PERSPECTIVES in genetic counseling

Volume 21 Number 1 Spring 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 Women's Health Care Services for a grant to support this newsletter.

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

THE CREATIVE JOB SEARCH

The debate continues. Will breakthroughs in genetic technology create a demand for more genetic counselors than training programs can possibly provide? Or are there more trained genetic counselors than there are job opportunities? While the debate rages on, many genetic counselors are carving new niches in innovative ways, expanding the profession in unanticipated directions.

VISION FOR POTENTIAL

Toni Pollin, MS

I didn't exactly create a job. I applied for one for which I was clearly overqualified. I applied for the position of Statistical Data Assistant in the Division of Diabetes, Obesity and Nutrition at the University of Maryland because my interests had moved away from clinical counseling toward the statistical aspects of genetics research.

The position — database management for

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EXPANDED SUPPORT ROLE

Trish Magyari, MS

Too many patients, not enough time, an all-too-frequent dilemma in genetic counseling. It is simply not possible in most medical settings to provide the depth and duration of supportive counseling patients require to address ongoing issues uncovered in the process of genetic diagnosis, testing or risk counseling. Since genetic counselors are uniquely qualified to

…to New Role, p. 7

UNRESOLVED DILEMMA: DUTY TO RECONTACT

Jennifer Peet, MS

In a recent listserv discussion, duty to recontact resurfaced. *(See sidebar, p 3)* The discussion centered around whether or not former HD predictive testees should be recontacted with updated information, as it is probably more pertinent to the testee's descendants than to the testee. Unresolved, the discussion led from one question to another. Do genetics professionals have a responsibility to recontact former patients with new information? If so, how can we determine which information is significant enough to warrant recontact? Would the duty to recontact be contingent upon new treatments or prevention information? Does our obligation to recontact depend on our client's reproductive age? How feasible is it to recontact each time new prognostic information becomes available?

LEGAL PRECEDENTS

While the genetics community has not yet reached consensus about recontacting patients, and thus offers no guidelines, the legal system has begun to address the issues of recontacting patients and informing parents of risk to offspring. For example, several cases have been successfully litigated against healthcare providers for negligence in

…to Duty, p. 3

Sleepless in Seattle…Issues & Actions Taken by Your Board!

Stefanie Uhrich, MS

Seattle provided the backdrop for an intense interim Board of Directors' meeting March 13-14. Several new and returning issues surfaced in what proved to be an action-packed meeting.

Documentation of Services

Katherine Schneider, Professional Issues Committee Chair, asked for guidance about a Time Survey and a Billing Survey. The former will address actual time spent on genetic counseling services; the latter, billing codes used for genetic counseling services. Both studies had received highest priority status in our 1998-2000 strategic plan. The Board gave its unconditional and unanimous support for proceeding with these surveys, and allocated funds budgeted for the strategic plan to ensure their timely and successful completion.

Full Membership Applications

The issue of "Who is a Genetic Counselor?" and "Who may have Full NSGC membership privileges?" was addressed by Kristin Niendorf, Membership Chair. In a lively discussion about those who have related masters or doctoral (PhD) degrees but are not specifically trained as genetic counselors, the Board decided to honor the spirit of our founders. Professionals with these credentials will continue to be accepted as Full members.

A by-law change clarifies Full membership status: Section 1.2ii will now read "…any person who has a Master's or PhD degree in a related field such as nursing, social work or public health *and* has a broad range of clinical genetics training *and* whose primary responsibility for at least three years prior to the date of such person's application has been genetic counseling" …

All applicants described above will be required to submit a CV and gain sponsorship from a Full member to complete the application process. These applications will be reviewed by the Membership Committee Chair or designee.

All applicants, regardless of membership status, will be required to sign an agreement to abide by the Code of Ethics at the time of each member's application.

The changes outlined do not apply to existing members.

Promotions at Conferences

Barbara Pettersen, Education Committee Chair, initiated a discussion and motion prohibiting "showcasing" products at education sessions by agencies, institutions and individuals, regardless of for-profit or not-for-profit status. Show- casing was defined as featuring a single product as the sole topic of a session. "Products" were identified as items that have financial or commercial value. The concept was endorsed, and a formal policy will be submitted for vote in the Fall.

New Committee Formed

Debra Lochner Doyle, President, moved that a new standing Communications and Publications Committee be established to oversee all communications functions. Subcommittees reassigned to this new committee are: Computer Users Group, Press/Media Subcommittee (Education); Publications/ Communications Subcommittee (Membership); as well as the *Journal of Genetic Counseling* and *Perspectives in Genetic Counseling*.

EMail Sharing

Maureen Smith, Past President I, proposed new EMail Guidelines. The policy was modeled after a recently adopted policy initiated by the Familial Cancer Risk Counselors SIG, which calls for keeping discussions and opinions expressed on the listserv confidential unless permission is asked of the author *or* all identifiers are removed. This guideline does not apply to information, notices or literature surveys. The Board recognized that intent rather than enforcement was the spirit of this guideline, and support rather than policing was the intent.

Practice Guidelines Approval

A process to approve Practice Guidelines was submitted by Robin Bennett, Genetic Services Committee Chair. The new system allows for early joint sponsorship by other professional genetics organizations as well as ample and early input from the membership.❖

Perspectives in Genetic Counseling is published quarterly by the National Society of Genetic Counselors, Inc. Send articles and correspondence to the Executive Office.

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Next issue ***June 15***
Submission deadline ***May 10***

DUTY TO RECONTACT, fr p. 1

recontacting patients (Schwartz v. United States, 230 F. Supp. 536 [E.D. Pa. 1964], Mink v. University of Chicago, 460 F. Supp. 713, 720 [N.D. Ill. 1978]). In one case, a patient sued her physician four years after her sole contact with him because she was not provided updated information (Tresemer v. Barke, 86 Cal App 3d 617, 150 Cal Rptr 384 [1979]). A few courts have also decided that informing parents when their offspring are at-risk for heritable conditions is an expected standard of care (Schroeder v. Perkel, 87 N.J.53, 432 A 2d 831 [1981], Pate v. Threkel, 661 So. 2d 278 [Fl 1995]). Therefore, it is possible that the duty to recontact former predictive testing patients may already legally exist, even though the information we could provide them is probably more relevant to their children.

DUTY TO RECONTACT: HD AS EXAMPLE

Predictive testing for Huntington Disease (HD) based on quantification of CAG repeat number within exon 1 of the IT-15 gene first became available to persons at risk in 1993. At that time, those with:

- < 29 repeats were considered to be gene negative
- 30-39 repeats had indeterminate results and
- >40 CAG repeats were considered to be gene positive.

Recently, a new classification system has been suggested, such that those with:

- < 26 repeats are considered gene negative
- 27-35 repeats are considered unlikely to develop HD but offspring may be at risk
- 36-39 repeats are considered gene positive but with reduced penetrance, and
- >40 repeats are considered gene positive.

This change in the classification system provoked a lively discussion on our listserv about recontacting individuals tested for HD, specifically the group falling between 27 and 39 repeats. ❖

CREATING GUIDELINES

Because genetic information is changing so rapidly, the question of how best to provide current information to families will continue to surface. Thus, it may be worthwhile for NSGC to creating specific guidelines.

On the Pro Side…

Generating formal guidelines may serve several purposes. First, having guidelines could prove beneficial to counselors when debating circumstances such as the one described in the sidebar. Second, although there have been court rulings which may be applicable to the genetics community, there does not appear to have been a case in the U.S. which has specifically dealt with the duty to recontact genetics patients. In the event that such a case occurs, a professional standard of care could prove helpful to the courts and ultimately to the genetics community. The court system seems to incorporate a profession's policy in its rulings, giving us an opportunity to impact the law in a positive way.

