# PERSPECTIVES in genetic counseling

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national society of genetic counselors, inc.



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

### Table of Contents

Public Relations and AEC 1
Grant and Support Awarded to NSGC. 1
Website Updates 1
President's Beat 2
Board Meeting Highlights
Genome Celebration
Exec Office Committee Final Report 4
Logo Deferred4
On the Road5
AEC03 Info
AEC04 Applications
Letters to the Editor 8
Then and Now 9
Research Network9
Resources
NHGRI News
Media Watch
Committee & SIG Updates 13
Classified

NSGC gratefully acknowledges Athena Diagnostics, Worcester, Massachusetts

for a generous grant to support this newsletter. See ad, p. 15



# PR Intersects with Annual Conference

Bea Leopold, MA

wo public relations successes showcased at our Annual Education Conference in Phoenix created quite a stir. First, our team at STAR/Rosen Public Relations created a plan that increased awareness of genetic counseling. Second, Sarah Richter Cox orchestrated a Consumer Outreach Program, in which dozens of consumers learned about breast cancer risks.

### VERTICAL AND HORIZONTAL PUBLIC RELATIONS PLAN

"Our team reviewed all of the abstracts to determine which were most newsworthy," said **Karen Cutler,** Senior VP and Partner at STAR/Rosen. "We selected the Alzheimer's research to reach the broad consumer and health reporters, and the multicultural research to target specific Hispanic and Asian media outlets, as well as the mainstream press."

This plan was initiated to draw interest in abstracts that related to the Alzheimer's REVEAL study and for follow-up results to the abstracts and plenary session related to issues in multicultural counseling. The PR team spearheaded the following:

• DRAFTED AND ISSUED MEDIA ALERTS.

We released an Alzheimer's alert on the New York Metro wire and to national contacts. A multicultural alert was released on the New York Metro wire and through national contacts. It was translated into Spanish and released on the National Hispanic

# Grant Writing Seminar Funded by TKT, NHGRI

s we go to press, we have learned that NSGC has been awarded a \$75,000 grant from Transkaryotic Therapies, Inc, to facilitate a 2-day grant writing seminar. Additional support has been committed by National Human Genome Research Institute. The seminar will be held June 22-23.

Full and Associate members of NSGC will be eligible to apply. What can you do now if you are interested in expanding your research skills? Jot down those research ideas, and check your mailbox in February. ❖

### **New Website Documents**

The 2002 Professional Status Survey, expanded and enhanced, will soon be available online.

rep

www.nsgc.org/CareerInformation.asp

Participate in our Annual Education Conference survey.

www.nsgc.org

New! Our Online Bookstore is open for business.

www.nsgc.org/amazon\_books.asp

### Coming Soon...

- Website redesign for enhanced navigability.
- IF JEMF & AHSPA (formerly Special Fund) proposals accepted online
- Get your computers ready! *PGC* is going online! Stay tuned. ❖

### PRESIDENT'S BEAT

y feet barely touched the ground — literally — as I flew home from Phoenix on a Thursday and turned around on Monday to attend the "Airlie II" Conference<sup>1</sup> in Virginia to engage in Strategic Planning for the National Human Genome Research Institute (NHGRI). It was an honor to represent NSGC at this visionary meeting. While the focus of the meeting covered the science of genetics, several of us clearly carried the message that the implementation of the Human Genome Project requires an increase in the workforce, including genetic counselors and funding for genetic counselor training programs. The final strategic plan will be released in April at the 50 year anniversary celebration of Watson and Crick's discovery of the structure of DNA. NSGC's Board of Directors will be meeting in conjunction with these landmark events to assure genetic counselor visibility. Mark your calendars for April 25th, "DNA Day."2

### STRATEGIC PLANNING

In anticipation of NSGC's strategic plan expiring at the end of 2003, the Board approved funding to engage a professional group to conduct strategic planning, beginning with an environmental scan to measure the pulse of our profession — how we are perceived by our members and the many external communities with whom we engage. The goal is to anticipate where we want NSGC and our profession to be positioned in the future. We will attempt to answer tough questions about how genetic counselors and NSGC are perceived by related and peripheral health professionals, consumers, industry and

Perspectives in Genetic Counseling 24:4 — Winter 2003

third party payors. The voice of NSGC's membership will be essential in this process. I have appointed a committee to conduct some initial strategic brainstorming about the

questions we need to be asking.

### FUND RAISING

The future is bright for NSGC as we begin this year with a \$1.5M endowment for the **Jane Engelberg Memorial Fellowship**. The **Engelberg Foundation** will manage the endowment and interest will be applied to the actual fellowship grant.

We are also grateful to receive from Mr. Al Engelberg a \$25,000 donation for the Audrey Heimler Special Projects Award. We are already receiving many generous donations from NSGC's membership as well as Audrey Heimler's family and friends.

We are in the process of setting up an NSGC Foundation. The Finance Committee is organizing a Development Subcommittee to explore funding for NSGC's future.

Our new amazon.com affinity program has just gone live. Don't forget to order birthday and graduation gifts through our website link. It's a great place to find books related to specialized genetic counseling topics ...and earn money for NSGC.<sup>3</sup>

#### **FURTHER OPPORTUNITIES**

Some other areas we will be focusing on over the next year include:

- examining and possibly revising the definition of genetic counseling
- partnering with ASHG and Genetic

Alliance to explore a family history education campaign, to be launched next Thanksgiving

• conducting a grant writing seminar, with funding from

NHGRI and Transkaryotic Therapies (TKT)

• taking an aggressive approach to issues of

Billing and Reimbursement

### **LEADING VOICES**

"The future is

bright for NSGC..."

Our 2002 Annual Education Conference was vibrant with energy, as evidenced during the committee meetings, in hallway discussions and at the Board meeting. The Board will acknowledge the amazing work of our membership over the next year with the "Leading Voices" program. Between now and our September meeting in Charlotte, members of the Board will send acknowledgement notes to NSGC members who are leading voices for our profession, as expressed through committee work, publications, representation at regional and national meetings and other activities. Each note will signify entry into a drawing for gift certificates from Amazon.com to be presented in Charlotte — the greater your participation in NSGC, the greater your chances of winning!

I look forward to representing NSGC and working with you over the next year. Happy Holidays!

Robin Bennett, MS, CGC President, 2002-2003

Wolia R. Bearely

#### RESOURCES

- Airlie II webcast and celebration sctivities www.genome.gov
- Learn about becoming a mentor for a local K-12 classroom Visit nhgriedk@mail.nih.gov or www.faseb.org/genetics/ashg
- NSGC amazon.com Bookstore: www.nsgc.org/amazon\_books.asp

### OUR FUTURE IS NOW

Cathy Wicklund, MS

nother highly productive Board meeting took place in Phoenix on November 13th, following the closing of the annual education conference. Many exciting issues were discussed including billing and reimbursement, lobbying, licensure and the future of the executive office.

### THINK BIG, THINK FUTURE

### **Executive Director, Bea Leopold,**

kicked off the meeting with an exercise that challenged us to think about our vision and our future.

**President Robin Bennett** discussed the opportunity of applying for an educational grant from **Transkaryotic Therapies (TKT)** to sponsor a grant writing seminar for NSGC full and

associate members. (See p 1)

Community Self-Indexing (CSI) will soon be available on a trial basis to members. The concept is to help members network by inviting them to share information about themselves in a secured database. CSI's goal is to increase connectivity among our members. The program will be launched in early Spring.

### TASK FORCES TACKLE EXEC OFFICE; BILLING AND REIMBURSEMENT

The Executive Office *ad hoc* Committee completed three years of work and submitted its report. (See p 4)

The final copy of the Billing and Reimbursement Task Force's recommendations was submitted. In addition to hiring a consultant to obtain outcomes research, three categories of opportunities were noted:

- Organizational those activities that NSGC can develop and provide to members
- COLLABORATIVE joint efforts with other professional organizations
- INDIVIDUAL MEMBERSHIP solutions that are the responsibility of members.

By combining these strategies, the report recommended, we can systematically begin to improve billing and reimbursement for genetic counseling services.

The Licensure Task Force submitted a draft of a document that will help genetic counselors write a genetic counselor licensing bill. Further input will be solicited; the final document will be presented to the Board in April.

