

# PERSPECTIVES

*in genetic counseling*

Volume 25 Number 1

Spring 2003

national society  
of genetic  
counselors, inc.



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

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NSGC acknowledges  
Women's Health Care Services of  
Wichita, Kansas, for a sponsor's  
educational grant to support this  
newsletter.

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



## LOBBYING — IN OUR BEST INTEREST?

**Cheryl Scacheri, MS**

**T**he NSGC's vision states that we want to be the leading voice, authority and advocate for the genetic counseling profession. Can we accomplish everything that statement promises by ourselves? How far can advocacy and public relations take us, and when does it become necessary to fight for changes in laws and policies? NSGC already lobbies for policy changes regarding social issues<sup>1,2</sup> and state licensure. Now, we are considering paying someone to lobby for NSGC interests.

### ISSUE AT THE TABLE

At our Board meeting in November, Lyle Dennis, a DC lobbyist, gave a presentation about lobbying. Some professional organizations, including ASHG and ACMG, employ a member of the organization to lobby. Other groups hire lobbying firms or non-

members to lobby on their behalf. Right now, the NSGC is considering three options: contracting with a professional lobbying firm, hiring an NSGC member to lobby for us or continuing with the volunteer efforts of our members.

### WHAT WOULD A PROFESSIONAL LOBBYIST DO FOR THE NSGC?

A contracted lobbyist is committed to a legislative agenda that is determined by the client. A Capitol Hill lobbyist

- navigates through the numerous policymaking bodies of the US government, attempting to establish (or abolish) policies as desired by a client
- monitors the legislative and executive branches of the government, tracking legislation, reviewing policies and establishing coalitions

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## \$1 MILLION MILESTONE

**Whitney Neufeld-Kaiser, MS**

**L**ast year, NSGC reached a financial milestone. Our revenues and expenses reached the \$1million mark. Several factors contribute to how we have grown so much and why so much money goes through our coffers.

### EDUCATION

The cost of planning and running the Annual Education Conference has increased 40% over the last three years. Much of the increase is due to increased costs for food and

beverage, as well as audio-visual equipment, especially the LCD projectors so favored by both audience and presenters for PowerPoint presentations. Luckily, attendance at the meetings has also increased — including non-members — and our Executive Director successfully obtains an increasing number of grants from organizations and corporations to offset some of our costs. Also, 2002 was an

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# PRESIDENT'S BEAT



Life always seems to throw unexpected detours in our path, as I recently experienced rushing into work to begin a full day of clinic to find myself tripping on a curb and ending up in the emergency ward at my workplace. I was on the wrong side of the insurance maze as the ER staff refused to treat me until my HMO approved the visit. In brief, I was approved for urgent knee surgery.

My assumption was that such accidents were always associated with glamorous stories of a ski jump or parasailing, but no such luck. In early March, I spent some "time out" recuperating with my recent book purchases from NSGC's amazon.com affinity program. My selections were *Middlesex* by J. Eugenides, "the astonishing tale of a gene that passes through three generations of a Greek American family and flowers in the

body of a teenage girl who is not like other girls, in fact she is not really a girl at all;" and the *Dimwit's Dictionary, 5,000 Overused Words and Phrases and Alternatives to Them*.

## ON THE ROAD

I'm hoping to be on my feet in time for the American College of Medical Genetics Meeting in San Diego. For those of you in attendance, be sure to stop by the NSGC poster summarizing the NSGC protocol for developing genetic counseling practice recommendations.

In July the NSGC is off to Melbourne Australia to participate in the meetings of the International Congress of Genetics and the Australasia Society of Genetic Counselors.<sup>1</sup> NSGC will have an exhibit, and several NSGC members are invited speakers including myself, **Allyn McConkie-Rosell**, **Diane Baker** and **Elizabeth Balkite**.

## NEW APPOINTMENTS

I'm pleased to announce that **Diane Baker** will head the NSGC Foundation Task Force. Our new development subcommittee will be chaired by **Kathleen Fergus**. **Barb Bowles Biesecker** and **Bob Resta** are chairing the Definition of Genetic Counseling Task Force.

Our approach to strategic planning and the environmental scan are being developed under the direction of

**Vivian Weinblatt** with input from the Industry SIG. We will have much to report at our Annual Education Conference in September.

## BOARD AT WORK

The Board looks forward to a busy meeting in April. We will be hearing from

the Billing and Reimbursement Task Force and the Licensure Task Force.

NSGC is receiving remarkable media attention—from **Kristin Niendorf's** appearance on the *Today Show* to many other interviews as outlined in *Media Watch*. (See p 12) Our new website is receiving accolades. I've heard from several visitors to the site who want to pursue a career in genetic counseling after seeing the "spotlights" on our website.

I'd like to take this opportunity to say an extra thank you to **Bea Leopold** for her steady leadership and dedication to our organization in these recent busy months. **Aubrey Turner** has also approached revered status in my book for his continued devotion to our website. The overall energy of NSGC's membership never ceases to amaze me!

Robin L. Bennett

President, 2002-2003

<sup>1</sup> [www.geneticscongress2003.com](http://www.geneticscongress2003.com)

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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 May 9  
Submission deadline June 16

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## UPCOMING SOCIETY DEADLINES

Society Award Nominations

Monday, March 31

Board of Directors Nominations

Tuesday, April 1

JEMF Proposals

Thursday, May 1

Abstract Submissions Online

Friday, May 2

AHSPA Proposals

Thursday, May 15

## NEW AVENUES OF VISIBILITY *from p 1*

especially strong year, with the Region II and Region VI regional conferences and the Board Review Course.

The advent of time-limited certification has created the need for continuing education units. These fees result in over \$20,000 of cash flow for NSGC each year.

### INCREASED VISIBILITY

Over the last few years, NSGC has embraced new ways of increasing the visibility of our organization and our profession. This includes the development and maintenance of our website as well as hiring a PR/marketing firm. With the storm of publicity surrounding last year's consanguinity guidelines and the recent *Today Show* feature, we have seen how powerful this exposure can be. These tools are expensive, with costs of about \$20,000 a year for our website and about \$70,000 a year for marketing. As an organization, NSGC has learned that hiring experts is worth the cost.

### NEW SERVICES

When NSGC was just 100 members strong and expenses were \$5000 a

year, it did not take much effort to keep our finances on track and accurate. As NSGC has grown, we have increasingly required the services of financial experts to help the volunteer Board members who were trained as genetic counselors, not CPAs. Over the last few years, NSGC has contracted with professionals to file our taxes, and in 2002, we contracted for our first audit. This year we have contracted with an accountant well-versed in non-profit organizations to take over the bookkeeping duties from the Treasurer.

### INSURANCE

The American Society for Association Executives recommends that non-profit organizations have at least one-half to one year's operating expenses in reserve for emergencies. NSGC has over \$570,000 in our long-term investment account, so we are meeting this recommendation. We also have earmarked \$120,000 as an insurance policy, should we need to cancel our Annual Education Conference on short notice.

Lastly, the Board has recognized for the last several years that at some point we will need to hire a new

Executive Director.

The Executive Office ad hoc committee, under the direction of **Lisa Amacker North**, estimated that NSGC would need at least \$400,000 (in 2001 dollars) to cover salaries and benefits, equipment and office space for the first year after Executive Director **Bea Leopold** retires. To that end, NSGC has systematically been saving money towards this goal and we are just over half way there.

### LOOKING AHEAD

As NSGC continues to grow and our profession continues to increase in number and visibility, a few new issues have emerged that will take increased resources to address.

- Billing and reimbursement continues to be the number one concern to the membership. The Billing and Reimbursement Task Force assembled in 2002 has identified several ways to make progress in this area, but almost all of them will cost money to implement.
- Is it time for NSGC to hire a professional lobbyist? The Board of Directors had a spirited debate at the Fall meeting about this topic. Although we are not financially in a position to do so now, the Board recognized that hiring someone to lobby for us is the most efficient way to get the results we want.

NSGC continues to be a thriving, growing organization, and this is reflected in many ways, not the least of which is our balance sheet. ♦

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### FINANCIAL RETROSPECTIVE OF NSGC'S GROWTH

	Total <u>Membership</u>	<u>Revenues</u>	<u>Expenses</u>	AEC <u>Expenses</u>
1982	480	\$12265	\$5196	\$7920
1987	695	\$84610	\$55345	\$38410
1992 <sup>1</sup>	1081	\$148275	\$95968	NA
1997	1599	\$587000	\$457400	\$113890
2002 <sup>2</sup>	2084	\$1229675	\$1029160	\$213220

<sup>1</sup> First year to top operating budget in excess of \$100K

<sup>2</sup> First year to top operating budget in excess of \$1M



## EVOLUTION OF A CAREER

Joan Scott, MS

When I graduated from Sarah Lawrence College in 1978, the opportunities for genetic counselors were pretty much limited to pediatric and prenatal diagnosis clinics. Although genetic counselors were viewed as important members of the clinical team, their job responsibilities were more limited than today. My own early career experience — from providing genetic counseling services in a general genetics clinic in an academic setting, to coordinating that clinic, to directing a genetic counseling training program, to developing training and education tools for health professionals and finally to managing a private practice prenatal diagnosis clinic — parallels the development of the field and the expanding roles of genetic counselors within the clinical setting.