On the Con Side…

In contrast to the potential advantages of creating guidelines, the potential to generate problems exists. For example, if it is decided that all former Huntington disease (HD) predictive testees should be recontacted, how often will recontacting families cause harm? Consider this case: AR, an at-risk man, tested at 29 repeats a few years ago and proceeded to have children only because he thought he was gene negative. He never dreamed that one day he would be recontacted with news that his children or grandchildren may actually be at risk. Other than causing AR great alarm, we are not able to offer him anything else, especially the information he will be most desperate to have — the gene status of his children. Is it ethical to recontact him? One could argue that knowledge of a potential gene expansion may provide him alternative reproductive options from this point forward but what if, after recontacting him, it is discovered that he has already had a vasectomy? Does this man have the right not to be contacted with the information? Would the group who recontacted this individual find itself being sued for inflicting emotional injury?

Another problem which would likely surface is that of trying to recontact persons who underwent gene testing using an alias or identification number. Record storage and potentially complicated cross-referencing systems could also prove to be burdensome.

Although the listserv discussion last summer began with the debate over whether or not former HD predictive testing patients should be recontacted, it quickly raised more universal issues. Because these issues have not been resolved and because they will continue to arise, it may be beneficial to establish a standard of care. ❖

Makowski, DR (1996) The Human Genome Project and the Clinician. *J. Florida M.A.*, 83: 307-314.

Andrews, LB (1997a) The Genetic Information Superhighway: Rules of the Road for Contacting Relatives and Recontacting Former Patients. In Knoppers BM, Laberge C (eds.) *Human DNA: Law and Policy: International and Comparative Perspectives.* Kluwer Law International, The Hague, pp133-144.

Branching Out to Other Health Professionals

Genetics, Behavioral Science Shake Hands

Rob Pilarski, MS & June Peters, MS

Behavioral Sciences and Genetics: New Roles, New Partners, an innovative NIH-funded workshop held last fall, was developed by the Advisory Council on Cancer Genetics of the American Psychological Association to promote multidisciplinary collaborations between the biomedical and behavioral sciences communities. The invited participants, all involved in cancer centers and/or cancer genetics programs, included seven genetic counselors and nearly 20 social scientists and psychologists. The goal was to increase mutual understanding and respect and to foster future research collaborations.

Research was presented on key issues such as: how self-perceived social support may impact on reactions to genetic testing; how families live with inherited disease; what people bring psychologically and culturally to the genetic counseling session; what actually "happens" in clinics and how people understand risk.

One expert felt that future fundable research in the behavioral sciences needs to be geared toward areas such as discourse analysis, decision-making models and predictors of adherence to screening recommendations. Studies on patient characteristics such as attitudes, motivation, persuasion and comprehension of information could inform our understanding of provider-patient interactions and the informed consent process.

This meeting was especially unique and successful in that it offered two experiential exercises: conducting a qualitative research study or working in small multi-disciplinary groups to develop and write mock grant proposals. Results of these workshops were then reviewed by potential funders who provided feedback.

We were quite impressed with the interest shown by psychologists and behavioral scientists in the field of cancer genetics, and especially the opportunities it presents for collaborations between our disciplines. ❖

Genetic Services Outreach in Virginia

Lorna Phelps, MS and Joann Bodurtha, MD, MPH

We received a grant from the Division of Women's and Infants' Health, Virginia Department of Health, to develop a human genetics continuing education program specifically designed for personnel in state health departments. A needs assessment and resulting workshop were conducted by the Department of Human Genetics at the Medical College of Virginia Campus of Virginia Commonwealth University.

Needs Assessment

We started with a genetic services needs assessment survey. Fifty-three surveys were mailed to Nurse Managers in each health district of the Virginia Department of Health (DOH) and Children's Specialty Services (CSS) Coordinators across the state. Of those, 37 were returned, a response rate of 70%. Fifty-seven percent of respondents to the survey felt that the genetic services needs of their patients were mostly or completely being met.

Barriers to accessing genetic services most often mentioned were:

- costs of services
- culture
- distance to genetic centers
- misinformation
- lack of transportation
- language

About 95% (35) of respondents said their agency's interest level for a genetics workshop was good to excellent, and they indicated their level of interest in various potential topics, including:

- referral processes
- ethical issues
- informational resources for families and providers
- prenatal diagnosis
- teratogens

Genetic Services Workshop

We recruited speakers from across the state to maximize the networking opportunities. An information and registration flyer was mailed to about 800 state employees; 87 attended. The day-long conference consisted of plenary and break-out sessions.

Evaluation

The participants all gave a satisfactory or above rating; many rated the workshop as excellent. Most of the participants anticipated making changes in their work setting as a result of what they learned. Several mentioned an increased awareness of making referrals to genetics. ❖

What's New in '99?

Laura Thomson, MS & Linda Robinson, MS
Conference Co-chairs

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**

Mini-courses Four 4-hour concurrent, optional mini-courses: a wet lab for hands-on learning about molecular diagnostics, a research update on muscular dystrophies and, back by popular demand, retirement planning with Greg Schick and an extension of last year's exciting personal development workshop with Chris Loving.

CEU Options You choose: Attend the main conference only and earn 2.2 CEUs. Register for one of the optional mini-courses and earn a total of 2.6 CEUs.

Optional Tours Sunday afternoon is free time! Explore the area or take advantage of one of three optional tours in the Bay Area:
1) wine tasting in Napa Valley
2) a city tour of San Francisco
3) a visit to see the Famous Giant Redwood Forest (Muir Woods) and Sausalito, a Mediterranean-like village on the Bay.
Information and registration for the tours will be included with your conference confirmation. Tours have limited space, so register early! Deadline for receipt of the tour registration is September 1. For advance details: Kim Barr, 415- 202-2996; Kimberly.Barr@ncal.kaiperm.org

Reaching Out

…to the media Many of us have grumbled about misconceptions and misinformation about genetic counseling presented by the media. This year's Media Committee will seek to take a proactive stance by inviting members of the media to our specialized educational sessions at our conference. We hope direct contact will engender good will and develop permanent professional links between NSGC and the media.

…to science teachers NSGC will present a 2-hour workshop to approximately 70 local science teachers on ways to educate their students about genetics and genetic counseling to start building bridges with the local education community. ❖

What's New for '00?

The planning committee for the 19th Annual Education Conference invite you to join in our effort to make next year's meeting a success! The conference will be held November 1-5, 2000 in Savannah, Georgia with a short course scheduled after the meeting. The theme is "Exploring the Counseling Role in Genetic Counseling." If you are interested in participating in the planning, please contact one of the co-chairs listed below. New and seasoned volunteers are welcome.

Conference Co-Chairs
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Members' Creative Job Searches Lead to Successful...

Vision *Pollin from p. 1*

clinical genetic research projects on diabetes and osteoporosis in the Amish — required a Bachelor's degree and at least one year of experience, preferably in genetic epidemiology. Upon reviewing my resume, the division head realized that I could bring to the position much more than the type of candidate he had anticipated hiring. My job description is growing to include field work as well as statistical data analysis in collaboration with statistical geneticists. Once the studies yield useful information, I will probably be involved in patient education.

> ***"I could bring ...much more than the type of candidate he had anticipated hiring."***

Once my duties are more established, there is a strong possibility that my job will be reclassified as a higher level position under the state system to take into account my expanded job description. I am enjoying my job, acquiring new skills, viewing my field from a different vantage point and realizing that my genetic counseling training is useful in ways that I never anticipated. ❖

Networking is the Key

Beth Rosen, MS

I first became interested in the genetics of psychiatric and behavioral conditions while working as a prenatal genetic counselor in New York City. I noticed an increasing interest from my patients about the use of psychiatric medications during pregnancy. And, as time went by, more and more families were interested in learning about recurrence risks for specific psychiatric conditions.

