

PERSPECTIVES

in genetic counseling

Volume 24 Number 2

Summer 2002

National Society
of Genetic
Counselors, Inc.



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

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to support this newsletter.

See ad, p. 15



MARKETING EFFORTS FLOURISH

KEY MESSAGES

We recommend that members insert at least one of the following key messages into all media interviews. The components are broken down into the primary message, or "point," and supportive documentation, or "proof."

POINT: Genetic counselors play an increasingly important role in empowering consumers about their health and wellness

PROOF: ...by providing vital information that allows them to make educated decisions about their health and wellness.

POINT: Genetic counselors support clients in making complicated health care choices

PROOF: ...by outlining the pros/cons and benefits/risks associated with genetic testing, e.g. prenatal testing options, cancer testing options, etc.

POINT: Genetic counselors translate complicated and confusing technical information into understandable terms

PROOF: ...by simplifying this technical information into terms people can understand.

POINT: Genetic counselors help people understand the difference between their perceived and actual risk

PROOF: ...by utilizing a balance of technical data and counseling skills, explaining risk in documented terms and assuring clients that everyone has genetic risk. ♦

*Bea Leopold, MA &
Angela Trepanier, MS*

One of the first recommended activities of our new public relations team, STAR/Rosen PR, was to recommend a series of short sound bite statements that help define a group. Often referred to as "key messages," they assist with media communications by explaining NSGC in a few words or phrases and often lead to great news. Having key messages ready gives the interviewee focus and helps maintain control over the discussion. Most important, they deliver the message *we* want to send to our target audiences.

...to page 3

Board Elections



Full members are urged to vote for this year's Board of Directors. Positions to be filled are: President-elect, Secretary, Treasurer-elect and Representatives to Regions II, IV and VI. The term of office is November 11, 2002 through September 13, 2003.

Ballots will be mailed the last week in June and must be received by July 31.

Voting is your opportunity to choose the leadership that will drive our Society forward.

Your vote counts!

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PRESIDENT'S BEAT



Katherine A. Schneider, MPH

One of the highlights of my Presidential year is representing NSGC at various professional meetings.

CALL FOR RESEARCH AT SACGT

On May 13-15, I attended the 13th meeting of the Secretary's Advisory Committee on Genetic Testing (SACGT) held in Baltimore.

The first day of the meeting was a one day conference sponsored by SACGT entitled "Genetic Testing and Public Policy: Preparing Health Professionals." It was wonderful to see so many genetic counselors attending this important conference! SACGT's business meeting took place on May 14-15, and I am happy to report that genetic counseling issues were prominent in many of the committee's discussions. In fact, the committee voted to recommend that Dr. Tommy

Thompson, Secretary of Health and Human Services, authorize the National Academy of Sciences' Institute of Medicine (IOM) to fund a study evaluating the efficacy of genetic counseling. My testimony on behalf of NSGC engendered many questions from the committee. Although there is no longer a genetic counselor on SACGT (hopefully a temporary situation), committee members appeared sensitive to and supportive of strategies to improve our billing and reimbursement woes.

One of the most significant barriers we face is that Medicare does not recognize genetic counselors as clinical providers. How can we become recognized Medicare providers? According to a Medicare representative testifying before SACGT, we need the following before Medicare will even consider granting us provider status:

- quantitative, published data on the efficacy of genetic counseling and
- state licensure.

So, research is a key element! We need to step up efforts to publish genetic counseling studies on cost, test interpretation, quality assurance and

enhanced patient satisfaction, knowledge and decision-making. And for those of you wondering whether there are any benefits to pursuing state licensure – the answer would appear to be yes!

WHAT'S HAPPENING IN JUNE?

NSGC's media blitz continues! On June 5-6, Vivian Weinblatt and I headed to the Big Apple for a 2 day media tour assembled by Linda Woody of the STAR/Rosen PR group. We held lengthy interviews with reporters at *Newsweek*, *US News & World Report*, *Wall Street Journal*, *Rosie* magazine, *New York Times* and *Child Magazine*. These interviews went very well and we are hoping to reap several articles featuring genetic counselors.

At the Endocrinology Society's annual meeting held in San Francisco on June 19 – 21, NSGC and ACMG co-hosted an interactive genetics module. Registrants were assigned a genetic condition (breast-ovarian cancer syndrome, multiple endocrine neoplasia, type 2 or hemochromatosis) and signed up to meet with a genetic counselor to learn their genetic test result. This was an exciting, high profile project, with an anticipated registration of 6000. I want to thank the 18 genetic counselors who agreed to participate and especially Gretchen Schneider who took the lead role in developing the genetic counselor guides. ♦

— *Katherine A. Schneider, MPH*
President, 2001 - 2002

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

Next issue September 16
Submission deadline August 9

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Follow Up

NSGC - GENAISSANCE RESOLUTION

Resolution to the Genaissance partnership is as follows:

- NSGC has received \$5000.
- The negotiations resulted in a complete release from the confidentiality agreement on behalf of the individuals and the Society.
- A Partnership Task Force, chaired by Steven Keiles, has been appointed to examine the issue of Partnership and develop recommended guidelines for future requests for collaboration. Their report will be presented to the Board of Directors this Fall. ♦

SACGT RESOURCES

- ☎ May 14 Meeting Complete Proceedings: www4.od.nih.gov/oba/sacgt.htm
- ☎ NSGC President's Oral Testimony: www.nsgc.org/nr_letter_051402.asp

WHEN THE MEDIA CALLS, *fr p. 1*

NONSTOP ACTIVITY

In the four months since our transition to STAR/Rosen PR, activity has been nonstop! They have:

- developed and refined four basic key messages for us to use when talking to the media. (*See p. 1*)
- developed questions for a survey to tease out media-worthy data about genetic counseling and genetic counselors. The survey will be conducted later this year or early next year.
- developed a strategic media list and interview opportunities surrounding a preimplantation genetic diagnosis announcement, coordinated interview and placement in *New York Times*.
- conducted a strategic plan for proprietary database searches to target reporters writing articles related to genetic counseling or genetic counselors; results yielded placements in *Pregnancy*, *Allure*, *Child Magazine* and *Baby Talk*.
- developed and implemented strategy for release of consanguinity study, worked with the University of Washington public relations department; distributed news release over the newswire resulting in teleconference with 12 major national media outlets and (*literally!*) hundreds of articles and interviews reaching international audiences (*See Media Watch, p. 12*); Robin Bennett continues to receive

requests for interviews regarding the topic, and Dr. Arno Motulsky, who served on the committee that drafted the guidelines, stated that in 50 years of practice and publishing he “hadn’t ever witnessed such media interest.”

- donated *pro bono* strategic sessions with the Communications Committee and Board leadership and attended the interim Board meeting to further deepen their knowledge of the profession and NSGC’s culture.
- orchestrated a media tour in June for President Kathy Schneider and Past President I Vivian Weinblatt; the media tour included visits with *Rosie*, *US News and World Report*, *Self*, *Newsweek*, *New York Times* and *Child Magazine*. Linda Woody, media specialist, accompanied them on this highly successful tour.
- provided feedback and ideas in a strategic brainstorming session.
- reviewed and provided feedback on a media primer developed by the Media Subcommittee, now posted on our website in Members-only section.

WINNING TEAM

STAR/Rosen PR was awarded the New York Public Relations Society of America’s prestigious Big Apple Award for their work in the “Best New Product/Service Launch” category. STAR/Rosen PR was part of the team that launched direct consumer banking giant ING DIRECT’s first

domestic cybercafe in New York City. The competition included the world’s largest public relations firms. *Go team!*

In other news, Karen Cutler, Partner and Senior Vice President at STAR/Rosen, has replaced Dina Silver Tau on the team working on our account. Karen is one of the most respected PR practitioners in the Greater Philadelphia area. She was named one of the region’s top 40 business people to watch under the age of 40 by the *Philadelphia Business Journal* in 1998. Linda Woody, Steve Rosen and John Wannenberg remain active on our account.

MEDIA COMMUNICATIONS

In other communications activities, after several years of development, the Media Subcommittee of the Communications Committee (formerly under the Education Committee) has completed *A Primer for Communicating Effectively through the Media*. The primer, posted on our website’s Members-only section, includes a plethora of information as well as selected comments from members who have had a range of media experiences. We hope you will find this new website addition a valuable resource when you are approached by or considering approaching the media. Our Key Messages are included.

In an effort to track our media exposure, we ask members to inform us of any interviews. We are available to answer questions and provide support prior to an interview.

☞ www.nsgc.org/members/tools_Primer_for_Communicating.asp

☞ Angie Trepanier
atrepani@genetics.wayne.edu

☞ Bea Leopold fyi@nsgc.org ♦

NEW LOGO, CORPORATE IDENTITY COMING

The Board of Directors has recently approved the redirection of some funds to create a new logo and corporate identity. A corporate identity is a “look” given to all print materials, including letterhead, booklets, newsletters, website, etc. The STAR Group will present several packages for consideration, under the direction of the Communications Committee. Members interested in following the progress of this project are invited to contact:

☞ Liz Stierman, Chair, Communications Committee nsgccomm@earthlink.net

☞ Bea Leopold, ☎610-872-5959; fyi@nsgc.org ♦

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BIOTECHNOLOGY - A NEW FRONTIER FOR GENETIC COUNSELORS

Lisa Andres, MS

After five years as a clinical genetic counselor, I decided to transition into industry. I enjoyed making a difference in the lives of individuals but wanted to make a more global impact. The biotechnology industry appeared to be an untapped market which I decided to target.

