PERSPECTIVES in genetic counseling

Volume 21 Number 2 Summer 1999

national society of genetic counselors, inc.

nsgc

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

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NSGC acknowledges GeneLink, Inc. for a generous grant to support this newsletter.

POINT COUNTERPOINT: CF POPULATION SCREENING

Cystic fibrosis is one of the first examples of a DNA test being used for population screening. The 1997 NIH Consensus Statement on CF Screening stated that all pregnant couples should be offered CF carrier testing. Genetic counselors and obstetricians are now in the position to offer CF screening to their patients. However this task is not without its challenges.

Why Screen Everyone?

Elinor Langfelder Schwind, MS

Implementing a testing program in populations with low disease frequency and poor test sensitivity (as low as 30%) is not consistent with long-held principles of population-based genetic screening. The difficulty in test interpretation for all populations raises concerns as well.

There is precedent in our field for offering genetic-based tests to some people but not to others. Decisions to offer testing are based on risk assessment and patient reports of ethnicity (e.g. Tay Sachs, hemoglobinopathies). Unlike HexA analysis or hemoglobin electrophoresis, CF testing has a poor carrier detection rate in lower risk populations.

Issues of cost effectiveness have played a significant role in the CF screening debates, with the "benefit" unabashedly resulting from the predicted termination of nearly all affected fetuses. But a 1989 study of African-American couples by Rowley *et al* reported a 39% pregnancy termination rate for another variable genetic disorder with reduced life span, sickle cell anemia. One wonders if the

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Caveat Emptor

Jill Borsuk, MS

The incidence of CF varies among different populations and the detection rate is at 90% or greater in only a select few ethnic groups. However, as long as patients are provided with complete information regarding the lower carrier detection rate in different ethnicities, they should have the right to decide whether or not to elect screening.

One proposed solution has been to offer screening only to populations in which there is a high frequency of CF and a high mutation detection rate. The United States is a multi-ethnic, multi-cultural population where it is difficult to delineate a person's origin. Africans and Asians have an incidence of CF estimated to be less than 1 in 50,000, while African-Americans have a CF incidence of 1 in 15, 300 and Asian-Americans an incidence of 1 in 32,100, presumably

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Questions and Answers about Continuing Education Units

On May 20, representatives of NSGC, American Board of Genetic Counseling (ABGC) and American Counseling Assocation (ACA) met to discuss issues that have arisen regarding the provision of continuing education for genetic counselors. Here are some answers to important questions that prompted the meeting.

Bea Leopold, MA and Virginia Corson, MS

What are the roles of NSGC, ABGC and ACA in the provision of CEUs for genetic counselors?

NSGC offers educational opportunities leading to Category 1 CEUs and therefore acts as a conduit for genetic counselors to achieve recertification and other benefits of CEUs.

ABGC certifies genetic counselors and accredits training programs, and therefore takes a part in reviewing educational programs to ensure quality control. ABGC also reviews programs for Category 2 CEUs.

ACA is a provider of continuing education and is approved by the National Board of Certified Counselors (NBCC) and American Psychological Association (APA) to award continuing education units.

Why is a $20 fee required for Category 1 continuing education?

- $15 goes directly to ACA to review and approve educational programs, maintain records of individuals receiving CEUs, prepare and mail certificates and meet stringent requirements necessary to maintain their provider status with both NBCC and APA.
- $4 goes to NSGC for financial and logistical administration, including: reviewing the programs requested for approval, moving pending programs through the channels to final approval or rejection and ensuring that fees and signatures are collected and processed to ACA.
- $1 goes to ABGC to oversee the quality and content of each program.

All three components are vital to ensure that the CEUs you are awarded meet the highest standards set by NBCC guidelines.

Can I sign up for Category 1 CEUs for a course I attended in the past, but did not submit CEU payment?

No. This would create a logistic and administrative nightmare! To maintain the highest degree of credibility, registrants must sign up either in advance or onsite and must sign in twice daily. ACA will not accept retrospective applications.

What if I lose a certificate for a Category 1 course I have attended?

Send $5, payable to ACA, directly to: Holly Clubb, Program Specialist, American Counseling Association, 5999 Stevenson Ave, Alexandria, VA 22304-3300. Checks or money orders *(no cash, please)* must accompany your request, along with a letter including your full name, social security number and the name and date(s) of the conference.

What are Category 2 CEUs?

Category 2 CEUs are the ABGC recognition of contact hours for which CEUs or continuing medical education (CME) credits are awarded by organizations other than ACA. Diplomates may apply directly to ABGC for programs related to genetic counseling and medical genetics as described in the April 20 memorandum to all diplomates and on the ABGC website, www.faseb.org/genetics.

Only those contact hours consistent with ABGC standards will be approved. Regularly scheduled grand rounds, case conferences, journal clubs, team meetings or supervisory sessions are not appropriate for Category 2 credits because they are routine job responsibilities.

Application can be made to ABGC prospectively or within three months from the last day of the program. A $20 administrative fee payable to ABGC must be submitted with the application. Up to 40% of the total 25 CEUs required for the ten-year recertification period can be acquired in Category 2. ❖

Fee Announcement

Beginning July 1, conference organizers must submit $150 with all applications for Category 1 CEUs. This fee will help offset NSGC and ABGC administrative costs of reviewing the application. NSGC national and regional meetings are exempt. ❖

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

Next issue ***September 15***
Submission deadline ***August 10***

POPULATION SCREENING: WHY SCREEN EVERYONE, fr p. 1

termination rate might be lower than predicted for CF as well. The persuasive cost-benefit analyses did not account for offering CF testing to African-Americans or other populations with disease frequencies as low as 1/32,000 (Asians).

Although certain mutations are ethnicity-based, a minimum CF mutation panel has not been standardized, and HMOs restrict our ability to select laboratories. Asking patients to pay out-of-pocket for other mutation panels may address a liability concern, but does not serve the economically disadvantaged. What do we do when a woman has coverage but her partner cannot afford his test? Will amniocentesis be offered without knowing the partner's carrier status? Pilot studies have not targeted a low-income population to address these issues.

CF test interpretation is complex. Identification of the common mutation R117H does not necessarily correlate with CF symptoms in any population, causing great anxiety for the carrier or carrier couple. We have little to offer beyond support after we have created their dilemma: a choice between terminating a potentially healthy pregnancy and keeping an affected one. Couples seeking any type of genotype/phenotype correlation are terribly disappointed that we cannot provide it.

It is not appropriate to implement widespread CF carrier testing only because pilot studies concluded that middle-class pregnant Caucasians are motivated to access this technology. At a follow-up NIH conference, there was indication that some minority groups do not support a universal CF screening program because it may detract from discussion of other pertinent concerns. We should not embrace screening policies that compromise our ability to assess and address the needs of the client. ❖

PETITION TO REVISE CF POSITION STATEMENT

The Social Issues Committee is in the process of revising our sorely outdated Statement on CF Screening. Here's a status check…

- Draft revisions submitted to membership as a petitition, requiring 10% of Full members to sign.
- Draft currently under review by Ethics Subcommittee and lawyer.

WHAT'S NEXT?

- Discussion in Fall issue of *Perspectives* and October 1999 Annual Education Conference open mike session.
- Final vote following above discussions with possible revisions.

Many members have commented. To review the statement for comment, look in the following places:

☞ **Open your 1999 Membership Directory, page 89**

☞ **Visit our website,** www.nsgc.org, **then click on Taking A Stand**

— Anne Spencer, MS

CAVEAT EMPTOR, fr p. 1

due to admixture. People of any ethnic background can have ancestors of Northern European Caucasian descent, increasing their carrier risk. It could be considered racial discrimination to offer the test to some and not others based on their percentage of Caucasian ancestry.

Two large pilot screening studies showed that both patient interest and uptake of screening were high. A survey performed in a CF clinic found that people who have CF or have children with CF are in favor of population screening.

As genetic counselors we are in the unique position to provide people with information to make the best decisions for themselves and their families regarding genetic testing. We are not gatekeepers of genetic technology. An acceptable detection rate may vary widely in patient perception. We should embark on CF screening and manage it wisely with patient-directed decision-making. ❖

IS IT REALLY MUCH DIFFERENT?

