PERSPECTIVES in genetic counseling

Volume 21 Number 3 Fall 1999

national society of genetic counselors, inc.

nsgc

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

TABLE OF CONTENTS

NSGC acknowledges Women's Health Care Services for a grant to support this newsletter.

CF POSITION STATEMENT REVISION CONSIDERED

In December, the membership will be asked to vote on a revision of the current Cystic Fibrosis Carrier Screening position statement. The current statement is published in your membership directory. The proposed revision is printed on page 3. The goal of this article is to provide members with the information necessary to make an informed decision regarding this upcoming vote.

Anne Spencer, MS

THE NEED

The original CF position statement, adopted in 1993, is outdated. An updated statement is needed because:

- Knowledge about CF carrier testing has increased significantly.
- Attitudes about carrier screening have changed, as reflected in the NIH consensus statement.
- The 1993 statement discourages population-based screening programs, but NSGC members individually are being asked to help develop such programs.

ISSUES ADDRESSED

The revision does three things:

- It encourages thoughtful participation in developing CF carrier screening programs.
- It specifically addresses the variation in carrier detection rates in different ethnic *…to p. 3*

MDA CAMP: COUNSELORS' EXPERIENCES

Cynthia James, Melissa Barber, Lori Hamby and Grace-Ann Olayinka

Each summer, the Muscular Dystrophy Association (MDA) sponsors week-long overnight camping experiences nationwide for children and young adults ages 6-21 who have been diagnosed with one of forty neuromuscular disorders covered by the MDA. The camps provide swimming, horseback riding, boating, fishing, arts and crafts, dance, adapted sports, motorcycle sidecar rides and much, much more. To ensure the health, safety and happiness of each camper, as well as to facilitate each campers' full participation, the MDA recruits volunteer counselors to be paired one-on-one with each camper.

As students in the Johns Hopkins University/National Institutes of Health Genetic Counseling Training Program, we had the opportunity to be volunteer counselors at our local MDA camp. Upon our return, we agreed that the experience had been personally and professionally invaluable. Camp provided us with an opportunity to get to know individuals personally who are usually our clients, and to gain a perspective beyond lectures and literature on what living with a neuromuscular disease is like.

…to p. 6

Calculating CEUs…What Counts?

Susan Schmerler, MS, JD

Are you interested in submitting for CEUs for a program you are planning? Are you anxious to gather credits toward recertification? ABGC has developed the following guidelines for calcu-lating program contact hours for programs offering Continuing Education Units (CEUs) to Genetic Counselors.

Course Content — *must focus on increasing the knowledge and/or skills generally recognized by the profession to be related to the practice of genetic counseling.*

Equivalency Table

1 contact hour = 60 minutes

1 contact hour = 0.1 CEU

10 contact hours = 1 CEU

Here's how CEUs are calculated:

- Fraction of hour: *Round to the nearest tenth hour*
- Fraction of CEU: *Round to the nearest tenth hour*
- Poster session: *count only that time when authors are present*
- Presidential address: *count only if professional/scientific paper is being presented*
- Open forum with experts: *only if professional/scientific paper is included*
- Q&A period: *only following professional/scientific presentation*
- Panel discussion following presentations: *yes*
- Panel discussion including presentations: *yes*
- Business meeting: *no*
- Luncheon with keynote speaker: *30 minutes for relevant topic*
- Luncheon with facilitated small group discussion on assigned topic: *yes*
- Program lists speaker, TBA: *no*
- Program lists speaker to be named, topic announced: *yes*
- Program lists speaker to be named, topic TBA: *no*
- Attendance at part of a program: *credit for hours attended*
- Breaks: *no* ❖

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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 ***December 15***
Submission deadline ***November 10***

Meet Your Board of Directors

We are pleased to announce the following elected, appointed and returning members who will serve as your Board in the coming year.

Officers/Executive Committee

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Jennifer Farmer, MS (0). . . . . Professional Issues
Anne Spencer, MS (1) . . . . . Social Issues
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**(n) represents previous years served on Board before this term*

Thanks to the Nominating Committee for a job well done: Maureen Smith, Chair; Rob Pilarski (I); Logan Karns (II); Kristin Paulyson (III); Deb Duquette (IV); Jeff Shaw (V) and Heather Brown (VI). ❖

CF Position Statement Revision from p. 1

populations.
- It recommends early testing to maximize families' reproductive options.

Issues Not Addressed

The revision does not take a stand on two relevant issues because they remain unresolved and controversial within the membership:
- No recommendation is made about whether CF carrier testing programs should target all ethnic groups or only those with high carrier rates of detectable mutations. We feel strongly that this issue must be discussed and debated but believe that, given the diverse opinions within the membership, inclusion of a recommendation on this issue is premature.
- The issue of newborn screening is not raised. We feel this is a separate issue which should be addressed independently.

Legal and Ethics Opinions

In accordance with NSGC's policy, the draft revision has been reviewed by NSGC's attorney and Ethics subcommittee. The NSGC attorney had no concern.

The Ethics subcommittee was impressed by how closely this statement adheres to the Code of Ethics. The four major points of the revised CF statement virtually mirror the four sections of the Code. The Ethics subcommittee supports the revised CF statement and feels it is a working model for

Proposed Revised CF Carrier Testing Position Statement

Regarding carrier testing for cystic fibrosis:

1) NSGC recommends that individuals who have a family history of cystic fibrosis, a relative who is a carrier of cystic fibrosis and the partners of such individuals should be offered CF carrier testing.