I contacted a Canadian company, Xenon Genetics, to learn what roles genetic counselors played within their company. I hoped to arm myself with this information and create a job for myself in the Bay Area. Xenon expressed an interest in interviewing me for a position within the company. The position sounded great! In November 2001, I packed up my husband and moved to Vancouver.

Xenon Genetics, a privately owned Canadian biotechnology company, is engaged in gene and drug discovery using clinical genetics and functional genomics. We are currently involved with multiple international projects targeting neurological, cardiovascular and metabolic disorders. Our goal is to identify genetic factors in these families which represent novel therapeutic targets for common disorders.

MY ROLES AND GOALS

At Xenon, I am an integral part of the clinical biology team, along with two other genetic counselors and three MDs. My responsibilities are exciting and diverse. I identify, assess and assist in the development of new research opportunities, and I also identify international collaborators.

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Once a new research opportunity is approved, I manage the project and help determine what clinical and family information we require. I work as a liaison with the collaborator to coordinate the transfer of clinical

'I don't think that a day has gone by when I haven't learned something new.'

information, genetic data, DNA and family information and ensure that

researchers obtain informed consent. My ultimate goal is to ensure the integrity of the data with the hope that the identification of genes in the research families will lead to further availability of clinical testing and therapeutics for complex conditions.

PROFESSIONAL GROWTH

I never imagined the extent that my skills as a clinical genetic counselor would play in industry. The clinical skills so necessary for providing patients with appropriate risk assessments are integral to my role in assessing potential research projects. Managing clinical care is similar to managing and coordinating projects. Perhaps one of the most important genetic counseling skills that I bring to this position is an ability to assess the ethics of research projects and protect the welfare and rights of patients.

My skills have definitely grown even within this short time period. I don't think that a day has gone by when I haven't learned something new. Working with business personnel, lawyers and scientists has definitely expanded my perspective and enhanced my skills in different areas.

I encourage genetic counselors considering the transition into industry to take the plunge. There is a lot that we can offer industry and much that industry can offer us. ♦



On the Road

GCs in IRBs

Beth Rosen-Sheidley was invited to speak at

"The Community IRB Member: Neighbor & Partner" in Gaithersburg, Maryland, in April. The conference, sponsored by the Human Subjects Research Program (US Department of Energy), gathered community organizations and Institutional Review Boards (IRB) to promote the protection of human subjects in scientific research.

The meeting focused on:

- finding and educating organizations with potential to provide new community members
- highlighting success stories of community members and IRB administrators
- exploring unmet needs and issues among community members
- exploring the concept of "community."

Community organizers, activists, legislators, researchers, bioethicists, clergy, IRB members and staff from the Office of Human Research Protections (OHRP) attended. Beth participated in a panel of several community organizations. Ours was the sole genetics community representative.

The Human Subjects Research Program hopes to build on the relationships formed through this meeting and is eager to see more genetic counselors serve on IRBs. With the near completion of the Human Genome Project, and the increased attention on pharmacogenomics, genetic counselors are a particularly useful addition to IRBs. ♦

☞ www.science.doe.gov/ober/humsubj/ or
Susan Rose, PhD, Human Subjects
Protection Program Manager,
Susan.L.Rose@science.doe.gov

DEVIL'S ADVOCATE VIEW ON LICENSURE

Anonymous

Licensure for genetic counselors has grown to be a very hot topic in the last year. In the Spring 2002 issue of this newsletter (*PGC* 24:1), Eric Rosenthal states, "Many counselors remain confused about the pros and cons of licensure, leading to ambivalence or active opposition." Genetic counselors who are opposed to or ambivalent about licensure are not necessarily confused about the issues.

When I look at the pros and cons of licensure outlined in the referenced issue, I admit to being confused because the points listed under the "pros" of licensure seem to be cons to me, or at best, moot points.

The article states that a genetic counselor's "certification" is a professional credential and licensure is a "practice" credential. If based on the exact same exam, is there any difference? Additionally, it is stated that "Licensure affords many benefits." My comments to these are as follows:

- "Assures quality counseling services." — I argue it does not. Most states are using the ABGC exam certification as their criteria for being licensed. This does not provide a *new* standard of testing, it is already in place. Furthermore, the ABGC exam in no way "assures" quality counseling services although it is considered by some to be the "gold standard" of evaluating genetic counselors.
- "Establishes a requirement of continuing education." — Continuing medical education is already required by those that are ABGC certified as of 1996.

- "Establishes a way to invoke disciplinary action for malpractice or unethical conduct." — In other words, it will be easy to sue genetic counselors.



- "Establishes consensus practice standards." — Shouldn't these standards come from within the profession as opposed to being dictated by the state government?

- "Sets standards for professional recognition." —

Does our graduation from a certified program and ABGC certification mean nothing? Exactly how many hoops do we need to jump through to be recognized?

- "May set the stage for obtaining reimbursement for genetic counseling services." — The key word here is "may." As the author pointed out, "The process [of licensure] is daunting . . ." This is an extreme amount of work for the *possibility* of being able to bill. With a lack of reimbursement by insurance companies, the lack of appropriate billing and diagnosis codes, is licensure the holy grail that will provide reimbursement for our services?

MORE QUESTIONS THAN ANSWERS

There are several states that simply do not have enough genetic counselors to make state licensure a reality or the political barriers to licensure are extreme. Will states that do have licensure be able to bill for services and financially support their services, or will they decrease the number of counselors willing to work in a state with more cost, regulation and risk involved in providing genetic counseling services? Will genetic counselors who relocate throughout their careers be required to obtain many licenses? Will licensure create yet another barrier to getting more counselors into training

programs? Finally, will licensure fragment the profession further, deliniating between certified and uncertified genetic counselors or those who must have CEUs versus those that do not?

There are many other valid cons listed in the *Perspectives* article. It would be interesting to hear input from genetic counselors

in the states that now have licensure as to how they plan to address these issues.

I applaud those who have been able to achieve licensure. I will look with interest on the implementation and consequences of their licensure. However, a healthy dose of ambivalence might not be all that bad for attaining a goal that could have limited benefits and significant downfalls.

Certainly this issue needs much further discussion and debate in public forums with our peers so we can understand the possible perils and promises of licensure. ♦

'...a healthy dose of ambivalence might not be all that bad for attaining a goal that could have limited benefits and significant downfalls.'

CORRECTION



RE: Utah status licensure in *Perspectives* (24:1, Spring 2002). Reference was made to "ACMG certified medical geneticist." ACMG does not certify anyone - they are a membership organization. ABMG is the organization responsible for the certification of MDs and PhDs in the field of genetics.

— Sharon Robinson
Administrator, ABMG

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SOCIAL ISSUES COMMITTEE DEVELOPS POSITION STATEMENT ON STEM CELL RESEARCH

STEM CELL RESEARCH

In accordance with strict medical and ethical guidelines, National Society of Genetic Counselors (NSGC) supports the use of embryonic stem cells as a legitimate and important area of scientific investigation and as a vital avenue of research toward the treatment and understanding of genetic conditions.

In regards to stem cell research, NSGC supports and endorses the following:

- The development and government funding for stem cell lines from the donation of cord blood or fertilized ovum that would otherwise be discarded, and the development of alternative sources of stem cells from adult cell lines.
- The collection of stem cells through donation, after thorough informed consent, rather than through the use of monetary incentives.
- The responsibility of stem cell banks to maintain a broad array of cell lines of sufficient diversity to meet the needs of our genetically diverse population and ensure equal access to potential transplant therapies.
- The importance of development and continual analysis of the medical, ethical, and legal guidelines and restrictions needed to protect and ensure proper use and application of the technology, fair dispersal of its potential benefits, and adequate privacy and safety measures for this research and its resultant therapies.
- The American Society of Human Genetics Statement on Stem Cell Research (www.ashg.org/genetics/ashg/ashgmenu.htm). ♦

Karen Wolff, MS

Position Statements, also called Position Papers, are created and adopted by NSGC to express our collective opinion on various issues of relevance to our profession. Currently, NSGC has adopted 14 statements on topics such as: Nondiscrimination, Confidentiality and Privacy of Test Results, Fetal Tissue Research, Prenatal and Childhood Testing for Adult-onset Disorders, Genetic Testing for Adult-onset Disorders, DNA-Sequence Patenting and Genetic Testing and Adoption. Once approved, they are listed in our membership directory and on our website.

These statements are not meant to express individual member's opinions, but are guidelines for the public and media in understanding our organiza-

tion's position specific topics.

The above draft was prompted last summer by President Bush's position on stem cell research, as well as by testimony submitted by NSGC via then President Vivian Weinblatt. The Social Issues Committee posted a call for volunteers over the general listserv. Jill Fonda Allen led the effort, and this statement is the result of their work. Note: As this is a *draft*, we ask that it not be used in anyway or format to represent NSGC.

A position statement cannot be adopted by NSGC without member's comments. To take this statement on Stem Cell Research to the next step — further refinement or dissolution — we need to hear your comments by Wednesday, July 31. ♦

✉ Jill Fonda Allen, ☎301-279-6060; jfonda@adventisthealthcare.com

✉ Karen Wolff, Chair, Social Issues Committee, ☎443-849-3131; Kwolff@gbmc.org

PLAN AHEAD FOR '03

The Conference Co-chairs for our 2003 Annual Education Conference, September 13-16, in Charlotte, North Carolina have begun to work on the conference. The working title is *Putting Science into Practice: Strategies in Genetic Counseling for the 21st Century*.