Ed Kloza, MS, Representative to the 6th Scarborough Conference, "Issues in Implementing Prenatal Screening for CF," member, ad hoc committee responding to NIH's CF consensus statement.

The controversy surrounding prenatal CF testing is a challenge to the paradigm of carrier testing. We have long recognized the appropriateness of using a simple screening query to determine a population where follow-up testing is available. *Are you 35 or older?* Then let's discuss amniocentesis. *Are you Ashkenazi Jewish?* Then let's discuss Tay-Sachs and other testing appropriate to your ethnic heritage. Why not then: *Are you or your partner of Northern European Caucasian ancestry? Then let's discuss CF testing.* We're talking about a screening test with sensitivity and specificity determined for various populations, and for certain groups it ought to be available.

Withholding a service in an area in which it can be reasonably applied seems inappropriate. ❖

Creative Job Search: Opportunities Yield Creative Results

Act III, Scene I: Scenes from a Varied Career

Whitney Neufeld-Kaiser, MS

After starting a prenatal diagnosis program in a local community hospital, when it was rare for a community hospital to have a genetic counselor on staff, Beth Balkite, went into private practice seeing prenatal patients and working with a neurologist. She then became a consultant to Genzyme Genetics when they began marketing laboratory services in Connecticut, and later she accepted a marketing position with Genzyme in Santa Fe.

In her latest career move, at Glaxo-Wellcome (GW) as Worldwide Genetics Education Strategy Advisor, Beth leads an inhouse genetics education team charged with developing a comprehensive genetics education program. Beth says the program will include basic genetics for all employees, as well as modules tailored to the different groups in the company.

"The position at GW was written for a genetic counselor because the company wanted someone knowledgeable in genetics who also had the ability to translate complex information into simple terms and who would be sensitive to employees' different needs," Beth said of her start-up position. "In my previous position, I had familiarized myself with educational websites, adult education and training and ways of evaluating adult learning."

Beth feels there is probably potential for more counselors in the pharmaceutical industry in education, clinical study design and ethical issues in research and informed consent. ❖

Working Out of the Box

Bea Leopold, MA

Following 22 years of service, Joe McInerney has resigned his position as Director, Biological Sciences Curriculum Study (BSCS) in Colorado Springs to assume the director- ship of a new Baltimore-based foundation devoted to genetic education and counseling.

This independent foundation will use results of current research on genetic contributions to schizophrenia and bipolar disease to develop new modes of counseling and education for complex human diseases.

"Although our initial focus will be patients and families, we expect to broaden our programs to encompass primary care providers and the general public, while addressing the genetic bases of a number of complex, multi-factorial diseases," he said.

When Joe joined BSCS in 1977, he was charged with helping to establish new educational programs in human genetics. Although administrative responsibilities drew him away from his educational mission, Joe's career has come full circle with this new challenge.

An NSGC charter member, Joe stated, "Just as I relied on the expertise of the genetic counseling community for genetic education at BSCS, I plan to involve NSGC integrally as we launch our educational programs h

Waiting for the Right Opportunity

Rajani Aatre MSc, MS

My position is as traditional as one can be in a busy prenatal setting, but my "non-traditional" methods of finding a job were a bit unusual. After graduating from Sarah Lawrence, I was geographically limited to the Detroit/Ann Arbor area. The job market wasn't promising, so I volunteered as a research assistant at the Karmanos Cancer Institute (KCI). Cancer genetics was one of my top interests, and I enjoyed the work as I not-so-patiently awaited Immigration and Naturalization Service (INS) clearance. In addition, I was working on compiling a manual on adult genetic disorders for primary care physicians through the Great Lakes Regional Genetics Group (GLaRGG) and the Michigan Department of Community Health. KCI found some funds to hire me as a part-time research assistant with clerical and clinical duties but INS rejected my application. With persistence and fortitude battling INS, I finally managed to obtain a temporary work permit for KCI.

In the meantime, Hutzel Hospital Department of Reproductive Genetics was seeking an experienced counselor and needed someone to help part time with routine cases. I split my days between cancer and prenatal genetics, which turned out to be a little tougher than I'd imagined. The lack of continuity of care in both places was my major concern, but I convinced myself that one would soon "click." Ironically, layoffs ultimately helped me, since hiring outside the health care system had become very difficult. Converting part time to full time was simpler, and I finally was offered a job, nine months out of school.

The message to genetic counselors who are limited geographically: Make connections! Be patient! And, above all, be visible! ❖

here." ❖

Creating A Career Ladder

Nancy Steinberg Warren, MS and Leah Hoechstetter, MS

At the 1998 Annual Education Conference we presented a poster, "Genetic Counseling Career Ladders: Maturation of a Profession." The proposal has since been approved by our Division Director and Human Resources Department, and a three-tiered ladder has been created.

What does this mean? *A lot!*

We finally obtained formal recognition for our unique preparation, skills and accomplishments. The job titles "GC I" and "GC II" will correspond to entry level and board-certified counselors, respectively. Acquisition of the title "GC III" will entail formal consideration by a review committee for individuals with five or more years of experience and significant accomplishments in the realms of research, programmatic development and regional/national service. There is about a 10% increase in salary for each advancing level. A "GC III," for example, who is paid at the top of the range, would earn 33% more than the highest salary before the new tiers were created.

There is now a formalized pathway for professional advancement and recognition of the quality work that is performed daily, which also serves as additional incentive to strive for ongoing pro-fessional growth and development.

Although several of us invested over 18 months of effort in obtaining this goal, we certainly believe it was worth every minute. We would be pleased to provide copies of our position descriptions or to discuss what we did. ❖

A Psychologist's Perspective: The Needs of Genetic Counselors

Jacquelyn Krogh, MS

Dr. *Gianine Rosenblum, a clinical psychologist, was coordinator and psychological consultant for the Samuel L. Bailey Huntington's Disease (HD) Family Service Center in New Jersey for two years. She has presented at several of our Annual Education Conferences. Currently, she is on the faculty at Sarah Lawrence College as instructor of the Seminar in Genetic Counseling.*

JK: What do you feel is the single greatest challenge facing genetic counselors in their daily work, and what are your suggestions?

GR: Setting reasonable boundaries. An enormous amount is expected of the genetic counselor in clinical practice: to convey a vast amount of complex information, ensure the client's comprehension, establish a trusting relationship, probe, explore and provide counsel on significant emotional issues and often manage administrative responsibilities, all in a compressed time frame.

Some of the boundary setting challenges facing genetic counselors (especially new graduates) are:

- setting limits on the behavior of clients or family members who may be behaving inappropriately;
- recognizing and acknowledging when a client might need more than the counseling or support a genetic counselor can offer;
- setting clear limits on colleagues who have unreasonable expectations of a genetic counselor's role; and
- keeping to time limitations.

Sometimes good boundary setting means knowing when a boundary is too rigid, or when boundaries need to be crossed because a client is in crisis. Excellent communication skills, a fine-tuned self-awareness, assertiveness and confidence in one's judgment, as well as support from peers and colleagues, are all critical in developing good boundary setting skills.

JK: What impact do you hope to make as you train genetic counselors?

GR: I'd like to help future genetic counselors leave training with a clear understanding of their goals in the psychosocial realm and equip them with necessary skills. Understanding the factors that impact a client's behavior, such as individual core beliefs, personal history, family myths or codes of conduct, social and cultural norms, and beliefs, is critical.

One fundamental principle of the "cognitive-behavioral orientation" of psychology is that people's beliefs about an event dictate their responses to it. For example, if a person hears a sudden loud noise and believes it is a gunshot, she will react very differently than the person who believes that same sound is a balloon popping. Similarly, a person who receives an abnormal amnio result, and believes it is because she is somehow bad or evil, will respond very differently than the person who believes it is a fluke of nature and has nothing to do with her character: same event, different belief, different reaction.

Understanding individuals in this way will enhance genetic counselors' communications with clients, tailor their interventions and hopefully make genetic counseling sessions as helpful as possible. ❖

Optimizing Patient Peer Support

Nancy Hanson, MS

Peer support is a one-on-one relationship between individuals with a shared experience. In the clinical genetics setting, the shared experience is often a crisis surrounding the diagnosis of a genetic condition in a fetus, child or adult.

Benefits and Pitfalls

There are many benefits but also potential pitfalls to peer support interactions.