Eight years ago, however, I left the clinical world for the biotech industry, first working for a clinical diagnostic lab and then a genomics company that provided tools and information for pharmaceutical companies to aid in drug discovery. Those experiences showed me that the talents and skills genetic counselors bring to the clinical setting translate very well into other settings. In the fall of 2002, I made one more major career change and entered the policy world by accepting a position as the Deputy Director of the Genetics and Public Policy Center at the Phoebe Berman Bioethics Center at Johns Hopkins University in Washington DC.

The Genetics and Public Policy Center is a new initiative funded by the Pew Charitable Trusts to provide the tools and environment needed by decision

makers in both the private and public sectors to carefully consider and respond to the challenges and opportunities arising from advances in human genetics. The first three-year project is to look at the policy implications of reproductive genetic technologies including genetic testing (preconception, preimplantation and prenatal testing), genetic modification and reproductive cloning.

Our objectives are to:

- 1) create a comprehensive information resource for policy makers, the media and public
- 2) perform social science research to assess public knowledge and attitudes
- 3) educate and engage stakeholder groups and opinion leaders and
- 4) develop a set of policy options supported by robust analysis and documentation to guide the development and use of reproductive genetic technologies.

As deputy director, I have administrative responsibilities and also direct the outreach efforts to engage and educate stakeholder groups around these issues.

Although these three settings, clinical care, industry and policy are very different in many respects, there are similarities as well, and the skills and experiences from one position

became the building blocks for the next. When counseling new genetic counselors about

how to expand their career possibilities, my advice is to use every professional activity as an opportunity to expand skills and experiences, but equally as important, to develop professional contacts.

The last two major career changes I made, first into industry and then into policy, were possible because of the personal and professional contacts I had made over the years. Someone who knew my professional history recommended me to a potential employer who was looking for someone with a particular set of skills and experiences. Genetic counselors are uniquely trained and positioned in today's market to fill a wide variety of positions. Creatively using those skills, seeing how they can be applied and developing an extended professional network can help maintain a long and interesting career as a genetic counselor. ♦

***“...developing an extended professional network will help maintain a long and interesting career as a genetic***

### CENTER TO STUDY KNOWLEDGE AND ATTITUDES ABOUT REPRODUCTIVE GENETICS

One of the Center's objectives is to perform social science research to assess what the public thinks, knows and feels about reproductive genetic technologies, including genetic testing, gene transfer and reproductive cloning. The first survey of the general public was completed in Fall '02 reflects the public's optimism and concerns around the use of these technologies. A more indepth qualitative research project is underway. ♦

www.dnapolicy.org

— Joan Scott, MS

# An Over-and-Above Experience Down Under

Kristin L. Frazer

This past summer, I completed my summer rotation at Genetic Health Services Victoria in Melbourne, Australia. I worked with several genetic counselors at Royal Women's Hospital, Royal Children's Hospital, Mercy Hospital for Women (a public, Catholic hospital) and Melbourne Ultrasound for Women (a private practice).

Throughout my rotation, I observed and participated in many genetic counseling sessions, including prenatal, pediatric, cancer and infertility. My observations involved many different ethnic groups and were translated in many languages. I observed how cultural differences

and differences in the health care system influence genetic counseling.

The hospitals had interpreter services for more than 12 of the most common languages spoken in Melbourne. One of the patients I observed came

in speaking English but wanted an interpreter present for the technical, scientific information. She was afraid she would not understand in English. She first asked for a Macedonian interpreter, but when that interpreter was already with another patient, she informed us that a Croatian or Serbian interpreter could also be

used. It was amazing to me that the hospital had interpreters for all of these languages. This showed me how the many different cultures were recognized and

incorporated into the health care services.

While in Australia, I also attended the Human Genetic Society of Australasia's annual

education conference in Adelaide, Australia. At the HGSA conference I met geneticists and genetic counselors from all parts of Australia, New Zealand, Great Britain and the United States.

Part of my experience also included collecting information about the history, training and certification of genetic counselors in Australia. Although the history of genetic counseling in Australia is different from that of the United States, the profession arose in both countries as human genetics expanded and created more need. Even though the training and certification differs in each country, genetic counselors fulfill the same roles.

Traveling in Australia enabled me to learn about genetic services, meet people from all over the world and learn about cultural differences first hand.

In the future, I hope that more genetic counselors and students will have an opportunity to study abroad so that cultural differences can be better understood and a greater appreciation for the global similarities of this profession can be gained. ♦

***"...many different cultures were recognized and incorporated into the health care services."***

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## AN AUSSIE IN AMERICA

Penny Pitt

My genetic counselling student experience in the United States took place this past November and December. My trip began in Phoenix, Arizona, where I attended NSGC's annual education conference. This was a great opportunity for me to meet genetic counsellors from all over the United States. As I work as an infertility counsellor in Melbourne, Australia, I was particularly interested to meet some of the counsellors who work in the infertility genetic field whilst at the conference. I hope that as this area of genetic counselling expands, counsellors in both Australia and the United States will more and more be able to share knowledge and learn from each other.

The second leg of my experience in the United States was a student placement at the University of South Carolina clinical genetics unit, supervised by Program Director **Janice Edwards**. Whilst on placement I was able to observe genetic counselling in the areas of primary professional interest to myself; infertility genetics and prenatal diagnosis. This was a very valuable experience, particularly as I was privileged to observe five different counsellors at work.

Through noticing some of the differences between genetic counselling practice styles, I was able to reflect on why we practice in a particular way in Melbourne. I am now less inclined to take this for granted, but rather have a deeper understanding of the principles underlying my counselling practice.

I also had the opportunity to sit in on some classes whilst in South Carolina. I was reassured to find that the material covered was very similar to the University of Melbourne course I had completed. I found that the main differences were related to culture, to the format of the training and to the prior work and academic experience of the students. I think there is an opportunity for links between genetic counsellors in the United States and in Australia to continue to strengthen in the future. ♦



**On the Road**

# Lobbying — In Our Best Interest? *cont fr p 1*

- establishes working relationships with Congressional staffers and knows the personalities, voting records and interests of Members of Congress.
- arranges for NSGC to be at the table for critical Congressional hearings and educational briefings and coaches NSGC members on how to give testimony
- educates legislative staff on Capitol Hill and arranges visits for our members with them
- provides legislative alerts and quarterly reports.

## MEMBER AS LOBBYIST

Although any NSGC member hired to lobby would have a lot to learn, there are benefits to having a genetic counselor in Washington. This person could increase the visibility of our profession by providing a consistent presence in coalitions, national media and on Capitol Hill. Currently, meetings are attended by local DC-area NSGC members who volunteer their time and by our President or presidential designee.

Together with the NSGC leadership, a genetic counselor serving in this position would

- set the legislative agenda
- monitor legislation
- provide representation by a colleague
- pursue opportunities to work with other groups to move our agenda forward
- facilitate workshops, Hill visits and legislative alerts.

## FINANCES OF LOBBYING

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Lobbying has huge potential benefits for our organization but it is not inexpensive. The cost of hiring a full-time lobbyist is estimated at \$50,000-75,000 per year and we would need to commit funds to this effort for multiple years. Alternatively, we could hire a part-time professional lobbyist or share expenses of a lobbyist with another group with similar needs.

## MEMBER VIEWS SOUGHT

Each of our options has advantages and limitations. The option we choose depends on what we hope to achieve — new laws? ...a presence in Washington? — and the feasibility of incurring the expense of lobbying.

We'd like to hear what you think.

✉ Cheryll@genedx.com

<sup>1</sup> [www.nsgc.org/newsroom/testimony.asp](http://www.nsgc.org/newsroom/testimony.asp)

<sup>2</sup> [groups.yahoo.com/group/NSGC\\_SIC/](http://groups.yahoo.com/group/NSGC_SIC/)

## SURVEY STATS REVEAL MEMBER PREFERENCES

### Heather Hampel, MS

The Annual Education Conference (AEC) Subcommittee conducted a three-year follow up study of our stand-alone conference. The survey was available on our website January 3 - 31 and by fax for those without Internet access.

### DEMOGRAPHICS

A total of 502 members completed the survey, representing 22.8% of the 2200 NSGC members: Qualities of this group include:

- Membership Status: 487 (97%) full members, 2 (<1%) associate members, 12 (2%) student members, 0 emeritus members and 1 no response.
- Years in Practice: 22 (4.4%) members 0 years; 194 (38.7%) 1-4 years; 125 (25%) 5-9 years; 67 (13.4%) 10-14 years and 0 >15 years.
- Attendance at Conferences: 290 (58%) attended in Savannah (2000); 313 (62%) attended in DC (2001) and 332 (66%) attended in Phoenix (2002).