The Planning Committee chairs have been chosen, as well. Choose an area of interest or reconnect with a colleague as a great way to become involved in NSGC.

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A short course will precede the conference on September 11 - 12. ♦

'04 IN DC

Our '04 Annual Education Conference will be held in Washington DC, October 8-11. A Short Course has been scheduled for October 6 - 7. ♦



'02 CONFERENCE UPDATE

November 8 - 9:

Advanced Topics in Cancer Genetic Counseling

November 9 - 13:

Strategies in Genetic Counseling: Beyond the Basics

DESTINATION PHOENIX WELCOME TO ARIZONA, THE HEART OF THE SOUTHWEST and Home to the Grand Canyon and Phoenix the Capital of Arizona. In early November, you can expect sun and temperatures in the 80's. Remember to bring your walking/running/hiking shoes, tennis rackets, golf clubs and swim suits. Arizona is also home to many a beautiful setting, so bring your cameras. Only hours away you will find yourself in the Red Rocks of Sedona, the quaint town of Prescott, or the high country of Flagstaff. The Grand Canyon is only about five hours north, but expect it to be cold there!

HYATT ENVIRONS Located in downtown Phoenix, our hotel is in close proximity to our Capital Buildings, America West Arena, Bank One Ballpark, or BOB as it is affectionately called and home to the 2001 World Series Champions, the Arizona Center, home to several eateries and a large movie theater, Historic Heritage Square, as well as several theaters and museums.

NEARBY GREAT EATS! Oregano's, 130 E. Washington St. ☎602-253-9577
Italian and Pizza
Hard Rock Café, 3 South 2nd St. *What is there to say?*
Chary's Place, 20 W. Adams St. ☎602-712-1918 *Cuban*
A League of Their Own, 455 N. 3rd St. ☎602-252-2131
Owned by three woman!
Crazy Jim's, 305 W. Washington St-#14, ☎602-254-6550
Very popular place
Matador Restaurant, 125 E. Adams, ☎602-254-7563
Mexican

Friday's Front Row Grill, @ Bank One Ballpark, 401 E. Jefferson ☎602-514-8400 *Located inside the ball park*
Compass, located on top of the Hyatt (*Spectacular view!*)
Sam's Café, 455 N. 3rd St, Arizona Ctr, ☎602-252-3545
Southwest

Bouvier-Teeter House, An 1899 Tea House @ Heritage Square

WORTH-A-TAXI EATS! Los Dos Molinos, 2611 N. Central, ☎602-243-9113,
Southwestern Cuisine with flare.
The Arizona Biltmore Plaza, 24th Street and Camelback Rd. *Loaded with restaurants, The Cheesecake Factory and others, as well as great shopping*
Town and Country Plaza, 20th Street & Camelback.
Do not miss Baby Kay's (Cajun cuisine), as well as fabulous shopping opportunities. ♦

HEARTWARMING CONFERENCE FEEDBACK

Just in case you were not sure about attending our conference in Phoenix this November, here are excerpts from letters we received from veteran counselors after our Annual Education Conference in Washington DC last year.

WORDS ABOUT CONTENT

“What a great AEC meeting in DC! ...as one of the more seasoned (translation: older) genetic counselors, I have found it difficult in the last few years to get excited about the education meeting. Most of the programs seemed suited only to [genetic counselors] with five or less years of experience and not us “seasoned professionals.” Not this year. The program committee really made an effort to reach everyone... They asked the membership and then more important, listened to what they said in putting the program together. It was diverse, interesting and yes, outstanding—and many sessions were standing room only.”

— Beth Balkite (SLC '79)

WORDS ABOUT SUPPORT AND NETWORKING

“I just returned to my office from the [Annual Education Conference] in DC. I thought it was a great conference ...the support that I received from everyone was really overwhelming. The feelings of being surrounded by a group of individuals with such compassion, empathy and caring is truly a blessing. ...how proud I am to belong to a profession and an organization of individuals of such high caliber.”

— Steve Keiles (SLC '87)

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RESOURCES



Raising a Child with a Neuromuscular Disorder: A Guide for Parents, Grandparents, Friends and Professionals

Author: Charlotte E. Thompson, MD

Publisher: Oxford University Press
1999

Reviewer: Kathleen Fergus, MS

This is a book that I wanted to like. I purchased it for a friend with an affected child and decided to skim it before passing it on. It is written by a pediatrician with over 30 years experience in neuromuscular disorders and is a comprehensive guide to dealing with the medical and psychosocial aspects of children with neuromuscular disorders.

There are 16 chapters that cover a diverse array of topics such as coping with the initial shock of the diagnosis, navigating through the medical maze, getting appropriate school placements and tips for dealing with families and friends. The chapters are organized so they can be read separately or in order and are a balanced mix of practical information and scientific explanations. Most of the chapters are geared toward all neuromuscular disorders with the exception of chapter four (Neuromuscular Disorders: Description and Treatment) which discusses specific disorders by classification: muscular dystrophies, spinal muscular atrophies, hereditary motor and sensory neuropathies, metabolic myopathies (glycogenoses, lipid disorders/mitochondrial disorders) and ion channel disorders. The book also has four appendices that contain

information on genetics, a summary table of all discussed disorders, a chore chart for children (by age) and a very detailed resource directory organized by state and by country. There is also a comprehensive glossary, a suggested reading list and thorough index.

So what's not to like? Well, I was merrily reading along and got to Chapter Three on genetics. I winced at a few of the explanations, which manage to be technically correct yet misleading. One example is a paragraph that discusses the increased incidence of recessive disorders in the Middle East because of interfamily marriages and concludes with the sentence, "When relatives marry, it is possible for a child to inherit half of the recessive gene pair from each parent." While this is true, it left the impression that this would only happen if the parents were from the same family — certainly not true. Unfortunately, Chapters Three and Four are full of sentences like this. Although Chapter Three is dedicated to the genetics of the disorders, the explanation of autosomal dominant, x-linked (no discussion of recessive or dominant) and autosomal recessive inheritance total less than one page and are confusing. However, there was an appendix, which I quickly flipped to expecting more details and possibly pictures. I was disappointed. The entire appendix is two pages long and contains no diagrams (which is true of the whole book). In addition, there is no discussion of any specific inheritance patterns at all here.

Not every book has to cover genetics, but this lack was especially grievous in light of the comments on page 24 under the subtitle — *Do all Parents Need to See a Genetic Counselor?* While the author doesn't come right out and disagree, she makes several statements about the difficulty of

making diagnoses in neuromuscular disorders and states that she is hesitant to suggest that parents talk to a genetic counselor unless that counselor has training in these disorders. A reasonable suggestion but annoying from someone who presents herself as an expert on genetics yet manages to make many incorrect/misleading statements about genetics throughout the book (i.e. Prader Willi inheritance: - from the father!). Additionally, the author suggests that parents first discuss genetic issues with their physicians since "there are no good sources to check on his or her [the genetic counselor's] background." The entire tenor of the paragraph suggests that genetic counselors do not have enough training to deal with these "complex" disorders.

While I wanted to like this book, ultimately it was undermined by the misleading genetic information. I think that the psychosocial and other information is valuable, in the end, I simply could not bring myself to give this book to my friend. ❖

WHAT'S ON THE WEB

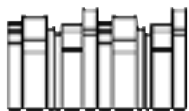
AMNIONET

Kathleen Fergus, MS



Amnionet.com provides information about prenatal testing — amniocentesis and ultrasound in particular — and contains over 20 pages of information covering such topics as chromosomes, risks of amniocentesis, miscarriage and nuchal edema. While this site contains some good information, it is ultimately undermined by informational inconsistencies and design flaws.

While I like the idea of this site, it includes biased, misleading and incorrect information clearly designed



RESOURCES



to promote amniocentesis, and there are some missing design elements such as dates, references and outside links.

This site is designed and authored by an amniocentesis practitioner who states that he is an expert in ultrasound and that he has published in the medical literature. While there are no links to back up these statements, a quick search in Pubmed reveals 84 articles in respected journals. So he may be an expert, but some of the assertions on his website are distressing. He is clearly biased toward early amnio, which his practice provides, and the website is clearly designed to sell it. That might not be a conflict, but he goes too far when he states that

one of the advantages to early amnio is that an early diagnosis of Down syndrome might enable a cure. An email querying him on this claim resulted in an unsatisfactory response about an as-yet unpublished discovery that he cannot discuss further.

While I have true misgivings, there are some things that I liked about this site. The use of sound files to listen to a recording of a fetal heartbeat was fascinating and some of the ultrasound images are truly amazing. However, these niceties do not in anyway make up for biased, inappropriate and incorrect information in this site. Overall, I would never refer patients to it, and if they did happen upon it, I

would anticipate spending a lot of time correcting misinformation!

✉ www.amnionet.com ❖

SUMMER FUN!

Kathleen Fergus, MS

Sometimes it is easier to let someone else do the picking! Check out the Scientific American website where "the editors have again sifted through the virtual piles of pages to find the top sites for your browsing pleasure." This eclectic mix of 50 sites covers the gamut from serious and information-packed to more whimsical sides of science and technology.