To learn more about this emerging area of genetics, I attended the 1997 World Congress on Psychiatric Genetics (See article, *PGC*, 19:4, p.8). I then began to look for ways to become more involved in psychiatric/behavioral genetics. I read books and articles and established a psychiatric disorders Special Interest Group (SIG). A move to Boston gave me the opportunity to reassess my career goals and put my interest to the test.

> ***"I then began to look for ways to become more involved in psychiatric/ behavioral genetics."***

I focused on finding a position with a group involved in psychiatric and/or behavioral genetic research and identified approximately 25 investigators in the Boston area, using the roster from the Congress I had attended. I sent my resumé with letters explaining my interest and highlighting my experience in behavior genetics and psychiatry, emphasizing the unique training of genetic counselors.

I was contacted by two investigators and ultimately was offered a position by Dr. Susan Folstein to work on a 4-year NIH grant studying the genetics of autism. Currently, we are training to administer approximately a dozen different tests and, once trained, will begin recruiting and meeting with families. ❖

Starting from Scratch

Heidi Nagel, MS

My husband and I moved to Colorado after I completed my graduate training. Having done my homework, I felt that the Fort Collins area could support a genetic counselor, although they had never had one in the past.

I learned as much as I could about the structure of the medical community, met with hospital administrators and visited obstetric, oncology and infertility clinics.

The response was overwhelmingly positive; however, none of the clinics was willing to hire me as staff. All expressed significant apprehension about reimbursement. Some of these concerns continue, and I have put in vast unpaid time.

Over the course of 18 months, I have gradually succeeded in carving a niche for myself in the local hematology/oncology clinic and with the local infertility specialist. The eight physicians in the OB/GYN clinic have assured me they will negotiate an agreement with me to provide prenatal and cancer counseling services on a consulting basis. Recently I was approached about joining a preventive clinic.

A short while ago, many in this community did not know what genetic counseling was. To have attained the visibility and respect to be invited to participate has been its own reward. ❖

...Results

New Role

Magyari, from p 1

understand the ramifications of these stressful situations *and* to provide interventions for them, we have an opportunity to carve a new role for ourselves. Community-based psychosocial genetic counseling will further expand the continuum of care we provide to our patients.

This winter, I opened a private practice to provide adjustment, integration, bereavement and decision-support counseling services to clients whose concerns stem directly from genetic issues, filling gaps in existing genetic service networks, including:

- Short term counseling, focusing on integration and adjustment to genetic diagnoses
- Grief counseling related to genetic etiology
- Decision support for those experiencing difficulty making decisions regarding genetic testing
- Supportive counseling, stress management and self-care plans
- "Circles of Care," a home-based, family-centered intervention designed to overcome isolation
- Support groups for couples waiting for prenatal diagnosis results or continuing affected pregnancies
- Linkage to support resources and referrals to in-depth psychotherapy, when indicated.

My personal vision is to have a community-based genetic counseling center within two years supporting two or three full-time genetic counselors with space for individual, couples, family and group counseling as well as space for weekend workshops. ❖

GC in Developmental Disabilities Settings

Brenda Finucane, MS

When I first wrote on this subject for *Perspectives* in 1991, genetic counseling jobs within non-medical settings for people with mental retardation were virtually nonexistent. Unfortunately, things have changed little and this year's genetic counseling graduates are still unlikely to find such positions. The good news is that attitudes within the mental retardation field are beginning to change. For the first time in many decades, a cautious window of opportunity may be opening.

Syndrome-specific support groups have gained visibility, and an increase in understandable, practical information has contributed to a new awareness of genetics among nonmedical professionals. Like any other industry, the mental retardation field is "customer-driven" and cannot ignore the burgeoning number of young children with specific diagnoses on its doorstep.

Ten years ago, when the parents of a child with Williams syndrome presented information about this diagnosis at a school meeting, they were likely to be told that etiology had no relevance for treatment. Today, when parents come armed with literature and videotapes documenting the unique learning and behavioral styles associated with Williams syndrome, they cannot be so easily dismissed.

The number of children with known genetic syndromes has reached a critical mass among preschool children whose families actively seek out genetic services. However, these families represent only the tip of the iceberg! The true opportunities for genetic counselors will be found among those older children and adults who have literally missed the diagnostic boat.

Did You Know?

Over 4 million children and adults in the United States have mental retardation requiring special educational and/or residential services.

The genetic counseling profession knows all too well that need does not readily translate into jobs. Nontraditional positions for genetic counselors in special education settings will not simply create themselves. Counselors seeking to carve out a niche in the mental retardation field must actively "pitch" their services to local centers which, more than likely, have minimal awareness of genetic counseling. Administrators at these schools will not be swayed by talk of reproductive counseling for families, but they are likely to be intrigued by the idea that a genetic counselor can contribute to syndrome-specific educational planning and behavior management. Counselors need to be well-versed in recent literature emphasizing the importance of genetic factors in the causation of mental retardation and able to effectively argue that etiology can make a significant difference in the school setting.

It is no easy task to change attitudes and create jobs in a reluctant field, but for those few of us who succeed, the final destination is well worth the trip. ❖

Media Watch: Keeping an Eye on Our Profession

Angela Geist, MS and
Roxanne Ruzicka, MS

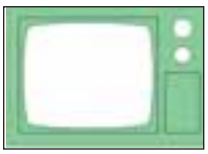
This new column has been created to discuss how genetics and genetic counseling are portrayed in the media. With this information — or misinformation — our patients come to their genetic counseling sessions. We will continue to report examples so that we can anticipate our patients' questions and beliefs.

Our Patients are Watching

• "LA Doctors" — BRCA gene testing was performed without a genetic counselor or any other appropriate professional. A genetic counselor was mentioned as a person who would use statistics to persuade an individual to pursue genetic testing. The patient convinced a doctor-friend to send her blood for BRCA analysis. She received her results in the mail and discovered she was gene positive. In another recent episode, the parents of a 3-year-old with Canavan disease struggled in a gut-wrenching effort to obtain gene therapy for their dying son, although genetics was never mentioned! The father did state his belief that *only* Jews could pass on this condition.

• "The Oprah Winfrey Show" — Dr. Bob Arnot promoted his book, *The Breast Cancer Prevention Diet*. Noting different breast cancer rates in various populations, he concluded that diet directly impacts a woman's breast cancer risk. His book's title is rather telling about our professional colleagues' perceptions!

• "ER" — The mother of a boy with adrenoleukodystrophy (ALD) was depicted after she fainted due to fatigue. The correct inheritance pattern was mentioned, as well as the need for respite care. In another scene, the mother stated that she had been given good news — her daughter was not found to be a carrier. The existence of a genetics department was repeatedly mentioned.



• "Chicago Hope" — A fertile couple wished to create a genius child by using egg and sperm from very intelligent donors. At an ethics committee meeting, doctors discussed how genetic technology allows us to determine a child's sex and some genetic traits and pondered the ethics of using this technology to create a genius.

Our Patients are Reading

• *Time* magazine (10/12/98) discussed breast cancer testing and its far-reaching implications by telling the story of a woman who had just learned that she was positive for BRCA1. Faced with dealing with the 60% chance of developing cancer in her other breast and 50% risk of ovarian cancer, she had to decide what to do. Should she have a bilateral mastectomy, take Tamoxifen or do nothing other than breast cancer screening? The issue of whether to include this medical information when applying for insurance or jobs was raised.

• *Time Magazine* (1/11/99) had several articles on the past, present and potential future of genetics, including the commercial race to map genes and make new discoveries. The articles brought up interesting questions about the future use of genetics for improving life as well as the potentially dangerous misuses of genetic technology.