### RESULTS

Nearly 70% of the respondents (312 of 460) indicated that they are pleased that our AEC is now a stand-alone meeting.

When asked how attendance would be affected if the AEC was held in the Spring, 81 (16.5%) indicate they would be more likely to attend, 72 (14.7%) indicated they would be less likely to attend and 338 (69%) indicated they would be equally likely to attend. It was noted that the fall timing of the meeting is preferable for genetic counseling students who use the meeting to interview for jobs and to get involved with the organization.

The criteria by which the respondents would like us to select future sites are:

- 134 (27.5%) would like first-tier cities, e.g. Boston, New York, San Francisco, Chicago
- 121 (24.8%) would like least expense, both airfare and hotel
- 117 (24%) would like to consider ease of travel, hub cities preferred e.g. Denver, Dallas, Atlanta, St. Louis
- 86 (17.6%) would like second-tier cities with activities, regardless of ease of travel, e.g. Charlotte, Oklahoma City, Savannah
- 29 (6%) would like resort/spa properties, e.g. spa, ski, golf resorts ❖

✉ [hampel-2@medctr.osu.edu](mailto:hampel-2@medctr.osu.edu)





MESSAGE FROM  
THE CO-CHAIRS

## '03 CONFERENCE UPDATE

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

The 2003 AEC planning committee has been working hard to put together an exciting meeting in Charlotte this September. We have expanded the meeting to last four full days to meet the changing needs of the membership. We found that it was very difficult to fit in enough contact hours for those who need to acquire CEUs, yet allow time for committee, SIG and ancillary meetings — not to mention some down-time to minimize brain overload!

Our team has planned an exciting line-up of plenary speakers along our theme, "Putting Science into Practice." As there are 19 different Educational Break-out Sessions to choose from, we are sure you will be able to find several that meet your educational needs. You will even have the unique opportunity to hear a local hand-bell choir by a group of talented adults with mental retardation during one of the breaks. Look for the 2003 Conference brochure coming soon in the mail. Hope to see you in Charlotte!

— **Stephanie Cohen**  
**and Ellen Schlenker**

ABSTRACTS

Abstracts for the 22<sup>nd</sup> Annual Education Conference must be submitted electronically between Monday, March 31 and Friday May 2, 11:59pm EST (*precisely*). Guidelines for abstract submission may be found on the NSGC website: [www.nsgc.org](http://www.nsgc.org).

✉ **Noelle Agan**, ☎314-569-6884; [agannr@stlo.smhs.com](mailto:agannr@stlo.smhs.com)  
**Shannan Delany**, ☎706-721-2809; [sdelany@mail.mcg.edu](mailto:sdelany@mail.mcg.edu)

SIMPLY HEAVENLY!

The Westin Hotel is located in downtown Charlotte, in the heart of the financial district and within easy, safe walking distance to restaurants, shops and museums. The hotel opened this year and, if you remember those wonderful rooms in Savannah, this hotel has those "Heavenly Beds" and "Heavenly Baths" — luxury upgrades in every room. Treat yourself to quality education and quality accommodations this year in Charlotte! ♦

'04 SHORT COURSE  
DEADLINE EXTENDED

The deadline for submissions for Short Course proposals has been extended to April 15. Instructions and forms may be downloaded on our website. Visit [www.nsgc.org](http://www.nsgc.org), enter the Password Protected area, then click on Committee Activities, Annual Education Conference Subcommittee

✉ **Heather Hampel** [hampel-2@medctr.osu.edu](mailto:hampel-2@medctr.osu.edu)

## WHAT'S NEW FOR AEC '04?

Planning for the 23<sup>rd</sup> Annual Education Conference is underway. The planners invite you to join the effort to make next year's meeting a success! The conference will be held October 7-11 in Washington, DC. A Short Course will be held October 6-7.

If you are interested in participating in the planning or have a topic or speaker to suggest, please contact one of the co-chairs listed below.

### Conference Co-chairs

**Liz Melvin** ☎919-684-4787  
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### Educational Break-out

#### Session Co-chairs

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New and seasoned volunteers are welcome! Go ahead, take the plunge! ♦

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## NSGC COLLABORATES WITH CDC FOR GENETIC TESTING STUDY

**Andy Faucett, MS**

The CDC, Office of Genomics and Disease Prevention (OGDP) and NSGC will be asking for your help with a joint study to assess the status of genetic testing among patients referred for genetic counseling. The purpose of the study is to characterize genetic testing that occurs within the counseling setting including types of tests, indications for testing, test results and follow-up. Data will be collected through a standardized questionnaire available to all NSGC members at the NSGC website.

Data will be collected on patients seen during five days in the spring of 2003. This is the first collaboration between NSGC and CDC. The information gained from this study will be used potentially to develop ongoing surveillance programs to monitor trends in genetic testing in the United States. ♦



## SILVER AWARD

Congratulations to **Beth Balkite** for winning a Silver Award for a GlaxoSmithKline R&D (Research and Development) project. She was acknowledged for "exceptional leadership in the development and implementation of the Genetics Research at GlaxoSmithKline e-Learning Programme." Awards are given at the Gold, Silver and Bronze level, and most of the time they go to a scientist who has made some big discovery. It is very unusual for a person in a discipline other than medicine or pure science to receive this award. ♦

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# Bulletin Board



## NEW! JGC/CEU PROGRAM

**Barbara Lerner, MS**

Earn Category 2 CEUs in the comfort of your own home, at your own pace and at a low price by reading the *Journal of Genetic Counseling*.

### Program Highlights

- Convenient
- Web based post-quiz
- Quizzes remain available throughout the year
- View quiz score immediately
- Take quizzes multiple times to pass
- Low price - only \$25 (plus a \$20 CEU fee) to participate for one year
- Online credit card payments

- Pre-approved by the ABGC for up to 1 Category 2 CEU per year

To register visit [www.nsgc.org](http://www.nsgc.org). Click on the homepage link for information about the JGC CEU Program under NSGC News. ♦

[jlerner@brandeis.edu](mailto:jlerner@brandeis.edu)

## Web News

**Lisa Brodeur**

Coming Soon! Members will soon be able to conduct archive searches for topics discussed on NSGC's general listserv. Check our website under "listserv info" in the members-only corner. Anticipated start-up date is later this Spring. ♦



## APPLY WITHIN: AHSPA DEADLINE NEARS

The Audrey Heimler Special Projects Award provides an annual award of \$5000 for projects that focus on the future of the genetic counseling profession and/or improving the provision of genetic services. The fund is an opportunity to enhance professional development; past projects have provided high-quality professional resources.

2004 project proposals must be submitted by May 15 by an NSGC member in good standing. Student thesis projects cannot be funded. Awards are based on the proposal's strength and feasibility, as judged by the AHSPA Committee. The winners will be announced at the Annual Education Conference in Charlotte.

The call for proposals was sent out with the Winter mailing in February. You can also find the submission instructions on the website.

[www.nsgc.org/members/ahspa.asp](http://www.nsgc.org/members/ahspa.asp)

### 2003 Audrey Heimler Special Projects Award Committee

**Lisa Kessler**, Committee Chair, **Renee Chard**, **Angela Gibson**, **Dawn Peck**, **June Peters** and *ex officio* members: **Peter Levonian** and **Teresa Brady**.

### Past Recipients of Audrey Heimler Special Projects Awards

- 2000 **Robin Bennett**: Recommendations for Genetic Counseling and Screening of Consanguineous Couples and Their Offspring
- 2001 **Barbara Lerner**: Current Issues in Genetic Counseling: Interactive Internet Based Continuing Education Program for Genetic Counselors
- 2002 **Beth Billings**, **Sara Goldman**, **Vickie Venne**: Genetic Counselor Licensure: Experiences and Opportunities
- 2003 **Sumedha Ghate**, **Anna Leininger**, **Cindy Solomon**, **Nicole Teed**, **Jill Trimbath**: A Child's Guide to Familial Adenomatous Polyposis (FAP) ♦



# GENETIC COUNSELING DEFINED AS AN ALLIED HEALTH PROFESSION

**Nancy Steinberg Warren, MS &  
Karen Potter, MS**

Our Society has been invited to join the Association of Schools of Allied Health Professionals (ASAHP). The ASAHP was chartered in 1967 as a not-for-profit national professional organization for administrators, educators and others who are concerned with critical issues related to allied health professional education. Allied health care professionals are defined as individuals who are "involved with the delivery of health or related service pertaining to the identification, evaluation and prevention of disease and disorders..."

Over 200 allied health professions are represented by ASAHP, including dietitians, medical technologists, audiologists, dental hygienists, diagnostic medical sonographers, speech language pathologists and respiratory therapists.