The ten categories are Archeology and Paleontology, Astronomy and Astrophysics, Biology, Chemistry, Computer Science, Earth and Environment, Engineering and Technology, Mathematics, Medicine and Physics. I particularly liked the Biology and Medicine categories.

The Biology category contains links to a database of amazing embryo images, a site that teaches about DNA using a variety of online media, a site that teaches about microbes, a site exclusively about fruitflies (more entertaining than I imagined) and a site on phylogeny and biodiversity.

The Medicine site includes links to sites like this: a virtual autopsy (you make the diagnosis), cancer knowledge with a news feature that is updated every 15 minutes, mental health knowledge exchange, the five senses and a biomedical network.

✉ www.scientificamerican.com

✉ www.scientificamerican.com/explorations/2002/060302webawards/ ❖

NEW CAREER POSTER INTRODUCED

THE MEMBERSHIP COMMITTEE has launched an eye-catching, cultural-friendly career poster under the able leadership of Robin Imagine who worked with designer, Thomas Prieto. The poster and matching brochure target high school and college students and can be used in other outreach or educational settings as well. A mailing to minority colleges will take place this summer.

Members may request copies at no charge.

✉ nsgclistQ@nsgc.org

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Web News

NSGC's WEBSITE EXPANDS

Check out the following information recently added to our website

GENERAL INFORMATION

- Presidential testimony to SACGT, May 14
- 2002 Annual Education Conference brochure and online payment
- A link to our Journal via Kluwer Online with searchable database beginning with Vol 9 (2000)
- Greatly enhanced career information

MEMBER'S ONLY SECTION

- Virtual Slide Swap
- Primer for Effective Media Communication
- Patient Satisfaction Surveys
- Student Corner
- Diversity SIG Spanish Resource List
- Guidelines for NSGC Publication Development

...and coming soon!

- JobConnection information and online listing and payment service
- Ethics subcommittee information

Surf around and let us know what you think! ♦

FREE JOURNAL OFFER FOR GCS

Free access is being extended to NSGC members for online access to a special edition of *Seminars in Medical Genetics*. The issue, "The Evolving Practice of Genetic Counseling" was guest edited by Bonnie Jeanne Baty and Diane L. Baker. Access will be available through August 1. ♦

✉ www3.interscience.wiley.com/trial/nsgc/index.html

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BULLETIN BOARD

MENTOR PROGRAM IN 7th YEAR

Troy Becker, MS

The Mentor Program, sponsored by the Membership Committee, is making plans for the 2002 match. The program networks professionals and students/recent graduates to exchange ideas and information about their current interests or experiences in genetics and genetic counseling.

The program typically runs over six months and will begin in October. Mentors and students are asked to contact each other every four to six weeks, determined by mutual interests.

Win Win

For practicing genetic counselors, the program offers an opportunity for contact with students that they may not otherwise have in their daily activities. For students, it provides an opportunity to have a resource outside of their training programs, a chance to discuss issues with experienced counselors and an inroad to begin the important process of networking.

Active Participation a Must

Reviews indicate that those students who are active in the program have the best outcome experiences. Students who are not actively in contact with their mentors tend to have poor experiences and tend to create frustration for the counselors who have volunteered to be mentors.

How to Begin

To join the mentor match, return the enclosed postcard by August 16. A short questionnaire will follow to assist in making the best possible match. Those who have participated in previous matches will not be automatically re-entered in the program. ♦

✉ Troy Becker BeckerT@allkids.org



ABGC EXAMS

Members with questions about taking the ABGC Board certification exams are advised to contact ABGC directly. NSGC does not maintain information. ♦

✉ Sharon Robinson ☎301-571-1885;
srobinson@genetics.faseb.org

PROFESSIONAL STATUS SURVEY GOES ONLINE

Kristen M. Shannon, MS

The NSGC 2002 Professional Status Survey is going online! It will be available on or about July 1 and can be accessed through the NSGC Member's Corner website. The survey will be maintained by Boston Information Solutions, the online company administering the statistical analysis.

Member ID Required

You'll need your NSGC ID# to enable BIS to verify that only NSGC Full members are completing it. Your confidentiality is absolutely guaranteed, as BIS has access to the data, only. They have been provided with identification numbers for verification purposes only; they do not have access to corresponding names. When the data is given to NSGC, it will be stripped of all identifiers.

It is vital that all Full members complete this survey.

The deadline for completing the survey is **Thursday, August 15!** ♦

✉ Contact for hard copy or specific survey questions: Kristen Shannon ☎617-724-1971;
keshannon@partners.org

✉ Contact for online problems:
www.bostoninfosolutions.com/pss/welcome.cfm

RESEARCH NETWORK

ANENCEPHALY AND OTHER NTDs

Duke University Medical Center has expanded their "Hereditary Basis of Neural Tube Defects" gene identification study to include families with an ongoing NTD pregnancy, including anencephaly. All NTD diagnoses are eligible. Family history of multiple affected individuals is not required.

Participation involves a telephone interview, review of medical records and collection of DNA samples. Pre-natal samples can be obtained on affected pregnancies, including amniocytes, cord blood or tissue. Participation is free, travel to Duke is not required and participation by phone or mail is acceptable. An annual newsletter is available to keep participants updated on research progress. Study brochures are available upon request.

✉ Liz Melvin, MS, ☎800-283-4316x2
emelvin@chg.mc.duke.edu or visit
www.chg.mc.duke.edu/patients/neural.html ❖

EYE MOVEMENT DISORDERS

GENETIC RESEARCH STUDY

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

The lab is looking for the genes responsible for these eye movement disorders and has currently identified three chromosomal regions associated with CFEOM and one associated with congenital ptosis.

Participation entails giving a sample of blood, completing a questionnaire and undergoing an eye examination or releasing eye examination records. There is no cost to participate and all information is strictly confidential.

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

TUBEROUS SCLEROSIS STUDY FOR IDENTICAL TWINS

Dr. David Kwiatkowski and colleagues are seeking identical twins with tuberous sclerosis for a research study investigating the genetic basis of variability in clinical manifestations of TSC.

Review of medical records, contact with treating physicians and a blood sample for analysis for mutations in the TSC genes are required.

✉ Dr. Kwiatkowski ☎617-278-0384;
dk@rics.bwh.harvard.edu ❖

FRIEDREICH ATAXIA STUDY

Two Friedreich Ataxia studies are being conducted at University of Pennsylvania and Children's Hospital of Philadelphia.

One study targets pregnant women with FA who have had one or more pregnancies in the past. This telephone interview/study addresses the social and medical challenges of pregnancy and raising children.

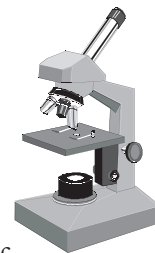
A second study, for males and females of any age, seeks to track the progression of FA over a short period of time, and involves participation in Ataxia Scales, contrast vision testing and a quality of life questionnaire.

✉ Jen Farmer, MS ☎215-614-0937;
farmerj@uphs.upenn.edu ❖

CONGENITAL VERTEBRAL MALFORMATIONS STUDY

Researchers at Children's Hospital of Philadelphia are interested in identifying the genetic etiology of congenital vertebral malformations, including congenital scoliosis, congenital kyphosis, Klippel-Feil syndrome, VATER and VACTERL associations, Goldenhar syndrome, Jarcho-Levin syndrome and Spondylocostal Dysostosis. Families

with one or more members are eligible to participate.



Participation includes collection of family and medical histories and a DNA sample. A study newsletter will be published, providing families with updated information on research related to congenital vertebral malformations. Participation is free, travel to Philadelphia is not required and all information is confidential.

✉ Melissa Tonnesen, MS
☎215-590-2928;
tonnesen@email.chop.edu ❖

KLINFELTER SYNDROME STUDY

The NIH Child Psychiatry Branch is conducting a study of the effects of sex chromosomes on brain development. This study hopes to determine if brain imaging studies of children with sex chromosome variations will help uncover core biological features of these conditions.

Volunteers ages 5-25 with any sex chromosomal abnormality (XXY, XYY, XXYY, XXXY, XXXXY) are sought, which involves a visit to the NIH for an interview, brief physical exam, cognitive testing (computer games), brain MRI, blood draw and genotyping.

Participants living outside the DC area receive transportation and lodging for 2-nights for the child and two parents. Additional family members will receive reduced airfare. Participants will receive a summary of results and souvenir photos of their brains.

✉ Liv Clasen, PhD
☎301-435-4513; ClasenL@codon.nih.gov;
<http://intramural.nimh.nih.gov/research/>

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The New York Times, 2/12/02 — “Why Some People Won’t Be Fit Despite Exercise” described several studies to determine the genes involved in a person’s athletic training ability. Genetic Counselor Erynn Gordon is involved in this NIH-supported study to assess how study participants react to learning their genetic profiles with regard to their athletic training abilities.

HHS Website, 2/22/02 — The U.S. Department of Health and Human Services announced the start of “Kids into Health Careers,” a program intended to encourage children to consider careers in the health care field, particularly nursing. As part of the program, participating schools will receive a “tool kit” on more than 270 health care professions, including information on the level of education required for each career and salary projections. Genetic counseling is one of the professions. While the description of genetic counseling on the website is largely accurate, the salary range reported is lower than demonstrated in our Professional Status Survey.

www.bhpr.hrsa.gov/kidscareers/genetic.htm

The Washington Post, 2/26/02 — “How to Build Your Family Tree” stated that “a complete medical family tree, also known as a pedigree, is now seen as the best way to link geneticists and doctors and lead both to diseases concealed in our genes.” Three to four generation pedigrees with ethnicity were recommended, as well as speaking with relatives about family health concerns, especially of early-onset. Joann Boughman, executive vice

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president of the American Society of Human Genetics, was quoted. Several software products and websites that assist with pedigree construction were listed as well. Once the family tree has been assembled, the article suggested asking your physician or a genetic counselor “to help you interpret it all” and recommend further genetic testing, treatment or changes in lifestyle. Ob-gyns are cited as good resources for finding a genetic counselor, as is NSGC’s website.