We hope to use this new column as a venue for discussing the portrayal of genetics in the media. Pass along ideas you may have for the column to us: Angela Geist aargeist@aol.com or Roxanne Ruzicka RoxanneR1@aol.com ❖

How to Handle "Official" Comments to the Media

Inspired to dash off a letter to correct misinformation presented by the media or raise awareness of genetic counseling? Here are some tips to remember. Responses to the media representing NSGC, that is, using NSGC's letterhead or using NSGC's name in the signature or body of the letter, must be reviewed by an NSGC-sanctioned committee or Board member.

- The Publications/Communications subcommittee reviews publications and media responses to ensure they comply with current policies and official statements.
  - ☞ Co-Chairs: Troy Becker ✆402-559-7560; tabecke1@unmc.edu and Bonnie Hatten, ✆612-863-4502; bhatten@allina.com
- When a member desires an official NSGC response, contact the President.
  - ☞ Deb Lochner Doyle, President ✆206-464-7752; dld2303@doh.wa.gov.

A Cautionary Note: Some institutions may have an internal policy about responding to the media. Please explore these policies before attaching your institution's name to your response.

Celebrate Ourselves

GCs Obtain NCI Grants

Investigators at Emory University, Duke University and UNC-Chapel Hill were awarded one of eight National Cancer Institute's Cancer Genetics Network grants. The grants establish a nationwide database of individuals at high risk for cancer based on family history. Genetic counselors involved are Angela Trepanier at Emory, Shelly Clark at Duke and Cecile Skrzynia at UNC-CH.

Teaching Excellence

Congratulations to Janice Edwards, University of South Carolina, who won the 1998 Teaching Advancement Award from the University of South Carolina School of Medicine. This faculty development award is given for excellence in teaching and contributing to the development of teaching programs.

USC's Genetic Counseling Program was once again awarded the Commendation for Excellence by the South Carolina Commission on Higher Education.

Member Couple Recognized

Congratulations to Donna Wallerstein, MS and Robert Wallerstein, MS, MD, who were honored as "Exceptional People" in the January issue of *Exceptional Parent* magazine. The recognition was for their exceptional volunteer efforts with the national support group, Chromosome Deletion Outreach. CDO helps families with rare chromosomal deletion syndromes locate accurate information about their child's disorder. Bob began his career as a genetic counselor prior to attending medical school. ❖

Research Network

Genetics of Autism and Specific Language Impairment

A study of autism and specific language impairment, funded by both the National Institutes of Neurological Disorders and Stroke (NINDS) and the National Institute of Mental Health (NIMH), is a collaborative effort aimed at identifying language deficits found with autism and further characterizing these language features in family members. The goal is to find genes that may contribute to these disorders.

The project has two locations: The Eunice Kennedy Shriver Center, in Waltham, Massachusetts, under the principle investigation of Dr. Susan Folstein, and the University of Iowa, under Dr. J. Bruce Tomblin.

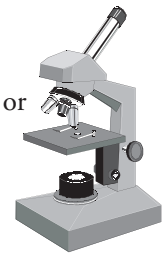
We invite families who meet either of the following criteria to participate:

- one child affected within the autism spectrum, age 4-14 years, and a sibling, age 4-16 years, or
- one child with a history of specific language impairment, language delay or language learning disability, age 4-15 years, and a sibling, age 4-16 years.

☞ Beth Rosen brosen@shriver.org Deborah Arin darin@shriver.org or Brian Winklosky ✆800-276-5148; bwinklosky@shriver.org.

Lipomatosis; Primary Pulmonary Hypertension

Jean Pfotenhauer, Dr. John Phillips and colleagues at Vanderbilt University are investigating the genetic basis of familial lipomatosis. They are seeking families with multiple members with lipomas.



☞ Jean Pfotenhauer or Dr. John Phillips, ✆615-322-7601; Jean.Pfotenhauer @mcmail.vanderbilt.edu.

Dr. John Phillips is also working with Dr. Jim Lloyd in an effort to map the gene for primary pulmonary hypertension, a rare autosomal dominant disease. They have identified a critical region of approximately 6Mb and would like to recruit other families to narrow the critical interval.

☞ Lisa Wheeler, ✆615-343-4253.

Neural Tube Defects

Liz Melvin at Duke University Medical Center is involved in a linkage project on NTDs. The project, headed by Marcy Speer, PhD, is looking for both singleton and multiplex families with any type of NTD. They are investigating genes involved in the folate pathway as well as other candidate genes with plans for a genome-wide screen. Participation in the research is free and does not require travel to Duke.

☞ Liz Melvin, ✆800-283-4316; www2.mc.duke.edu/depts/medicine/medgen/.

Hemophilia A

Tracy Jennings and Nancy Callanan are participating in an ELSI-funded project looking at the educational and informational needs of women with close relatives who have hemophilia A. Study participants are being recruited from the families of affected patients attending the UNC Hemophilia clinic.

☞ Nancy Callanan, NPC@med.unc.edu or Tracy Jennings, Tracey_Jennings@unc.edu. ❖

RESOURCES

This review is not intended to advertise or serve as an endorsement by NSGC. The author of *The Practical Guide to the Genetic Family History* currently serves on the Board of Directors.

BOOK

The Practical Guide to the Genetic Family History

Author: Robin L. Bennett, MS
Publisher: John Wiley and Sons, Inc., 605 Third Ave., New York, NY; pp: 256
Price: $44.95(pb)
Reviewer: Kathryn Steinhaus, MS

One recent addition to the growing number of publications by fellow genetic counselors is this informative new book regarding the genetic family history. This book, directed to health professionals, presents the family history as a practical screening tool to assist in the assessment of which client could benefit from more extensive genetic evaluation and testing. Author Bennett, who led the recent drive towards standardization of pedigree nomenclature, makes the case for all clinicians, not just those in genetics, to obtain a detailed family history.

Spiced with personal and historical vignettes, this book provides a complete review of numerous disorders we encounter every day and suggests specific detailed medical and family history questions to assist in establishing an accurate diagnosis, prognosis and recurrence risk for our clients. This book provides even the most experienced genetic counselors with useful information to hone our skills in providing our clients with accurate information. Disorders reviewed include: deafness, vision impairment, mental retardation, autism, neurological disorders, seizures, dementia, mental illness, renal disorders, skeletal anomalies and disorders of short stature, diabetes and cancer. Other situations include infertility and multiple miscarriages, a fetal abnormality diagnosed on ultrasound, adoption and assisted reproductive technologies.

This book is a valuable resource for the experienced genetic counselor as well as clinicians with little genetics background. It includes a review of forms of inheritance, classification of birth defects, how to locate a genetics specialist, what to expect from a genetics referral, a comprehensive glossary, references and case studies. This book raises the family history to the level of prominence it deserves.

While it may be tempting for genetic counselors to say "I know how to take a family history, I've done it for years," we can never learn too much about taking an accurate family history. This wonderful new book has taught even this "old dog" a few new tricks! ❖

VIDEOS

Deadly Inheritance

Authors: Luc Bourgon, Ian French & Daniel Sekulich
Producer: Northern Lights Television, Inc.
Distributor: Fanlight Productions, 47 Halifax St, Boston, MA 02130; 800-937-4113.ISBN#1-57295-257-1, VHS, color, 44 min
Reviewer: Beverly Yashar, MS, PhD

After a blood sample is drawn for presymptomatic testing, what does a family think about while it waits for the results? *Deadly Inheritance* provides a very personal answer to this question by following 38-year-old Christie Kilgore and her family over a five week period while they wait for the results of her genetic test for Huntington disease. *Inheritance* is a documentary, not an educational piece. It consists mainly of personal narratives by Christie, her 16-year-old daughter and her husband.