Benefits of successful peer support include: feeling less isolation, learning from others' experiences and experiencing a sense of satisfaction by helping others.

Potential pitfalls arise when individuals in crisis have more need than the peer supporters can handle or when peer supporters feel a need to give advice beyond their expertise. The involved individuals' own "issues," both personal and with each other, may also lead to additional potential conflict.

Prenatal issues are of particular concern. If a patient has not decided whether to continue a pregnancy, the peer supporter must be comfortable sharing information, even if the patient ultimately chooses to abort.

Most problems can be avoided by establishing very clear expectations of each person's role. One way to ensure clear expectations is to use well-established matching programs. Many national and local support groups have family matching services, which include:

- a sufficient pool of volunteers
- training programs for volunteer peer supporters in communication skills, empathic listening, recognition of personal values and strategies for providing resources and information
- a systematic approach to matching individuals
- documentation of encounters
- evaluation measures.

Steps to Successful Matches

An established program cannot fill every need.

To assess the individual in need:

- Will a peer referral fill a need for her?
- Does he need professional psychological support instead of or in addition to peer support?

Locate and assess peer supporter

- Is there a peer supporter who has dealt with similar issues?
- How compatible is the match?
- Has she offered to help?
- Is he in a good emotional place to help?
- Does she have good communication skills?

Contract the Following with Both Parties:

- Confidentiality of interactions
- Acceptance of different viewpoints
- Desired scope of the interaction
- Availability of support from professionals, if needed
- Feedback on the usefulness of the interaction

Logistics

Make the first contact with each party and set expectations, including how direct contact will be made. Document that a peer referral was initiated and any feedback from the interaction in the medical record. ❖

Peer Matching Networks

National Parent to Parent Support and Information System (NPPSIS)
✆706-374-3822;
800-651-1151;
Fax: 706-632-8830;
nppsis@aol.com; http://www.nppsis.org

Mothers United for Moral Support (MUMS)
✆920-336-5333;
Fax: 920- 632-8830;
mums@netnet.net;
http://www.waisman.wisc.edu/~rowley/mums/home.htmlx

What's New at the '99AEC ?

Laura Thomson, MS & Linda Robinson, MS,

Short Courses

October 14 - 15	**Legal Issues in Genetic Counseling Practice**
October 14 - 15	**Qualitative Research in Genetic Counseling**

Annual Education Conference

October 15 - 19	**Lifecycle Genetics — From Preconception to Adulthood**

ASHG for a Day: Attend ASHG on Wednesday only at no charge by showing your NSGC conference badge. To attend the entire ASHG meeting, registration is required. CEUs are available for the entire ASHG meeting but will not be granted for the single day admission.

Mini-courses: Stay for our newest educational addition and earn a total of 2.6 CEUs. Please be sure to check your preference on your registration form, including "Not Attending." Mini course choices are binding!

- WetLab: Molecular Diagnosis. *Spend the morning in the lab. Use your own buccal cells to perform PCR on a region of the genome. This is a great way to learn about the latest molecular diagnostic techniques.*
- Muscular Dystrophy Review and Research. *Become a specialist! Learn about new research with a focus on gene therapy, SMA molecular carrier testing as well as oculopharyngeal and other adult onset muscular dystrophies.*
- The Value of Understanding in the Workplace. *Last year, many participants left Chris Loving's workshop wanting more…and we listened! If you crave a deeper understanding of yourself, others, and the workplace, don't miss this opportunity!*
- Retirement Planning. *They say it's never too early, and it isn't! Learn what it will take for you to retire with money still in the bank.*
- Tools for your Trade: Promoting Genetics Services to Primary and Specialty Care Providers. *Use these teaching materials (slides and outline) to make effective presentations to healthcare providers to help them better understand the role of genetic testing and genetic services in patient care.*

Save Some Bucks! Before you book your flight, check airfares to both the San Francisco and Oakland airports. You may be surprised at the cost difference! Shuttle service is available to the hotel from both.

Deadline: Your Registration and Information brochure was mailed in early May! Be sure to set it aside in your "Top Priority" stack. Deadline to register without financial penalty is **Friday, August 6.**

AEC '00: Let the Planning Begin

When One Door Closes…

Abstract submissions for the 18th Annual Education Conference closed in May. Missed the deadline? Have some research or clinical project that just wasn't far enough along to be ready to submit this year? Why not start thinking about presenting in 2000?

Between now and our conference this fall, we hope to recruit about 30 committee members to review and rank abstracts. What's in it for you? You can anticipate a multi-faceted adventure that encompasses preparatory and on-site participation. If you've never worked on an NSGC Annual Education Conference, this is a great way to test the waters. We invite you to join the Y2000 AEC Abstract Committee.

☞ Stephanie Cohen,
✆317-338-3487; sacohen@stvincent.org
or Lyn Hammond,
✆843-876-1504; hammondl@musc.edu

A Personal Invitation

Savannah is a living, historic city and it is thriving due to the recent publicity surrounding "Midnight in the Garden of Good And Evil." It is a wonderful walking city, and it boasts one of the nation's largest National Historic Landmark Districts. The city consists of garden-like squares, and there are no hills. Early Fall is always pleasant and one of the best times to visit.

I encourage you to arrive a few days early or depart a few days late to truly experience the "low country."

Andy Faucett, MS
Logistics Co-chair

Mentor Match Enters 4th Year

Troy Becker, MS

"[We] will most likely continue our relationship past [the] program's end."

"My mentor was incredibly responsive and, in describing her other experiences, actually helped me make several major decisions."

"It has been very helpful in making contacts for employment and asking questions about jobs."

NSGC's Mentoring Program, sponsored by our Membership Committee, recently completed its third year and is making plans for 1999. The program's purpose is to allow professionals, students and recent graduates to exchange ideas and information about their current interests or experiences in genetics and genetic counseling. Mentors and students are asked to contact each other every 4-6 weeks over a six month period.

For practicing genetic counselors, the mentoring program offers contact with students they may not otherwise experience in their daily activities.

"I enjoyed being able to help and hopefully I provided some guidance. This is an important program for NSGC."

For students, the program provides an opportunity to build relationships outside of their training program, discuss a variety of issues and concerns with an experienced counselor and begin to network. Guidance in the transition from student to professional is particularly useful.

"It was nice to be able to talk frankly about the program and the field of genetic counseling with someone who wasn't a supervisor or other authority."

Optimal Outcomes

The outcome and success of the mentoring process are tied to several key issues. The program is student-oriented. Student reviews indicate that those who are more active in the program have the best experiences. The participation of the practicing counselors in the program is equally important. The matches are mainly based on the student's criteria of location and specialty. The 1998 match was reasonably successful in its goal of quality matches.

"It was useful to be able to prioritize the characteristics of a desired mentor (i.e. location, specialty, etc). This was a very useful service."

About 77% of students received one of their first two specialty requests; 68% were placed in one of their top two requested geographic areas.

Time well Spent

"It was nice to have someone outside of my training program to get feedback from and to bounce off ideas — to ask for a fresh perspective."

In the past, some counselors have raised the concern that volunteering for another project might add a significant time burden onto an already full schedule. Our survey shows that the average time required is about one hour per month. An increase in the number of volunteers and diversity in their regional representation and specialty areas would improve our ability to provide quality matches. Interested members are urged to complete the postcard included with this newsletter. ❖

Liaison Report

Rosalie B. Goldberg, M.S.

The National Advisory Council for Human Genome Research met on May 17. Dr. Francis Collins presented the NHGRI Director's report highlighting both scientific and legislative issues.

Of Importance to our Community

Dr. Collins announced that he had recruited Dr. Alan Guttmacher, a medical geneticist, to serve as Special Assistant to the Director for Clinical Affairs. Dr. Guttmacher will provide advice and guidance on clinical issues, will lead the NHGRI outreach program targeting health professionals and will consult on clinical genetics issues having ethical, legal and social implications. I spoke with Dr. Guttmacher and am delighted to report that he has worked closely with and is very supportive of genetic counselors.

On the Scientific Front

As of May 1999, *16.9%* of the human genome has been sequenced; finished sequence: 329,238 kb, representing 10.2% of genome; draft sequence: 215,053 kb, representing 6.7% of genome. The goal of the publicly funded Project and its new initiative, the SNP Consortium, is to produce finished human sequence that is accurate and without gaps.