The Professional Issues Committee recently suggested that the NSGC join ASAHP as an agency affiliate. An agency affiliate has an interest in the ASAHP's mission to enhance the effectiveness of education for the Allied Health Professions. To fulfill its mission, ASAHP has established the following goals: to promote collaboration and partnerships, to

influence health care policy, to promote and strengthen research and scholarship, to promote and support academic leadership and to promote high quality and innovation in education.

## EXPECTATIONS

As an agency affiliate, NSGC can participate in non-governance committees and create or participate in special interest sections. We expect that membership in ASAHP will result in several positive outcomes. As a represented profession, the visibility of genetic counseling will be increased among allied health care agencies and providers. Also, we have the opportunity to be involved in planning strategies for reauthorization of federal allied health funding legislation. Should efforts to obtain allied health funding be successful, there would likely be grant opportunities for genetic counselors and training programs.

The ASAHP has shown considerable interest in the genetic counseling profession and feels that its membership will benefit from our involvement with their organization. The Executive Director and President of ASAHP have invited NSGC and genetic counselors to submit articles to their journal, the *Journal of Allied Health*, and the newsletter, *Trends*, to educate their membership about genetic counselors and genetic counseling issues. Members of our Professional Issues Committee are drafting an article for *Trends* and are beginning the process of educating ASAHP members about genetic counseling.

☞ [www.asahp.org](http://www.asahp.org) and *Journal of Allied Health* ♦

## Research Network

### SPINA BIFIDA

The Spina Bifida Research Resource (SBRR) is an ongoing research project investigating the causes of spina bifida. The study's Principal Investigator, **Laura Mitchell**, has recently relocated to the Institute of Biosciences and Technology, The Texas A&M University in Houston. **Katy Hoess**, study coordinator, remains at The University of Pennsylvania in Philadelphia. **Sarah Guerra**, study coordinator, has joined the team. Ms. Guerra is bilingual and can discuss the study with Spanish-speaking individuals.

Families with one or more members affected with spina bifida are eligible to participate. Participation includes the collection of family and medical histories and either cheek cells or blood samples. A study newsletter provides participants with updated information on ongoing research related to spina bifida. There are no costs to participants, travel is not required and all information is confidential.

Counselors as well as families may contact:

☞ Katy Hoess, MS, ☎866-275-SBRR (toll free) or 215-573-9319, [khoess@cceb.med.upenn.edu](mailto:khoess@cceb.med.upenn.edu) or Sarah Guerra, ☎866-521-SBTX (toll free) or 713-667-7573, [sguerra@ibt.tamu.edu](mailto:sguerra@ibt.tamu.edu) or Laura Mitchell, PhD, ☎713-667-7582, [lmitchell@ibt.tamu.edu](mailto:lmitchell@ibt.tamu.edu) or [www.sbrr.info](http://www.sbrr.info) ♦

### DEVELOPMENTAL GENOME ANATOMY PROJECT (DGAP)

Patients with apparently balanced chromosomal rearrangements and multiple congenital anomalies are being sought for participation in a gene discovery research project. Goals of the DGAP include rapid mapping of chromosomal breakpoints, positional cloning of genes interrupted or dysregulated at the breakpoints and validation of genes identified in specific anomalies through creation of animal models. Further description of DGAP, sample submission and patient consent forms and contact information are available on the website.

☞ **Azra Ligon**, ☎617-732-7984, [aligon@rics.bwh.harvard.edu](mailto:aligon@rics.bwh.harvard.edu) or [dgap.harvard.edu](http://dgap.harvard.edu) or **Heather Ferguson**, ☎617-525-5769, [hferguson1@partners.org](mailto:hferguson1@partners.org) ♦





***CRIPPLED JUSTICE: The History of Modern Disability Policy in the Workplace***

**Author:** Ruth O'Brien

**Publisher:** The University of Chicago Press, 2001, ISBN 0-226-61659

**Reviewer:** Joann Bodurtha, MD, MPH

Ruth O'Brien's own experience of bilateral forearm tendonitis, and the wide range of responses librarians had to her request not to put down the photocopier lid, led her to explore the roots of the disability rights movement. Her background as a political scientist and government professor in combination with clear writing create a thought-provoking book. She argues that "since the term 'disability' encompasses so many different types of physical and mental impairments, people with disabilities present a perpetual precedent-setting threat to the workplace." She builds a strong case to support her thesis that most "work" in the United States is about employer control. Her citations provide evidence that Congress and all levels of the judiciary have been more concerned about protecting employers' freedom to contract and control than meeting the needs of employees. Her historical review characterizes professionals of the rehabilitation movement as more concerned with returning persons with disabilities to "normal," than about addressing the limitations of the workplace and environment that handicap people.

Beginning as early as 1945, persons focused on the disability rights approach argued that programs should give people with disabilities the opportunities to care for themselves

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## RESOURCES

and that society must accommodate by removing barriers. O'Brien details the politics, arguments and people involved in section 504 of the Rehabilitation Act that was finally signed in 1977. The path from this Act to the passage of the Americans with Disabilities Act (ADA) in 1990 is paved with repeated instances of the Supreme Court majority's rejection of the rights model and its underlying principles of equality of opportunity and individual autonomy. She asserts that, "according to a majority of justices on the Supreme Court, society has reason for prejudice because disabled people are 'different'."

The most disturbing chapter focuses on the events after the passage of the ADA. Few individuals with disabilities have actually achieved relief from discrimination because of an ironic dilemma: either the disability is not serious enough to warrant legal protection or is so severe that the individual is not qualified to work. O'Brien's focus on specific Supreme Court Justice's arguments emphasizes the importance of the selection of Justices in determining the actual outcome of legislative policy. She argues that giving persons with disabilities the capacity to challenge the hierarchy between employer and employee is more disturbing to the existing power structure than prohibiting discrimination on the basis of fixed categories like race and gender.

This book is important reading for those who are actively working on legislation regarding genetic discrimination, and perhaps more important for those who are sitting by. History is being written by our actions and inactions. How are we addressing these issues and counseling about our differences? How are we advocating for the rights of persons with different genetic traits and conditions? How much are we emphasizing "normalcy?"



Focusing on prevention? This short book presages the legislative and judicial history of genetic disparities that has yet to be written.



***Waiting with Gabriel***

**Author:** Amy Kuebelbeck

**Publisher:** Loyola Press, Chicago.

**Reviewer:** Jamie H. Fisher, MS

*Waiting with Gabriel* is Amy Kuebelbeck's story about her son's brief life. At 25 weeks gestation, an ultrasound exam revealed that Amy's baby had hypoplastic left heart syndrome (HLHS). Amy shares her family's experience of learning about HLHS and the options available. After intensive soul searching, Amy states that the "choice we were being asked to make on behalf of our son was not between life and death but between a painful death and a peaceful one." The family decided to comfort and love their baby for the remainder of his life.

This story is about the family's journey in loving Gabriel. Amy views her three and one-half months of knowing as a gift. The family was able to plan how they wanted to spend their time with him, taking extra care to cherish his life in the womb. They documented the pregnancy with photographs and even took Gabriel to a baseball game. The family created many loving memories during his two hours of life outside the womb. Many pictures were taken; family and friends were present and involved; mementos were collected; Gabriel was baptized; and he died in his mother's arms. Funeral planning began during pregnancy, and Gabriel was buried in a casket lovingly made by his grandfather.

The epilogue is as touching as the story itself. It is composed of short stories about the family's experiences since Gabriel's death. The stories



speak about the pain of their grief, the responses of others and the moments when they have experienced Gabriel's continued presence in their lives. The epilogue will speak to any family who has experienced the death of an infant.

This is a wonderful story that is well written. Although it brought me to tears, I would highly recommend this book both for families who are continuing pregnancies knowing that their babies have lifelong limiting conditions and also for the professionals who support them. ❖

## CANCER OUTREACH

**FORCE: Facing Our Risk of Cancer Empowered** is the only national nonprofit organization devoted to serving those affected by hereditary breast and ovarian cancer and those concerned about hereditary cancer risk.

### *Mission Statement*

- To provide women with resources to determine whether they are at high risk for breast and ovarian cancer due to genetic predisposition, family history or other factors.
- To provide unbiased information about options for managing and living with these risk factors.
- To provide support for women as they pursue these options.
- To provide support for families facing these risks.
- To represent the concerns and interests of our high-risk constituency to the cancer advocacy community, the scientific and medical community, the legislative community and the general public.
- To promote research specific to hereditary cancer.

☛ **Sue Friedman**, Executive Director  
 ☎954-255-8732  
[www.facingourrisk.org](http://www.facingourrisk.org)

# RESOURCES



***Your Genetic Destiny: Know Your Genes, Secure Your Health, Save Your Life***

**Author:** Aubrey Milunsky, MD, DSc

**Publisher:** Persus Publishing, Cambridge, Mass. 2001; 410 pages

**Reviewer:** Beverly Yashar, MS, PhD

The integration of genetics into the vocabulary of both health care professionals and the public has created a strong need for books like ***Your Genetic Destiny***. This 27-chapter book presents a comprehensive overview of the genetic basis of disease, with a primary focus on understanding how genetics contributes to the development of common complex conditions. It contains a wealth of information on diseases where we have some understanding of how genes are involved (heart disease, diabetes, cancer and mental illness) and those where our understanding is fairly minimal (obesity and longevity). The author provides perspectives on the genetic etiology, prevention and treatment of these conditions that are accessible by a wide audience of readers. This information is grounded in a nice introductory section on genes and chromosomes and the basics of clinical genetics.