Monologues are interspersed with details of their day-to-day lives, including a trip to see two affected family members. There is limited information about the disease and the testing process, and it is unclear if Christie participated in a testing protocol prior to the blood draw. In spite of this omission, the factual information that is provided is accurate and the video provides a unique opportunity to learn what really matters to each member of this family. All three are quite articulate; they describe how the choice to proceed with testing was made and the potential consequences of the results for each of them. At times they become quite emotional. In one section Christie talks in detail about the test, itself. She is very upset by the idea that once the blood is drawn someone else "knows the answer."

The strength of this video arises from the openness with which this family discusses growing up with the disease, the relationships between affected and unaffected family members, the centrality of HD to their views of themselves, their fears, and finally, their hopes. Christie tells us that the reason she is pursuing testing is that she wants the gift of time. As the countdown slows from days to hours and finally to minutes, we watch her emotional meltdown and wonder how ready

she is for the answer. Christie's husband talks about how they would face a future life in which she is affected by the disease. He tells us that he has agreed to help her end her life when she decides the time is right. The personal and moral basis for this decision is cogently argued, but it brings into question the appropriateness of this video for individuals who are considering testing. However, what we learn from the Kilgores in *Inheritance* are considered, honest life perspectives about HD and for that reason, a viewing of this film by both new and established counselors is highly recommended. ❖

Is My Pregnancy All Right? Maternal Serum Screening and Other Tests

Producer: Ontario Maternal Serum Screening Steering Committee
Distributor: Medical Audio Visual Communications, dwc@mavc.com ✆905-602-1160; 800-757-4868
Reviewer: Jessica Mandell, MS

More than a review of maternal screening and amniocentesis, this new patient education video uses a multimedia format to detail the prenatal testing experience, from the timing of the first ultrasound to the concept of autonomous decision making and the benefits of genetic counseling.

The presentation begins with an initial "contract," outlining topics to be discussed. Two doctors take turns speaking, an older male and a younger female, dressed professionally in a comfortable office.

Ultrasound is reviewed first, including the technique, its use in measuring growth and development, and its inability to detect all possible fetal abnormalities. Throughout the tape, the doctors carefully stress that no prenatal test can guarantee a perfect baby.

The second section is a bit less straightforward, explaining the use of triple marker screening to detect increased risks of chromosome problems and neural tube defects (NTDs). Accurate pregnancy dating and ways of interpreting screen positive versus screen negative results are explained amidst a discussion of the etiologies and symptoms of Down syndrome and NTDs. Chromosomes are presented, advanced maternal age statistics are accurate, and an animated video showing neural tube formation is excellent.

The section "What's Next?" considers steps if serum screening is positive. An overview of amniocentesis accompanies a video clip. The autonomy of the woman is stressed here, with the doctors urging each woman to discuss testing decisions fully with her "doctor, genetic counselor or midwife," and her partner, "if she wishes." The brief discussion of termination or continuation of pregnancy is straightforward and nonjudgmental. The last moments of this section promote counseling again to help "explore feelings," noting that this process is "useful to help you make the decision that is right for you, but does not make decisions for you."

The doctors conclude by validating the natural desire for a perfect baby and feelings of anxiety around prenatal testing. Smiling faces and conversational style add to this video's appeal, but the setting and language seem to target an educated audience with good English comprehension. As a pre-counseling tool to enhance discussion between patient and medical professional, or as a post-session review of prenatal choices, this tape seems a worthwhile addition to a prenatal video library. ❖

The Burden of Knowledge: Moral Dilemmas in Prenatal Testing

Authors: Wendy Conquest, Bob Drake and Dennis Elliott
Distributor: Fanlight Productions, 47 Halifax St, Boston, MA 02130; 800-937-4113.
Reviewer: Roxanne Ruzicka, MS

In the prenatal setting, our patients continue to grapple with decisions of which testing they wish to pursue and how they intend to use their test results, even after our extensive counseling. A supplement to the counseling session, such as a video, that explores the thoughts, concerns and experiences of other patients in the same situation, may greatly aid in the decision making process.

This documentary chronicles several patients' and couples' experiences with prenatal testing, starting with the decision whether screening, the results, meeting with the genetic c deciding or not tc amnioce finally their reactions to the amniocentesis results. The couples discuss the reasons for pursuing prenatal testing, the limitations and

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VIDEOS from p. 11

strengths of AFP screening and amniocentesis, the difficulty of dealing with probabilities, and the anxiety inherent in these decisions and uncertainties.

Several patients and counselors examine the purpose and process of genetic counseling. Look for cameo performances from a few well-known faces in genetics circles. A few thought-provoking moral debates are presented and analyzed as well, including the values of knowledge and choice. Counselors and patients address the concept of the "tentative" pregnancy, which defines the time between when results are pending and the decision of whether or not the pregnancy will come to term.

The strong points of the video are its presentation of a balanced view of the prenatal counseling and testing experience. It covers a wide range of emotional responses and different decisions. Some patients recount their initial fear and then relief and joy with the receipt of normal results and others vent their anger and disappointment with their results or the manner in which the information was relayed. They also discuss the extreme anxiety felt by many during this time, especially while waiting for their amniocentesis results. This presentation should be helpful to parents who are experiencing the same concerns.

The downfalls of the video are its length (almost one hour) and a disturbing scene of amniocentesis. The video also contains a scene of a non-traditional birth, which seems out of place given the main focus of the video.

The use of a jerky, frame-by-frame type camera technique becomes annoying after a while. This video would not be practical in most clinic settings because of the length but may be suitable for some couples to view at home.

Overall, the video provides a provocative look at prenatal testing and the burden of making these decisions which some patients may find a valuable addition to their counseling session. It may also bring up issues for couples to consider more completely. ❖

ListServings

Hot Resources!

PRENATAL TUNE-UP?

☞Prenatal videos (amniocentesis and amnio/CVS) are available from Milner Fenwick, Inc, 2125 Greenspring Drive, Timonium MD 21093; ✆800-432-8433 or 410-252-1700; fax 410-252-6316.

☞French/Haitian Creole brochure on amniocentesis available from the New Jersey Medical School ✆201-982-3300.

☞ A book, *Expecting Adam,* by Martha Beck. A Harvard educated, ambitious couple decides to continue a pregnancy after Down syndrome is prenatally diagnosed, a decision that ultimately reassesses their value systems. A funny, inspiring memoir.

☞To explain pregnancy losses to children, try *No New Baby* and *Thumpy's Story,* from the Centering Corporation, ✆402-553-1200, and *The Frog Family's Baby Dies,* a cartoon book for young children by Jerri Oehler, RN, at the Duke University School of Nursing. Also the *Heart Breaking Choice* web page and chat room may yield the names of other parents for consultation. Look in the catalogue, "A Place to Remember," ✆800-631-0973; or www.APlaceToRemember.com.

SUPPORT GROUP INFO REQUESTED

If you have been involved in support groups for couples who have terminated a pregnancy after the diagnosis of a fetal anomaly, Gabrielle Mettler, MSc in Ottawa would love to learn from your experience. Her centre is considering starting a group. Contact her at: ✆613-738-3277; fax 613-738-4822; mettler@cheo.on.ca

BOARDS!

The Helix database contains a temporary link (until the Boards are over) on their home page, http://healthlinks.washington.edu/helix, called "Studying for the Boards?" that leads to two reports: Gene, Chromosome Locus & Protein Product and Diseases with Clinically Available Testing. ❖

JEMF: Looking Back

Allyn McConkie-Rosell, MSW

My interest in fragile X syndrome began in 1986. Once accurate diagnostic and carrier testing became available, families began to discuss their concerns about when to be tested, how to go about the process of testing and how to inform family members about the diagnosis. Little information about these very real and difficult issues existed in the literature. Like many counselors, I lacked the experience and time to design and implement these questions into a study which would lead to clinically applicable answers.