2) NSGC supports the development of population-based screening programs which offer carrier testing to pregnant women, women planning a pregnancy and their partners. These programs should provide adequate educational resources for medical personnel and patients and should address the complexities related to carrier frequencies in different populations, the sensitivity and specificity of test results, and the implications of such results for reproductive decisions. To this end, population based screening programs should have available genetic counseling by an appropriately trained genetics professional (e.g. a genetic counselor or medical geneticist who is certified by or an active candidate for the ABGC/ABMG). NSGC is committed to working with other professional organizations and consumer groups to develop appro-priate materials and facilitate a gradual and responsible integration of genetic testing services into standard prenatal and prenconceptional care.

3) NSGC supports the development of a minimum standard CF mutation panel that would maximize CF carrier detection rates for a variety of ethnic groups. In the absence of such a standard, health care providers should incorporate knowledge of the significant differences in laboratory standards (e.g. sensitivity, specificity, accuracy and the informativeness of CF carrier testing in different populations) into their screening practices.

4) The offer of CF screening should be timed to maximize reproductive options for patients (i.e. preconceptionally or as early as possible in the pregnancy). ❖

New Column to Feature Actions of Genetics Community

In this issue of *Perspectives in Genetic Counseling,* we are debuting a new column entitled, "Reaching Out: The Larger Genetics Community."

The purpose of this column is to report on the activities, resources and resolutions of other genetics groups, such as ASHG, ACMG, CORN and NHGRI, to increase our awareness as a community and to foster stronger relationships with these groups. We invite anyone active in other organizations to write a column or suggest ideas for articles with these issues in mind.

See page 8 for our first article.❖

Correction

In the previous issue of *Perspectives,* we noted Judith Benkendorf's appointment as the AAAS Congressional Fellow. We inadvertently omitted that this fellowship is sponsored and funded by ASHG. ❖

Creative Job Search: An International Approach

Karen Barnett, MS

After graduation in 1998, I followed my husband to the island republic of Singapore, hoping to be able to use my genetic counseling degree. Before moving, I did my homework. I focused on learning about thalassemia and Asian cultural beliefs. I contacted all six geneticists located in Singapore's three large university hospitals, letting them know of my qualifications and asking their advice as to how to go about becoming Singapore's first genetic counselor. One reply was brief; the others were silent. Off I went.

Culture Shock

There are about four million people in Singapore, a multi-ethnic country with Chinese, Malay, Indian and European influences and religions. Four major languages, Mandarin, Malay, Tamil and English, are spoken. Singapore's medical care is equivalent to that of most US cities. However, Singaporeans' expectations of medical care are different. Singaporeans do not question their doctors, and explanations are not provided. Options or alternatives are not discussed, and second opinions are frowned upon. Women over the age of 35 are offered amniocentesis without a discussion of the risks and benefits. If the results are normal, fine. If the results are abnormal, the decision making process is easy, or so I'm told. If the patient is Chinese, she aborts her fetus with an abnormality. If the patient is Malay, being Muslim, she does not.

Getting Started

After arriving in June of 1998, I immediately contacted obstetricians as well as infertility and oncology clinics. I registered a business called "Genetic Support Services" and after two months received approval through the Ministry of Health to work as a genetic counselor. During this time, I wrote a brochure entitled, "Genetic Counseling in Singapore" and mailed it to all 50 obstetricians serving the community. I included a page on why an obstetrician or oncologist would refer a patient for genetic counseling. This generated only mild interest. I followed up by sending out letters discussing genetic disorders I'd seen written about as human interest stories in the *Singapore Straits Times.* I spoke to several doctors who appreciated my skills and letter and said they would call me if they ever had a patient with a genetic syndrome, but my phone remained quiet.

Breakthroughs

Recently, I was asked to speak on a news radio show about genetic counseling. During the program, the radio station was flooded with calls about the "intelligence gene," myopia, Down syndrome and the possibility of an Asian having blue eyes. I spoke off the cuff, trying to keep my answers short and precise, yet fun. I didn't want to scare anyone off. After the show, I felt certain I would receive calls, but I did not.

Last month I had a series of interviews with the administrator and oncologists of the National Cancer Centre. We spoke of my being hired on a consulting basis to do cancer counseling and possibly employee training. A letter in late July said they were looking for funding to open a genetics department and would keep me in mind.

Stumbling Blocks

I have not given up on doing genetic counseling in Singapore, but after a year I'm beginning to understand some of the barriers to providing this service.

Singaporeans are worried about hiring an expatriate because most only stay in the country temporarily. Others realize I don't speak the other three languages of Singapore and fear that I may not understand their cultural beliefs. The depressed Asian economy is also a factor. Counseling is seen as an "extra," not a necessary part of medical treatment. Insurance does not cover it.

A new problem has emerged. I've discovered that when a young expatriate woman is faced with a difficult decision involving her fetus, she often goes home to her mother and physician in her country of birth. I've lost two prospective clients this way.

Small Steps

I hope to do more public speaking to make Singaporeans aware of genetic counseling. I am now working for the Breast Cancer Foundation giving community talks, doing staff development and individual client counseling.

I do believe that as the months go by, and as I keep sending out my articles to the doctors of Singapore, they will eventually realize the value of the service I can provide, and they will call. ❖

Maybe Next Time: Update on Foundation Activities

Lisa Amacker North, MS and Kristine Courtney, MS

In the summer of 1998 we asked the question, "Is NSGC old enough to "Birth a Foundation?" in an article in *Perspectives* (20:2). Following that article, NSGC's Board of Directors formed an *ad hoc* committee to study the possible formation of a foundation. These are our findings.