The book is meant to empower people and help them to promote both their own health care and that of their family members. Dr. Milunsky's years of clinical experience allow him to write from multiple perspectives. He does a good job of mixing molecular and clinical genetics to discuss these topics and uses many personal stories to bring examples to life. The multiple tables, case examples and appendices (containing "Frequently Asked Questions," a listing of genetic support groups and agencies and additional reference books) are quite useful. The textbook



format of this book makes it useful for either selected reference or reading in its entirety.

Unfortunately the value of the information in this book is severely tainted by Dr. Milunsky's view of genetic conditions as evils that must be eradicated. The principles of non-directive counseling do not inform any aspect of Dr. Milunsky's model of clinical care. In the chapter on presymptomatic and predictive testing, he argues that genetic testing is the only appropriate course for at-risk individuals; there is no real consideration of personal choice. While we can all agree that it is important for our patients to share genetic information with their at-risk relatives, Dr. Milunsky uses the burden of guilt to support his arguments.

The press release for this book states that Dr. Milunsky explains genetic counseling. It is within this context that this book's failings become most striking. His perspectives on the role of genetic counseling and genetic counselors are misleading. Masters trained genetic counselors are barely mentioned, leaving the reader to the conclusion that MD geneticists are the primary providers of genetic counseling. He also states that genetic counseling is useful only after a clinical diagnosis has been made. The utility of this book resides in the breadth and depth of information that is considered. However, given Dr. Milunsky's narrow views on clinical genetics, it would be a disservice to the profession of genetic counseling to recommend this text. ❖

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Angela Geist, MS & Roxanne Ruzicka, MS

**Nov 11 — NPR, "Talk of the Nation"**

**Jill Fischer** described the role of genetic counselors in the PGD/IVF arena, exploring potential ethical issues and explaining the importance of patient autonomy and the support patients receive from genetic counselors while they undergo PGD/IVF.

**Jan 10 — Philadelphia Business Journal, "Giving Voice to Genetics"**

**Executive Director Bea Leopold** was featured in a Growth Strategies article. She discussed how NSGC has grown in the last 15 years as well as her efforts to ensure that NSGC is a financially successful organization.

**Jan 12 — PBS, "Our Genes, Our Choices"**

**Barbara Biesecker** was featured in a panel discussion about the ethical issues of genetic testing, pre-implantation genetic diagnosis and cloning. She described how genetic counselors educate and assist patients in making their own decisions about pursuing genetic testing. She also role-played delivering different potential amniocentesis results.

**Jan 20 — 7th Heaven**

**Ruthie** befriended a girl with cystic fibrosis and learned that it is okay to ask people with health concerns about their problems. The girl with CF served as a role model for overcoming obstacles. The medical information presented during the show was generally accurate.

**Jan 31 — Law & Order: SVU**

**A** baby who had been killed and abandoned was discovered, and the investigation found that the baby had been euthanized by its mother

because it had Tay-Sachs disease. Red spots in the baby's retina noted by the pediatrician led to DNA testing that confirmed the diagnosis. Tay-Sachs was described correctly as a progressively degenerative autosomal recessive disease most common in the Ashkenazi Jewish population. This episode raised the interesting debate of euthanasia for a lethal condition versus facing certain death from a devastating disorder.

**Feb 4 & Feb 6 — Today Show**

**This** two-parter showcased genetic counseling. **Kristin Niendorf** appeared with a patient who underwent genetic testing for a strong family history of breast cancer and a known BRCA2 mutation in the family. Her test results were revealed during the second episode. Indications for genetic counseling, what happens in a genetic counseling session and references for people interested in finding out more information about genetic counseling were presented. The MSNBC website also had text about this segment and links to the NSGC website.

**Jan 03 — CAP (College of American Pathologists) Today, "CF carrier screening-making it meaningful"**

**This** article outlined the pros and cons of CF mutation screening. The author stated that genetic counselors are not the only professionals capable of providing counseling to patients. However, they remain invaluable in "providing information to physicians...reviewing patient samples, requesting and reviewing samples from family members...and talking to physicians about the interpretation of testing outcomes."

**Feb 6 — ER**

**A** high school girl was involved in a car accident that resulted in the

injury of some of her classmates. Tests revealed that the girl had Wilson disease, which was described by the ER doctors as a genetic condition that results in the accumulation of copper in the body and can be associated with a flat affect and movement disorders. After receiving the diagnosis, the girl suggested that maybe an unintentional movement caused her to step on the accelerator rather than the brake, leading to the accident.

**Feb 7 — Law & Order: CSI**

**A** man of short stature kills his average stature daughter's fiancé (who is of short stature) because of the risk of their having a child with short stature. The detectives investigate this murder at a Little People of America convention and their interviews bring up some of the societal issues and concerns of people with dwarfism. The genetics of certain dwarfisms were mentioned, and all the information seemed to be correct.

**Feb 17 — Boston Globe, "A 'Normal' in Genetics Test Can Bring New Problems"**

**Q**uoted were three genetic counselors, **Robin Bennett, Kathy Schneider** and **Nathalie McIntosh**, in an article that discussed the emotional effects that can occur after DNA testing has determined that an individual is no longer at-risk for a particular genetic disease. The role of genetic counselors in helping individuals through this difficult adjustment was discussed.

**Feb 22 — The Lancet**

**M**onica Alvarado was interviewed for an article that describes a folic acid education project that she and her colleagues have been developing over the last year. The folic acid "fotonovela" educates young Latinas about the benefits of periconceptual folic acid through a narrative told through photographs and captions. The fotonovela will be distributed in areas with a large Latino population in Los Angeles. ❖



# COMMITTEE & SIG ACTIVITIES

## Position Statements

### GENETIC SERVICES COMMITTEE SHEPHERDS IN ONE; USHERS OUT ANOTHER

#### STANDARD PEDIGREE SYMBOLS POSITION STATEMENT APPROVED

The Genetic Services Committee announces that the following Position Statement has been adopted by NSGC:

The National Society of Genetic Counselors advocates the use of pedigree symbols as presented in "Recommendations for Standardized Human Pedigree Nomenclature", (*Am J Hum Genet* 56: 745-752, 1995), in both clinical practice and in medical/scientific publications.

Standardized pedigree symbols offer a consistent method of recording and interpreting family history, increasing uniformity of medical information and enhancing quality control in clinical genetics, medicine, genetic education and research. ♦

#### CF STATEMENT TO BE RETIRED

In November 2001, the Genetic Services committee determined that the Cystic Fibrosis (CF) Screening position statement, written in 1993, needed to be reviewed. Following that decision, a lead committee was formed with members representing various expertise in cystic fibrosis screening and/or diagnostic testing.

Upon reviewing the 1993 statement and consulting with the authoring committee, made the following recommendations:

- the existing CF Screening position statement be retired and that screening recommendations for individual conditions would be more appropriately handled in the context of practice guidelines
- a broader position paper pertaining to general population screening, one that will stand the test of time, be developed

- separate position statements be developed for 1) preconception/ prenatal genetic screening, 2) newborn genetic screening and 3) predisposition genetic screening.

✉ **Heather Ferguson**

ferguson1@partners.org ♦

#### SOCIAL ISSUES COMMITTEE TO ADDRESS HUMAN CLONING

The Social Issues Committee is working on a position statement on human cloning and invites interested members to join the working group.

✉ **Nancy Kramer** ☎310-423-9924,

nakramer@earthlink.net ♦

## ETHICS SUBCOMMITTEE ACTIVITIES

Do you have a case that you feel challenges your professional ethics? A case where it is not clear how to proceed? The Ethics subcommittee invites you to use our services. We offer formal and informal consults to help work out issues of professional ethics based on the NSGC Code of Ethics that are completely confidential.

We will be presenting an educational break out session at the Annual Education Conference in Charlotte, where we will be discussing actual cases that involved ethical dilemmas and how to apply the Code to such cases. Submissions are encouraged, and all identifying information will be removed.

For ethics consults, contact any Ethics subcommittee member or visit [www.nsgc.org](http://www.nsgc.org); log in, then click on "Ethics consults."