Looking for Funding…

After developing a qualitative and quantitative study, I encountered new barriers to funded research — lack of protected time and paucity of pilot data. Naturally, attempting to obtain funding for research without pilot data and proven experience is exceedingly difficult. Receiving the Jane Engelberg Memorial Fellowship (JEMF) gave me the opportunity to pursue all of this. Additionally, the JEMF gave me the opportunity to work with some wonderful collaborators, from whom I have learned a tremendous amount. Finally, the JEMF grant led to additional funding from the March of Dimes.

Increased Funding

Funding for JEMF has doubled. In times of changing medical standards and care, JEMF provides genetic counselors with an excellent opportunity to develop ideas into projects that contribute to medical knowledge and patient care, molding and influencing the direction of their own profession. ❖

Cancer Risk SIG

Stephanie Kieffer and Shelly Cummings, SIG Co-chairs

The Cancer SIG is actively addressing the goals of NSGC's strategic plan to:

- Dispel the myth of the shortage of genetic counselors.
- Create brochures customized for targeted audiences.
- Develop practice guidelines.

Activities planned for 1999 include:

Communications Committee

Anna Newlin & Ellen Parker

- Review literature in breast, colon, prostate and pediatric cancers
- Provide updates of conferences
- Write newsletters for members not on the listserv, outlining listserv highlights and literature reviews.
- Create NSGC Web page links.

Liaison Committee

Monica Alvarado & Maureen Smith

- Initiated contact with NCI, ONS, ISONG, ASCO, ACS and oncology social workers.
- Won two GeneAmp awards: 1) an exhibit of the NSGC booth at the ASCO and Society for Surgical Oncology meetings, and 2) an advertisement banner on the Breast Cancer Network website.
- Surveyed NCI-funded comprehensive breast centers about the availability of genetic counseling and other services

Research Committee

Rob Pilarski & Vickie Venne

- Enacted a mentorship program
- Published a directory of research projects, circulated by e-mail; hard copy also available.
- Increase collaborations with psychologists conducting research in cancer genetics.
- Collect and assess psychological instruments used by cancer counselors.
- Conduct survey research using the listserv and SIG membership.

Education Committee

Jennifer Graham & Heather Hampel

- Distributed starter packets to SIG members by e-mail in draft format.
- Drafted fact sheet on BRCA1 and BRCA2 for genetic counselors unfamiliar with cancer genetics.
- Working to develop two patient brochures on the topics of hereditary breast-ovarian cancer and hereditary colon cancer.
- Developing a slide swap.

Practice Issues Committee

Mary Ahrens & Cate Walsh Vockley

- Develop curricula for cancer genetic counselors in the future.
- Draft practice guidelines for many aspects of cancer genetic counseling.

Pediatric SIG

Julie Rutberg, Chair

The Pediatric SIG has determined the following goals for 1999:

- Sponsoring a practice-based symposium addressing sibling issues.
- Identifying literature appropriate for children affected by genetic disorders.
- Fostering research by genetic counselors into aspects of pediatric genetic counseling.

☛*Unless otherwise noted, contact SIG chair directly for more information about any of the activities noted.* ❖

EMPLOYMENT OPPORTUNITIES

OAKLAND CA: Immediate opening for 90% permanent BC/BE Genetic Counselor. Bilingual in Eng/Span or Cantonese; 3-5 yrs exp pref. Join large, mutltidisc, busy PNDx/perinatal ctr serving entire East Bay area: AMA, positive XAFP, u/s, teratogens, fetal reductions, peds, pregnancy loss.
☞ Dolores Madden, MS, Alta Bates Perinatal Center, 5730 Telegraph Ave-Genetics, Oakland CA 95609; ✆510-204-5355; Fax 510-923-9314. EOE/AA

ORANGE CA: Immediate opening for BC/BE Genetic Counselor. Span fluency desired; computer skills pref. Provide amnio, CVS, AFP, terat counseling; wide variety of genetic subspec clins; molec genetics.
☞ Khalil N. Zadeh, PhD, Genetics Center, 1000 W LaVeta Ave Ste 9, Orange CA 92868; ✆714-667-1965; ✆888-4GENETIC; Fax 714-667-1106; nzadeh@aol.com; www.geneticscenter.com. EOE/AA

PALO ALTO CA: Immediate opening for Genetic Counselor/Medical Geneticist. Dynamic, versatile personality, exp req. Join start-up phase company focused on providing & automating genetic risk assessment for common diseases. Provide family med hx svcs, work closely w/ software engineers & collaborators to develop tools to automate collection & assessment of family med hx.
☞ Human Resources, LINEAGEN, Inc, 1166 Channing Ave, Palo Alto CA 94301; ✆650-321-5088; Fax 650-941-8603; lscole@earthlink.net. EOE/AA

MODESTA (NORTHERN) CA: Immediate opening for BC/BE Genetic Counselor. Min 24 hrs/ week req; F/T possible. Exp & bilingual (Eng/Span) pref. Primarily PN svc for diverse pt population: AMA, XAFP (TMS), teratogen, DNA referrals.
☞ Beth Bronstein Genzyme Genetics, PO Box 9322, Framingham MA 01701-9322; Fax 508-872-5234; bbronstein@genzyme.com. EOE/AA

SAN JOSE CA: Immediate opening for P/T temp BC/BE Genetic Counselor. (approx 28 hrs/week through the end of March) Provide primarily PN GC svcs. Diverse pt population, AMA, XAFP (TMS), teratogen, DNA referrals.
☞Beth Bronstein, Genzyme Genetics, PO Box 9322, Framingham MA 01701-9322; Fax 508-872-5234; bbronstein@genzyme.com. EOE/AA

SAN JOSE CA: April 15 - August opening for F/T BC/BE Genetic Counselor. Join active team in estab genetics prog. PN, triple marker scrng follow-up & teratogens.
☞Cindy Soliday, MS, Kaiser Permanente, Genetics Dept, 5755 Cottle Rd, San Jose CA 95123; ✆408-972-3332; Fax 408-972-3298; Cindy.E.Soliday@ncal.kaiperm.org. EOE/AA

NEW HAVEN CT: Immediate opening for highly motivated, BC/BE Genetic Counselor. Excellent commun skills; min 2 yr cmtmt req. Join academic cancer GC prog: provide GC in on-site & satellite clins; partic in clin rsrch & tchg. Excellent oppty for growth & educ development.
☞ Ellen T. Matloff, MS, Yale Cancer Center, Box 208028, New Haven CT 06520-8028; ✆203-785-5938. EOE/AA

FT MYERS FL: June '99 opening for Oncology Genetic Counselor in cancer care center. Exp in genetics and cancer pref. Provide direct risk assessments and GC; maintain accurate referral resources for pts & families; public and prof educ re: cancer risk scrng.
☞ Jean Curry, Lee Memorial Health System, 2776 Cleveland Ave, Ft Myers FL 33901; ✆800-642-5627; ✆941-334-5648; jean.curry@leememorial.org. EOE/AA

SAVANNAH GA: Immediate opening for BC/BE Genetic Counselor at Memorial Medical Ctr in collab w/ Baylor College of Medicine. Join expanding genetics prog in 530-bed, tertiary care tchg facility. Work closely w/ 3 MFM physicians: PNDx: AMA, PN scrng, U/S, family hx & teratogens. Prog expanding to include oncology & peds. Work closely w/ back-up from geneticists at Baylor.
☞ Lisa G. Shaffer, PhD, Baylor College of Medicine, One Baylor Plaza, Houston TX 77030; lshaffer@bcm.tmc.edu. EOE/AA