IRS-Speak

NSGC is registered as a tax-exempt, 501(c)(6) not-for-profit organization. That is, we work to improve the professional climate for our membership. Individual and corporate contributions to NSGC may be deductible as business expenses but not as charitable contributions.

Foundations are 501(c)(3) tax-exempt organizations, which are, according to IRS code, "organized and operated exclusively for charitable, scientific or educational purposes." Many (c)(6) organizations have separate foundations that undertake the organizations' scientific and educational missions and can accept tax-deductible charitable contributions.

Considerations

The Foundation *ad hoc* committee considered the possibility of an NSGC foundation for several reasons: to increase research and education in genetic counseling and to increase the fund raising options available to meet those research and education goals. NSGC currently sponsors research through the Jane Engelberg Memorial Fellowship (JEMF), Special Projects Fund and our GeneAMP marketing effort, and education through the Annual Education Conferences and Short Courses. We do not have the financial support to provide scholarships or fund large research projects. NSGC has tried a few fund raising projects, including the 10th Anniversary Fund ($20,000 raised) and the current 20th Anniversary Fund. Other donations, including JEMF, the Beverly Rollnick Memorial Lecture, the Natalie Weisberger Paul Fund and memorials to NSGC members who have died, have been unsolicited. We have accepted unsolicited donations without clear direction from our strategic plan. Also, we are concerned that tax code restrictions in charitable giving may be limiting donations to NSGC.

Consultation

The committee met in the fall of 1998 and in the spring of 1999 to discuss the possibility of creating an NSGC foundation. We talked with two lawyers regarding the legal and tax implications of a foundation. We met with a foundation fund-raising consultant to discuss the work involved in running a foundation. A subcommittee surveyed other foundations regarding their missions, organization and fundraising. Another subcommittee worked on vision and mission statements for a foundation. During the entire process, we kept looking at the financial and personnel resources of NSGC. We realized a foundation would only be feasible if it would bring benefits to NSGC and would not draw away resources.

Benefits

Advantages of starting a foundation were easy to see. We would be able to:

- consolidate existing research programs
- establish prioritized goals for research and education
- raise funds
- designate donations as tax deductible
- establish new granting and fundraising goals.

Limitations

Disadvantages were just as clear from the start. Running a foundation requires:

- time and ongoing commitment
- supporting a second organization
- staffing by professionals. NSGC's Executive Office is currently unable to house or staff a second organization. The cost of hiring an outside group would drain resources from the foundation.

Fundraising in our profession would be challenging given our track record, the demographics of our profession and the changing climate of corporate giving.

Decision

Given the advantages and disadvantages, the committee came to a well thought out conclusion. The formation of a foundation should be put on hold for two to five years. Within this time, NSGC goals, changes in the executive office, increased volunteer interest and 20th Anniversary fundraising experience will provide valuable information about our energy and the resources needed to start the foundation. The Finance Committee will continue to look at these issues and will be submitting a proposal to sponsor a fundraising workshop at the 2000 Annual Education Conference in Savannah. ❖

MDA CAMP: PROFESSIONAL LESSONS TURN PERSONAL *from p. 1*

MELISSA BARBER

My camper was 9 years old. We spent most of our time together singing, painting our pinewood derby race car, making crafts and playing whiffle ball. Of course, we also had "discussions" about eating all the vegetables on his plate, taking the requisite number of showers and not touching the other kids' power wheelchair controls without permission. After all, boys will be boys!

This realization was where the personal and professional rewards of camp intersected for me. As a genetic counseling student, I have access to a seemingly boundless supply of information about Duchenne muscular dystrophy. I know what causes it, how it is inherited, what happens physiologically to the muscles. What I *didn't* ever have was the occasion to contemplate the whole picture of a little kid who happens to have DMD. It is so easy to get caught up in the problems and difficulties of a child and family with DMD and lose perspective on the reality that children are children and they love summer camp.

LORI HAMBY

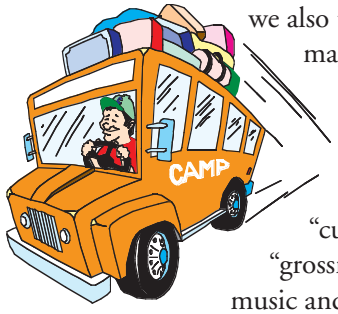
I spent my week at MDA camp with a female teenager with myotonic dystrophy. I gained as much from her as she might have from me. I was reminded constantly by her life and her personality that I am pursuing my profession for the people and not purely because of an interest in the conditions.

The moment that I met the campers, I forgot about muscular dystrophy completely and thought only of the smiling children. This perspective will be invaluable to me as a genetic counselor and also as a person. It is truly indescribable how great an impact the experience of a single week can have on the other 51 weeks of the year.

CYNTHIA JAMES

I spent my week at camp with a smart, self-confident, somewhat reserved 10 year-old girl with spinal muscular atrophy type II. As the start of camp approached, I was excited but a bit nervous. Would I be able to lift my camper? How do you recharge a power wheelchair? What would going swimming with her entail?

These concerns were quickly put aside. There was an excellent orientation session, my camper was quite able to make her needs known and experienced counselors were always willing to lend a hand. My camper and I spent the week emersed in the usual camp activities. Since our cabin housed 8-12 year-old girls, we also took preteen magazine quizzes, spent hours preparing for the dance and evaluated the "cuteness" and "grossness" of various music and television stars!



In addition to being great fun, getting to know the bright, engaging girls in our cabin reminded me of the importance of getting to know people as unique individuals first who then happen to have a disability or illness. Watching the girls intersperse conversations about the merits of hairclips and musical groups with discussions about what diagnosis they had, what aides they used at school and why only some of them had affected siblings also brought home how beneficial this unique type of support can be. It also reinforced how important it is that we as professionals provide such opportunities not only for parents and affected adults but also for children and adolescents.