Ethics committee members:

**Peter Levonian**, Chair

**Melinda Cohen**

**Erynn Gordon**

**Kim Hart**

**Michelle Moore**

**Myra Roche**

**Roxanne Ruzicka**

[pjlevoni@gundluth.org](mailto:pjlevoni@gundluth.org)

[melinda.cohen@mcmail.vanderbilt.edu](mailto:melinda.cohen@mcmail.vanderbilt.edu)

[egordon@cnmcresearch.org](mailto:egordon@cnmcresearch.org)

[hartk@peds.ucsf.edu](mailto:hartk@peds.ucsf.edu)

[michelle.moore@memhospcs.org](mailto:michelle.moore@memhospcs.org)

[Myra\\_Roche@med.unc.edu](mailto:Myra_Roche@med.unc.edu)

[RoxanneR1@aol.com](mailto:RoxanneR1@aol.com) or [rruzicka@uci.edu](mailto:rruzicka@uci.edu)

#### ART& INFERTILITY SIG CREATES EDUCATIONAL PROJECT

The ART and Infertility SIG has developed a lecture series for training genetic counseling graduate students. A CD of the PowerPoint presentations and outlines were sent to every training program. Topics included: general ART information, genetics of both male and female factor infertility, preimplantation genetic diagnosis (PGD), screening of donor gametes and psychological issues of infertility. Additional handouts containing information about IVF cycling, references and ART and infertility web sites were included. ART & Infertility SIG members are available to present these talks at the training programs if desired.

✉ **Jill Fischer**, [JillF@sbivf.com](mailto:JillF@sbivf.com) or

**Lauri Black**, [BlackLD@sutterhealth.org](mailto:BlackLD@sutterhealth.org)

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■ **BIRMINGHAM AL:** Immediate opening for BC/BE lab-based Genetic Counselor. Exp pref. Self-motivated, enthusiastic team player w/ good commun & org skills req. Lab offers molec, cytogenetic & PN scrng svcs. Liaison between referring MDs & pts. Opptys for face to face GC, tchg & develop educ materials.  
✉ CV & ltr of interest: R. Lynn Holt, MS, CGC, University of Alabama - Birmingham, Dept Genetics, Kaul 210E, 1530 3rd Ave S, Birmingham AL 35294-0024; ☎205-934-4983; Fax: 205-975-6389; lholt@uabmc.edu. EOE/AA

■ **LITTLE ROCK AR:** Immediate opening for Cancer Genetics Counselor. Join multidisc team at major tertiary cancer ctr. High motiv, independent, adaptable, work in fast-paced high growth programs. CA risk asmt, GC & tstg, educ staff/students/public, clin rsrch, use telemed tech.  
✉ Becky Butler, LCSW, University of Arkansas for Medical Sciences, Arkansas Cancer Research Center, cancer Genetics Program, 4301 West Markham, UAMS Slot 506, Little Rock AR 72205-7199; ☎800-358-7229; Fax: 501-296-1701; butlerbeckyb@uams.edu. EOE/AA

■ **LOS ANGELES CA:** Immediate opening for 2 BC/BE Genetic Counselors. Seeking 1 Sr. GC/Clin Coordinator w/ min 3-5 yrs exp in cancer/adult genetics & 1 Jr. GC pref w/ trng/exp in cancer genetics. Join busy acad adult genetics prog: primarily cancer GC w/ some referrals for cardiovasc disease & genrl genetics. Both offer tchg & clin rsrch opptys.  
✉ Ora Karp Gordon, MD, MS, GenRisk Program, Cedars-Sinai Medical Center, 444 S. San Vicente Blvd, Ste 604, Los Angeles CA 90048; ☎310-423-9905; Fax: 310-423-9946; ora.gordon@cshs.org. EOE/AA

■ **NORTHERN CA:** Immediate opening for PT BC/BE Genetic Counselor. Spanish pref. Provide c'hensive PN GC svcs at Oakland, San Ramon & Modesto sites.  
✉ Amy Foster, Corporate Recruiter, Genzyme Genetics, 3400 Computer Dr, Westborough MA 01581; ☎508-389-6623; Fax: 508-389-5558; amy.foster@genzyme.com. EOE/AA

■ **ORANGE CA:** Immediate opening for Genetic Counselor. Spanish pref. Genzyme Genetics is at the forefront of applying genetic knowledge for disease prevention outcome improvement & med cost reduction. Excellent compensation & benefits package including 3 wks pd vacation, a 401(k) plan w/ a company match extensive insurance benefits & an Employee Stock Purchase Plan. Position offers an oppty to join large growing team of GCs. Work independently at multiple perinatal offices w/ support from our team of geneticists & colleagues.  
✉ Amy Foster, Corporate Recruiter, Genzyme Genetics, 3400 Computer Dr, Westborough MA 01581; ☎508-389-6623; Fax: 508-389-5558; amy.foster@genzyme.com. EOE/AA

■ **ORANGE CA:** Immediate opening for BC Genetic Counselor for Asst Clin Professor. Exp req. Excellent clin & org abil, computer proficiency & i'personal skills req. GC in Spanish desired. Provide GC for adults & children in genrl genetic clin; asst Div Director w/ devel of new clin progs. Partic in &/or coord clin rsrch progs expected. Tchg respon: didactic & clin trng of GC grad & med students, residents, fellows & other health prof; commun outrch. UCI is the only full-service acad hosp in extended geographic region & serves large pt base.  
✉ CV & 3 refs: Suzanne B. Cassidy, MD, Director, UCI Medical Center, Div Genetics - Dept Pediatrics, 101 The City Dr, Bldg. 2 - 3rd Fl - ZOT 4482, Orange CA 92688; ☎714-456-6873. EOE/AA

■ **PASADENA CA:** Immediate opening for BC/BE Genetic Counselor. Some Spanish GC req. Join perinat priv prac. PN GC at Pasadena & West Covina PDC clinics.  
✉ Bharat D. Shah, MD, 50 Alessandro Place, Ste. 150, Pasadena CA 91105; ☎626-449-8706; Fax: 626-449-3464. EOE/AA

■ **SACRAMENTO CA:** Immediate opening for BC/BE Genetic Counselor. Spanish desired. Work w/ 4 GCs in CA State-cert PN Dx Center: AMA, abnorm U/S, CVS, amnio, 1st tri scrng.  
✉ Diana Allen, 300 University Ave, Sacramento CA 95825; ☎916-779-3255; Fax: 916-779-3260; PNDX1@aol.com. EOE/AA

■ **WEST HARTFORD CT:** Immediate opening for PT (50%) PN GC. Min 2 yrs exp in PN beyond grad req. Potential for FT w/in yr. Full academic appt as Instructor with tchg respon at UCONN Medical School.  
✉ Fax CV: Robert M. Greenstein, MD, Director, UCONN Health Partners, Div Human Genetics, Bldg. 65 - Kane St 1st Fl West, Hartford CT 06119; ☎860-523-6499; Fax: 860-523-6465; greenstein@nso1.uchc.edu. EOE/AA

■ **SOUTHERN FL:** Immediate opening for Genetic Counselor. Spanish applicants or willingness to learn Spanish pref. Genzyme Genetics is at the forefront of applying genetic knowledge for disease prevention outcome improvement & med cost reduction. Excellent compensation & benefits pkg incl 3 wks pd vaca, 401(k) plan w/ matching extensive insurance benefits & Employee Stock Purchase Plan. Oppty to work independently to manage & maintain top quality genetic svcs primarily for busy perinat prac in Miami and support for GC svcs in growing infertility prac.  
✉ Amy Foster, Corporate Recruiter, Genzyme Genetics, 3400 Computer Dr, Westborough MA 01581; ☎508-389-6623; Fax: 508-389-5558; amy.foster@genzyme.com. EOE/AA

■ **OAK LAWN IL:** Immediate opening for Genetic Counselor. Abil to work independently; excellent commun & org skills req. Exp pref. Join 3 med geneticists & 2 GCs in busy univ-based hosp in SW Chicago suburb: provide svcs in busy, c'hensive perinatal svc, coord & GC in metab clin. Oppty for GC students & resident/med student tchg.  
✉ Brea Douglas, Advocate Christ Medical Center, 4440 W. 95th St, Oak Lawn IL 60453; ☎708-346-5139; Fax: 708-346-4440. EOE/AA

■ **INDIANAPOLIS IN:** Immediate opening for BC/BE Genetic Counselor. Excellent org/commun skills & independence req. Spanish a plus. Join busy univ-based c'hensive PNDx clin. Trav to satellite clins req. Oppty to s'vise GC students, teach med students & residents.  
✉ Send CV & ltrs of rec: Kristyne Stone, MS, Indiana University Med Ctr, PNDx Clinic, 550 N. University Blvd, Rm. 2405, Indianapolis IN 46202; ☎317-274-7022; Fax: 317-278-0104; krstone@iupui.edu. EOE/AA

■ **BOSTON MA:** Immediate opening for PT BC/BE Genetic Counselor. Exp in cancer genetics pref. GC for risk factors, fam hx cancer genetics. Org risk program & sched. Knowledge about insurance issues & discrim, calculating risk w/ models avail. Possibility for FT.  
✉ Patty Thomas, Recruitment-Human Resources, Beth Israel Deaconess Medical Center, Div Hem/Onc, 330 Brookline Ave, Boston MA 02215; ☎617-632-9418; Fax: 617-632-8155; pthomas1@bidmc.harvard.edu. EOE/AA