Arthur Holden, Chairman and CEO of the SNP Consortium, a group of 10 pharmaceutical companies, five leading academic centers and a private British Trust, presented the Consortium's plan for free and unrestricted access to the database. They intend to find polymorphic patterns among individuals from which novel therapies and even tailor-made therapies may evolve. These advances in sequencing and mapping technologies, Dr. Holden reported, can fundamentally change the practice of medicine.❖

Celebrate Ourselves

New HHS Committee includes Past President

Donna Shalala, Secretary of Health and Human Services, has named **Ann H. Boldt** to serve on a newly-appointed committee, the Secretary's Advisory Committee on Genetic Testing. This 13-person committee will help HHS formulate policies on the development, validation and regulation of genetic tests. Ann was selected among 200 nominees who were deemed to be experts in the field of genetics.

AAAS Fellow Named

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

Oooopps!

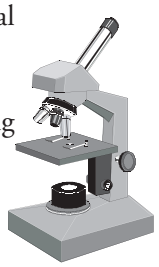
Two members were inadvertently omitted from important recognition in our 1998 Annual Report.

- **Nancie Petrucelli** was named co-investigator with **Ellen Matloff** on the project, "The Impact of Cancer Genetic Counseling on Providers," for the 1998 Special Project Fund. A move from New Haven to Detroit precluded her from completing the work on this project.
- **Martha Shaw,** now at Houston's LBJ Hospital, was awarded the student Best Poster Award at our 17th Annual Education Conference in Denver for work she conducted as a student at University of Cincinnati Genetic Counseling Program. Her poster was titled "Acceptance of Invasive Prenatal Testing in Private Versus Public Health Care Setting." ❖

Research Network

Genetics of Hearing Loss

Researchers at Gallaudet University and the Medical College of Virginia have been awarded a grant by the National Institutes of Health to identify genes that cause hearing loss. Testing for connexin 26 is being offered as part of this study. Mutations in this recently identified gene are believed to be the cause of 50-80% of known recessive deafness and 10-37% of sporadic deafness. In addition, the researchers have established a DNA repository for deaf/hard of hearing people and their family members. As tests for other genes that cause hearing loss become available, samples in the repository will be tested. Linkage to find novel genes is also available for large families.



Individuals and families are asked to provide information about their hearing loss and family history and to provide a blood sample. Participation in the research is free and does not require travel to either college. Participants will receive results.

☞ Katherine Oelrich, MS; ✆800-451-8834, x5258; Mary.Oelrich@gallaudet.edu ❖

Genetic Linkage of Epilepsy to be Studied

We are seeking families for a genetic linkage study on epilepsy directed by Ruth Ottman, PhD, associate professor at Columbia University. The study's goal is to identify genes that contribute to risk factors for various types of epilepsy.

Families must have either a pair of living affected siblings *or* three or more living affected individuals.

For purposes of the study, "affected" is defined as:

- any type of epilepsy (i.e., at least two unprovoked seizures),
- age at onset 25 years or younger,
- no associated mental retardation,
- no past medical condition or brain injury (e.g. brain tumor, stroke, severe head injury, etc, that may explain the seizures).

☞ Christie Barker-Cummings, MPH, Project Director, ✆212-305-9188; cb118@columbia.edu ❖

Genetic Linkage of Alzheimer's Disease in Caribbean Hispanic Families

We are seeking families for a genetic linkage study of Alzheimer's disease directed by Richard Mayeux, MD, Professor of Neurology, Psychiatry and Public Health at Columbia University. The goal of the study is to identify genes that may increase the risk for Alzheimer's disease among Caribbean Hispanics, in particular families from the Dominican Republic.

To be eligible, families must have:

- at least one individual diagnosed with Alzheimer's disease (AD) with a living brother, sister, parent or child diagnosed with AD, or
- two or more living family members diagnosed with AD.

☞ Vincent Santana, Study Coordinator, ✆212-305-2309 or 877-MEM-LOSS

☞ Jennifer Williamson, MS, ✆212-305-4655; william@sergievsky.cpmc.columbia.edu ❖

What's New on the Web?

Beth Billings, MS

Have you visited our website lately?

NSGC's website, www.nsgc.org, has been growing and changing by leaps and bounds over the last year. If you haven't checked it out lately, stop by for a visit.

Our website has become the first stop of many potential students and clients before they reach a genetic counselor, the training programs or the Executive Office. It is also our own resource, allowing NSGC members to:

- learn more about conference and funding opportunities
- join or access ResourceLink
- order NSGC publications
- contact our Board of Directors
- access the current list of training programs

…and, for the first time this year

- submit abstracts for our Annual Education Conference *online.*

Website Submission Form

Now you can be part of how our website reflects our member activities and reaches the public. If you have an idea for the website, contact any committee or SIG chair and get a copy of our new Website Submisson Form. Your idea will need to be developed until it is workable and must be supported by a committee, SIG or the Board.

You name it, and with your help, we can make it happen.
☞ Beth Billings, Computer Users Group Chair, (an Education Committee subcommittee) eabillin@iupui.edu; ✆317-274-7022. ❖

The Link and the List! How Can We Do Better?

Lyn Hammond, MS and Steve Keiles, MS

Listserv. Was that a grumble we heard? Too many listserv messages, not enough time? ResourceLink. Has it generated too many or too few referrals or queries to make it worthwhile?

We know you have opinions and great ideas. But we don't know your thoughts and suggestions until you put a pen to paper. Please complete the survey enclosed with this issue to give us feedback, even if you don't use one or both of these electronic tools. We hope to compile results for discussion, planning and action when the Computer User's Group (CUG) meets at the Annual Education Conference this Fall.

Let your time translate to make a difference. …and Thanks! ❖

Resources from the ListServ

This resource list is not intended to be an advertisement or serve as an endorsement by NSGC.

Lyn Smith Hammond, MS

Cancer Genetic Counseling: A Guide for Communicating Genetic Information, a flipstyle book of visual aids for cancer genetic counseling, sells for $35, postage included. Topics include: genetics, cancer statistics, breast cancer, ovarian cancer.
☞ Michael Banke University of Pittsburgh, Dept Human Genetics, A300 Crabtree Hall, GSPH, 130 DeSoto Street, Pittsburgh, PA 15261; ✆412-624-0133; fax: 412-624-3020; mbanke@helix.hgen.pitt..edu

A Parent's Guide to Understanding Retinoblastoma, a 21-page booklet with glossary reviews genetics and defines genetic testing, diagnosis, treatment and long-term consequences of retinoblastoma.
☞ IRIS Medical ✆650-962-8848 x3089, or download from a great website on Rb http://www.lowvision.org/retinoblastoma.htm

Schizophrenia Genetic Risks: A Guide to Genetic Counseling for Consumers, their Families and Mental Health Workers, by Irving Gottesman and Steven Molden.
☞ National Alliance for the Mentally Ill http://www.nami.org

Understanding Ventral Wall Defects, a pamphlet published by the Foundation for Blood Research, covers both omphalocele and gastroschisis.
☞Ed Kloza ✆207-883-4131; fax: 207-883-1527; ekloza@fbr.org.

Spinocerebellar Ataxia Type 3 (Machado Joseph disease): Find a profile for SCA3 and an overview of the ataxias
☞ http://www.geneclinics.org

Gamete Donor References

Lewis *et al.* (1999) Genetic screening of oocyte donors. *Fertil Steril* 71(2)278-281.

Conrad *et al.* (1996) Current practices for commercial cryobanks in screening prospective donors for genetic disease and reproductive risk. *Int J Fert Menopausal Studies* 41; 298-303.

Morgan *et al.* (1998) Current Genetic Screening Practices of IVF Centers that Participate in Oocyte Donation. *J Genetic Counseling* 7(6):476 (abstract). ❖

Bulletin Board

Call for Proposals

The Association for Death Education and Counseling (ADEC) is accepting proposals for their 22nd Annual Conference, April 6 - 9 in Charlotte. Tracks include: research reports, scholarly papers, practice reports, symposia/panel discussions, experiential workshops, personal experience and reflection and poster presentations. Proposal deadline: September 13.