GRACE-ANN OLAYINKA

I spent a whole week with one of the youngest campers at MDA camp this summer. His 6 year-old spirit and excitement for swimming, horseback riding and canoeing kept me on my toes. MDA camp was a self-discovery experience for my camper because, prior to attending camp, he was not even aware that he had muscular dystrophy.

He just knew that he would be going to a camp with other kids that "had a hard time walking, running and keeping up with the other kids at school." However, by the end of the week, my camper proudly proclaimed, "That's what I have!" when the camp director was speaking to him about MD.

For me, camp was a place to gain insights from the campers about the realities of what it is like to live with a disability. I learned from the best teachers, young people who are so sincere with their words and actions that they touch your heart without even trying.

For more information, or to volunteer at an MDA Summer Camp, call your local MDA office or MDA's National Office ✆520-529-2000. ❖

What's New at the '99 AEC ?

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**

Reunions Genetic Counseling Training Program reunions will be held on Sunday evening, October 17, at 9:00pm, after the practice-based symposia. The following reunions have been scheduled:
Beaver College
Brandeis University
California State University - Northridge
Indiana University
Medical College of Virginia
Northwestern University
Sarah Lawrence College
University of California, Berkeley
University of Cincinnati
University of Minnesota
University of Pittsburgh

The locations will be on the Ancillary Meeting page of the Conference program book.

Business Meeting Our annual business meeting gives you an opportunity to hear about the many activities conducted by the leaders of your Society. Plan to attend the business luncheon on Saturday, October 16.

Public Thanks! NSGC acknowledges all of the members who stepped forward to work on the success of this year's conference. In particular are those who stepped up to take leadership roles:

Linda Robinson and Laura Thomson, Co-Chairs

Leah Hoechstetter and Karen Wcislo, Abstracts

Denise Tilley-Howard, Communications

Kim Barr, Logistics

Dawn Allain and Heather Hampel, PBS

Kathryn Murray, Program

Michael Banke, Resources

Kelly Ormond and Lyn Hammond, Workshops

Jennifer Farmer, Elaine Sugarman and Cathi Rubin Franklin, Mini-courses

Susan Schmerler, Legal Short Course Chair

Barbara Lerner, Bob Resta and Vickie Venne, Research Short Course Chairs

Thank you, Planning Teams! We couldn't have done it without you! ❖

2000 and Beyond

AEC'00 Planning

A planning meeting for the 19th Annual Education Conference will be held October 16 at 5:30pm in Oakland. Look for the location in this year's program book. The meeting will give all of the parts of the planning committee an opportunity to brainstorm together.

One of the committees requiring the earliest jump start is the Abstract Committee, which recruits, receives and reviews abstracts, posters and submitted papers. "We now have a dozen committee members and hope to gain about twenty more. Please join us in Oakland to find out more! And should you choose to be a committee member, anticipate a multi-faceted adventure, one that encompasses preparatory and on-site participation," writes co-chair Lyn Hammond.

Never worked on an NSGC conference committee? What a great way to test the waters.

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

AEC'01
Co-chairs Named

A hearty thanks to Lyn Hammond and Denise Tilley-Howard, who have agreed to co-chair the Annual Education Conference in 2001. Combined, Denise and Lyn have participated in every aspect of our conference planning in recent years. ❖

Partnership for Genetic Services

Nisha Isaac, MS and Bowie Little, MHA

The Partnership Program represents the Alliance of Genetic Support Groups' long-standing commitment to provider education. By working with providers-in-training and providers-in-practice, this Pilot Program strives to enhance genetic services delivery.

PROVIDERS-IN-TRAINING

The providers-in-training portion is an intensive three-day workshop on articulating the reality of living with genetic conditions. Participants are consumers of genetic services who then give panel presentations about their experiences to medical students.

We have integrated our speakers into the curriculum of 12 midwest medical schools to sensitize students to the unique needs of consumers and to alert them to the resources available within the local support groups and geographic communities.

PROVIDERS-IN-PRACTICE

The providers-in-practice portion targets providers in managed care organization (MCO) pilot sites. The four phases of the MCO portion are to:

- assess current levels of genetic services provision
- integrate resources into the current service delivery system
- evaluate the effectiveness of the integrated resources and
- disseminate results.

We are now completing the initial phase of collecting baseline information from targeted disciplines within our pilot sites. This involves 40-60 minutes of group discussion with pediatricians and family practitioners to assess provider understanding and utilization of both genetic services and consumer-oriented resource materials. For illustrative purposes, we developed one page condition-specific fact sheets that contain information about the condition, website and support group resources and existing medical guidelines. The conditions represented were selected from a list of those more commonly seen in clinical practice within each site and discipline. Preliminary feedback from providers indicates a great desire for this type of tool.

PROGRAM GOALS

The ultimate goals of the Partnership Program at our MCO pilot sites are to: assist medical management in understanding the current delivery of genetic services to plan members; integrate condition-specific resources for providers and plan members into existing information systems, and orient providers to both the need for genetic services and the use of existing consumer resources.

Getting into the managed care system and finding allies who are willing and able to work on a

specialized part of the health care delivery system was a more time consuming process than originally anticipated. In addition, rapid changes in the MCO environment (bankruptcy, mergers, takeovers) have also provided the Partnership Program with several challenges in obtaining and maintaining MCO pilot sites.