■ **WESTBOROUGH MA:** Immediate opening for temp (approx 26 wks, through late summer) BC/BE Genetic Counselor. Excellent verbal/written commun skills, flex & abil to multi-task req. Daily interactions w/ GCs, health prof w/ variable knowledge of genetics & lab staff. Excellent compensation & benefits pkg incl 3 wks pd vaca, 401(k) plan w/ matching extensive insurance benefits & Employee Stock Purchase Plan. Join hi-volume molec dx tstg lab: coord tstg, commun DNA results to clients, asst w/ review & reporting of results.  
✉ Amy Foster, Corporate Recruiter, Genzyme Genetics, 3400 Computer Dr, Westborough MA 01581; ☎508-389-6623; Fax: 508-389-5558; amy.foster@genzyme.com. EOE/AA

■ **WESTBOROUGH MA:** Immediate opening for temp (w/ potential for permanent) BC/BE Genetic Counselor. Excellent verbal/written commun skills, flex & abil to multi-task req. Daily interactions w/ GCs, health prof w/ variable knowledge of genetics & lab staff. Excellent compensation & benefits pkg incl 3 wks pd vaca, 401(k) plan w/ matching extensive insurance benefits & Employee Stock Purchase Plan. Join hi-volume molec dx tstg lab: coord tstg, commun DNA results to clients, asst w/ review & reporting of results.  
✉ Amy Foster, Corporate Recruiter, Genzyme Genetics, 3400 Computer Dr, Westborough MA 01581; ☎508-389-6623; Fax: 508-389-5558; amy.foster@genzyme.com. EOE/AA

■ **WORCESTER MA:** Immediate opening for BC/BE Genetic Counselor. PT possible. Join growing molec dx tstg lab: pre- & post-test commun w/ clients; case-mngmt of PN samples, coord rsrch collab w/ outside rsrch laboratories.  
✉ Kara Houde Ng MS, Athena Diagnostics Inc, Four Biotech Park, 377 Plantation Street, Worcester MA 01605; ☎800-394-4493 x3021; Fax: 508-753-5601; kara.houdeng@athenadiagnostics.com. EOE/AA

# CLASSIFIED



■ **BALTIMORE MD:** Immediate opening for BC/BE Genetic Counselor. Join growing clin molec lab: Pre- & post-test commun w/ referrers, data interpret & reporting; partic in regulatory lab activ. Oppty for tchg genetic fellows & GC students.

✉ Barbara Karczeski, MS, DNA Diagnostic Lab, CMSC 1004, Johns Hopkins Hospital, 600 N. Wolfe St, Baltimore MD 21287; ☎410-955-0483; Fax: 410-955-0484; bkarczes@jhmi.edu. EOE/AA

■ **BOSTON MA:** Immediate opening for BC/BE Genetic Counseling Associate or Nurse Geneticist. Some exp pref; not req. Coordinate busy DNA dx prog and GC in Genetics Clinic and in hi-risk Perinatal Clinic. Rsrch involvement encouraged.

✉ Aubrey Milunsky, MD, DSc, Center for Human Genetics, Boston University School of Medicine, 700 Albany Street - W-408, Boston MA 02118; Fax: 617-638-7092; amilunsk@bu.edu. EOE/AA

■ **WORCESTER MA:** Immediate opening for temp BC/BE Genetic Counselor. Strong org & i'personal skills to work w/ peds, PN & adult pts. Exp pref. Join 5 GCs & 2 MD geneticists in full spectrum commun hosp-based prac. Obtain fam hx, educ pts/fam, facil case mngmt plans.

✉ Linda Costello, MBA, Director, Fullerton Genetics Center, 14 Victoria Rd, Asheville NC 28801; ☎828-213-0030; Fax: 828-213-0039; Linda.Costello@msj.org. EOE/AA

■ **CHARLOTTE NC:** Immediate opening for BC/BE Genetic Counselor. Spanish a plus. Hi-motiv, flex req. Ability to multi-task & commun effectively w/ team req. GC for variety of PN reasons in hi-vol clin staffed by 4 GCs, 5 MFMs & 6 U/S techs. Work closely w/ genetic colleagues, assist w/ GC & resident trng, oppty for prof growth.

✉ Cheryl Dickerson, MS, Carolinas Medical Center, Women's Institute, PO Box 32861, Charlotte NC 28232; ☎704-355-7916; Fax: 704-355-5891; cheryl.dickerson@carolinashealthcare.org. EOE/AA

■ **DURHAM NC:** May-June opening for 2 BC/BE Genetic Counselors. Enthusiastic, motiv, i'pendent prof w/ good commun & org skills. Span a plus; will consider new grads. Cover several maternity leaves from May-December 2003. Temp may become permanent. Join expndg MFM prac in acad ctr to provide GC svcs to PN/preconcep pts in PNDx, terat, ART. Expndg opptys for diverse GC activ, rsrch & tchg.

✉ Kristin Paulyson Nunez, MS, Coordinator Prenatal Diagnosis, Duke University Medical Center, DUMC Box 3390, Durham NC 27710; ☎919-684-3604; Fax: 919-668-6223; pauly001@mc.duke.edu. EOE/AA

■ **NEWARK NJ:** Immediate opening for BC/BE Genetic Counselor. Spanish speaking a plus. Broad range of PN & pediatric pts at full svc genetic ctr in inner city univ setting w/ onsite cyto-, biochem & molec labs. Join 4 GCs, 3 MDs & 5 PhDs. Opptys for clin prac, tchg & clin rsrch.

✉ Lorraine Suslak, MS, UMDNJ-NJ Medical School, Doctors Office Center Suite 5400, 90 Bergen St, Newark NJ 07103; ☎973-972-3311; Fax: 973-972-3310; suslaklo@umdnj.edu. EOE/AA

■ **NEWARK NJ:** Immediate opening for BC/BE Genetic Counselor. Min 2-3 yrs clin exp in MFM pref at St Barnabas-affil hosp. OB/GYN GC: PNDx or PN GC for hi-risk pts & fam, intake scrngs risk assmt, assist during dx procedures.

✉ Mike Gould, Newark Beth Israel Medical Center, 201 Lyons Ave, Newark NJ 07112; ☎973-926-7521; Fax: 973-391-0079; mgould@sbhcs.com. EOE

■ **ALBUQUERQUE NM:** Immediate opening for BC/BE Genetic Counselor. Bilingual Span/Eng given pref. Join PNDx & Genetics Team: wide variety of PN & preconcep cases; opptys for tchg & clin rsrch. Exceptional benefits.

✉ Apply online at [www.unm.edu/HealthSciences/CenterJobs](http://www.unm.edu/HealthSciences/CenterJobs) Requisition # H34917 or Valerie Rappaport, MD, University of New Mexico HSC, Dept. of Ob/Gyn - 4ACC, 2211 Lomas Blvd NE, Albuquerque NM 87131; ☎505-272-6611; vrappaport@salud.unm.edu. EOE/AA

■ **LAS VEGAS NV:** Immediate opening for FT or PT BC/BE Genetic Counselor. Join 4 perinatologists & 1 GC to

expand priv prac: all aspects of PN GC incl 1st trimester scrng & CVS.

✉ Elyse Mitchell, MS, Center For Maternal-Fetal Medicine, 400 Shadow Lane, Ste #206, Las Vegas NV 89106; ☎702-382-3200; Fax: 702-382-3575; emitchell@mfmcenter.com. EOE/AA

■ **NEW YORK NY:** Immediate opening for BC/BE Genetic Counselor. Exp pref. Join team of 3 GCs & 1 MD geneticist in active and diverse PN setting with oppty for peds and adult contact. Work with diverse pt pop in all aspects of PNDx. Oppty for tchg & student s'vision.

✉ Fax CV & ltr of int c/o Victor Penchaszadeh, MD, Beth Israel Medical Center, Div Medical Genetics, 350 E. 17th St - 6BH10, New York NY 10003; ☎212-420-4179; Fax: 212-420-3440; vpenchas@chpnet.org. EOE/AA

■ **COLUMBUS OH:** Immediate opening for BC/BE Genetics Counselor. Strong clin skills w/ fam in crisis; exp in prog mgmt/admin desired w/ abil to work independ & with multidisc team. Provide non-cancer adult genetics w/ emphasis on cardiac thrombosis & neurogenetics. Educ & rsrch oppty.

✉ CV & ltr of interest: Charis Eng, MD, PhD, c/o Jane S. Pierce, Ohio State University, E308 Doan Hall, 410 W. 10th Ave, Columbus OH 43210; ☎614-293-7775; Fax: 614-293-7435; pierce.6@osu.edu. EOE/AA. W/M/VV/D encouraged to apply.

■ **PHILADELPHIA PA:** Immediate opening for BC/BE Prenatal Genetics Counselor. Exp pref. Join staff of 2 GCs & 2 OB geneticists. Close affil w/ Children's Hospital of Phila.