NPR, CNN, “Good Morning America,” *Time* magazine, *The New York Times*, *USA Today*, BBC, MSN.com, yahoo.com and many others, week of 4/4/02 — All reported findings by a study conducted by Robin Bennett, *et. al.*, regarding the risk of birth defects in the offspring of consanguineous relationships. NPR’s website incorrectly reported that “first cousins can have children together without an increased risk of birth defects.” *The NYT* reported the results more accurately by saying that “contrary to widely held beliefs, first cousins can have children together without a great risk of birth defects or genetic disease.” *The NYT* mentioned that the article is in the current issue of *JGC* and mentioned NSGC, as did CNN. *Time* magazine quoted Robin, who reports that she’s been interviewed by the media in several European countries, Latin and South America and Asia. This research was funded by NSGC, and it clearly put us on the media map!

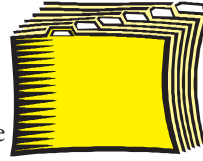
Medscape website, 4/8/02 — “New Genetic Tests Pose Cost, Ethical Dilemmas,” highlighted a panel presentation at the American Association for Cancer Research

meeting. The article quoted Katherine Schneider and noted that in spite of the public perception that genetic tests are 100% sensitive and specific, very few tests meet those criteria.

People, 4/15/02 — In “Clergy Crisis,” Dr. Fred Berlin was quoted as stating “males born with Klinefelter syndrome — an extra female chromosome — appear to have a greater likelihood of developing pedophilia.” The evidence justifying this statement was not provided.

Associated Press Wire, 5/8/02 — “EEOC and BNSF settle genetic testing case under Americans with disabilities act.” This press release reported on a settlement of \$2.2 million for employees of the Burlington Northern and Santa Fe Railway Company (BNSF). BNSF violated the Americans with Disabilities Act of 1990 by genetically testing or seeking to test 36 of its employees for a chromosomal marker for carpal tunnel syndrome without their knowledge or consent. Equal Employment Opportunity Commission (EEOC) Commissioner Paul Steven Miller noted that “...while the EEOC did not find that BNSF had used genetic tests to screen out employees, employers should be aware of the EEOC’s position that the mere gathering of an employee’s DNA may constitute a violation of the ADA.” Nancy Buelow, a board member of Washington-based Genetic Alliance, indicated the need for concrete laws and court decisions about these issues to set precedents. (If the railroad had consulted a genetics professional first, they might have realized that the testing was very unlikely to be positive and only would have indicated an increased risk for carpal tunnel syndrome, not a certainty!) ❖

COMMITTEE & SIG UPDATES



ETHICS SUBCOMMITTEE

Beverly Yashar, PhD, MS & Ethics Subcommittee

While our Code of Ethics can serve as a powerful guide for the practicing genetic counselor, unraveling an ethical dilemma is rarely simple. The Ethics subcommittee provides confidential consultations to help NSGC members work through these conflicts. The committee's response is intended to guide rather than provide directive advice. We offer the following insights from a recent challenging case.

ETHICAL CHALLENGE

A genetic counselor was contacted by adoption social services requesting presymptomatic molecular testing for three children, ages 1-12, who, based on family history and molecular diagnostic testing, are at 50% risk for both von-Hippel Lindau disease and spinocerebellar ataxia. The prospective parents, also family members, have stated that without the molecular results, they will not adopt. The genetic counselor discussed medical screening, presymptomatic testing and special considerations for minors with the social workers. The adoptive parents persisted. *Should the children be tested?*

CONSIDERATIONS

Among our considerations in this case were: the impact of the genetic test results on the future success of the adoption, the possibility of future discrimination if testing occurred and the psycho-emotional impact of the results on the children. We discussed the ethical principles of autonomy and non-maleficence, the NSGC Ethics Code and NSGC, ASHG and ACMG position statements on childhood testing and adoption. A variety of conflicting needs, benefits and risks in this case were confused by the diffi-

culty in defining the client. The desire to provide benefits to these children by facilitating an adoption was considered against the possibility of doing harm.

USING THE CODE OF ETHICS

We considered multiple sections of the Code in our response, including IV.5 on preventing discrimination, III.4 on working with colleagues to provide optimal services and sections II.1-5 on the relationship between genetic counselors and their clients. We were concerned about the appropriateness of using the results of genetic testing in determining the outcome of an adoption and were guided by the ASHG position statement which suggests that genetic testing performed during the adoption process should be consistent with that recommended for all children of a similar age. The Code encourages the making of informed decisions, however it did not obligate the genetic counselor to support a position s/he finds inappropriate (II.4). In the risk-benefit analysis, we considered:

- the importance of the continued involvement by the genetic counselor to provide the highest quality of care
- altering our standard of care based on the client's needs
- the value of encouraging other professionals to reevaluate their practice standards.

This last item had the greatest impact on the outcome, and the children were adopted without genetic testing.

By definition, there is never a single solution to an ethical dilemma. In every ethics consultation, multiple viewpoints are explored with the intent of helping to make an informed decision about resolving the conflict. ♦

Continuing Ed Subcommittee RESULTS OF JGC/CEU SURVEY

Barbara Lerner, MS

This Spring, 344 (31.2%) full members subscribing to NSGC's general listserv completed a survey about their interest in obtaining CEUs for reading the *Journal of Genetic Counseling*. Seventy-two percent of the respondents were certified in 1996 or later, while 27% were Board certified before. Three respondents do not plan to become certified. Of those certified before 1996, 73% still collect CEUs.

Ninety percent of the respondents said they were interested in this program, and 15% of them wanted modifications made to the program as it was described.

The program would cost approximately \$25 to administer, and participants would then be sent a certificate to send to ABGC, along with a \$20 fee, to obtain up to one Category 2 CEU, covering an entire JGC volume. The majority indicated \$25 was a fair administrative fee.

Of importance to the respondents were:

- the ability to obtain Category 1 rather than Category 2 CEUs
- the ability to get partial credit based on the number of tests passed and number of articles read
- a web-based program design for other professional journals in addition to *JGC*.

Our anticipated launch date is February 2003. However, there are several hoops to jump through before we begin. Additional information will follow in future issues of *Perspectives* and in the Winter membership mailing. ♦

✉ Barbara Lerner Lerner@Brandeis.edu

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CLASSIFIED



■ **LITTLE ROCK AR:** July 1 opening for BC/BE Genetic Counselor in busy statewide PNDx svc. GC for all PN indications: in-depth case mgmt & fol/up; terat info svc & triple scrn prog, online med & U/S student educ, oppty for rsrch & tchg. Partic in rapidly expndg telemed PNDx clins.

☞ Shannon Barringer, MS, University of Arkansas for Medical Sciences, 4301 W. Markham, Slot 506, Little Rock AR 72205; ☎800-358-7229; Fax: 501-296-1701, BarringerShannonN@uams.edu. EOE/AA

■ **DUARTE CA:** Two immediate openings: 1) BC/BE GC or RN w/ MS specialty in genetics to join a growing Cancer Scrng & Preventn Prog in S. CA. Exp in Cancer Genetics strongly pref; Span a plus. Cancer risk asmt in on-site & satellite clins, clin rsrch, grant writing, trng MDs & GCs & CME educ activ. 2) BC/BE w/ career focus in cancer genetics rsrch. Fellows complete a paid 1-yr prog of trng in onc, genetics, epidem, rsrch meth, mentored clin trng & rsrch proj.

☞ Ltr & CV: Bernadette Pabillare, Project Coordinator, Dept of Clinical Cancer Genetics, City of Hope National Medical Ctr, 1500 E. Duarte Rd, Duarte CA 91010; ☎626-256-8662; Fax: 626-930-5495; bpabillare@coh.org; www.cityofhope.org/ccgp. EOE/AA

■ **LOS ANGELES CA:** Immediate opening for BC/BE Genetic Counselor. Exp in Adult Genetics/Cancer Risk GC pref. Join active, expndg adult genetics clin. Emph on cancer & cardio risk asmt. GC & educ, partic in rsrch & med/GC/residents & fellow s'vision. ☞ Mark Pinto, MS, GenRISK Program, Cedars-Sinai Medical Ctr, 444 S. San Vicente Blvd, Ste 604, Los Angeles CA 90048; ☎310-423-9911; Fax: 310-423-9946. EOE/AA

■ **LOS ANGELES CA:** Immediate opening for PT or FT BC Genetic Counselor. Abil to work in Span & min 2 yrs exp pref. Primarily PN in busy, expndg Ob/Gyn priv prac.

☞ Maria Moline, MS, GENCO-Genetic Consulting Services, 34 E. Floral Ave, Arcadia CA 91007; ☎909-457-7042; marilomol@aol.com.