The Partnership Task Force submitted a first draft of guidelines for future partnership opportunities. Their efforts will continue to create a working document.

The logistics of forming a Foundation continue. Information regarding cost and maintenance has been gathered. A mission, budget and business plan will be developed before the next Board meeting. Look forward to more updates in future issues of *PGC*.

Lyle Dennis, partner in a DC lobbying firm, gave an informative presentation on lobbying and the pros and cons of hiring a lobbyist. Past President I, Kathy Schneider, and Social Issues, Chair, Cheryl Scacheri, presented three models; have volunteers within NSGC continue their lobbying efforts, hire a genetic counselor as our lobbyist or hire a professional lobbyist. A lively discussion followed examining the benefits and limitations of each option. More information needs to be gathered to make an informed choice. ❖

50 Years of DNA: From Double Helix to Health

### APRIL '03 SET FOR GENOME CELEBRATION

**April 2003** will witness the historic culmination of the sequencing of the human genome. It will also mark the 50<sup>th</sup> anniversary of **James Watson** and **Francis Crick**'s Nobel Prize winning description of the DNA double helix and will launch a landmark scientific report that will describe the future of the field of genomics. To mark these events, NHGRI is planning a month-long series of scientific, educational, cultural and celebratory events.

**April 13** — The opening of a preview of a genomic exhibit, "Genome: The Secret of How Life Works" at the Smithsonian Institution's Arts and Industries Building, produced by Clear Channel Communications with support from Pfizer, Inc. The full exhibit will open at the Smithsonian in June 2003. Genetic Counselor **Amanda Bergner**, Johns Hopkins University, was interviewed for her perspective of the art of genetic counseling for the exhibit.

**April 14 - 15** — A two-day scientific symposium will be web cast within NIH and to institutions around the world. Participants—including **James Watson** and members of the International Human Genome Sequencing Consortium—will describe the science and history of the Human Genome Project. In addition, the symposium will explore the future of science and medicine made possible by breakthroughs in genomic science and will include the unveiling of NHGRI's new strategic plan. NHGRI will bring in teacher-student pairs from across the U.S. to Washington DC to participate.

**April 12 - 14** — NSGC's Board of Directors has scheduled its Interim Board of Director's meeting in DC to enable us to have a presence at some of the events and celebrations. **STAR/Rosen** is planning a Media Tour to ensure that genetic counseling remains visible within the framework of the events. ❖

### **EXECUTIVE OFFICE & OUR FUTURE**

### Lisa Amacker-North

n 1999, the Executive Office ad hoc Committee (EOC) was established to look at issues related to the future needs of the executive office. This committee was appointed at the request of Executive Director **Bea Leopold** to ensure that a succession plan was in place. "It's important to plan ahead before the clock starts ticking down toward an actual departure date.," said Bea. "Succession planning is acting responsibly toward NSGC's future."

### HISTORICAL DATA

In 1987, **Bea Leopold** was contracted to provide meeting planning services for NSGC. The following year, she became our first Executive Director. Since that time, NSGC has expanded from a membership of 600 to greater than 2000 and from no planned budget to one in excess of \$1M. Bea

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Perspectives in Genetic Counseling 24:4 — Winter 2003

began with one high-school student who did the mailings to a current staff and consultant group numbering nine.

### **COMMITTEE ACTIVITIES**

Over these past three years, the EOC conducted research via a membership survey and a visit to the office to interview staff. We researched the management options, including:

- a review of other professional associations' management
- the creation of a spread sheet of financial estimates for costs of relocating and expanding staffing
- a review of options for processes of hiring a new Executive Director.

In 2002, as a result of the work we had accomplished, we wrote threemonth and one-year transition plans. The plans were designed to provide a road map for the future Board of Directors to aid in the transition of our organization's Executive Office to a new location, under a new Executive Director. Key issues addressed were location of the office and professional background of the new top executive.

### CHAIR'S RECOMMENDATIONS

When the topic of a future change in the EO arises, many people have strong opinions about where we should be and who should be leading our office. As chair of this committee, I recommend that we separate the issue of where we are located and who runs the office from the issues of wanting a stronger presence in Washington DC. The majority of the work of our Executive Office includes strategic planning, meeting planning, communications, member relations, staff management, fund raising, marketing and Board of Directors support. All of these functions require expertise in association management regardless of where the office is located. �

NOTE: NSGC gratefully acknowledges the following members for serving NSGC on this committee:
Lisa Amacker North (Chair),
Judith Benkendorf, Ginny Corson,
Cindy Soliday, Angela Trepanier and
(ex officio) Kathy Schneider and Bea
Leopold.

### NEW NSGC LOGO ON HOLD

### Liz Stierman, MS

As part of our ongoing efforts to publicize genetic counseling, NSGC is updating its image--including a new logo.

In Round 1, we explored several logo concepts: a stylized DNA with a human element, a globe symbolizing that everyone is touched by genetics and a compass depicting our role as the leading voice for our profession.

Members were invited to give input, online or at the Annual Education Conference. The response was overwhelming ...but not very enthusiastic. We decided that rather than tweaking these motifs, we will start over to find a symbol that better represents us.

In the meantime, NSGC task forces are assembling, one to update our definition of genetic counseling and another on strategic planning. We've decided to delay logo development until a definition is finalized to enable the new logo to fit conceptually.

Thanks to all of you who took the time online and at the conference to voice your opinion. It mattered! Stay tuned for further developments. •

# SIG OUTREACH TO NATIVE AMERICAN GROUP DEEMED A RESOUNDING SUCCESS

Ana Morales, MS

product of my involvement with the Diversity SIG was an opportunity to speak at the annual meeting of the Society for Advancement of Chicanos and Native Americans in Science (SACNAS). Soon after I joined this SIG, I connected with Gloria Sánchez because of my interest in promoting the genetic counseling profession in Puerto Rico.

Gloria talked about her plans to write a proposal to present at the 2002 SACNAS conference, and she asked if I would be interested in speaking. What followed was one of the most fulfilling experiences I have had in my relatively short professional life! Thanks to Gloria, I met key individuals from Mexico and Puerto Rico who are interested in the field of genetic counseling.

During meals at SACNAS we met students, professionals and college recruiters from many different locations and ethnic backgrounds. Our conversations usually revolved around our profession and about the increasingly important role of genetic counselors in modern healthcare practice.

#### **AWARENESS**

The SACNAS conference also helped to increase my awareness about the Native American culture. I learned about surnames, tribes, words, art and physical features. On Friday night, we went to the SACNAS Pow Wow, a ceremony honoring this traditional Native American gathering.

Our talk, "The Genetic Counseling Profession: Expanding and Diverse Career Opportunities," was part of a group of presentations that were scheduled to take place simultaneously. The room was almost filled to capacity. Our diverse

audience included students and a SACNAS executive who seemed to be very curious about our talk.

Our presentation was sprinkled with diversity as well. We had Gloria, who has been a genetic counselor for many decades, **Ana Martínez**, a genetics nurse, and me, a recent genetic counseling graduate working in a non-traditional role.

### PRESENTING DIVERSITY OF FIELD STIMULATED INTEREST IN CAREER

During our talk, Gloria defined "genetic counseling" and outlined important historic milestones of our profession. She also talked about traditional and non-traditional roles and explained how to become a genetic counselor.

Then Ana presented an inspiring personal vignette narrating how she became a genetics nurse. I talked about my experience in the genetic counseling field and described my job position, emphasizing that the NSGC is interested in better reflecting the population we serve. At the end, we had an open discussion about timely ethical, legal and social issues in genetics.

After the talk, many students approached me about their interest in pursuing a genetic counseling career.

'...one of the most fulfilling experiences I have had in my relatively short professional life!'



### **ACCOLADES**

Our presentation was ranked with no less than a 4 out of 5, for "excellent" and the audience's written comments showed that we had made an important difference.

We were most proud when the SACNAS executive, who had been paying close attention to our presentation, approached Gloria to tell her how much he had enjoyed our talk. He added that they'd love to invite us again next year to present at the teacher's workshop, one of the most important activities at the SACNAS annual conference.