☞ADEC HQ: ✆860-586-7503; or visit www.adec.org. ❖

Brochures Now Available in Spanish

Thanks to Luisa Perez, a student at California State Northridge Genetic Counseling Program, the *So You've Been Told, Your Baby has…* series, featuring five prenatally-diagnosed conditions — spina bifida, Down syndrome, gastroschisis, hydrocephalus and congenital heart disease — is now available in Spanish for purchase through NSGC. These brochures were written in 1993 by Beverly Tenenholz, a project funded by NSGC's Special Project Fund. The translations were funded by a SPRANS Grant, funded through the Olive View-UCLA Medical Center, Prenatal Diagnosis Unit, where Luisa interns.

Current prices are available in NSGC's Publication Order Form, which was mailed to every member in September 1998. Desk a mess? For another copy, visit our webpage www.nsgc.org and click on Contact Us or call 610-872-7608, mailbox 3. ❖

Media Watch

Roxanne Ruzicka, MS & Angela Geist, MS

"Human Body 2000" — This TV documentary contained a segment about a child with ambiguous genitalia. The child was initially considered to be a girl and had normal female chromosomes, but testes were present. In contrast to the decision made by 90-95% of parents in this situation, the couple chose to have a penis constructed and raise the child as a boy. The parents stated that at age 12 they would allow their child to choose whether to be male or female.

"Providence" — A child was diagnosed with familial dysautonomia, which is more prevalent among Ashkenazi Jews. Both of the parents were Catholic. However, through examining their history in more detail, the parents discovered that they were probably both of Ashkenazi Jewish descent. The doctors and parents discussed that you cannot escape your ancestors' genetic makeup.

"ER" — A child presented with multiple fractures of the ribs. The parents were being accused of child abuse. But when another fracture appeared while the child was in the hospital, the doctors thought of the possibility of a diagnosis of OI, which turned out to be correct.

"60 Minutes" — A pregnancy was diagnosed 47,XX,+18 by amnio and the fetus was terminated. The autopsy report stated that the baby appeared to be a normal male. The parents felt that the amnio result was incorrect, and the potential inaccuracy of amnio results was the main point made. Confirmation studies on the tissue did verify 47,XX, +18, but that point was not made until the end of the show and was not stressed. The show did a poor job of communicating that amnio is highly accurate in detecting chromosome abnormalities, and that a fetus with trisomy 18 can appear grossly normal and can have ambiguous genitalia. President Deb Lochner Doyle responded.

Prevention Magazine (April) — "Outsmart your 'Bad' Genes" discussed the importance of taking steps to lower one's risk of developing cancer or heart disease. The article reviewed the benefits of a healthy diet and exercise as well as the importance of providing an accurate family history to allow the doctor or genetic counselor to assess one's risks and identify appropriate preventive measures. ❖

Student Listserv Changes Hands

Thanks to Steve Koczak, who graduated from the University of California at Irvine Genetic Counseling Training Program this year, for his able handling of the student listserv for the past two years. Welcome Carrie Stanfield, who assumed this responsibility in June. ❖

Special Projects Fund Extended Deadline

The Special Projects Fund awards up to $3000 for projects focusing on the future of the genetic counseling profession and/or the provision of genetic services. Award recipients will be notified by late September and announced at the Annual Educational Conference in October. Don't miss this bonus chance to submit a project crying out for funding.

☞ **Extended Postmark Deadline: August 9.** ❖

Letters to the Editor

Persistence Pays

To the Membership:

Upon establishing a private practice and adding a business telephone line in my home, I received a free *Yellow Pages* listing. I was offered the heading of "Pregnancy Consultation" since there was no genetic counseling/counselor heading. Not satisfied with this, I wrote to the regional headings department in San Francisco to request a new heading. I sent brochures and materials to educate them about genetic counseling, pointing out our numbers nationwide and that there are about 125 NSGC members in Northern California.

The response was disappointing. I was told that because it takes years for directory users to become aware of a new market, a new heading for "Genetics" was not warranted.

In November, I was notified of a new policy for test marketing new headings and my request file was reopened. The heading "Genetic Information, Counseling, & Testing" is now available. This heading will be test marketed for three years. I encourage anyone in genetics within the Pacific Bell domain to contact a *Yellow Pages* representative to obtain a listing under this heading, and I urge genetic counselors everywhere to practice diligence in obtaining this listing in your local areas. Its availability is advertising for our profession, and the more it is used, the more likely it is to become permanent.

Robbin Palmer, PhD
Reno NV

Membership Status Questioned

To the Editor:

I read with interest the article in the most recent *Perspectives in Genetic Counseling* (21:1,p2), "Sleepless in Seattle…Issues and Actions Taken by Your Board!" I was particularly struck by the section on full membership applications. In the past, I have asked the Board to review *all* NSGC members to be certain that *all* individuals with Full membership are entitled to that status. My concern relates specifically to the growing number of NSGC members who achieved full membership status without a Master's or PhD degree in human genetics from a program established for the training of genetic counselors. I believe that there are individuals in our organization who have full membership who do not meet the criteria established by the Bylaws. … it is imperative that we maintain high professional standards and guarantee that anyone we call a genetic counselor has earned that title. It is obvious in other organizations that if a member's status were found to be inappropriately assigned, the member would then be moved to the correct membership category. …I, therefore, call upon the Board of Directors of the NSGC to review the membership status of *all* NSGC members to make certain that we have not inadvertently validated the professional status of any individuals who have not earned that title. I would like to remind the membership that there is a precedent for such action… ."

Michael Begleiter, MS
Kansas City MO

Response from Membership Chair and President

We are in complete agreement that the NSGC should strive for encouraging the highest level of excellence in the field of genetic counseling. However, achieving membership status in a professional society neither designates one as a genetic counselor nor does it guarantee that these individuals adhere to high professional standards. We believe we can promote excellence most effectively through our educational programs and working with colleagues and other interested stakeholders who share a common vision.

You have requested on multiple occasions that a complete audit of the NSGC membership be conducted. The Board has denied this request since such an undertaking would be costly, onerous and unnecessary considering that a sincere effort has always been made to determine the appropriate membership status of all applicants.

We view the American Board of Genetic Counseling as an organization designed to establish the professional standards by which genetic counselors are measured. There is a large difference between an inclusive membership such as the NSGC that welcomes all parties who share a similar vision versus an exclusive organization such as the ABGC whose membership is limited to only those who meet strict training criteria and pass an examination. Ultimately, both organizations will be challenged with promoting and ensuring the highest standards in the field of genetic counseling.

Debra Lochner Doyle, MS
President
and Kristen Baker Niendorf, MS
Membership Committee Chair

SIG Updates: Activities Abound

Developing Prenatal Practice Guidelines

Reneé Laux, MS and
Melissa Kershner, MS,
Prenatal SIG Co-Chairs

Advances in ultrasound technology have increasingly challenged genetic counselors with new ultrasonographic findings and ambiguous interpretations, carrying unclear implications for the fetus. The literature offers conflicting evidence based on small or poorly designed studies, presenting diverse and often opposing opinions about the risks associated with these findings and how to manage the pregnancy. This situation creates a dilemma in deciding when and what type of testing to offer.

Addressing the Dilemma

To document the extent of the problem, a questionnaire was sent to members of the Prenatal SIG to ask about risks quoted and tests offered for various 'gray-area' ultrasound diagnoses which confirmed that there is variability in practice among counselors and institutions. We determined that developing practice guidelines would provide more consistent prognostic and testing information when counselors faced equivocal ultrasound findings. To help ensure medical/ legal safety, and to provide continuity of care, these guidelines are being extensively researched and reviewed with the intent of making them available for clinical use, with room for appropriate individualization for each client.

Survey Results

Of 125 surveys mailed, 32 were returned (25%). Counselors were asked to provide the risk they would quote for a chromosome abnormality or adverse outcome associated with each sonographic finding.

There was no consensus as to the risk quoted in any of the scenarios given. For example, risks given for isolated choroid plexus cysts seen at 18 weeks gestation ranged from 0.5% to 3% to "no exact given." Even more variability was seen in the case of echogenic bowel, with risks ranging from 1-2% for cystic fibrosis or Down syndrome all the way up to 10% for each condition. For isolated ventriculomegaly, answers ranged from "slightly increased risk" to as high as 10-15% for a chromosome abnormality. The greatest variability in risk was given for increased nuchal lucency noted prior to 12.9 weeks gestation, ranging from "no increased risk" to 80% risk for a chromosome abnormality.