■ **ORANGE CA:** Immediate opening for BC PN Genetic Counselor. Excellent clin & org abil & i'personal skills req. GC in Span desired, not req. Join 4 GCs, 5 clin geneticists & 3 add'l human genetics rschrs: PN GC in variety of settings & for didac & clin tchg in GC trng prog; partic in &/or coord clin rsrch prog exp desired. Tchg med students, residents, fellows & other health prof, commun outreach.

☞ CV & 3 ref: Suzanne B. Cassidy, MD, Director, Div Human Genetics, Dept Pediatrics, UCI Medical Center, 101 The City Dr, Bldg 2, 3rd Floor, ZOT 4482, Orange CA 92668; ☎714-456-5870. EOE/AA

■ **PASADENA CA:** Immediate openings for BC/BE Genetic Counselors (2) Pasadena CA & (1) Ft. Lauderdale FL. Crisis i'vention, i'view techniques skills & abil to work i'pendently req. Span &/or Vietnamese pref for CA; Span pref for FL. AMA, MSM scrng, family hx, terat exposure & U/S abnorm.

☞ CV, brief cover ltr & 2 ltrs of rec: Human Resources, Alfigen, Inc, 11 W. Del Mar Blvd, Pasadena CA 91105; Fax: 626-568-9643; HR@alfigen.com. EOE/AA

■ **SAN JOSE CA:** Immediate opening for temp PT BC/BE Genetic Counselor. PN GC svcs at state-approved PDC. Join a team of 4 GCs & 4 perinatologists. GC for AMA, triple marker scrng, fam hx, multiple SAB, infertility, terat exposure & US abnorm. Flex schedule pref w/ antic need 1-4 days/wk May -August/September '02.

☞ Kim Rittenhouse, MS, PhD, Obstetrix Medical Group, 2520 Samaritan Dr, San Jose CA 95124; ☎408-356-1883 x 114; Fax: 408-358-9474. EOE/AA

■ **SAN JOSE CA:** Immediate opening for BC/BE Genetic Counselor. PN GC svcs at state-approved

PDC. Join team of 4 GCs & 4 perinatologists. GC for AMA, triple marker scrng, family hx, multiple SAB, infertility, terat exposure & U/S abnorm. position.

☞ CV & 2 ltrs rec: Kim Rittenhouse, MS, PhD, Obstetrix Medical Group, 2520 Samaritan Dr, San Jose CA 95124; ☎408-356-1883 x 114; Fax: 408-358-9474. EOE/AA

■ **TORRANCE CA:** Immediate opening for PT BC Genetic Counselor. Strong writing & org skills req. Involve in genetics clin & educ progs. Diverse pt pop, estab progs in PNDx & newborn scrng, reg i' action w/ med students, residents & fellows.

☞ Henry J. Lin, MD, Div Medical Genetics, Harbor-UCLA Medical Center, 1124 W. Carson St-E4, Torrance CA 90502; henry_lin@humc.edu. EOE/AA

■ **WASHINGTON DC:** Immediate opening for Director of Innovative International Information Center. BC, 5 yrs exp req. Provide strategic & creative ldrshp of educ outreach prog for pts/clinicians seeking info about genetic/rare conditions; s'vise growing staff of info specialists; foster teamwork; ntwk w/ health advocacy orgs & federal biomed agencies; fundraising; problem-solving; eval/build prog.

☞ Mary Davidson, The Genetic Alliance, 4301 Connecticut Ave. NW #404, Washington DC 20008; Fax: 202-966-8553; mdavidson@geneticalliance.org; www.geneticalliance.org. No phone calls please. EOE/AA

■ **WASHINGTON DC:** Immediate opening for Executive Office Coordinator at fast growing, busy nonprofit. Self-directed, 5-7 yrs exec admin skills req. Strong writing, editing, graphics, computer (MS Office, FileMaker Pro) skills; prob solv, teambldg, multitask skills req. Write, edit, proof documents; coord workload; act as exec office liaison; facilitate ED's schedule/calendar; arrange travel for ED/board; triage/scrn calls, coord board mtgs; maintain nltr & publication system; format & compile workbooks. Salary Range: Mid-upper \$30s w/ good benefits.

☞ N. Muschette, The Genetic Alliance, 4301 Connecticut Ave. NW #404, Washington DC 20008; Fax: 202-966-8553; nmuschette@geneticalliance.org; www.geneticalliance.org. No phone calls please. EOE/AA

■ **WASHINGTON DC:** Immediate opening for Outreach Director. Grassroots health advocacy, strategic plng, coord progs & collab w/ diverse commun. Min 3 yrs commun org req. Excellent writing skills, computer proficiency with MS Word, Excel, databases critical. Enhance access to quality info, policy resources & genetic health svcs by expanding mship & creating public forum ntwk linking consumers, commun orgs, underserved pop, Title V Recipients and govt agencies. Prog devel, fundraising, implement & eval outreach progs.

☞ N. Muschette, The Genetic Alliance, 4301 Connecticut Ave. NW #404, Washington DC 20008; Fax: 202-966-8553; nmuschette@geneticalliance.org; www.geneticalliance.org. No phone calls please. EOE/AA

■ **WILMINGTON DE:** Immediate opening for BC/BE Genetic Counselor. MS in GC, RN w/ Masters or MSW w/ genetic trng. Peds GC exp & BC pref. Peds GC & genetic supt svcs: asst geneticist, assess family, provide fol-up svcs & coord associated svcs.

☞ Resume, specifying position: Human Resources, The Alfred I. duPont Hospital for Children, PO Box 269, Wilmington DE 19899; Fax: 302-651-6119; aid-hr@nemours.org. EOE/AA

■ **FT LAUDERDALE FL:** (See Pasadena CA)

■ **ATLANTA GA:** Immediate opening for Genetic Counselor. PN GC & lab operations interest or exp req. BC pref, not req. Skills: org, flex & abil to handle variety of respon, incl c'hensive pt fol- & back-up for colleagues. Span, incl GC sessions, highly desired. Join team of 10 GCs in acad environ to provide PN GC to reg'l/outreach affiliates & priv perinatology grps.

☞ Cathy Tesla, MS, Emory Genetics Laboratory, 2711 Irvin Way, Suite 111, Decatur GA 30030; ☎404-297-1521; Fax: 404-297-1517;

clt@rw.ped.emory.edu; www.emory.edu. EOE/AA

■ **ATLANTA GA:** (See Research Triangle Park NC)

■ **CHICAGO IL:** Immediate opening for BC/BE Genetic Counselor. Oppty to partic in peds, metab &/or PN GC. Coord rsrch protocol. May work w/ clin DNA & cyto labs &/or partic in trng med, GC students & fellows.

☞ Darrel J. Waggoner, MD, Dept Human Genetics, The University of Chicago, 5841 S Maryland-L161, MC 0077, Chicago IL 60637; ☎773-834-0555; Fax: 773-834-0556; dwaggoner@genetics.uchicago.edu. EOE/AA

■ **INDIANAPOLIS IN:** Summer 2002 opening for BC/BE Genetic Counselor. Excellent written/verbal commun skills req. Exp pref, not req. Excellent oppty to work in growing MFM practice w/ 4 perinatologists & 3 GCs: PN & preconcep GC for variety of indication; some trav to satellite clins. Educ oppty. ☞ Human Resources, St. Vincent Hospital, 2001 W. 86th St, Indianapolis IN 46260; Fax: 317-338-3425; www.stvincen.org. EOE/AA

■ **INDIANAPOLIS IN:** Immediate opening for Genetic Counselor. Exp & BC pref. Join exp team of 4 GCs & 4 MD geneticists in univ ped/genl clins. Coord Indiana Teratogen Svc. GC prog tchg & s'vision. ☞ Susan Romie, MS, Dept Med & Molecular Genetics, Indiana Univ Medical Center, 975 W. Walnut St-1B-130, Indianapolis IN 46202; ☎317-274-1061; Fax: 317-274-2387; sromie@iupui.edu. EOE/AA

■ **BALTIMORE MD:** Immediate opening for BC/BE Genetic Counselor. Biologic or biochem lab exp req. Assist clin and lab dx for inborn errors of metab. GC & supt svcs for pts, incl design & coord clin rsrch studies, biochem analysis for ongoing clin studies. ☞ Ref Job #7270, c/o KKI Resume Processing Center, 28501-A Ryan Rd.-A-105, Warren MI 48092; apply online www.kennedykrieger.org. EOE/AA

■ **BOSTON MA:** Immediate opening for BC/BE Genetic Counselor. Some exp pref, not req. Busy molec DNA dx prog & PNDx prog. Involve in MSAFP prog. Rsrch oppty avail. Newly available: PN GC in hi-risk OB clin & partic in med genetics clin. ☞ Aubrey Milunsky, MD, DSc, Boston University School of Medicine, 700 Albany St-Suite W-408, Center for Human Genetics, Boston MA 02118; Fax: 617-638-7092; amilunsk@bu.edu. EOE/AA

■ **BOSTON MA:** Immediate opening for BC/BE Genetic Outreach Manager at neurodegeneration & repair ctr. Exp pref. Oversee genetic rsrch studies: IRB appl process, collect study samples, track study progress. Org & implement genetic educ for study coordinators. ☞ Gretchen Schneider, MS, Harvard-Partners Center for Genetics and Genomics, 77 Avenue Louis Pasteur, HIM Suite 640, Boston MA 02115; ☎617-525-5752; gschneider@partners.org. EOE/AA

■ **BOSTON MA:** Immediate opening for BC/BE Genetic Studies Coordinator. Rsrch exp pref. Strong org skills & abil to work i'pendently a plus. Join HMS Center for Neurofibromatosis & Allied Disorders. Coord rsrch collab, write & submit IRB protocols, recruit pts, obtain informed consent, track study progress. Respond to inquiries about clinical svcs & rsrch oppty, partic in educ endeavors. ☞ Gretchen Schneider, MS, Harvard-Partners Center for Genetics and Genomics, 77 Avenue Louis Pasteur, HIM Suite 640, Boston MA 02115; ☎617-525-5752; gschneider@partners.org. EOE/AA

■ **BOSTON MA:** Immediate opening for PT (32 hrs) BC/BE Genetic Counselor. 2 yrs exp desired. Join 2 GCs & 1 MD geneticist in busy multispec prac.GC for PN genetics, peds & adult genetic conditions. Oppty for growth.