### FOLLOWING THE FOOTSTEPS

While flying back home, I realized that I had given NSGC a voice at SACNAS, one of the most influential and solvent organizations advocating for the professional advancement of minorities in the United States. I am already looking forward to next year in New Mexico. I hope that in 2003, I can tell you about my experience at the teacher's workshop. •

### PR Activity from p. 1

Business/General News wire.

- On Air Interviews. NSGC member **Tamsen Brown** was interviewed by ABC National Radio regarding her work in the Alzheimer's REVEAL Study. The story ran Thanksgiving weekend on affiliate stations around the country. **Monica Alvarado** was interviewed on KTLA, the WB affiliate in Los Angeles. The story focused on Hispanics and prenatal counseling.
- DRAFTED AND ISSUED MEDIA ALERTS FOR MULTI-CULTURAL AUDIENCES. We distributed an article based on the multicultural abstract, translated into Chinese and sent to Asian Enterprise Magazine, Boston Chinese News, The Epoch Times and The Sino American Times.

  There is ongoing interest in feature stories related to this release.
- Web Interview. Monica Alvarado was interviewed by Healthscoutnews.com about the breast cancer risks in BRCA1 carriers who take birth control pills. This website will include a link to NSGC's website.

### **CONSUMER OUTREACH PROJECT**

Sarah Richter Cox, conference logistics chair, organized a highly successful Consumer Outreach Project for women with breast cancer, "Cancer and You: A Cancer Genetics Seminar." The program included an introduction to genetics, the what, whys and hows of cancer testing, a patient's perspective and a pediatric cancer overview. Nearly 50 women attended the half-day seminar.

In addition to Sarah, thanks to members **Jeff Weitzel**, **Kathy Blazer Jane Congleton**, for their planning and presentation expertise. �

Perspectives in Genetic Counseling 24:4 — Winter 2003

Bea Leopold, MA

The enjoyed many PR successes in our first year of our partnership with **STAR/Rosen Public Relations**. They hit the ground running with the consanguinity survey,

which garnered media coverage around the world, including the front pages of *The New York Times* and *USA Today.* It was carried by Associated Press nationally and internationally, as well as by United Press International. The story ran on most national broadcast media, including CBS Evening News, CNBC, CNN with Paula Zahn, CNN Headline News, Good Morning America, FOX National News,



Radio America syndicate and National Public Radio, as well as more than 50 regional TV affiliates. National magazine coverage included *U.S. News & World Report, TIME Magazine, New York Times Magazine* and *Discover.* The story also went around the world with the BBC-TV, BBC Radio, *Agence France Press, Moscow Times, Ottawa Citizen* and *Toronto Star.* It was even made part of a joke on The Tonight Show with Jay Leno. Other notable placements include: *Cosmopolitan, Boston Globe, Atlanta-Journal Constitution, Los Angeles Times, Sacramento Bee, San Diego Union Tribune, San Francisco Chronicle, KITV News Hawaii and Yahoo! News.* 

In addition, **Vivian Weinblatt** and **Kathy Schneider** went on a successful New York City media tour to introduce key national media to NSGC. The tour included meetings with *U.S. News & World Report, Newsweek, Self Magazine, Rosie Magazine, New York Times* and *Child Magazine.* 

By issuing media alerts and spokesperson advisories, STAR/Rosen has maintained an ongoing dialog with all of the key national healthcare and science reporters. This key group of media now knows NSGC as a source for expert commentary.

### A LOOK AHEAD

STAR/Rosen is very excited about continuing the momentum into 2003 and broadening the scope of our PR effort. The plan is grounded in the mission to raise NSGC's public profile and awareness. The overriding objectives cover

- getting the general public interested in genetic counseling as a routine part of medical decision making
- educating doctors and other medical decision-makers about the value of genetic counseling
- reaching out to related professional associations to gain exposure at their meetings (speaking opportunities, breakout sessions and curbside consultation); secure placement in their publications and on websites.

### NSGC's 2003 PR TEAM

Steve Rosen, President (Supervisor)

Karen Cutler, Partner, Sr Vice President (Primary Contact)

John Wannenburg, Partner, Senior Vice President (Ongoing Counsel)

Melanie Sole, Account Executive (Media Relations/Account Support) ❖

# September

New Format FOR BREAKOUTS

### **'03 CONFERENCE UPDATE**

September 11 - 12: Short Course, Psychiatric Disorders September 13 - 16: Annual Education Conference registration for the AEC will begin on Sept 12

Workshop? Practice-based Symposia? Minicourse? What's the difference anyway? The format of break-out sessions is changing, and 2003 will be a transition year. Mini Courses will no longer be offered; workshops and practice-based-symposia will no longer exist. Instead, we will be offering several two-hour sessions that will be known as "EBS", or Educational Break-out Sessions. At the AEC03 in Charlotte, there will be four two-hour EBS timeslots, with several EBS choices at each time. A track system will begin at AEC04. There will be four EBS tracks from which to choose, tentatively set as cancer, prenatal, pediatric/adult and other categories. Counselors will have the option to attend the track of their subspecialty or choose to attend an EBSs of other subspecialties.

**'03 PLANNERS** 

It's not too late to volunteer to serve on a planning committee for our 2003 Annual Education Conference in Charlotte. Contact the following chairs to learn how you can participate in making this conference a success.

CONFERENCE CO-CHAIRS

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 Studinski.April@mayo.edu

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 jrutberg@OHRI.CA

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Cheryl Dickerson . . . cheryl.dickerson@carolinashealthcare.org

**'03 SHORT COURSE** 

Genetic Counseling for Psychiatric Disorders promised to be an excellent, cutting-edge program to instruct genetic counselors how to take a psychiatric family history, perform risk assessment and address counseling issues that frequently arise. Experts in psychiatry, genetics and psychology and individuals living with psychiatric disorders will present.

'04 CHAIRS NAMED

**Liz Melvin** and **Julie Rutberg** have been named Co-chairs of our 2004 Annual Education Conference scheduled for October 8-11 in Washington DC. Registration will begin on October 7. ❖

'04 Conference Opportunities

### CALL FOR APPLICATIONS TO JOIN ABSTRACT COMMITTEE

The AEC Abstract Committee has eight positions available for 2004. Applicants should have some experience in research, publication and/or editing. In addition, applicants must be Full or Associate members and have access to email.

Successful applicants will serve a three-year term and will be required to attend a mandatory training program at the 2003 Annual Education Conference in Charlotte NC. We encourage colleagues of all levels of experience to apply. It's a great way to get involved in NSGC.

The deadline for applications is April 4. Candidates will be notified by April 18.

Request an application: Janice
Berliner, 2004 Abstract Co-chair,
©908-522-5925; berlinjl@umdnj.edu

### SHORT COURSE PROPOSALS

Applications for a Short Course to be held in conjunction with the 2004 Annual Education Conference, October 6-7, in Washington DC are being accepted through Tuesday, April 1. Members who have an innovative and high quality idea for a short course topic are encouraged to apply.

Recent Short Course topics have included: advanced cancer topics, metabolic disorders, legal issues, research and assisted reproductive technologies.

Guidelines and applications:

Heather Hampel, Annual

Education Conference Subcommittee Chair, €614-293-6694,

hampel-2@medctr.osu.edu ❖

### **Defining Genetic Counseling from Within**

Recently we received two Letters to the Editor that reflect quite different viewpoints. The first is from a seasoned counselor frustrated by forces outside our genetic counseling community, while the second is a new voice, enthusiastic about the future of our profession. So that each may be a wake up call, I invite you to weigh in on these issues by writing a Letter to the Editor yourself.

— Janice Berliner, Editor in Chief

### **JADED EYES**

To the Editor:

n response to the talk on the listserv about health care providers performing genetic counseling (GC), I would like to point out that we are a profession of extremely loose edges. Bit by bit other medical professionals pick at the edges of what genetic counselors do. We need to give careful thought about what this means, for some of our colleagues right now and for the profession in the long term.

Years ago, the bread and butter of genetic counseling for most of us was seeing women of "advanced maternal age" for counseling about amniocentesis. Many of these patients are now confidently handled by the OB. Even the money-generating amnio, instead of being done in the genetics department, is now often performed by the private OB, with the chromosome testing being done through large commercial labs.

But that's just the tip of the melting iceberg. We used to see patients regularly for "multiple miscarriages." Now most such patients are seen by infertility specialists and endocrinologists who order and interpret chromosome analyses, CF testing, etc.