Two survey respondents said…

"I so often quote… these risks without remembering where I learned them, but they seem 'standard of care' somehow. Other risks are not even agreed upon by the perinatologists I work with. The same is true for pregnancy management options."

"As the only counselor at our center, I struggle with interpreting the vast amount (and sometimes conflicting) information out there about isolated ultrasound findings… . I have worked with eight MDs, all of whom have their own plan for management of these cases."

From these results, the need for concise practice guidelines is clear. At the upcoming Annual Education Conference in Oakland, the Prenatal SIG is sponsoring a practice-based symposium to present and discuss proposed guidelines. Once finalized, these guidelines will be published. ❖

New Chair for Psychotherapy and Expanded Roles SIG

Welcome to the new chair of the Psychotherapy and Expanded Roles SIG, Vivian Ota Wang. Much appreciation to Luba Djurdjinovic for three years of dedication to nurturing this SIG from its inception. Activities have included: supervision sessions (members only), practice-based symposia and workshops at our Annual Education Conferences.

☞ Vivian Ota Wang
✆602-727-6933; otawang@asu.edu

Neurogenetics SIG Offers Video Lending Library

The Neurogenetics Special Interest Group is maintaining a video lending library, available to all NSGC members. Currently we have about 20 videos on topics including ataxia, dystonia, HD, myotonic dystrophy, NF and the brain.

Tapes will be sent free of charge to the borrower about one week prior to the date needed. Materials are then returned at the borrower's expense (via FedEx or Airborne Express) to Deborah de Leon within two weeks of date requested.

☞ Deborah W. deLeon, Co-chair
✆212-844-8719;
ddeleon@bethisraelny.org

For an order form…

☞ Karen Krajewski, Co-chair
✆313-577-8317; ac5339@wayne.edu

EMPLOYMENT OPPORTUNITIES

IRVINE CA: Immediate opening for BC/BE Genetic Counselor II (Job # CU-3258L). Provide GC & genetic risk educ for pts in br/ov, colon/rectum, prostate & other cancer genetics studies using cohesive cancer risk assessment, couns & tstg protocols. I'view, collect data, & follow-up.
☞ Cover ltr, CV & refs to Patricia J. Realo, MPA, Epidemiology Div, U California, 224 Irvine Hall, Irvine CA 92697-7550; Fax 949-824-4773; pjrealo@uci.edu. EOE/AA

LOS ANGELES CA: Immediate opening for Genetic Counselor. Conduct case follow-up on reports of abnormalities in pregnancies or live births; i'view male applicants (detailed info re: applicants' med/fam hx; pedigrees) for anonymous semen donor prog
☞ Marilyn Ray, MPH, California Cryobank, 1019 Gayley Ave, Los Angeles CA 90024-3425; ✆800-231-3373x21 or 310-443-5244x21; Fax 310-443-5258; mara@cryobank.com. EOE/AA

PALO ALTO AREA CA: Immediate opening for PT/FT BC/BE Genetic Counselor. Abil to work i'pendently & high motivation a must. Exp pref. Spanish a plus. Join 2 GCs in busy expanding PN practice & at satellite locations. Variety of ethnic backgrounds served.
☞ Send CV to: Athena Guy Malloy, MS Peninsula Prenatal Diagnostics, 1580 W. El Camino Real, Mountain View CA 94040; ✆650-938-6066; Fax 650-964-1522. EOE/AA

SACRAMENTO CA: Immediate opening for BC/BE Pediatric Genetic Counselor. Exp pref. Join large multi-spec private med group.
☞ Mark Roché, Human Resources, Perinatal & Pediatric Specialists Medical Group (PPSMG) , 650 University Ave, Ste 200, Sacramento CA 95825; ✆916-925-0190; Fax 916-925-4684; ppsmgadmn@aol.com EOE/AA

SACRAMENTO CA: Immediate opening for BC/BE PNDx Genetic Counselor. Exp pref. Join large multi-spec private med group to support work of 4 perinatoilogists.
☞ Mark Roché, Human Resources, Perinatal & Pediatric Specialists Medical Group (PPSMG) , 650 University Ave, Ste 200, Sacramento CA 95825; ✆916-925-0190; Fax 916-925-4684; ppsmgadmn@aol.com EOE/AA

SAN FRANCISCO CA: Immediate opening for 2 BC/BE Cancer Genetic Counselors. Join active multidisc team to implement cancer GC & tstg prog to meet high pt volume on-site & satellite clins. Provide cancer risk assessment for br/ov, colon/rectum, prostate & other cancer genetics studies; prof & commun educ; grant writing oppty.
☞ Send CV & 3 ltrs of recommendation. Beth Crawford, MS or Peggy Conrad, MS, UCSF, Stanford Cancer Risk Program, 2356 Sutter St, Box 1714, San Francisco CA 94115; BC: ✆415-885-7779; PC: ✆415-885-7481; Fax 415-885-3787. EOE/AA

SAN JOSE CA: Immediate opening for BC/BE Genetic Counselor. Admin exp pref. Function as Clinical GC & PN Screening Prog Coordinator. Focus in 1st yr primarily as CF, Tay Sachs and Canavans scrng coord: prog devel, OB educ, day-to-day operations & tracking, molec & clin labs coord, quality assurance & prog rept. Function as clin resource for 45 GCs regionwide.
☞ Karen Wcislo, MS, Kaiser Permanente, Genetics Dept, 260 International Circle, San Jose CA 95119; ✆408-972-3306; Fax: 408-972-3298; karen.wcislo@ncal.kaiperm.org EOE/AA

STRATFORD CT: Immediate opening for BC/BE. Genetic Counselor /Manager of Genetic Testing Services, Genetic Svcs Dept. Exp req. Limited pt contact. Familiarity w/ databases, excellent written & verbal commun & org skills; abil to interact w/ variety of professionals req, Act as client liaison, review & report results, track specimens & results, review requisitions, partic in devel new tasks, inhouse & client educ & trng. Work closely w/ maternal serum scrng, cyto & molecular genetics labs, process, accession, rept, mktg & sales depts.
☞ EM or snail CV & ltr: Dr. Steven Gersen, Director, Genetic Svcs, DIANON Systems, 200 Watson Blvd, Stratford CT 06615; Fax 203-380-4554; gerses@dianon.com EOE/AA

WASHINGTON DC: Immediate opening for BC/BE Genetic Counselor. Exp in GC, bioethics, healthcare & public policy; familiarity w/ internet, support group & consumer-oriented resources. Excellent commun & written skills; computer proficiency req, Respond to helpline requests, direct helpline activ & develop new resources. Manage & develop helpline resources, s'vise GC students & interns, follow public policy issues of concern to consumers.
☞ Mary Davidson, Exec Director, Alliance of Genetic Support Groups, 4301 Connecticut Ave, NW, Ste 404, Washington DC 20008-2304; ✆202-966-5557; Fax 202-966-8553; info@geneticalliance.org EOE/AA

GAINESVILLE FL: Immediate opening for BC/BE Genetic Counselor. PNDx exp req. Provide PNDx svcs for Women's Health Group in tchg hosp/clin setting. Oppty for tchg & rsrch.
☞ Liane Taylor, Box 100347 Gainesville FL 32610; ✆800-325-0367; Fax: 352-395-7948 EOE/AA

CHICAGO IL: Immediate opening for BC/BE Genetic Counselor. ART prog: screen egg donors, implement 1st trimester PAPPA-U/S scrng prog; PN GC: CVS, amnio, MSAFP & preimplantation genetics.
☞ Christina Masciangelo, MS or Yury Verlinsky, PhD, Illinois Masonic Medical Center, Dept Medical Genetics, 836 W. Wellington, Chicago IL 60657; ✆773-296-7095; Fax 773-871-5221 cmascian@immc.org EOE/AA

EVANSTON IL: Immediate opening for BC/BE Genetic Counselor. Exp pref. Direct pt contact & GC: prog dvlpmt for risk assessment of adults for cardiology, neurology, ENT & other specialities. Educ med professionals through specific prog dvlpmt, grand rounds & dept mtgs; commun educ. Estab & staff genr'l genetics clins.
☞ Beth Leeth or Susan Nelson, Evanston Hospital, Evanston Northwestern Healthcare, Genetic & Risk Assessment Program, 2650 Ridge, Evanston IL 60201; BL: ✆847-570-2864; SN: ✆847-570-2407 EOE/AA