☞ Susan Mecas-Faxon, MS or Alexis Poss, MS, Harvard Vanguard Medical Associates, 133 Brookline Ave, Boston MA 02215; ☎617-421-3320; Fax: 617-421-1355. EOE/AA



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■ **CAMBRIDGE MA:** Immediate opening for FT or PT Genetic Counselor. Excellent commun, org & i'personal skills req. Famil w/ Progeny software desired. I'view male applicants for anonymous semen donor prog. Obtain detailed info re: applicant's personal & fam med hx, draw pedigree & eval suitability of donor for program. Facil donor genetic tstg & scrng; provide results & approp follow-up.
 ☞ Marilyn Ray, MPH, California Cryobank, Inc, 1019 Gayley Ave, Los Angeles CA 90024-3401; ☎800-231-3373x21; ☎310-443-5244x21; Fax: 310-443-5258; mara@cryobank.com. EOE/AA

■ **WORCESTER MA:** Summer/Fall opening for temp FT (July - Oct) Genetic Counselor. BC/BE req. Respon: contact physicians with positive test results, assist physicians with GC issues, collect clin/fam hx info, assist lab director on case-specific issues & coord rsrch collab.
 ☞ Kara Houde Ng, MS; Athena Diagnostics, 377 Plantation St - 4 Biotech Park, Worcester MA 01605; ☎800-394-4493x3021; khoude97@hotmail.com. EOE/AA

■ **ANN ARBOR MI:** Immediate opening for PT (50%) BC/BE Genetic Counselor. Strong commun skills & willingness to share expertise w/ progressive, multidisc team of perinatologists, GC, U/S techs & perinatal nurses req. Join Perinatal Assmt Ctr w/ exposure to broad range of genetic issues; inter-dept acad oppty.
 ☞ K. Hanlon-Lundberg, MD or Rajani Aatre, MS, OB/GYN Dept, Univ of Michigan Health System, 1500 E. Medical Center Dr-L4000 Women's Hospital, Ann Arbor MI 48109-0264; ☎734-764-1406 (KH-L); ☎734-763-4264 (RA). EOE/AA

■ **ROBBINSDALE (MINNEAPOLIS) MN:** Immediate opening for BC/BE Cancer Genetic Counselor.

Cancer risk exp. pref; will consider new grads. Join expndg, onc-based cancer genetics program (IGC & 1 oncologist). Provide c'hensive cancer GC svcs.
 ☞ Barb Steffes, Human Resources, North Memorial Health Care, 3300 Oakdale Ave, Robbinsdale MN 55422; ☎763-520-5317; Fax: 763-520-5228; barb.steffes@northmemorial.com. EOE/AA

■ **ASHEVILLE NC:** Immediate opening for BC/BE Regional Genetic Counselor. Self-motiv, well-org & team player skills req. Some travel req. Join state Public Health Genetics Prog. GC in peds satellite clins, reg'l health depts. Commun educ.
 ☞ Elizabeth G. Moore, Director, Genetics Health Care Program, 1928 Mail Service Center, Div Public Health, Raleigh NC 27699-1928; ☎919-715-3420. EOE/AA

■ **RESEARCH TRIANGLE PARK, NC:** Immediate opening for BC/BE Lab Genetic Counselor. Min 2 yrs exp req. Coord pre-and post-analytical phase of specimen tstg, report results, act as client liaison, provide client and in-house educ through lectures and written materials, phone GC for pts. Add'l openings for BC/BE GCs to provide PN pt GC in Philadelphia PA and Atlanta GA. Work independently, oppty for GC beyond PN. Prof growth, unique career path, commun educ.
 ☞ EM or fax 2 ltrs rec & CV: Trisha Brown, MS, AVP, LabCorp, 5503 Darby Rd, Rocklin CA 95765; ☎877-396-3438; Fax 916-435-9533; brownt@labcorp.com. EOE/AA

■ **NEW BRUNSWICK NJ:** Immediate opening for BC/BE Genetic Counselor. Multidisc cancer genetics prog; clin svcs onsite & at affiliate institutions, coord NCI grant funding educ progs for health care prof.

☞ Jill C. Baran, MS, The Cancer Institute of New Jersey, 195 Little Albany St, 2nd Floor Alcove, New Brunswick NJ 08903; ☎732-235-9652. EOE/AA

■ **ALBUQUERQUE NM:** Immediate opening for BC/BE PN Genetic Counselor. 1-2 yrs exp pref, students may apply. Oppty for wide variety of PN & preconcep cases, outtrch opptys.

☞ Apply online: www.unm.edu or Katherine Hunt, MS, Dept OB-GYN, University of New Mexico School of Medicine, 2211 Lomas NE - 4ACC, Albuquerque NM 87131; ☎505-272-6315; Fax: 505-272-1311. EOE/AA

■ **NEW YORK NY:** Immediate opening for BC/BE Genetic Counselor. Cancer GC exp pref w/ min 2 yrs exp. Proven ability to work i'pendently, as well as on team; demonstrated writing & public spkg skills req. Join Continuum Cancer Centers of NY, a multisite, hosp-based, cancer genetics team. Opptys for prog devel, rsrch, prof & public outrch.

☞ Bert M. Petersen, Jr, MD, Beth Israel Medical Center, 10 Union Square East-4E, New York NY 10003; ☎212-844-8955; Fax: 212-844-8954; bpetersen@bethisraelny.org. EOE/AA

■ **AKRON OH:** Immediate opening for BC/BE Genetic Counselor. Cancer exp pref. Join 5 GCs & 2 MDs in dynamic reg'l ctr. Prim focus cancer GC & cancer prog devel; back-up for PN, peds, adult & educ prog.
 ☞ Attn: HR, Children's Hospital Medical Center of Akron, One Perkins Square, Akron OH 44308; Fax: 330-543-3176; hresources@chmca.org; www.akronchildrens.org. EOE/AA

■ **COLUMBUS OH:** Immediate opening for BC/BE Genetic Counselor. Exp pref, not req. Join busy, univ-based perinatal prac: PNDx clins, weekly conf w/ opptys for tchg & prog devel. Interact & collab w/ multidisc genetics network.
 ☞ Betsy Schmalz, MS, Ohio State Univ, 546 Means Hall, 1654 Upham Dr, Columbus OH 43210; ☎614-293-4716; Fax: 614-293-8993. The Ohio State University is an equal opportunity/affirmative action employer. Qualified women, minorities, Vietnam era veterans and individuals with disabilities are encouraged to apply.

■ **COLUMBUS OH:** Immediate opening for BC/BE Cancer Genetics Counselor to join 4 cancer genetics counselors and 3 geneticists in busy clinical cancer genetics prog. Exp in cancer risk GC pref. GC pts for potential hereditary risk; coord rsrch protocols; partic in writing grants and IRB protocols; provide public and prof presentations. Salary Range: \$45-60,000.
 ☞ Jane S. Pierce, Administrative Associate, E308 Doan Hall, 410 W. 10th Avenue, Columbus, OH, 43210; ☎614-293-7775; Fax: 614-293-7435, pierce2@medctr.osu.edu. The Ohio State University is an equal opportunity/affirmative action employer. Qualified women, minorities, Vietnam era veterans and individuals with disabilities are encouraged to apply.

■ **OKLAHOMA CITY OK:** Immediate openings for 2 BC/BE Genetic Counselors. Join growing clin genetics prog. GC for wide variety of indications incl genrl peds, metab disorders, adults, cancer & pre-sympt tstg for adult-onset disorders. Excellent oppty for rsrch & tchg. Univ-based fac position. New GC Trng Prog in last stages of devel, to provide add'l opptys for tchg & admin, depending upon cert & desire.
 ☞ Send ltr of interest, CV, & names of 2 prof ref: Susan Hassed, MS, OU Medical Center - Children's Hospital Room 2B 2418, 940 NE 13th St, Oklahoma City OK 73104; ☎405-271-8685; Fax: 405-271-8697; susan-hassed@OUHSC.edu. EOE/AA

■ **OKLAHOMA CITY OK:** Immediate opening for BC, BE Genetic Counselor / Public Health Genetics Education Coordinator. Self-directed, creative, innovative, interest in public health genetics and program development, trav req. Partic in establishing c'hensive statewide genomics educ prog for prof & public, collab with state genetics advisory council assist genetics program, newborn scrng program and the birth defects registry; Play essential role in implementing Oklahoma State Genetics Plan: assessmt, policy devel & QA; collab w/ nat'l stakeholders, local genetic ctrs & health care providers; oppty to address genetics from preconcep to adults. Salary range \$32,000 - \$48,000.
 ☞ Cov ltr, CV & 2 prof ref: Pam King, MPA, RN, State Genetics Coordinator, OSDH, 1000 NE 10th St-Room 709, Oklahoma City OK 73117-1299; ☎405-271-9444x56737; fax: 405-271-4892; pamk@health.state.ok.us. EOE/AA

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from previous page

■ **PHILADELPHIA PA:** Immediate opening for BC/BE Genetic Counselor. New grads invited to apply. Coord clin & rsrch proj studying Cornelia de Lange Syndrome & genetics of hearing loss: estab (CdL)/run (HL) multidisc clins. Other rsrch & clin opptys also avail.