Recently I got a call from a pediatrician wanting to do DNA testing for Connexin 26. No need to send the patient to genetics, he says. He just wants to know what lab does the test, what tubes, etc. Then I got a

call from a nurse in an oncology group who did "genetic counseling." She said that they don't do full genetics — "You know, just BRCA1, BRCA2 and Colaris." The patient's insurance won't cover it if she sends out the sample but will cover it if I do, and she wants me to help her get the blood drawn. Increasingly, genetics is becoming incorporated into all of medicine and countless doctors and nurses from so many different specialties feel comfortable ordering and interpreting genetic tests. And we are being left out of the loop.

Can we constantly let pieces of our pie be taken away and then reinvent ourselves with something new to offer? With rare exception, GCs do not pay for themselves. Will we still be able to justify our jobs to an administrator or granting institution if doctors stop referring because their offices can provide the "genetic counseling?" This is not idle chatter. I have seen colleagues fired solely for financial reasons.

Who and what are GCs? If any medical professional can order genetic testing, interpret the results and discuss it with patients, why do we as a profession exist? What do we have to offer that is unique and of important value to the patient? If we fail to figure it out and prove it we are constantly going to be chasing after the next thing, and job insecurity will be everpresent.

— **Seth Marcus, MS**Sarah Lawrence, '82
Lutheran General Hospital
Park Ridge IL

### **BRIGHT EYES**

he importance of genetics in the future of medicine and the value that genetic counselors can lend to this future is undeniable. As research uncovers the mysteries of the causative and contributing factors of multiple diseases and predispositions, genetics professionals will be called upon to educate, facilitate awareness and counsel. This April will mark the 50th anniversary of Watson and Crick's proposal in *Nature* of the accurate physical structure of DNA. It is also the predicted month of completion of the final version of the Human Genome Project.

Let's take this opportunity to work together to educate our communities, physicians and state legislatures about genetics in medicine and help the genetic counseling profession's visibility. In doing so we can empower individuals to be more knowledgeable and to take better control of their health. We can help shape public policy and prevent genetic discrimination and fight for reimbursement for our services. Educating physicians about the significance of genetics in their practices, by means of taking accurate family histories and by illustrating the availability of genetic counselors, may make a difference in others' lives.

I am confident that if we pull together, nationwide, and put forth a whole-hearted effort, we will live up to the NSGC's vision of being the "leading voice, authority and advocate for the genetic counseling profession."

— **Jessica Blasko, MS** Arcadia University, '01 Children's Hospital Boston MA

### Then and Now

### BETSY GETTIG: A CAREER OF TWISTS AND TURNS

Elizabeth (Betsy) Gettig, MS

hen I entered the field of genetic counseling, I had no clue about the journey I was embarking on and the twists and turns (read: opportunities) I'd take on that journey.

### **BEGINNINGS**

I chose a job in pediatric counseling and loved the launch of my career in North Carolina where I had spent my pre-Sarah Lawrence life. Later, I moved to Pittsburgh where I found that some of my best counseling was performed in a prenatal setting. Prenatal work enabled me to find my professional identity and to keep my eye on a counselor's central object — the patient and patient care.

### **FIRST TURNS**

While sitting innocently at my desk at West Penn Hospital, I received the recruitment call to



become the director of the University of Pittsburgh Counseling Program, an option I never envisioned coming my way, as I was not a Pitt graduate. Besides, I had an informal agreement with Sarah Lawrence College to assume the program director's role upon Joan Marks' retirement. Joan generously gave me a year as the Pitt director to make my final decision about future plans to move to New York. My decision was to stay in Pittsburgh which oddly enough is my actual birthplace.

#### **OPPORTUNITIES**

So what have the opportunities been?

- 60 Minutes called to consult with me and so did the TV series Guardian, for a story lines about Huntington Disease.
- I testified before Congress
- Being elected NSGC President was a surprise and delight
- In my wildest dreams, I never thought part of my salary would be supported by bioterrorism funds, but it is, due to my educational expertise with curriculum development and course management.
- I brought the Board Review Course to NSGC and the partnership has been outstanding!
- I never could have envisioned a foreign country consulting with me about development of counseling programs but three have: Japan, India and Qatar.
- I was a speaker at an international meeting.
- Finally, as my friends and students know, I am a movie maven. Movies are my greatest coping mechanism, so a great gift was the significant role I played in NSGC being listed in the credits (forever!) of the movie *Lorenzo's Oil*.

I have worked on every from of educational format from conferences to CD-ROMs to distance education. Getting the message out remains a critical mission of this profession. I have moved with the profession, as most of us do, picking up skills and developing areas of interest. I can honestly say that genetics is as, if not more, intellectually stimulating as the day I started practice. ❖

### Research Network

### NATIONWIDE STUDIES FOCUS ON EARLIEST SIGNS OF HUNTINGTON'S DISEASE

The Huntington Study Group (HSG) is undertaking two large studies (PREDICT-HD and PHAROS) to investigate the earliest symptoms that people at risk for Huntington's Disease experience. Investigators at 45 centers across North America are participating in the studies.

PHAROS (Prospective Huntington At Risk Observation Study) is a study for people at risk for Huntington's disease who have chosen not to undergo genetic testing. The sister study, PREDICT-HD (Neurobiological Predictors of Huntington's Disease), is for people who have undergone testing (either positive or negative results). Participants in either study must be asymptomatic at the time of enrollment. The studies include yearly neurological exams over 5 years, with comprehensive behavioral and cognitive evaluations.

Your help in sharing information about these studies with potential participants is critical to the success of PREDICT-HD and PHAROS. Because the study involves asymptomatic individuals, you may be the only link to potential participants, who may come to you for counseling or for predictive testing.

HSG is a consortium of physicians and other health care providers from medical centers in the U.S., Canada, Europe and Australia, experienced in the care of Huntington patients and dedicated to clinical research of Huntington's disease.





Finding Hope When a Child Dies - What Other Cultures Can Teach Us

Author: Sukie Miller, PhD

Reviewer: Faye L. Shapiro, MS

eath is a natural part of living, part of the normal cycle of life. But when death occurs in a baby or child, it defies the laws of nature and shatters the world of the bereaved parents. Our Western culture has no good language to explain to these bereaved parents and family members what happens to children after they die. The main purpose of this book is to explore the beliefs of other cultures in which language does exist to try to answer some of the questions about what happens to children after they die, thus bringing comfort to bereaved parents.

The book is written by Dr. Sukie Miller, a practicing psychotherapist who has done extensive research in other cultures' beliefs in the afterlife. The book is divided into three parts and uses examples from several of her counseling clients as the bereaved parents and family members. Part I explores the obstacles we face in grieving the loss of a child. Part II explores several different cultures' beliefs in the death of a child, destiny and the afterlife. This part also includes a chapter on death of an unborn child through miscarriage and stillbirth and describes very vividly the customs carried out in Indonesia and modern Japan when an unborn baby dies. Part III focuses on returning to life following such a tragedy and how changed the world seems to be to the bereaved parents. It describes the whole journey through grief as an initiation and examines the outcomes

Perspectives in Genetic Counseling 24:4 — Winter 2003

### RESOURCES

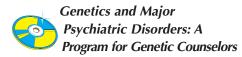
of some of the "initiates" whose stories have been told throughout the book.

What gives this book strength is the actual accounts of real clients who have lost children, as well as the author's first hand experiences with the leaders of the cultural groups whose customs are described. The incredible detail allows for clear imagery of the customs and ceremonial events that take place following the death of a child. Also, because the author takes us through her clients' whole journies through grief and back into the real world, other bereaved parents who read this book may be able to gain hope that they can do the same.