Focus groups and surveys sent to Alliance members were used to develop the *Consumer Indicators of Quality Genetic Services*, an articulation of the consumer's perspective on the essential elements of genetic services delivery. The Consumer Indicators serve as tools in medical schools, to demonstrate what families want and need, and in MCO pilot sites, to evaluate strengths, weaknesses and gaps in genetic services delivery.

This is an exciting time for the Partnership Program as we evaluate the impact of consumer presentations in medical schools and begin charting provider activities in MCOs. The models, tools and resources developed and tested in this program will better equip the Alliance to enhance the provision of genetic services for individuals and families living with genetic conditions. ❖

SELECTED QUOTES

"...provides information that will help me give better care as a physician."

"I like interacting with real life families. …I think I listen more."

"…I think it will make me a more caring physician."

"..This information can't be obtained from a book."

"..realization that genetic disorders have a major and lifelong impact on families and family dynamics."

RESOURCES

My Mother's Breast: Daughters Face Their Mothers' Cancer

Author: Laurie Tarkan
Publisher: Taylor Publishing Co.
Cost: $14.95pb
Reviewer: Janice L. Berliner, MS

Laurie Tarkan was only 11 years old when she lost her mother. Her young childhood was profoundly affected by watching her mother suffer. Her purpose in writing this book was to "shine the light on these issues that are felt powerfully by daughters but often go unnoticed by the larger community."

Breast cancer changes the lives of all family members. Daughters are particularly affected. They are frequently the caretakers, watching the pain and suffering, mending troubled relationships, putting their own lives on hold and facing their own increased risk for the disease. Of course, having watched all this suffering makes it all the more frightening.

Ms. Tarkan takes the reader through the experiences of many women who have faced their mothers' breast cancers. The women openly discuss their fears, grief, guilt and exhaustion during and after the process of caring for their mothers. Many expressed resentment at having to put their lives on hold because their fathers and siblings were neither able to cope nor willing to help. Some felt guilty that they weren't more patient with their mothers, more willing to sacrifice or more generous of spirit. However, many also described how enlightening the experience had been, allowing them to have more open relationships with their mothers and giving them insight that would otherwise not have been gained.

It is fascinating to see the differences in coping styles among the daughters and their mothers and to learn of their personal growth, regardless of the mother's prognosis. Ms. Tarkan describes some daughters who not only cared for their mothers, but also younger siblings, in an unsettling role-reversal difficult to accept for both mother and daughter. Some of the daughters were so profoundly affected that they began support groups, took up careers in family therapy or opened cancer centers to care for others. They also tended to take better care of themselves, partly to protect against the threat of cancer, and partly, I suspect, to honor their mothers.

In addition to the case histories, the author reviews basic cancer genetics, preventive measures, ways to determine risk and a resource chapter that, yes, includes NSGC. I was impressed by how often Ms. Tarkan stressed the misconception that anyone with a family history of cancer is at high-risk and that actual risk for the daughters was generally lower than perceived.

This book is so personal, so honest, that the reader can't help but be moved. As stated in the book's press release, "By sharing stories of strength and courage, *My Mother's Breast* provides long-overdue support for the loved ones of breast cancer patients." It is also an invaluable tool for genetic counselors to help in the understanding of our patients' experiences and fears, and for our own lives. ❖

GENECLINICS™ AT ONE YEAR

Cindy Dolan, MS and Roberta Pagon, MD

GeneClinics™, a new online database at the University of Washington, integrates the use of molecular genetic testing into patient care by providing health care providers and patients with up-to-date information on disease specific uses of genetic testing. GeneClinics™, a companion resource to GeneTests™ (formerly Helix), debuted last October.

The GeneClinics™ website currently has approximately 40 disease profiles and four overviews. *Disease Profiles* are highly structured entries describing specific inherited disorders and the role of genetic testing in diagnosis, management and genetic counseling. *Overviews* describe the use of testing in a category of diseases.

In addition to expert-authored and peer-reviewed information, each disease profile has links to GeneTests™ and to other genomic resources (e,g. OMIM, Human Gene Mutation Database and locus-specific databases). A resource section links to consumer-oriented and disease-specific national organizations.

The reference section includes links to policy statements and guidelines regarding genetic testing, PubMed abstracts of the cited literature and custom PubMed searches on the profile topic and authors.

☞ www.geneclinics.org ☞ www.genetests.org

Post-Marks Era at SLC

Jessica Mandell, MS

So what's life like at Sarah Lawrence since Joan Marks retired?

This fall, Sarah Lawrence College (SLC) welcomes a diverse class of 23 human genetics graduate students and several innovations under the leadership of Caroline Lieber, MS, Program Director, and Bruce Haas, MS, Assistant Director. Lieber and Haas completed their first year of directorship following Joan H. Marks, MS, who developed and directed the genetic counseling program at SLC from 1969-1998, the first of its kind in the U.S. "Bruce and I have tremendous pride stepping into a program so well established and esteemed, and we value the legacy that Joan Marks created," said Lieber.

Lieber and Haas bring their own expertise to the program. Lieber was a genetic counselor at Hackensack (NJ) University Medical Center since 1980 and manager of their genetics department since 1992. Haas's background includes genetic counseling at Memorial Sloan-Kettering Cancer Center, Cornell University Medical Center/New York Hospital and Chinatown Health Clinic. Prior to that, he was a therapist and cytogenetic technologist. Both graduated from SLC's Human Genetics Program and have played recent critical roles there, Lieber as three-year director of clinical fieldwork and Haas as a faculty member.

Together, they envision several areas of growth. These include lengthening the first-year students' clinical fieldwork and adding a semester of "Issues," a backbone of the program in which students explore genetic counseling via readings, lectures, group-work and role-play. The new semester will be a hands-on analysis of students' fieldwork cases with a team of practicing counselors.