☞ Cov ltr, CV & 2 prof ref: Ian Krantz, MD, Div Human Genetics and Molecular Biology, 1002 Abramson Research Center, The Children's Hospital of Philadelphia, 34th St & Civic Center Blvd, Philadelphia PA 19104; ☎215-590-2931/2828; Fax: 215-590-3850; ian2@mail.med.upenn.edu. EOE/AA

■ **PHILADELPHIA PA:** Immediate opening for BC/BE Pediatric Cardiology Research Genetic Counselors. Interest in major rsrch prog on genetic etiology of congenital heart disease req. Recruit & GC families w/ children w/ congenital cardiac defects, partic in many aspects of rsrch. Opptys for limited clin partic.

☞ Apply online or by fax, Job Ref ID 41: Children's Hospital of Philadelphia, Philadelphia PA; Fax: 215-590-4644; <http://careers.chop.edu>. EOE/AA

■ **PHILADELPHIA PA:** (See Research Triangle Park NC)

■ **GREENWOOD SC:** Immediate opening for BC/BE Genetic Counselor. Join active group of 9 BC medical geneticists & 9 GC located throughout state. Primarily peds w/ approx 10% PN & cancer. Opptys to partic in genetic educ and rsrch. Onsite state-of-the-art cyto, biochem & DNA dx labs.

☞ Dr. Laurie Seaver, Greenwood Genetics Center, 1 Gregor Mendel Circle, Greenwood SC 29646; ☎888-GGC-GENE; lseaver@ggc.org. EOE/AA

■ **MEMPHIS TN:** Immediate opening for BC/BE Genetic Counselor. Exp pref. Join 3 clin geneticists & 3GC/RN's in univ setting, the only full svc genetic team in city. Wide range of oppty: dysmorph, spec clins for newborn scrng, tchg.

☞ Dr. Jewell C. Ward or Diana Chambers MS, Center for Health Sciences, Univ of Tennessee-Memphis, 711 Jefferson # 523; Memphis TN 38105; ☎901-448-6595; Fax: 901-448-4117; dchambers@utmem.edu. EOE/AA

■ **DALLAS TX:** Immediate opening for BC/BE Genetic Counselor. Coord serum scrng prog & PN genetics clins, GC for PN indications, weekly fol-up w/ pts w/ dx abnorm, resident/fellow educ in genetics/GC, partic in weekly U/S abnorm conf &

biweekly ped/PN conf.

☞ Phyllis Avery, Parkland Health & Hospital System, 5201 Harry Hines Blvd, Dallas TX 75235; ☎214-590-6857; Fax: 214-590-2767; pavery@parknet.pmh.org; mgibbs@parknet.pmh.org; www.pmh.org. EOE/M/F/D/V

■ **GALVESTON TX:** Immediate opening for BC/BE Genetic Counselor. Exp & Span pref. Join busy, univ PNDx unit w/ 7 MFM specialists. Respon incl face-to-face & telemed GC for PN indications, work w/ ongoing OB rsrch grants. Opptys for prof educ.

☞ Jennifer M. Lee, MS, FASTER Clinical Coordinator, UTMB at Galveston, 301 University Blvd, Rm 3.305 UHC, Galveston TX 77555; ☎409-747-8234; Fax: 409-772-2989; jmllee@utmb.edu. EOE/AA

■ **HOUSTON TX:** Immediate opening for BC/BE Genetic Counselor. Join well estab, large acad genetics group in new position: 15 geneticists, 1 GC & fellow. Work w/ inpt ped consults, NF & adult clins.

☞ Katie Plunkett, MS, Baylor College of Medicine, 6621 Fannin CC1560, Houston TX 77030; ☎832-822-4295; Fax: 832-825-4294; plunkett@bcm.tmc.edu. EOE/AA

■ **HOUSTON TX:** Immediate opening for BC/BE PN Genetic Counselor. Span req. Outrch in commun clins w/ diverse pt pop, 95% Span spkg. Flex, autonomy req. Join 5 OB/geneticists, 3 MFMs & 2 GCs.

☞ Katie Plunkett, MS, Baylor College of Medicine, 6621 Fannin CC1560, Houston TX 77030; ☎832-822-4295; Fax: 832-825-4294; plunkett@bcm.tmc.edu. EOE/AA

■ **SALT LAKE CITY UT:** Immediate openings for BC/BE Genetic Counselors. Cancer GC exp pref. Strong public spkg skills req, willingness to trav. Primary respon: educ health care prof re: hereditary risk asmt & genetic tstg through didac lectures, on-site case reviews & trng. Secondary respon: ongoing clin supt for health care providers offering risk asmt/

tstg, cont educ to sales force, lectures to commun & health care prof groups interested in hereditary cancer. ☞ Email cov ltr & resume: Heather L. Shappell, MS, Myriad Genetic Laboratories, 320 Wakara Way, Salt Lake City UT 84108; hshappel@myriad.com. EOE/AA

■ **FAIRFAX VA:** Opening for BC/BE Genetic Counselor. Excellent commun skills req. Abil to work in i'pendent setting req in i'natl-known PN genetics, dx lab & repro techn spec ctr. Join exp GCs, med & lab geneticists in busy PN genetics prac providing c'hensive dx svcs. Phone commun with pts & clients. ☞ Lee Fallon, MS, Genetics & IVF Institute, 3022 Javier Road, Fairfax VA 22031; lfallon@givf.com. EOE/AA

■ **RICHMOND VA:** Immediate opening for BC/BE Genetic Counselor. Knowledge of PH principles & prac, birth defect surveillance & educ req; excellent org, admin, plng, verbal & written commun skills & demonstrated abil to mng statewide proj, analyze & interpret data & use computer & information systems also req. Work w/ statewide birth defects

registry (VaCARES, Virginia Congenital Anomalies Reporting & Education System) to enhance birth defects surveillance, preven & educ at VA Dept Health in collab w/ state genetics ctrs, health prof, CDC, commun groups & fams.

☞ Send CV, cover ltr & 3 ltrs ref: Joann Bodurtha, MD, MPH, Dept Human Genetics, Virginia Commonwealth University, Box 980033, Richmond VA 23298. EOE/AA

■ **BELLEVUE (SEATTLE) WA:** Immediate opening for BC Genetic Counselor. Abil to work i'pendently, excellent commun skills req. Program admin skills pref. Trav btwn 2 sites likely req. Join 3 MFMs & 1 rad to provide c'hensive PNDx svcs: serum scrng, AMA, abn U/S, fm hx, terat etc.

☞ Martin Walker, MD, Eastside Maternal-Fetal Medicine, 1125 116th Ave NE Suite 320, Bellevue WA 98004; ☎425-688-8111; Fax: 425-688-8111; martin_walker@obstetrix.com. EOE/AA

■ **KIRKLAND WA:** Immediate opening for BC/BE Genetic Counselor. , 2-3 yrs clin exp pref. Strong i'personal, verbal, written, org, planning skills; flexible, multi-task, i'pendent req. Join thriving hosp-based MFM clin team of 2 GCs, 4 perinatologists, RNs, sonographers providing multidisc MFM svc: serum scrng, AMA, abnormal U/S, family hx, terat. Trav btwn 2 sites req.

☞ Ellen Conroy, HR Specialist, Evergreen Hospital Medical Center, 12040 NE 128th St, Kirkland WA 98034; Fax: 425-899-2510; erconroy@evergreenhealthcare.org. EOE/AA

■ **HUNTINGTON WV:** Immediate opening for Research Genetic Counselor. GC Masters req. Exp in genetic rsrch pref. Join Appalachian Cardiovascular Research Network (ACoRN). Respon: pt ID, GC, data collect & pedigree analysis. Salary: \$45,000.

☞ Donald Primerano, Dept Microbiology, Marshall University, Joan C. Edwards School of Medicine, 1542 Spring Valley Dr, Huntington WV 25704. EOE/AA

In Canada

■ **MONTREAL, QU:** Immediate opening for Pediatric Genetic Counselor. MS in GC, rsrch & peds exp req. Excellent knowledge of French & English, computer skills, spoken and written. strong clin & consult skills, org, commun & i'personal skills all req. Abil to work on team & interact w/ different levels of staff. Knowledge of supt systems to guide fam. Primary respon: biomed genetics: provide asmt, GC & fol-up care to ind, parents & fam, act as liaison for commun/supt groups. Partic in policy making & implement prac protocols, estab & implement QA progs. Salary range \$ 659.97 - \$ 1,218.84/wk.

☞ Nancy Newman, Personnel Management Agent, HR Services, The Montreal Children's Hospital of the McGill University Health Centre, 2300 Tupper Street, Montreal, QU CANADA H3H 1P3; ☎514-412-4403; Fax: 514-412-4387; nancy.newman@muhc.mcgill.ca. EOE/AA