Although I have never lost a living child, I recently experienced the loss of an unborn child very late in pregnancy, and could well relate to many of the themes in this book. I



found this book easy to read and very comforting. I would highly recommend this book to any person who has lost a child, either before or after birth, or any professional who works with such grieving families. \*



PI: Joseph McInerney, MA, MS Project Director: Holly Peay, MS

This excellent educational CD-ROM program, published by National **Coalition for Health Professional Education in Genetics (NCHPEG), is** intended for individuals with a background in genetic counseling. The CD was sent to Full members of NSGC and will soon be available online at the NCHPEG website. The project was funded by U.S. Department of Energy. www.nchpeg.org ❖

### **NHGRI News**

### Jean Jenkins PhD, RN, FAAN

he newly-revamped NHGRI website highlights 2002 NHGRI activities, many with potential implications for healthcare professionals. Find out more about each of the topics highlighted below and more...

www.genome.gov

• PLANNING THE NHGRI'S FUTURE – A VISION FOR THE FUTURE OF GENOMICS. Results from this planning process provide the backbone to the development of recommendations for a new NHGRI research plan. NSGC President Robin Bennett participated in the process.

www.genome.gov/page.cfm?pageID=10001307

- A CELEBRATION OF THE GENOME 50 YEARS OF DNA: FROM DOUBLE HELIX TO HEALTH. A celebration not only of the publication of the NHGRI's vision for the future of genomics mentioned above, but also of the 50th anniversary of the Watson & Crick DNA article and of the anticipated completion of the human genome sequence.
- www.genome.gov/page.cfm?pageID=10005641
- INTERNATIONAL HAPMAP PROJECT. An international initiative to complete a genetic variation mapping project within the next three years.
- www.genome.gov/page.cfm?pageID=10005336
- MENTORSHIP PROGRAM. NHGRI and American Society of Human Genetics (ASHG) are offering a web-based mentorship program to high school teachers on genetics.
- www.genome.gov/Pages/EducationKit/mentor.html



Author: Nicholas Wade

Reviewer: Shelly Cummings, MS

he Human Genome Project has been described in extravagant terms such as the "Book of Life" written in the "language of God." Despite all of the aggrandized terminology, the work is of mortal scientists who possess the entire breadth of human virtues and flaws. Life Script is their story.

Those who read The New York Times "Science Times" section, are familiar with the name Nicholas Wade, who has written and edited books under the Times' auspices. In his latest work, Life Script, Wade tells the increasingly familiar tale of the biologists whose race for knowledge, wealth and scientific celebrity led to the sequencing of the human genome. The characters include James Watson, the co-discoverer of DNA, Craig Venter, a rebel, entrepreneurial geneticist and many others. Along the way, egos clash, principles are debated and money, power and prestige are a major factor — but in

### RESOURCES

the end, science prevails. Although not evident by the title, about a third of the chapters recount the drama of the race itself. The pursuit involves the public consortium of academic researchers, originally directed by Nobel Prize-winner James Watson and currently by Francis Collins, and the profit-making venture, Celera, headed by Craig Venter, competing to be the first to sequence the human genome.

The book concludes with the implications that new knowledge of DNA will perplex ethicists, aid medical research and ultimately benefit humanity for decades.

Wade surmises that genotyping will enable doctors to match drugs to patients and the scalpel could be replaced by the use of therapeutic cells and proteins, increasing our life spans considerably by the careful manipulation of genes. Wade dismisses the criticism that this will lead to "invocations of eugenics." He believes that the true dangers of genetic engineering "lie in the question of what changes should be



permitted, if any, other than those directly related to health." I found this interesting in that it is difficult to say what is healthy and who will determine degrees of healthiness.

Wade does an excellent job of not "dumbing down" these complex issues or clogging readers with facts but allows readers to ponder such questions for themselves.

This book is an excellent resource for more advanced consumers who are interested in learning about the history of the Human Genome Project. A glossary would have been a valuable asset to this riveting and informative book that will have a place prominently on the shelf in the consumer health section of public libraries. �



Molecular Testing for the Marfan Syndrome

Publisher: National Marfan Foundation, 14pp booklet

This new booklet provides geneticists, genetic counselors and genetic labs with up-to-date information about the current status of genetic testing for Marfan syndrome. The booklet also offers affected individuals and those seeking a diagnosis for Marfan syndrome some background for a discussion with their medical geneticist or genetic counselor about the capabilities and limitations of genetic testing.

® €800-8-MARFAN, staff@marfan.org; www.marfan.org \*

Genetics in Clinical Practice: A Team Approach — Dartmouth Medical School

his CD ROM won an EMMA in the category of eLearning 18+ Fixed Media - CD, noting it as a

"fantastic example of educational use of 'simulation' using rich media coupled with a solid, well-researched pedagogy. Betsy Gettig was involved in the original creation, design and scope of the project. She helped choose the advisory board and some of the experts. Andy Faucett helped with second stage design, editing and filming, and he's been the major spokesperson for the program. Both Betsy and Andy are on the CD-ROM in a section on Genetic Risk Assessment and Risk Communication.

The International EMMAs (Electronic Multimedia Awards) recognize excellence in digital media content creation through the acknowledgement of best practice and ongoing educational programs. This European based international award attracts entries from over 40 countries.

http://iml.dartmouth.edu/education/cme/Genetics/



### Media WATCH

Angela Geist, MS & Roxanne Ruzicka, MS

### August 11 — Los Angeles Times, "Firms Sell Gene Tests Directly to Public"

This article discussed companies that are marketing genetic tests and products designed specifically for individual genotypes directly to consumers. Customers do not need a physician's approval, and results are reported to them directly. Experts are concerned that these marketing efforts may lead consumers to buy tests that are unneeded or of doubtful value and the results may provoke unnecessary anxiety by giving questionable results. Genetic tests in particular pose tricky questions, and experts suggest that patients review test results with doctors or genetic counselors.

### August 19 — *Des Moines Register,* "The Secret to Long Life"

Approximately 1,400 elderly Americans are participating in an ongoing study by Centagenetix to examine the genetic basis for longevity and to develop products that promote vigorous health into old age.

They have found that a region of chromosome 4 has been linked to longevity and there is evidence of a genetic component to longevity based on the finding that brothers of centenarians are 17 times more likely and sisters are eight times more likely than the general population to reach the age of 100. **Stephanie Jo Brewster,** a genetic counselor in charge of research study recruitment, said she has talked to centenarians who ride their bikes daily, take college classes or learned a musical instrument in their 80s or 90s.

Perspectives in Genetic Counseling 24:4 — Winter 2003

## September 02 — American Baby, "Should You See the Genetic Counselor?"

Allison Gregory were interviewed for the article, it contained several errors. An MD stated that "all major organs are developed between conception and eight weeks," so a genetic disease that will affect a fetus' organs "will show up in an ultrasound during that time." Gastrochisis was described as "a chromosome anomaly" which was "cured by surgery."

### October 3 — National Public Radio

This radio network presented a one-hour discussion about prenatal testing and the decisions that come with that testing. The discussion was based on the story "Choosing Naia," which profiles a couple's decision not to end a pregnancy in which the baby had Down syndrome.

# October 30 — Yahoo Health and ACS News Today, "Experts Question Ads Pitching Gene Tests To Public"

According to NIH experts, consumers should be wary of advertisements which suggest that genetic testing can tell them their cancer risk because the influence of inherited genes on cancer risk is much more complex than many ads suggest. Ads for tests for BRCA gene mutations are running now on TV, radio and in print. These ads suggest women talk with their doctors "if breast cancer runs in your family" but don't define what that means. The article stated that due to the limitations and risks of genetic testing (including discrimination by insurance companies and employers), women should not seek genetic testing without genetic counseling.

Harmon Eyre, MD, chief medical officer of the American Cancer Society, was quoted as saying, "Genetic counseling by a qualified genetic counselor is crucial to protect those considering testing. It is very important that be done before — not after — any decision is made about whether to be tested."

### November 7 — "ER" TV show

26-year old woman with severe alpha-1 antitripsin deficiency came to the ER in respiratory distress and liver failure. She asked the doctor to sign a DNR because she understood that she was dying. A medical student convinced her to take back the DNR order and keep fighting because with stem cell transplant it could be possible to correct the underlying problem and save her life. The doctors had discrepant views about giving this patient hope for a cure that is probably still several years off. It was mentioned that this is a genetic condition.

# November '02 edition - *Parents*Magazine - "10 Moves to Make Before You Get Pregnant Again"

This article gave tips on how to get your body ready for the healthiest pregnancy possible. Tip number 10 stated, "If you are over 35 and have a family history of mental retardation or a genetic condition, talk to a genetics counselor, who can assess your risk and recommend further testing."