Another development, "Educational Outreach," requires students to split into groups and devise genetics education programs for community resources of their choice. One program's response at the Bedford Hills Correctional Facility sparked the creation of a semester course called "Genetics and Health Policy" within the facility's College Bound Program, which human genetics students will co-teach with SLC graduate students in Health Advocacy.

Lieber and Haas are also introducing "Film Series," a weekly viewing and discussion of popular movies containing "life" issues, such as family conflict and difficult choices. "Film Series is designed to expand students' vision of working with people as well as science in genetic counseling," said Haas.

Blending the science with the psychosocial is central to the SLC framework. Team-teaching and enhanced communication among faculty will help build a cohesive curriculum. A first-year psychosocial symposium will provide early introduction to these issues.

"We've spent the first year getting our feet wet and have learned that integration is the key," said Lieber. "Our faculty remains dedicated, and our entering class spans all NSGC regions and several countries. We look forward to collaboration with the Sarah Lawrence community as well as with NSGC, SIGs and other genetic counseling programs." ❖

Research Network

Familial Dilated Cardiomyopathy (FDC)

Cardiologists Dr. Ray Hershberger and Dr. Kathy Crispell are seeking large families composed of at least three generations with multiple individuals carrying a diagnosis of idiopathic or familial dilated cardiomyopathy (FDC) for an NIH-funded linkage study at Oregon Health Sciences University in Portland. The study's goal is to characterize large families with FDC and to map the gene or genes that cause or predispose one to the condition. Participation is free and does not require travel to Portland.

☞ Emily Hanson, MS, ✆503-494-3959; hansone@ohsu.edu; //www.fdc.to ❖

Aneurysms

Linkage studies on abdominal aortic and intracranial aneurysms are being conducted at the Center for Molecular Medicine and Genetics, Wayne State University School of Medicine in Detroit. These studies are directed by Drs. Helena Kuivaniemi and Gerard Tromp. The goal of these studies are to identify the gene(s) that predispose at-risk family members to the formation of aneurysms.

To be eligible, families must have: two or more blood related family members diagnosed with aneurysms, living or deceased, and have had no diagnosis of Marfan or polycystic kidney disease, or any other genetic syndrome. Participation is free and does not require travel to Michigan.

☞ Alicia Salkowski, MS, Study Coordinator, ✆313-577-9735; asalkow@cmb.biosci.wayne.edu; //cmmg.biosci.wayne.edu/ags/ ❖

Liaison Report

GROWING TOGETHER: NSGC COLLABORATES ON INTERNET INFO

by Beth Billings, MS

I spotted the lush leather chairs in a high info-techy setting long before I saw the placard with my name on it, summoning me to join the group. It was the first gathering of public agencies, pro-fessional, academic, charitable, consumer and commercial organi-zations with an internet presence and a commitment to providing quality genetic information online. As Chair of the Computer Users' Group, I represented NSGC.

The conference, held August 17 in Bethesda, was opened by Francis Collins, Director of the National Human Genome Research Institute, and co-sponsored by the Office of Rare Diseases. The impetus behind the meeting was an awareness that the multiple and rapidly expanding web-based resources in genetics might profit from learning about each other and discussing common issues. The more than 50 individuals present briefly introduced themselves and commented on their 28 organizations' current and planned relationships to the web.

Hearing these descriptions and the longer presentations of selected sites that followed, I realized how unique our own ResourceLink was. We alone have the only means for students, clients, journalists, policy-makers and even genetic counselors to contact a living, breathing genetic counselor around the country, and indeed the world. The only other group with anything remotely comparable is the Alliance, which has a Helpline.

After an active group discussion of common issues, we considered whether gaps of services existed. The discussion quickly enlarged to include common obstacles, needs assessment, site evaluation and concrete steps to move forward.

Outcomes of the meeting were:

- an acronym (of course!) GROW: Genetic Resources on the Web
- an agreement to collaborate through a listserv and to meet again in March.
- a commitment to increase access of genetic information to primary care physicians and the public.
- the formation of two working groups: 1) A Search Working Group to consider how to make our sites appear on the searches of external engines, web directories and portals such as Yahoo, DrKoop.com, etc. and how to create a capability for searching across all our sites simultaneously. 2. An Assessment Working Group to develop a standardized instrument for evaluating sites
- a press release regarding GROW will await the creation of worthwhile products.

Our NSGC website will shortly have a link to all GROW sites. Please take a moment to visit www.nsgc.org and check out (bookmark!) these links. There is much for us to learn from them.
☞ Beth Billings, eabillin@iupui.edu. ❖

MEDIA WATCH

Roxanne Ruzicka, MS and Angela Geist, MS

Goodhousekeeping (May 1999) — "Cancer Genes: Should You Get Tested?" discussed guidelines for individuals who should consider genetic testing for breast, ovarian and colon cancer as well as the costs and possible implications of the genetic testing. The importance of meeting with a genetic counselor was stressed. Information on how to contact NSGC and a quote from Katherine Schneider were included.

New Yorker (May 17, 1999) — "Miracle Kid" was the story of the trials and triumphs of a family whose second child was born with Fraser syndrome. Recessive inheritance was accurately and understandably described.

Washington Post (July 21, 1999) — "Genetic Testing's Human Toll" discussed how genetic testing is not regulated and laboratory errors can have profound implications for patients and their families. The need for some method of regulation of laboratories performing genetic testing as well as the importance of educating doctors and patients about genetics and genetic testing were reviewed.