SPRINGFIELD IL: Immediate opening for BC/BE Genetic Counselor. Exp in genr'l & cancer GC pref, not req. New grads welcome to apply. Enthusiastic, motivated, dedicated, good i'personal, written and verbal skills req. Provide cancer genetic svcs in Women's Health Center: risk assessment, pre- and post- test GC, tstg; commun and prof educ.
☞ Shawnia Forrester, MS or Virginia Kimonis, MD, Southern Illinois University School of Medicine, Dept Pediatrics, PO Box 19658, Springfield IL 62794-9658; ✆217-782-4839; Fax: 217-785-4117;SF: sforrester@pav-ntl.siumed.edu; VK: vkimonis@pav-ntl.siumed.edu; EOE/AA

WORCESTER MA: Immediate opening for Genetics Counselor. Exp pref. FT opening created from new expansion at biotech company.providing tstg svcs for neurological disorders. Rapidly growing, fast paced environment creates a unique oppty to help develop & implement new GC prog.
☞ Michelle Gallant, Athena Diagnostics, Human Resources, 377 Plantation St, Worcester MA 01605; ✆508-756-2886; Fax: 508-753-5601; AthenaHR@aol.comEOE/AA

ROCHESTER MN: Immediate opening for BC/BE Genetics Associate, Dept Lab Medicine & Path. Prior exp as lab liaison w/ biochem genetics focus pref. Excellent org skills, abil to work i'pendently & on team, highly developed i'personal & commun skills to enable multidisc collab, actively demonstrate ongoing personal devel & prof growth all pref. Provide pre- & post- tstg consults & tech support for genetic tstg & high level genetic tstg expertise to physicians & clients.
☞ Carrie Miesbzuer, Mayo Clinic, Human Resources Staffing Ctr, 200-0E-1, 1st St SW, Rochester MN 55905; Fax 507-284-1445; miesbauer.carrie@mayo.edu or www.mayo.edu EOE/AA

ESPANOLA NM: Immediate opening for PT, BC/BE Genetics Counselor. Exp pref, not req. Bilingual (Eng/Span) pref. Self-motivation, ability to work independently, good communication & organizational skills req.
☞ Robin E. McBride, MS, Genetic Centers of America, 11125 Rockville Pike, Ste 302, Rockville MD 20852; ✆301-770-5300; Fax 301-770-2005; geneticcon@aol.com EOE/AA

NEW YORK NY: Immediate openings for Genetic Counselors. 1-3 yrs exp pref, not req. Large, comprehensive genetics dept recruiting GCs; oppty for tchg & clin rsrch avail.
☞ Randi Zinberg, Mount Sinai School of Medicine, Dept Human Genetics, 100th St & Madison Ave, Box 1497, New York NY 10029; ✆212-241-6947; Fax 212-860-3316; RZinberg@smtplink.mssm.edu EOE/AA

STATEN ISLAND NY: Immediate opening for

EMPLOYMENT OPPORTUNITIES

BC/BE Genetic Counselor. Join comprehensive genetics prog: all aspects of PN/Peds. Cyto-, molec, & biochem labs. Spec'ty clins, supt grps, rsrch.
☞ Personnel (Ref #860), NYS Institute for Basic Research in Developmental Disabilities, Comprehensive Genetics Disease Program, 1050 Forest Hill Rd, Staten Island NY 10314 ✆718-494-5240; Fax 718-494-1072; ssbsi@webspan.net EOE/AA

CHAPEL HILL NC: Immediate opening for BC/BE Genetic Counselor. Exp pref. Join busy, large, multi-disc, univ-based PNDx prog. All aspects of PN GC, maternal serum multiscreen prog; opptys for commun outreach & rsrch; tchg residents, fellows & GC students; interact & collab w/ other genetic specialties.
☞ CV & references: Rachel Baughman, MS, University of North Carolina, Prenatal Diagnosis Program, Dept of OB/GYN, CB#7570 - MacNider Bldg, Chapel Hill NC 27599-7570; ✆919-966-2229; Fax 919-966-1999; baur@med.unc.edu EOE/AA

RESEARCH TRIANGLE PARK NC: Immediate opening for Director, Genetic Counseling. Min 5 yrs exp req. Manage GC Dept: develop GC for clients, consult w/ MDs & GCs; develop pt & prof educ; write/edit individualized test repts; perform reg'l & natl in-svc & sales trng lectures & teleconferences.
☞ LabCorp, Human Resources, 1904 Alexander Dr, Research Triangle Park NC 27709; ✆800-833-3984; Fax 919-572-7423; Questions: Dr. Papenhausen ✆800-872-5727 x7142. EOE/AA

WINSTON-SALEM NC: July '99 PT opening for BC/BE Genetic Counselor. Partic in prof & med school educ, GC trng prog req. Potential for FT. Join large academic med inst: coord PN, ped clins & maternal serum scrng progs.
☞ CV & 3 ltrs rec: Daragh Conrad, MS or Tara Stamper, MS, Wake Forest University School of Medicine, Dept Peds/Section Genetics, Medical Center Blvd , Winston-Salem NC 27157; ✆336-716-2213; Fax 336-716-7575 DC: dconrad@wfubmc.edu; TS: tstamper@wfubmc.edu EOE/AA

CINCINNATI OH: Immediate opening for PT, BC/BE Genetics Counselor. Exp pref, not req. Self-motivation, ability to work independently, good communication & organizational skills req. Potential for FT. All aspects of PNDx.
☞ Robin E. McBride, MS, Genetic Centers of America, 11125 Rockville Pike, Ste 302, Rockville MD 20852; ✆301-770-5300; Fax 301-770-2005; geneticcon@aol.com EOE/AA

CINCINNATI OH: Immediate opening for BC/BE Genetic Counselor. Some clin exp w/ strong interest in Cancer GC pref. Excellent written & verbal commun skills; abil to network w/ referring MDs. Oppty work w/ large, estab, multidisc genetics team: Provide direct risk assessments & GC for a variety of inherited cancer syndromes, partic in expansion of busy adult-onset cancer prog affil w/ academic ctr. S'vise, teach students.
☞ Karen Huelsman, MS or Granger Butler, MHSA, Children's Hospital Medical Ctr, The Hereditary Cancer Program, 3333 Burnet Ave-PAV 3-52, Cincinnati OH 45229; KH ✆513-636-3871 or GB ✆513-636-2491; KH: huelk0@chmcc.org or GB: butlg0@chmcc.org EOE/AA

CINCINNATI OH: July '99 opening for BC/BE Genetic Counselor. Enthusiasm & motivation req. New graduates welcome. Join active, reg'l, multidisc ctr w/ active outpt & inpt consult svcs, integrated prog for dx & mgmt of inherited metabolic disorders. Complete cyto, biochem, & molec genetics lab svcs on-site. Assist geneticists in genr'l genetic clins & w/ inpt ped consults. Coord outrch clins; some instate travel expected. Partic in tchg.
☞ Dr. Gail Herman, Children's Hospital Research Foundation, 700 Children's Dr - Rm W403, Columbus OH 43205 Fax 614-722-2716; HermanG@pediatrics.ohio-state.edu EOE/AA/W/M/VV DV/D

COLUMBUS OH: Immediate opening for BC/BE Genetics Counselor/Craniofacial Genetic Research Coordinator. Exp coord clin rsrch &/or providing care for individuals w/ craniofacial anomalies in a team setting desired. Scrn & recruit pts & fam w/ craniofacial anom as part of estab genetic rsrch prog to identify genes for Cleft Lip, Cleft Palate & add'l Craniofacial Anomalies as part of local, national & i'national collab effort.
☞ Andrew Lidral, DDS, PhD, The Ohio State University, College of Denistry, Section Orthodontics, 4140 Postle Hall, 305 W. 12th Ave, Columbus OH 43210; ✆614-292-3526 Fax: 614-688-3077; lidral.1@osu.edu EOE/AA