### Middlesex by Jeffrey Eugenides

amily history issues and questions of genetic determinism are discussed in this novel in which the main character has 5- alpha-reductase deficiency and struggles with gender identity.

Our Genes/Our Choices will be aired on Public TV in January. This three-part series was produced by Fred Friendly Seeminars.

www.pbs.org/fredfriendly/outgenes

### **COMMITTEE & SIG ACTIVITIES**

### **2003 SPECIAL INTEREST GROUPS**

Are you considering joining a SIG this year? ...or becoming involved in SIG activities? Here is a list of active SIGs and their respective chairs. Con-tact them to learn about SIG activities.

#### ■ ART/INFERTILITY

Lauri Black.... BlackLD@sutterhealth.org Jill Fischer..... JillF@sbivf.com

#### ■ CLINICAL SUPERVISORS

Sue Demsey ..... sue.a.demsey@kp.org Monica Barth ..... mbarth@nmh.org

#### ■ DIVERSITY

Tressie Dalaya .....tdalaya@meridianhealth.com Kathryn Spitzer Kim ... kkim@Brandeis.edu

### ■ FAMILIAL CANCER RISK

Jeff Shaw . . . . . . . . JeffShaw@centura.org Kristin Niendorf. . . . kniendorf@yahoo.com

#### **■ I**NDUSTRY

Lisa Andres . . . landres@xenongenetics.com Lori Ann Correia . . . lcorreia2@hotmail.com

#### **■ LABORATORY**

Melissa Bennett ... Bennem@labcorp.com Eric Schmitt .... eschmitt@bcm.tmc.edu

#### ■ LEGAL

Sandra Factor ..... engravitas@aol.com

Tracy Field . . . . . . tracy.field@agg.com

#### ■ Neurogenetics

Suellen Hopfer ..... SHopfer@mednet.ucla.edu Jennifer Williamson ..... william@sergievsky.cpmc.columbia.edu

#### **■ PEDIATRICS**

Helga Toriello

. . . . . helga.toriello@spectrum- health.org

#### ■ PRENATAL

Renee Chard. . . . . . chardr@poa.mmc.org Molly Carpenter . . carpem@poa.mmc.org

#### ■ PRIVATE PRACTICE

Kristen Beck .... kristen@geneticsnw.org

### ■ PSYCHIATRIC DISORDERS

Holly Peay.....hlpeay@nchpeg.org

### ■ PSYCHOTHERAPY & EXPANDED SKILLS

To be announced

#### ■ PUBLIC HEALTH

Deb Lochner Doyle . . . . . . . . Debra.Lochner Doyle@doh.wa.gov

#### ■ RESEARCH

Robin Grubs. RGrubs@helix.hgen.pitt.edu Emily Hanson . . . . ehanson@meriter.com

**■ TELEGENETICS** 

Robin Bennett. robinb@u.washington.edu Becky Butler. . . . butlerbeckyb@uams.edu

### NEW SIG STARTS IN '03

A new Special Interest Group has emerged. Juliann Stevens-Harvey will chair the Metabolism/Lysosomal Storage Disease (LSD) SIG. The SIG will promote the role of the genetic counselor in this subspecialty, educate our membership regarding metabolic/LSD disorders and serve as a resource for us. Join by adding this SIG in the 'other' category on your invoice or online

- https://www.nsgc.org/payments/ membership.asp
- **☞ Juliann Stevens-Harvey,** Chair

### **COMMITTEE NEWS**

### DEVELOPMENT SUBCOMMITTEE TO BE FORMED

The Finance Committee soon will be creating a Development Subcommittee. Members with an interest or expertise in fund raising are invited to inquire about activities.

■ Whitney Neufeld-Kaiser whitneyn@u.washington.edu

### GENETIC SERVICES INFO ON WEBSITE

Lever wonder how a Position Paper becomes adopted? ...or the process we use to update existing statements? The Genetic Services Committee has added a plethora of information to our website about these systems.

www.nsgc.org/members/mem.comwork\_com\_sub.asp

### CANCER SIG AWARDS GRANTS TO MEMBERS

The Familial Cancer Risk SIG has awarded funds for two projects for 2002. Updates of these projects will be published in a future issue of *Perspectives*.

 A Pilot Study to Evaluate Family Communication of Prostate Cancer Risk Among Men with Prostate Cancer and their Families.
 PI: Mónica Alvarado, MS, CGC-USC/Norris Comprehensive Cancer Center, Los Angeles, CA. Amount funded: \$1456.

The project will collect pilot information from prostate cancer patients to evaluate their knowledge and awareness of familial prostate cancer risks and the frequency with which they communicate with their sons, brothers, fathers and other relatives about these issues.

 Current Protocols in Counseling about Genetic Testing for Hereditary Cancer Syndromes. PI: Karen Huelsman, MS, CGC-Children's Hospital Medical Center, Cincinnati, OH. Amount funded: \$1000.

The purpose of this study is to define the range of current practice standards, to evaluate the role and time commitment of counselors and allow professionals to share original approaches to the provision of cancer genetic services. �

### CLASSIFIED

- MADERA CA: Immediate opening for BC/BE Genetic Counselor. Valid BLS req. GC & case management of prenatal detection, pediatrics, cancer & adult genetics patients. Serve as liaison between patient, primary care provider, community agencies & departments, elicit & provide medical & genetic info in collaboration w/ geneticist & psychosocial support. Competitive salary, sign-on bonus & relocation package.

   Dennis Yee, Children's Hospital Central California, 9300 Valley Children's Place, Madera CA 93638; ©559-353-7058; Fax: 559-353-7070; dyee@childrenscentralcal.org; apply online: www.childrenscentralcal.org. EOE
- TAMPA FL: Immediate opening for BC/BE Genetic Counselor. Join active, expanding prog at NCI-designated Moffitt Cancer Ctr (MCC), affil w/ USF. Outpt GC; partic in clin cancer genetics rsrch.
- Jenny Permuth Wey, MS, Lifetime Cancer Screening, 4117 E. Fowler Ave, Tampa FL 33617; ©800-456-3434 x 6770; Fax: 813-558-4807; permutjm@moffit.usf.edu. EOE
- HONOLULU HI: Immediate opening for BC/BE Genetic Counselor. Exp pref. Highly motiv & flex team player to work in multcult setting. Join dynamic team of 4 MFMs: 1 MFM/BC Geneticist, 2 BC GCs/1 BE GC & 1GYN/Onc. All aspects of PN & cancer GC.
- Apply online: www.hawaiipacifichealth.org. Click on Careers or Tammy Stumbaugh, MS, Fetal Diagnostic Ctr, Kapiolani Medical Ctr for Women & Children, 1319 Punahou St Ste 540, Honolulu HI 96826; ©808-983-6893; fax: 808-983-8989; tammys@kapiolani.org. EOE/AA
- BOSTON MA: Immediate opening for BC/BE Genetic Studies Coordinator. Rsrch exp pref. Strong org skills & abil to work independently a plus. Join HMS Center for Neurofibromatosis & Allied Disorders to coord rsrch collab, write & submit IRB protocols, recruit pts, obtain informed consent, track study progress. Respond to inquiries re clin svcs & rsrch opptys. 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 Sr. Genetic Counselor (32 hrs w/ full benefits) Must work well independently, prior s'visory exp pref. Exciting oppty at Harvard tchg hosp. Join 2 GCs & 1 MD geneticist in busy acad high-risk PN genetics prog. Opptys for tching, cancer GC & partic in rsrch.
- ™ Lisa Paglierani, MS, Beth Israel Deaconess Medical Ctr, 330 Brookline Ave, Boston MA 02215; ©617-667-3792; Fax: 617-667-1551. EOE/AA.

Perspectives in Genetic Counseling 24:4 — Winter 2003

- Boston MA: Immediate opening for .6 FTE BC/BE Genetic Counselor. Strong org skills & abil to work independently req. Lab exp pref. Join HPCGG Molec Med Lab. Assist in start up of LMM clin tstg svcs, respond to inquiries about tstg, commun tst results to referring providers, develop/maintain LMM & HMS Ctr for Hereditary Deafness websites, partic in rsrch & educ activ.
- ™ Gretchen Schneider, MS, Harvard-Partners Ctr for Genetics and Genomic, HIM Suite 640, 77 Avenue Louis Pasteur, Boston MA 02115; ©617-525-5752; gschneider@partners.org. EEO/AA
- BOSTON MA: Immediate opening for BC/BE Genetic Counseling Associate or Nurse Geneticist. Some exp pref. Expanding oppty involving coord busy DNA dx prog, GC in Genetics Clinic & in high-risk Perinatal Clin. Rsrch project involve encouraged.