National Public Radio — "DNA Files" is a series of nine one-hour documentaries about genetic research and the ethical, social and legal issues involved. Contact your local NPR station for information.

Dear Abby — A column included a grossly inaccurate portrayal of con-sanguinity, "Since the advent of genetic testing for couples contemplating marriage, the risk of defects can be evaluated and ruled out." ❖

Tips for Supervising Students

Kathryn Spitzer Kim, MS

The clinical supervisors and faculty of the Brandeis Genetic Counseling Program meet several times a year to discuss issues relevant to student supervision. These meetings have been a wonderful forum to exchange ideas. In May, our theme was "Strategies for Successful Internships." We focused on increasing positive learning experiences for students. A panel addressed four major topics.

Classroom Prep

First on the panel, I described classroom preparation for clinical rotations. During the first year, students take courses in genetics and counseling, seminars in pedigree drawing, medical terminology, what to expect at an internship site and clinical exams, and they observe in clinic monthly. These activities prepare students to assume their roles in the clinic, which begin in the summer following their first year.

Orientation Process

Holly Nee from the Perinatal Diagnosis Center, Lexington, Mass, described her orientation process. She conducts a brief telephone orientation, then mails a packet containing an overview of expectations for the rotation and patient education materials. Students visit prior to their clinical rotation. At that time, Holly introduces the student to everyone in the clinic. Expectations for the rotation are discussed, including interactions with patients, appropriate dress, daily scheduling and confidentiality. These activities make a student feel welcome, included, respected and accountable.

Evaluation Process

An approach to evaluation was discussed by Dale Lea, Foundation for Blood Research in Scarborough, Maine. Since FBR has multiple counselors at multiple sites, Dale has developed a written form that the counselor completes for each case a student conducts. The form solicits data on assessment skills, information gathering, informative and supportive counseling, organization and follow-up. A copy of this form is given to the student, and the original is kept by Dale.

This system helps clearly document students' strengths, weaknesses and progress. The final internship evaluation, therefore, holds no surprises.

Supervision Hour

Our final panelist was Janet Rosenfield, formerly of Beth Israel Hospital, Boston. She spoke about the importance of a specified, uninterrupted supervision hour in which a safe and accepting environment is created, and both process and content issues can be explored.

At this time, students develop self evaluation skills and talk openly about different approaches to cases and people. Topics for discussion often come from the journal students keep. In this way the supervisor empowers the genetic counseling student.

We have found that these strategies maximize satisfaction, reduce stress, increase success and benefit everyone. ❖

In Memory of Diana Platt Frenkel

It is with great sadness that we inform NSGC's membership about the passing of Diana Platt Frenkel, who died on August 5th after an eighteen month struggle with NF-1 related brain cancer. Diana was a schoolmate, a colleague and a friend to many.

She attended the University of Michigan's Cellular and Molecular Biology Program as an undergraduate, while working in Francis Collins' laboratory researching chromosomal markers for Neurofibromatosis Type 1. She graduated from Michigan with honors, despite an NF-related stroke at the age of 19. Living with a genetic disease piqued Diana's desire to help others as a genetic counselor, and in 1992 she entered the Brandeis University Genetic Counseling Program with its first class of students. After graduating in 1994, Diana moved to California, where she became a board certified genetic counselor in 1996, worked as a genetic counselor with Genzyme until 1997 and then with Kaiser until 1999.

Diana was an active member of the genetic counseling community and was eager to explore the changing roles of genetic counselors as her career progressed. Perhaps most importantly, Diana wanted to educate others about the experience of living with a chronic illness and the experience of being a genetic counselor with a genetic disease. Despite her struggle with cancer, Diana's outlook always remained positive. She was acutely aware of the importance of living life in the moment, of enjoying friends, family and new experiences. At the age of 32 she was truly wise beyond her years and had much to contribute. She will be missed profoundly. ❖

Committee and SIG Updates

Social Issues Committee Explores Impact of Outside World on Profession

Anne Spencer, MS

The Social Issues Committee (SIC) is looking for members to participate in the core committee or one of its two subcommittees — legislative and research.

Committee Charge

The SIC is charged with identifying, studying and responding to social, legislative, cultural, religious or ethical issues which have a real or potential impact on the profession of genetic counseling. We are generally the lead committee involved in recommending and drafting position statements and points-to-consider documents. As one member put it, "We're the paper generating committee." Over the past year, our committee has been involved in revising the cystic fibrosis carrier testing position paper, drafting a biotechnology points-to-consider document, reviewing the ASHG position paper on adoption and streamlining the position paper approval process.

Subcommittees

The Committee has two subcommittees, legislative and research. The legislative subcommittee monitors policy developments and communicates with the membership. Over the past year, the research committee has worked on developing documents to update IRBs on genetic counseling research.

Historically, most of the committee membership has been from these two subcommittees. As committee chair, I am hoping to increase the membership of the core committee. I am particularly hoping to recruit members with a general interest in social issues to coordinate projects and review documents and also members with interests or expertise in specific social issues who could draft documents in those areas. Students and new graduates are particularly encouraged to participate. Perhaps your thesis or other graduate school project might be the starting point for a great NSGC document.

This is an open committee. Members interested in joining may either contact Anne or attend the committee meeting at the upcoming Annual Education Conference in Oakland. ❖

New Committee to Streamline Communication Efforts

Liz Stierman, chair of the newly instituted Communications Committee, sees this as a consolidation effort. "Many of the components have been in place," she said. By housing all of our efforts under one roof, we can begin to build a strong foundation of communication and recognition."

