ potential future growth in peds.
✉ Jennifer Wilson, General Manager, Rouge Valley Health System, Womens' Health Program, 2867 Ellesmere Rd, Toronto ON M1E 4B9 Canada; jwilson@centen.on.ca.

■ **TORONTO ON:** Immediate opening for CAGC BC/BE Temp PT Genetic Counselor (through 3/31/2001). MS in GC w/ up to 6 mo exp or equiv combination of educ & exp. Heart, OV cancer genetics exp an asset. Demonstrated knowledge of genetic scrng issues for susceptibility; org, analytic & computer (database & spreadsheet) skills; exlnt i'personal, oral & written commun skills all pref. Partic in plng, devel, implement & eval of reg'l prog to ID fam at risk for hereditary forms of BR/OV cancers. Provide related clin GC svcs to fam as part of multidisc team.
✉ Human Resources Dept, Toronto-Sunnybrook Regional Cancer Centre, 2075 Bayview Ave, Toronto ON M4N3M5 Canada; Fax: 416-480-6102; hr@tsrcc.on.ca

■ **VANCOUVER BC:** Immediate opening for BC/BE Genetic Counselor or related degree w/ relevant exp. Travel to Quebec req. Familiar w/ linkage analysis & Cyrillic 2.1 req. Join Canadian biotechnology company engaged in drug discovery using clin genetics & functional genomics for complex diseases.
✉ CV & cover ltr: David Nykl, Executive Coordinator, Research & Development, Xenon Genetics, Inc, 100-2386 East Mall, Vancouver BC V6T1Z3 Canada; ☎604-221-8478; Fax: 604-221-8423; dnykl@xenongenetics.com; www.xenongenetics.com.