PHILADELPHIA PA: Immediate opening for BC/BE Cancer Genetics Counselor. Strong initiative, excellent commun skills, abil to work w/ different depts req. Build growing cancer genetics prog to meet growing demand. Join active multispec genetics team to design & implement new cancer couns & tstg prog; coord menopause risk assessment prog. Potential for local travel to satellite clins. Must provide PN & peds svcs coverage, PRN.
☞ CV & 3 ltrs rec req: Tanya M. Bardakjian, MS, Albert Einstein Medical Ctr, Div Genetics 5501 Old York Rd, Levy 2 West, Philadelphia PA 19141; ✆215-456-8722; Fax 215-456-2356; EOE/AA

PHILADELPHIA PA: July '99 opening for BC/BE for PT Genetics Counselor. Strong initiative, excellent commun skills & abil to work w/ different depts essential. Local travel & evening lectures req. Must provide PN, ped & cancer coverage, PRN. Join busy division: coord comprehensive Ashkenazi Jewish Population Carrier Screening Initiative; Set up new prog, outrch educ (prof & at-risk individuals) & GC.
☞ CV & 3 ltrs rec: Joyce E. Barbagallo, MS, Albert Einstein Medical Ctr, Div Genetics, 5501 Old York Rd, Levy 2 West, Philadelphia PA 19141; ✆215-456-8722; Fax 215-456-2356; EOE/AA

PROVIDENCE RI: Immediate opening for BC/BE Genetic Counselor. Maternity leave cover - min 6 mos. Strong potential for extension beyond maternity leave. Join busy PNDx ctr. All aspects of PN GC: abnorm multiple marker serum scrng, AMA, amnio & CVS, fam hx, teratogen & abnorm U/S GC. Cancer GC & tchg opptys.
☞ Lindsay Jordan, MS, Women & Infants' Hospital, Prenatal Diagnosis Center, 79 Plain St, Providence RI 02903; ✆401-453-7510; Fax 401-453-7517; ljordan@aol.com EOE/AA

AUSTIN/SAN ANTONIO TX: Immediate opening for BC/BE Genetic Counselor. Join a growing company offering comprehensive clin & lab svcs in rapidly expnd mkts. Focus on PN w/ growth into peds, adult & cancer programs planned.
☞ Karen Copeland, Applied Genetics, ✆210-614-4363; Fax: 210-614-3669; KLC@applied-genetics.com EOE/AA

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nsgc

233 Canterbury Drive
Wallingford PA 19086-6617

Employment Opportunities, from p. 15

Corpus Christi TX: Immediate opening for BC/BE Genetic Counselor. Spanish a plus. Some travel to satellite locations. Join a busy expanding PN ctron team svg the entire S. TX area: state-of-the-art cyto & triple screen dx lab; on-site U/S dept in each office. AMA, abnorm triple marker scrn, U/S, terat, abnorm fam hx, SABs etc. Some oppty for peds & cancer.
☞ Van Tran, MS, Center for Genetic Services, 7121 S. Padre Island Dr, Ste 202, Corpus Christi TX 78412; ✆361-985-6600; Fax 361-985-6603 EOE/AA

Dallas TX: Immediate opening for Genetic Counselor. New grads welcome. Join large, private genetics lab providing cytogenetic svcs to a nat'l referral base. PN consult & GC for wide diversity of indications; i'act w/ perinatologists at major hosp & outrch clins.
☞ Cathy Blanchard, Human Resources Manager, LGS, 7400 Fannin, Ste 1200, Houston TX 77054; ✆713-798-9500; Fax 713-798-9595; cblanchard@lgsgenetics.com; www.lgsgenetics.com EOE/AA

Salt Lake City UT: Immediate opening for BC Genetic Counselor/Director, Medical Education. 2+ yrs related exp desired; med educ exp pref, excellent oral & written commun skills, travel & public speaking req. Must u'stand implications of specific dx tests. Create educ materials & progs for pt & physician educ, provide phone supt for complex genetic tstg, admin estab speakers' prog, supt off-site GCs & sales & mktg employees, rsrch involvment.
☞ Susan Manley, MS Myriad Genetics Laboratories, 320 Wakara Way, Salt Lake City UT 84108; ✆800-469-7423 x505; Fax 801-584-3515; smanley@myriad.com EOE/AA

Lynchburg VA: Immediate opening for BC/BE Genetic Counselor. Join 2 busy perinatologists in expndng priv prac w/ close hosp affil. All apsects of PN GC: AMA, AFP, U/S, terat. Oppty for close perinatal commun i'action.
☞ CV & 3 ltrs rec: Delia Jones, Women for Women, 2215 Langhorne Rd Ste 101, Lynchburg VA 24501; 804-528-5290; Fax: 804-528-3952 EOE/AA

Kirkland WA: Summer '99 opening for PT BC/BE Genetic Counselor. PN & preconception GC in busy, growing perinatal practice: amnio, CVS, AFP & terat. Provide GC to families re: genetic risks, dx, prognosis, dx tstg & options. Work closely w/ perinatologists. Significant respon & autonomy. Serve as resource for community & other professionals.
☞ Rebecca Zacharias, MS, Evergreen Hospital Medical Ctr, Maternal Fetal Medicine Dept, 12040 NE 128th St, Kirkland WA 98034; ✆425-899-2200; Fax 425-899-2210; rzacharias@echc.org EOE/AA

Seattle WA: Immediate opening for BC/BE Genetic Services Specialist. 2 yrs clin exp & limited travel req. Commun skills (written & oral) a must. Salary range: $37,752-$48,300. Implement statewide genetics educ plan, pop-based rsrch, incl: improving state's birth defects surveillance prog & devel of universal NB hearing scrng prog. Opptys for public policy devel, work w/ state legislative system & oversee reg'l genetics clin system.
☞ Debra Lochner Doyle, MS, State Coordinator for Genetic Svcs, Washington State Department of Health, Maternal & Child Health Genetic Services Section, 1511 Third Ave, Ste 808, Seattle WA 98101; ✆206-464-7752; Fax 206-389-2812 EOE/AA

Seattle WA: Immediate opening for BC/BE Genetic Counselor in large br/ov cancer hearing . Exp GC for inherited br/ov cancer a must. Must be motivated & willing to work independently & w/ a team. Work in large breast & ovarian cancer rsrch population & inherited hearing loss population. Pretest couns, results couns & long term follow-up involved. Position includes: ascertaining & screening new individuals & fams for rsrch, tracking & maintaining connection w/ existing population, obtaining blood samples, tissue samples, pathology reports, couns, involvement in high risk clin, tchg & educ duties to students, the larger health care community, & genrl public, grant & paper writing, local cancer & genetics organizations & consultation w/ other health care profs & primary care providers.
☞ Jamie Dann, MS, Univ of Washington, MC King Laboratory, Box 357720, Seattle WA 98195; ✆206-616-4293; Fax 206-616-4295 jamie@polaris.mbt.washington.edu EOE/AA

Milwaukee WI: Immediate opening for BC/BE Genetic Counselor. 3-5 yrs clin exp req; prev exp in cancer or perinatal genetics pref. Exceptional commun skills essential. Woek directly w/ pts to provide assessment, GC, follow-up and referral. Work in collab w/ perinatal assessment ctr and lab; train residents, med & nursing students; partic in rsrch activ; attend clin conferences
☞ Stacey Nolan, Central Employment, Aurora Health Care, 3033 S 27th St Ste 101, PO box 343910, Milwuakee WI 53234;✆414-649-7951; Fax: 414-649-7180. EOE/M/F/'D/V.

In Canada

Toronto, ON: Immediate opening for Genetic Counselor. Master in GC & up to 6 mos related exp or equiv comb educ & exp. BC/BE w/ CAGC. Exp in colorectal cancer genetics an asset. Demonstrated knowledge of issues surrounding scrng for genetic suscept, org & analytic skills, facility w/ computers, incl databases & spreadsheets. Excellent i'personal, oral & written commun skills. Partic in plng, devel, implement & eval reg'l prog to identify families at risk for hereditary forms of colorectal or other cancers; coord NIH Colorectal Study; provide related clin GC svcs to families on multidisc team.
☞ Human Resources, Toronto-Sunnybrook Reg'l Cancer Centre, 2075 Bayview Ave, Toronto, Ontario, Canada M4N 3M5; ✆416-480-4876