SAVANNAH GA: See Dallas TX

SCARBOROUGH ME: Immediate opening for BC/BE Genetic Counselor in Reg'l Genetics Services Prog. Direct GC svcs to PN, peds & adult pts in reg'l clins; GC svc to FBR lab scrng programs in PN, CF; outrch educ svcs to HS, college & med students/residents.
☞ Dale Halsey Lea, RN, MPH, Supervisor, Foundation for Blood Research, Box 190, Scarborough ME 04074; ✆207-883-4131; dlea@fbr.org. EOE/AA

BOSTON MA: Immediate opening for F/T or P/T Research Genetic Counselor. High motivation, desire to take active role in defining new disease phenotypes & genotypes req. Join lab studying inherited disorders of eye movement to learn about early brainstem dvlpmt. Identify, contact, enroll & provide GC for participants & family members, focus on linkage analysis, physical mapping & candidate gene analysis of human disease genes. Serve as a liaison between rsrch lab & collab physicians.
☞CV, ltr & 3 ref: Elizabeth C. Engle, MD, Children's Hospital, Div of Genetics, Enders 5, 300 Longwood Ave, Boston MA 02115; ✆617-355-8371; Fax 617-355-7588; engle@rascal.med.harvard.edu. EOE/AA

WORCESTER MA: Immediate opening for 1/2 time Genetics Counselor. Potential for F/T possible. Exp pref. Expansion opening in biotech company. Rapidly growing, fast-paced environment creates unique oppty to help develop & implement new GC prog.
☞ Michelle Gallant, Athena Diagnostics, |377 Plantation St, Worcester MA 01605; ✆508-756-2886; Fax 508-753-5601; AthenaHR@aol.com. EOE/AA.

BALTIMORE MD: Immediate opening for F/T MS Genetic Counselor /Recruitment Coordinator. Excellent commun & interpersonal skills. Familiarity w/ classification of psychiatric illness, knowl Jewish culture, exp recruit rsrch protocols pref. Recruit individuals in Ashkenazi Jewish commun to partic in genetic studies of schizophrenia & bipolar disorder. Develop referral sources nationwide: PR, public spkg, coord ad campaigns, w/ targeted population, admin semi-structured scrng phone i'views; design annual nltr. Work w/ PI to develop GC arm of rsrch protocols.
☞ Don Boswell, Sr. Employment Specialist, Johns Hopkins Univ School of Medicine, PO Box 2454, Baltimore MD 21203-2454; ✆410-955-0455; Fax: 410-955-0644. EOE/AA

BETHESDA MD: Temp opening (to 6/11/99) for BC/BE Genetic Counselor/Genetic Nurse. MS in GC or equiv trng in nursing genetics. Enroll families in clin genetics studies, conduct GC, facilitate clin data collection, collation and follow-up.
☞ Kathy Peters, MS or Dr. Leslie Biesecker NHGRI / NIH, Bldg 10 - Room 10C101, Bethesda MD 20892; EOE/AA.
KP: kpeters@nhgri.nih.gov; ✆301-402-9653;
LB: leslieb@helix.nih.gov; ✆301-402-2041.

SILVER SPRINGS, MD: Immediate opening for Genetic Counselor. Enthusiastic, dedicated, team-oriented. MS or RN, computer literacy req. Verbal & written commun skills essential; Exp in OB or Peds req. Some travel.
☞ Send cover ltr & resume: Mitzi Janas, GeneCare, PO Box 4270, Chapel Hill NC 27515-4270; GeneCare@earthlink.net. EOE/AA

COLUMBIA MO: Opening for BC/BE Genetic Counselor to join 4 GCs & 3 MDs: direct small, estab MSAFP+ prog, PNDx, genr'l genetics clins, in-hosp consults. Oppty for prof growth, rsrch & prog development.
☞ Judith Miles, MD, PhD, Div Medical Genetics, Dept Child Health, University Missouri Hospitals and Clinics, Columbia MO 65212; ✆573-882-6991; milessjh@missouri.edu. EOE/AA

RESEARCH TRIANGLE PARK NC: Immediate opening for Genetic Counselor w/ min 3 yrs exp. Consult w/ MDs and GCs; develop pt

EMPLOYMENT OPPORTUNITIES

and physician materials; write/edit individual test repts; perform reg'l & natl insvc & sales scrng lectures & teleconferences.
☞ Anne Allen, Human Resources, LabCorp 1904 Alexander Dr, Research Triangle Park NC 27709; ✆800-833-3984; Fax: 919-572-7423. EOE/AA

HACKENSACK NJ: Immediate opening for BC/BE Genetic Counselor. Exp & cmtmt to excellence req; strong org skills; highly motivated; interest in cancer genetics pref. Spanish, computer skills a plus. Commun outrch, tchg and research oppty, varied caseload. Interface w/ multiple subspecialties.
☞ Sivya Twersky, MS, Manager, Hackensack University Medical Center, Pediatrics Center, Genetics Svc, 30 Prospect Ave, Hackensack NJ 07601; ✆201-996-5264; Fax: 201-996-0827. EOE/AA

ALBANY NY: Immediate opening for BC/BE Genetic Counselor. Exp pref. Join multidisc team in a tchg hospital: PN, peds, subspecialty, & satellite clins.
☞ Lenore Palladino, MS, RN, Peds/Clin Genetic, Albany Medical Center, 43 New Scotland Ave MC 88,, Albany NY 12208; ✆518-262-5120; Fax 518-262-5924. EOE/AA

BROOKLYN NY: Immediate opening for BC/BE Genetic Counselor. Spanish a plus. Join team of 2 perinatologists, medical geneticists and GC to provide PN GC to ethnically and culturally diverse population.
☞ Michael Cabbad, MD, The Brooklyn Hospital Center, Repro Genetics 3rd fl, 240 Willoughby Brooklyn NY 11201; Fax: 718-250-8660. EOE/AA

NEW YORK NY: Opening for BC/BE Genetic Counselor. MS, 2 yrs exp, bilingual (Eng/Span) pref. Provide AMA, serum scrng, teratogen, population scrng in NY metro area.
☞ Beth Bronstein Genzyme Genetics, Dept BB-98-779, Framingham MA 01701-9322; Fax 508-872-5234; bbronstein@genzyme.com. EOE/AA

CINCINNATI OH: Sept 1 opening for BC Genetic Counselor. Faculty Appointment. Masters from accredited GC trng prog; min 5 yrs exp w/ demonstrated tchg exp. Join expansion of GC trng prog: curriculum development/revision, clin tchg & s'vision, rsrch & scholarly activ; thesis s'vision; prof svc activ.
☞ Nancy Steinberg Warren, MS, Director, Graduate Program in Genetic Counseling University of Cincinnati & Children's Hospital Medical Center, 3333 Burnet Ave, Cincinnati OH 45229-3039; ✆513-636-8448; Warrn0@chmcc.org EOE/AA

TULSA OK: Immediate opening for BC/BE Genetic Counselor w/ 1 yr clin exp (grad clin internship applies). Excellent written/oral commun skills; computer proficiency in word processing, databases req; abil to provide confidential pt care & apply ethical principles. Report directly to clin geneticist & Director, Chapman Institute.
☞ Nancy J. Carpenter, PhD, H.A. Chapman Institute of Medical Genetics, 5300 E. Skelly Dr, Tulsa OK 74135; ✆918-628-6363; Fax 918-664-0596 ncarpenter@hillcrest.com. EOE/AA

PHILADELPHIA PA: Immediate opening for P/T (21 hr/wk) BC/BE Genetic Counselor. Provide PN GC to pts in clin setting, as well as in busy perinatal practice. Flex schedule.
☞ Sue Moyer, MS, Thomas Jefferson University Medical Ctr, 1100 Walnut St, MFM Dept, 19107, ✆215-955-1116, Fax 215-955-7560. EOE/AA