✉ Rose Giardine, MS, University of Pennsylvania Medical Center, Dept Ob/Gyn - Genetics - 5 Dulles, 3400 Spruce St, Philadelphia PA 19104; ☎215-662-3232; Fax: 215-349-5893; rgiardine@mail.obgyn.upenn.edu. EOE/AA

■ **PHILADELPHIA PA:** Immediate opening for BC Genetic Counselor. Exp pref; new grads encouraged. Cancer risk assmt for BR/OV, GI & skin cancers on multidisc team providing genetic risk assmt, educ & GC for cancer predisposition. Travel to satellite hosps, partic in genetic rsrch studies.

✉ Cary M. Armstrong, MS, or Josephine Wagner Costalas, MS, Fox Chase Cancer Center, Family Risk Assessment Program, 7701 Burholme Avenue, Philadelphia PA 19111; ☎800-325-4145; Fax: 215-728-4061; CM\_Armstrong@fccc.edu; J\_Costalas@fccc.edu. EOE/AA

■ **PHILADELPHIA PA/SOUTHERN NJ:** Apr 1 opening for FT temp (maternity leave) BC/BE Genetic Counselor. Potential for permanent.

✉ Amy Foster, Corporate Recruiter, Genzyme Genetics, 3400 Computer Dr, Westborough MA 01581; ☎508-389-6623; Fax: 508-389-5558; amy.foster@genzyme.com. EOE/AA

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■ **PHILADELPHIA PA/NORTHERN NJ:** Immediate opening for BC/BE Genetic Counselor. PN exp pref. Excellent commun skills, abil to work independently req. Oppty forprof growt. Respon: PGD, ethnic & pop scrng, PN & preconcep GC; work w/ creative & evolving GC Svc. PN & CA GC oppty also avail. ☞ Email or fax 2 ltrs rec, cov ltr & CV: Eric Krivchenia, MS, Director, GC Services NE, LabCorp, 9 Eves Dr - Ste. 110, Marlton NJ 08053; ☎800-762-4522 X142; 800-631-5250x 4850; krivche@labcorp.com. EOE/AA

■ **HOUSTON TX:** Immediate opening for BC/BE Genetic Counselor. Join expanding, full svc priv genetics ctr svg entire S. TX area w/ travel to satellite locations. Primarily PN GC. Main office site includes cyto, maternal serum screen labs and U/S. Referrals incl: peds, AMA, serum screens, U/S abnormalities, terat, ethnic scrng, cancer and abn fam hx. ☞ Niki Pfeffer, MS, c/o Raymond C. Lewandowski, Jr., MD, PA, 7121 S.P.I.D., Suite 202, Corpus Christi TX 78412, ☎361-985-6600; Fax: 361-985-6603; nlpfeffer@yahoo.com. EOE/AA.

■ **HOUSTON TX:** Immediate opening for BC/BE Genetics Counselor. Must be highly motivated, be able to work independently & enjoy a fast paced high growth environment. Some trav req; flex & adaptability meeting client needs emphasized. GC & case mngmt: PNDx & cancer risks assmt; GC for perinatologists, obstetricians & oncologists in priv prac setting. Tchng nurses, med students, genetic lab trainees & commun grps. 1st Trimester PN Serum Scrng. Ongoing educ opptys. ☞ CV & salary hx c/o: Katherine Thompson MD, Center for Medical Genetics, 7400 Fannin St Suite 1150, Houston TX 77054; Fax: 713-790-1903; mthacker@geneticstesting.com. EOE/AA

■ **HOUSTON TX:** Spring/Summer opening for BC/BE Genetics Counselor. Join dynamic expanding Clinical Cancer Genetics Program. Provide c'hensive GC svcs to diverse cancer pt pop. Opptys

for prof growth incl publishing rsrch educ & GC student trng.

☞ CV or resume, cover ltr & 2 ltrs ref: Joey Baham, HR Staffing, UTMD Anderson Cancer Center, Unit 629 P.O. Box 301402, Houston TX 77230-1402; jbaham@mdanderson.org Info: Karen Copeland, MS, ☎713-745-7391; kcopelan@mdanderson.org. EOE/AA

■ **RICHMOND VA:** Immediate opening for BC Genetic Counselor. Work in large acad med ctr genetics dept w/ 6 GCs, 4MDs, 10PhDs: provide pt care, grad educ, clin rsrch & public svc. Broad range of clin cases & involv in MS GC training program. Growth oppty.

☞ CV & 3 ltrs rec: Lauren Vanner Nicely, MS, or Joann Bodurtha, MD, MPH, VCU Health System - MCV Hospitals, Dept Human Genetics - PO Box 980033, Richmond VA 23298-0033; ☎804-828-9632 x135 or 112; Fax: 804-828-7094; lvanner@hsc.vcu.edu; bodurtha@hsc.vcu.edu. EOE

■ **VIRGINIA BEACH VA:** Immediate opening for BC/BE Genetic Counselor. New Grads may apply. Join team of 3 GCs in natl-recognized MFM Div w/ state of the art U/S/PNDx prog:aAll aspects of PNDx GC incl CVS, amnio, MSAFP, U/S, fam hx terat, preconcep. ☞ CV & 3 ltrs rec: Renee Laux, MS, Eastern Virginia Medical School, 1080 First Colonial Road, Suite 305, Virginia Beach VA 23454; ☎757-395-8883; Fax: 757-395-8935; lauxra@evms.edu. EOE/AA

■ **SEATTLE WA:** Immediate opening for BC/BE Genetic Counselor. Lab exp pref. Excellent writing & commun skills. Join GeneTests website project: 1) maintain GeneTests Laboratory Directory, integrate testing info into GeneTests website, 2) commun w/ labs to obtain tstg inf to develop edit &/or review molec genetic tstg info in GeneReviews, 3) genetics educ writing. ☞ CV & ltr interest: Cindy Dolan, MS, GeneTests, Children's Hosp & Reg Med Ctr, 4800 Sand Point Way NE, CN-1, Seattle WA 98105; ☎206-527-5742; Fax: 206-527-5743; cdolan@u.washington.edu. EOE/AA

■ **SEATTLE WA:** Immediate opening for BC/BE Genetic Counselor. Self-motivation, abil to work independently & on team req. Exp pref. FT through July, then 20 hrs/wk. Join dynamic clin genetics prog: GC for wide variety of indications incl general pes, adult CA & pre-symptomatic tstg for adult-onset

disorders. Oppty for rsrch & educ progs.

☞ Apply online c/o #99496 to: www.ghc.org. Becky Petersen, Nurse/Clinical Recruiter Group, Health Employment, 12501 East Marginal Way, South Tukwila WA 98168; ☎206-988-7743; 800-848-4259; Fax: 206-988-7713; Petersen.b@ghc.org. EOE/AA

■ **MADISON WI:** Immediate opening for FT or PT BC Genetic Counselor. Min 2 yrs exp req. Provide clin GC svcs and genrl case coord to pts & fam in Biochem Genetics Clin. Prog coord duties will also involve asst in prep of NB Scrng annual rept. Coord fol/up tstg and referral for positive NB metab scrns. Partic in trng and s'vision of 1st yr GC grad students & students from other disciplines, NB Scrng Educ & Metab Subcmtes, clin rsrch and pub. ☞ Mary Rasmussen, Univ Wisconsin, 361 Waisman Center, 1500 Highland Ave, Madison WI 53705; ☎608-263-5993; Fax: 608-263-0530; mlrasmus@facstaff.wisc.edu. EOE/AA

■ **MILWAUKEE WI:** Immediate opening for BC/BE Genetic Counselor. Min 2 yrs exp req. Abil to work independently, good commun & org skills, plus u'stndg of GC procedures. Provide GC svcs in growing c'hensive genetics prog: work with perinatologist in Burlington, WI providing primarily PN GC svcs and fol/up, provide referrals to agencies & assns, commun educ, maintain knowledge in field of clin genetics ☞ Jane Martell, 8701 Watertown Plank Road, MFRC 756, PO Box 26509, Milwaukee WI 53226; Fax: 456-6539; jmartell@mail.mcw.edu; www.mcw.edu. EOE/AA.

## In Canada

■ **WHITBY ON:** Immediate opening for BC/BE Genetic Counselor. 2 yrs exp in Canadian genetics prog. Hi-motiv individual w/ superior commun, i'personal, org skills req. Comfort working independently & on team req. Join multidisc regl med genetics clin 25 min east of Toronto. PNDx, peds, preconcep, adult & cancer genetics. Salary \$27.29-\$33.81/ hr, 37.5 hrs/wk. '03 grads enc to apply. ☞ Human Resources, Lakeridge Health, Whitby 300 Gordon St, Whitby ON L1N 5T2; ☎905-668-6831 x3765; Fax: 905-665-2408; recruitment@lakeridgehealth.on.ca. EOE/AA