   Aubrey Milunsky, MD, DSc, Boston University School of Medicine, Center for Human Genetics, 700 Albany St W-408, Boston MA 02118; Fax: 617-638-7092. EOE/AA
- SOUTHERN FL: Immediate opening for BC/BE Genetic Counselor. Spanish req. Join dynamic team of GCs in S. FL area. Oppty to work independently, providing PN GC svcs for clients in S. FL, primarily Miami.

   Job Code #1822 c/o Amy Foster,
  Genzyme Genetics, 15 Pleasant Street
  Connector, PO Box 9322, Framingham MA 01701-9322; ②800-357-5744 x23728;
  Amy.Foster@genzyme.com.
  Apply online www.genzyme.com. EOE/AA
- BALTIMORE MD: Immediate opening for BC/BE Genetic Counselor. Join Ped/Adult Genetics Clin at univ hosp. Primary respon:
  GC in weekly clin & ward consults; coord spec & outrch clins; trng & s'vising students; providing hosp-wide consults for genetic tstg; partic in commun genetics educ. Potential for fac position in Institute of Genetic Medicine.

   Amanda Bergner, MS, McKusick-Nathans Institute of Genetic Medicine, Johns Hopkins Hospital, 600 North Wolfe Street, Blalock 1008, Baltimore MD 21287; ©410-955-3071; Fax: 410-614-9246; abergne1@jhmi.edu. EOE/AA
- NORTHERN NJ/PHILADELPHIA PA: Immediate opening for BC/BE Genetic Counselor. Min 2 yrs PN exp req. Excellent commun skills, abil to work independently req. PGD, ethnic & population scrng, PN & preconcep GC. Work w/ creative & evolving GC svc. Oppty for prof growth & unique career path. PN & CA GC oppty also avail.
- Email/fax 2 ltrs rec, cov ltr & CV: Eric Krivchenia, MS, Dir. GC Services NE, LabCorp, 9 Eves Drive, Ste 110, Marlton NJ 08053; ©800-762-4522 x142; ©800-631-5250 x 4850; krivche@labcorp.com. EOE/AA

- ALBUQUERQUE NM: Immediate opening for BC/BE Genetic Counselor. Spanish an asset. FT position made up of 2 PT positions: 60% SW perinatology, PN GC; 40% UNM ped outrch clins. Multicultural environ. Negotiable benefit package.
- Milisa, MS, Stephanie Hedstrom, MD or Carol Clericuzio, MD, 101 Hospital Loop #106, Albuquerque NM 87109; ©800-884-7420; ©505-272-0340; Fax: 505-883-5322; jmilisa@salud.unm.edu. EEO/AA
- ALBUQUERQUE NM: Immediate opening for Senior Genetics Counselor. 5+ yrs exp req. Knowledge of hereditary cancer syndromes and cancer GC. Provide genetic education, GC and psychological counseling, ID at risk families, interpret med evals & dx re: disorders, analyze inheritance patterns, eval and implement pt care progs. Full job description: unm.edu, Req #H34798.
- ™ Susy Golden, University of New Mexico Cancer Research and Treatment Center, 900 Camino de Salud NE, Room 208, Albuquerque NM 87131; ©505-272-4443; fax: 505-272-5865; sgolden@salud.unm.edu. EOE/AA
- BROOKLYN NY: Immediate opening for BE/BC Genetic Counselor. Recent grads welcome to apply. Join Div of Genetics & Sickle Cell/ Thalassemia Prog; c'hensive genetic svcs to Peds/OBGyn/Med, incl fam cancer risk assmt.

  □ Dr. Karen David, Chief NY Methodist Hospital, 506 6th St, East Pavillion 3rd flr, Brooklyn NY 11215; ©718-780-5256; ©718-857-5643; Fax: 718-780-3259; Fax: 718-857-6798; aakd97@pol.net; bellevuer@aol.com. EOE/AA
- BROOKLYN NY: Immediate opening for BE/BC Genetic Counselor. Exp pref; Spanish a plus. Join busy team of 2 perinatologists, med geneticist & GC to provide GC for PN, ped & cancer pts, lecture med students, write for hosp pubs, s'vision of GC interns.

   Fax CV c/o Michael F. Cabbad, MD, Director, Reproductive Genetics, The Brooklyn Hospital, 161 Ashland Place, Brooklyn NY 11201; 718-250-8032; Fax: 718-250-8660;
- New York NY: Immediate opening for BE/BC Genetic Counselor. Dynamic, rsrch-oriented w/strong ldrship, commun & writing skills req. Exp in rsrch, proj mngmt pref. GC & study coord for REVEAL Study (Risk Evaluation and Education for Alzheimer's disease), a 4-site NHGRI-funded proj offering susceptibility genotyping, disclosure & GC. Work w/ natl leaders in genetics, ethics & Alzheimer's disease resrch.

mje9002@nyp.org. EOE

Fax or EMail resume/CV & Itr of interest: Andrea Solomon, Cornell Memory Disorders, 428 E. 72nd St. Suite 500, New York NY 10021; 212-746-6581; Fax: 212-746-5584; ams2013@med.cornell.edu; www.med.cornell.edu/jobs. EOE/M/F/D/V

### CLASSIFIED

- New York NY: Immediate opening for BC Clinical Research Genetic Counselor. Join clin rsrch team: recruit & scrm pts for clin rsrch. Take fam hx, determine eligibility for trails, hook pts up for med i'ventions, coord genetic samples, GC pts for risk assmt & answer hotline requests as apppropriate. Excellent benefits and generous vacation policy. Salary \$40's.
- Linda Antillon, FACHE, Dept Human Genetics, Mount Sinai School of Medicine, 1425 Madison Ave, Box 1498, New York NY 10029; Fax: 212-360-1809; linda.antillon@mssm.edu. EOE/AA
- **COLUMBUS OH:** Immediate opening for BC/BE Genetic Counselor. GC exp in non-cancer adult genetics (emphasis on cardiac, thrombosis & neurogenetics). Strong clin skills w/ families in crisis & exp in prog mgmt/admin desired. Abil to work independently & on multidisc team. Educ & rsrch oppty. Join newly developing Div Human Genetics with highly competitive recruit pkg.
- Send CV & Itr of interest by March 1: Charis Eng, MD, PhD c/o Jane S. Pierce, Ohio State University, 410 W. 10th Ave, E308 Doan Hall, Columbus OH 43210; @614-293-7775; Fax: 614-293-7435; pierce.6@osu.edu. EOE/AA Qualified women, minorities, Vietnam era veterans & individuals with disabilities are encouraged to apply.

- Bridgeville PA: Immediate opening for BC/BE Genetic Counselor. Must be a team player. Join 3 GCs in newborn scrng lab: pre/post-test consults, tech support & GC expertise to referring hosps & physicians. Commitment to customer svc. Oppty for rsrch. Bethany A. Sgroi, MS, Neo Gen Screening, LP, Abele Business Park, 90 Emerson Lane, Suite 1403, Bridgeville PA 15017; ©412-220-2300; Fax: 412-220-0785; bsgroi@neogenscreening.com.
- PHILADELPHIA PA: Immediate opening for BC/BE Genetic Counselor. GC for hereditary cancer pts in Div of Genetic & Preventative Med & Jefferson Hereditary Cancer Ctr. Work closely w/ Div Director & Advanced Practice Nurse in Genetics. Tchg & rsrch opptys avail. EM or mail resukme w/ salary reg c/o Patricia Starr, Thomas Jefferson University, 201 South 11th St, Philadelphia PA 19107-5595; Fax: 215-503-4329; Patricia.Starr@mail.tju.edu; http://employment.tju.edu. EOE/AA
- PHILADELPHIA PA: Immediate opening for BC Sr. Genetic Counselor. 5 yrs exp coord multidisc genetics svcs; published rsrch req. Manage clin progs, s'vise GCs, conduct rsrch. Join expanding adult genetics clin at acad med ctr w/ 2 GCs & 3 MD geneticists.
- Reed Pyeritz, MD, PhD, Univ Pennsylvania, Medical Genetics, 538 Maloney Bldg, 3400

Spruce St, Philadelphia PA 19104; ©215-614-0933; Fax: 215-614-0298; reed.pyeritz@uphs.

upenn.edu. EOE/AA

■ PHILADELPHIA PA: Immediate opening for BC Genetic Counselor. Exp pref. Cancer risk assmt for breast, ovarian, GI & skin cancers as part of multidisc team providing genetic risk assmt, educ & GC for cancer predisposition. Travel to satellite hosps; conduct genetic rsrch studies. Salary commensurate w/ exp; excellent benefits. Cary M. Armstrong, MS or Josephine Wagner Costalas, MS, Fox Chase Cancer Center Family Risk Assessment Program, 7701 Burholme Ave, Philadelphia PA 19111; 800-325-4145; Fax: 215-728-4061; CM\_Armstrong@fccc.edu or J\_Costalas@fccc.edu.