PHILADELPHIA PA: Immediate opening for a 2-year, paid fellowship in Cancer Genetic Counseling. Exp in cancer not req. Position offers training and mentorship in cancer GC, functioning in cancer risk assessment programs for breast, ovarian, GI and prostate cancers on multidisc team. Fellow will partic in and conduct genetic rsrch studies.
☞ Sherry Campbell Grumet, MA or Josephine Wagner Costalas, MS, Fox Chase Cancer Center, Family Risk Assessment Program, 7701 Burholme Ave, Philadelphia PA 19111; ✆800-325-4145; Fax: 215-728-4061; j_colstalas@fccc.edu; *or* sl_campbell@fccc.edu. EOE/AA

UPLAND (PHILADELPHIA AREA) PA: Immediate opening for P/T BC/BE Genetic Counselor. PN exp req; interest and/or exp in cancer risk assmt & GC; willingness to travel to satellite clin. Job share in well-estab PN prog w/ expansion into cancer GC at large suburban Phila med ctr; work closely w/ med geneticist & 2 perinatologists; rsrch, tchg & commun outreach prog oppty available.
☞ Nursing Services, Crozer Medical Center, 1 Medical Center Dr, Upland PA 19013; ✆610-447-2054; Fax: 610-447-2064. EOE/AA

COLUMBIA SC: Immediate opening for BC/BE Genetic Counselor. Join high risk pregnancy mgmt svc; tchg oppty w/in Training Prog. Oppty for projects in clin svc, educ & rsrch.
☞ CV & 3 ltrs of rec to: Janice Edwards, MS, Univ South Carolina School Medicine, Two Medical Park, Ste 103, Columbia SC 29203; ✆803-779-4928 x227; Fax 803-434-4596; jedwards@richmed.medpark.sc.edu. EOE/AA

DALLAS TX: Immediate opening for BC/BE Genetics Counselor w/ exp & motivation. Anticipated openings in San Antonio, Savannah. Exp; motivated GC to join growing private company offering comprehensive clin & lab svcs in rapidly expanding markets. Focus on PN with growth into peds, adult and cancer programs planned.
☞ Karen Copeland, Applied Genetics, 7622 Louis Pastuer #200, San Antonio TX 78229; klc@applied-genetics.com.

FORT WORTH TX: April opening for BC/BE Genetic Counselor. Join busy priv prac. All aspects of PN coun in multi-center perinatal practice w/ locations in Fort Worth, Arlington & Abilene. Add'l outreach clins possible.
☞ Mark Maberry, MD or Kim McMillen, Office Manager, Texas Maternal Fetal Medicine,

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national society
of genetic
counselors, inc.

nsgc

233 Canterbury Drive
Wallingford PA 19086-6617

Employment Opportunities, *from p. 15*

1325 Pennsylvania Ave, Ste 690, Fort Worth TX 76104-2133; ✆817-878-5298; Fax 817-878-5289. EOE/AA

Houston TX: Immediate opening for BC/BE Genetics Counselor. Span helpful. Join busy PNDx clin in univ setting affil w/ GC Training Prog; 3 days PN in priv clin; 2 days preconcept in county hosp; tchg, s'vise GC students w/ oppty to facilitate/lecture.
☞ Patti Furman, MPH, University of Texas OB/GYN & Reproductive Sciences, 6410 Fannin #350, Houston TX 77030; ✆713-704-5112; Fax: 713-704-5174; pfurman@obg.med.uth.tmc.edu. EOE/AA

Houston TX: Immediate opening for BC/BE Genetics Counselor. Min 3 yrs exp in medical genetics setting or 2 yrs exp post BC, working knowl of molec tstg, strong abil to multi-task, abil to work on team req. Must exhibit strong knowl of genetics and math principles to provide interpret of DNA lab results. Primary role: educ prof re: molec tstg, review case-specific info & data, interpret & report rsults. Partic in rsrch proj; develop prof educ materials for lab tests; partic in DNA lab review mtgs.
☞ Ben Roa, PhD, Acting Director, Baylor DNA Diagnostic Laboratory, One Baylor Plaza, #T536, Houston TX 77030; ✆713-798-6536; Fax: 713-798-6584; broa@bcm.tmc.edu. EOE/AA

Salt Lake City UT: Immediate opening for BC/BE Genetic Counselor. Cancer genetic counseling exp pref. Abil to work independently as well as on team; initiative, writing & speaking skills req. Provide clin svcs w/ oppty for rsrch, prof & public outreach.
☞ Merlene Timmons, Univ of Utah, Huntsman Cancer Institute, 15 North 2030 East, Ste 4110A, Salt Lake City UT 84112; ✆801-585-3800; Fax 801-585-9099; merlene.timmons@hci.utah.edu. EOE/AA

San Antonio TX: See Dallas TX

Seattle WA: Immediate opening for F/T or P/T BC/BE Genetic Counselor. Enthusiasm, motivation, & independence req. Join growing medical genetics clin in tertiary care hosp, predominantly adult w/ minimal PN or peds. Close interaction w/ MD Geneticist. Excellent oppty for diverse clin activities, rsrch & tchg.
☞ Send CV & 3 current prof ref: Robert Hershberg, MD PhD, Virginia Mason Medical Center, 1100 9th Ave, GI Section, C3GAS, Seattle WA 98111; ✆206-223-6391; Fax 206-223-7638; rhershbe@vmmc.org. EOE/AA

Seattle WA: Immediate opening for BC/BE Genetic Counselor. 80% w/ potential for F/T. Foundation in biochem, exp w/ database software & metabolic genetic disorders a plus; abil to work independently req. Join well estab clin team incl: nutritionists, GCs & medical geneticists in a Biochemical Genetics Clin. Provide genetic assessment & GC svcs to families w/ inborn errors of metabolism at a weekly clin, primary rsrch & database collection for pts w/ tyrosinemia & Gaucher. Assist w/ grant writing, human subjects review & manuscripts. Work closely w/ referrals to DNA & metabolic tstg labs. Tchg opptys.
☞ Robin Bennett, MS, Univ of Washington, Box 357720, Div Medical Genetic, Dept Medicine, Seattle WA 98195-7720; ✆206-616-2135; Fax 206-616-2414. EOE/AA

In Canada

Scarborough, Ontario: Immediate opening for Genetic Counselor w/ MS in GC or BSN; min 2 yrs exp as GC or courses in genetics or counselling; demonstrated ldrshp, organizational, decision making, communication skills; computer skills helpful. FT/PT negotiable. Join multidisciplinary team to interview, assess and counsel pts under direction of physician-geneticist
☞ Jennifer Wilson, General Manager, Women's Health Program, 2867 Ellesmere Rd, Scarborough, Ontario M1E 4B9 Canada; Fax: 416-281-7323; jwilson@centen.on.ca

Toronto, Ontario: Immediate opening for BC/BE Genetic Counselor. 2 yrs exp highly desirable. Join active Univ Hosp Clin Rsrch Prog in cancer genetics, multidisc approach involving Oncology & Genetics; prim ped pts & families; involve w/ couns rsrch & tchg.
☞ Cheryl Shuman, The Hosptial for Sick Children, 555 University Ave, Dept Genetics, Toronto, Ontario, M5G 1X8 Canada; ✆416-813-6386; Fax 416-813-5345.

Toronto, Ontario: Immediate opening for Masters level Genetic Counselor. Exp in similar setting pref. Join part of Provincial Reg'l Genetics network to provide GC & support to pts & famiies, arrange investigations & follow-up of results, work closely as a member of a multidisc team, provide formal & informal educ activities. Svcs available: PNDx, genrl GC; adult & peds, MS Scrng, Huntington's Predictive Tstg, familial BrCa Clin. Works closely w/ labs.
☞ Anne Neidhardt, Program Director, North York General Hospital, 4001 Leslie St, Genetics Program, Toronto, Ontario, M2K 1E1; Canada; Fax 416-756-6727.