EOE/AA

- PHILADELPHIA PA: Immediate opening for BC/BE Assistant Director, Perinatal Genetics. Work with BC perinatologist & geneticist. Clin & rsrch oppty. Provide GC to pts in diverse MFM practice. Attractive compensation pkg incl pre-paid tuition, competitive salary & benefits. Forward resume & salary history, via e-mail c/o Req. #9902726: HR Manager, Temple University School of Medicine, 1601 N. Broad St., Room 203 USB, Philadelphia PA 19122; Recruiter.5@temple.edu; www.temple.edu. EEO, m/f/d/v
- PROVIDENCE RI: Immediate opening for BC/BE temporary (6 months) position January - June. Busy PNDx Ctr. Highly motivated, independent work style req.
- Debbie Owens, RNC, MS, Professional Coordinator, Prenatal Diagnosis Center at Women & Infants Hospital, 79 Plain Street, Providence RI 02903; @401-453-7510; Fax 401-453-7517; dowens@wihri.org. EOE/AA
- COLUMBIA SC: Immediate opening for BC/BE Genetic Counselor. Abil to work independently req. Knowledge of psych genetics & phlebotomy skills a plus. Serve as Project Coord for rsrch study on genetics of autistic disorder: recruit fam for partic in study, conduct fam & med hx interviews, arrange for collection of blood & maintain active contact w/ parent study at Duke Univ.
- 🖙 Ruth Abramson, PhD, William S. Hall Psychiatric Institute, University of South Carolina, 1800 Colonial Dr. Columbia SC 29203; ©803-898-2343; Fax: 803-898-1170; RKA07@WSHPI.DMH.STATE.SC.US. EOE/AA
- MEMPHIS TN: Immediate opening for BC/BE Genetic Counselor. Cancer GC exp pref; new grads welcome. Independence, initiative, excellent writing & speaking skills essential. Join GC in diverse clin role incl expanding GC svcs (onc, PN, cardiovascular) in hosp system. Some travel req. Competitive salary w/ exceptional benefits.
- Eric Fowler, MS, Baptist Cancer Institute, Baptist Memorial Health Care Corporation, 350 North Humphreys Blvd, Memphis TN 38120; ©901-227-0036; Fax: 901-227-4096; eric.fowler@bmhcc.org. EOE/AA
- Nashville TN: Immediate opening for BC/BE Cancer Genetic Counselor. Exp pref. Work w/ Advanced Practice Nurse in Genetics & multidisc team: cancer risk assmt & GC in NCIdesignated C'hensive Cancer Ctr. Add'l roles incl aid in plng CME conferences, commun educ & work in adult genetic med sfc.
- S CV & Itrs of rec: Susan W. Caro, RNC, MSN, APNG, Family Cancer Risk Service, 1500 21st Avenue South, Ste 2500 Village at Vanderbilt, Nashville TN 37212; @615-343-0738; Fax: 615-343-0746; susan.caro@vanderbilt.edu. EOE/AA

...next page

Perspectives in Genetic Counseling 23:1 — Spring 2001



New tests available from Athena MYOTONIC DYSTROPHY TYPE 2 Complete CADASIL Evaluation (Covering all 23 exons)

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233 Canterbury Dr Wallingford PA 19086

Our Genes, Our Choices," a 3-part Fred Friendly Seminar to be aired on PBS

> 31 — Deadline for Responses to Annual Education Conference Logistics Survey

'04 Short Course Proposal Deadline

4 — '04 Abstract Committee Application Deadline

Manager Deadline

John — Jane Engelberg Memorial

Fellowship Proposal Deadline

2 — Abstracts Deadline for 22<sup>nd</sup> Annual Education Conference

15 — Audrey Heimler Special Projects Award Deadline

# CLASSIFIED,

from previous page

- Dallas TX: Immediate opening for BC/BE Genetic Counselor. Excellent org, commun and written skills a must. Bilingual/Spanish pref. Work in busy PN dept: manage serum scrng prog, coord PN genetics clins, GC pts for PN indications, weekly follow-up with pts with diagnosed abnormalities, resident/fellow educ in genetics/GC, partic in weekly U/S abnorm conf & biweekly ped/PN conf.
- Phyllis Avery, Employment Services,
  Parkland Health & Hospital System, 5201 Harry
  Hines Blvd, Dallas TX 75235; ©214-590-6857;
  pavery@parknet.pmh.org; www.pmh.org.
  FOF/AA
- SALT LAKE CITY UT: Immediate opening for BC/BE Genetic Counselors (Miami FL, Billings MT Las Vegas NV, Oklahoma City OK, Austin/San Antonio TX). Strong presentation skills, abil to work independently, passion about impacting pt care req. Non-traditional oppty avail in Cancer Genetics. Educ physicians & other health care providers on hereditary

Perspectives in Genetic Counseling 24:4 — Winter 2003

cancer syndromes & genetic tstg available. Candidates expected to share info w/ organization, incl feedback on current mktg progs, potential new tests from MGL & new creative ideas or concepts.

Angie Brochu, Myriad Genetics, 320 Wakara Way, Salt Lake City UT 84108; Fax: 801-584-3741; humanres@myriad.com. No phone calls. EOE/AA

- SALT LAKE CITY UT: Immediate opening for Clinical Genetic Counselor. BC/Active Candidate Status req. Join dynamic team of 3 GC & 6 med geneticists for expanding ped & general genetics pop. Opptys for growth & spec in acad setting incl outrch /spec clins, inpt consults, educ & clin rsrch.
- Far: 801-585. Falumbos, MS, LGC, Univ Utah Medical Ctr, Div Medical Genetics/Dept Pediatrics, 50 North Medical Dr, 2C412 SOM, Salt Lake City UT 84132; ©801-581-8943; Fax: 801-585-7252; janice.palumbos@hsc.utah.edu. EOE/AA

### In Canada

■ HALIFAX NS: Immediate opening for BC/BE Administrative Coordinator. Recent relevant exp (min 5 yrs pref), proven ldrshp skills in formal ldrshp position, abil to multitask.
Facil strategic growth & devel of
Genetics Svcs for Maritime
Provinces: daily mngmt of
personnel & clin svcs, provide GC
ldrshp, incl svc provision, prof devel. Work w/
acad institutions to foster beneficial
relationships.

\*\*Application form & resume c/o Position #B574 Attn: Human Resources, IWK Health Centre for Children, Women & Families, 5850/5980 University Ave, PO Box 3070, Halifax NS B3J3G9; ©902-470-8012; Fax: 902-470-6612.

■ TORONTO ON: Immediate opening for Genetic Counselor (perm PT 30 hrs wk). Exp & BC status pref. Excellent i'personal & org skills req. Join active univ hosp genetics team, primarily peds but some PN & adult: 1 genrl genetics clin/wk & new multidisc clin; involve w/ rsrch & tchg at U of Toronto w/ fac position in GC MSc program.

Fig. Applications, CV & 3 reference ltrs c/o
Helen Karbaliotis, Hospital for Sick Children,
555 University Ave, Div of Clinical and
Metabolic Genetics, Toronto ON
M5G 1X8; ©416-813-7552; Fax: 416-8135345; helen.karbaliotis@sickkids.on.ca.