The committee will encompass the efforts of several subcommittees currently in existence: Computer Users Group, Press/Media Subcommittee (formerly within Education Committee) and Publications/Communications Subcommittee (formerly within Membership Committee).

This committee's first meeting will be held in Oakland. Members interested in communications, both internal and external, are invited.

Liz has asked for members who have been featured in the media to send those articles or clips to her c/o 320 S Kingsley Dr, Los Angeles, CA 90020. ❖

New Research SIG Chairs

Emily Burkette Hanson and Robin Grubs have agreed to co-chair the Research SIG, effective this October. Many, many thanks to Kim Wentzlaff, who spearheaded the initiation of this active SIG.

☞ Emily Burkette Hanson, ✆503-494-3959;hansone@ohsu.edu

☞ Robin Grubs, ✆412-624-3018; RGrubs@helix.hgen.pitt.edu

Diversity SIG Plans Outreach

The Diversity SIG has been helping NSGC to establish a Minority Recruitment Speakers Bureau. The bureau will involve genetic counselors who will agree to volunteer as speakers, role models and mentors. Volunteers are expected to provide outreach education at local middle schools, high schools and higher learning institutions with a large minority enrollment. To date, 50 volunteers representing the US, Canada and Mexico have joined this effort. The SIG will provide training on recruitment strategies to volunteers during the Annual Education Conference in Oakland.

The SIG has also established a list of objectives that could foster increased diversity within the genetic counseling profession. These will be used in strategic planning for upcoming activities as the profession celebrates its 20th anniversary.

SIG members are also coordinating a Practice-based Symposium on religious beliefs and reproductive genetic technology for the upcoming AEC.

☞ Ilana Mittman, ✆410-602-8662; imittman@home.com.❖

EMPLOYMENT OPPORTUNITIES

ANCHORAGE AK: Mid Sept - Dec '99 FT or PT Genetic Counselor. Provide coverage for maternity leave. Ability to work independently, exp a plus. Work w/ 2 perinatologists: perform primarily PN & some BRCA GC.
☞ Human Resources, Providence Health System Alaska, PO Box 196990, 701 East Tudor, Ste 135, Anchorage AK 99519; ✆907-565-6400; Fax 907-565-6499; www.providence.org. EOE/AA/Drug screen req.

BALDWIN PARK CA: Immediate opening for BC/BE Genetic Counselor. GC exp, development of genetics educ programs, knowledge of govt regs, analytic & diagnostic reasoning skills all req.
☞ Ref Code: SGX9900799GEN, Kaiser Permanente, Baldwin Park Medical Ctr, Baldwin Park CA 91706; ✆562-461-6648; Fax 562-461-4999; maripi.x.dionisio@kp.org. EOE/AA.

MADERA CA: Immediate opening for BC/BE Genetic Counselor. Excellent organizational and i'personal skills req. Exp pref, new grads encouraged. Provide PN, peds, adult & cancer GC svc.
☞ Susan Wisniewski, Manager, Valley Children's Hospital, Dept Genetic Medicine, 9300 Valley Children's Place GE-06, Madera CA 93638-8762; www. valleychildrens.org. EOE/AA

PASADENA CA: Immediate opening for PT (w/ FT potential) BC/BE Genetic Counselor at new outreach centers. Excellent communication, organization, follow through skills req. Join new outreach centers in Pasadena, CA/ Boston, MA at IVF ctr: provide GC svcs to infertility pts: coord & provide preimplantation GC, pt recruitmt, prof educ. Potential for independent rsrch & public spkg.
☞ Chris Masciangelo, MS, Emily Bennett, MS or Yury Verlinsky, PhD, Reproductive Genetics Institute, 836 W. Wellington, Ste 4504, Chicago IL 60657; ✆773-296-7095; Fax 773-871-5221; emily_bennett@immc.org; cmascian@immc.org. EOE/AA.

RIVERSIDE CA: Immediate opening for BC/BE Genetic Counselor. High energy, interest in PN req; bilingual Span/Eng pref.
☞ Send CV w/ 2 ltrs of rec to: Dr. Robin Clark, Genesis Laboratories, Inc., 5750 Division St, Riverside CA 92506. No phone calls. Fax 909-781-9924. EOE/AA

SAN JOSE CA: Immediate opening for BC/BE Genetic Counselor. Exp pref. Join active team in estab, comprehensive genetics program in HMO setting. Provide broad range of genetic svcs: PN, CA, peds & adult. Oppty to partic in spec clins.
☞ Cindy Soliday, MS, Genetics Dept, Kaiser Permanente, 5755 Cottle Rd Bldg 1, San Jose CA 95123; ✆408-972-3332; Fax: 408-972-3298. EOE/AA

WALNUT CREEK CA: Immediate opening for BC/BE Genetic Counselor. Exp pref. Ability to work independently req. Join a busy PNDx/ perinatal ctr svg the East Bay. Pt referrals: AMA, +XAFP, U/S abnormalities, teratogens, hx of birth defects/genetic disease & pregnancy loss. Multidisc team: 1 geneticist, 3 perinatologists & 3 sonographers.
☞ Angela M. Musial, MS, Perinatal Practice Management, 106 La Casa Via, Ste 260, Walnut Creek CA 94598; ✆925-937-0620; Fax 925-937-7489. EOE/AA

SAN FRANCISCO CA: Immediate openings for internet-savvy, BC Genetic Counselors to develop and support online genetic services. 3-5 years clin exp & strong admin skills req. GeneSage, founded by Drs. Philip Reilly & Paul Billings, is an internet start up providing genetic information, products and services.
☞ Jennifer Hinshaw, c/o MBD, 577 2nd St, Ste 101, San Francisco CA 94107; 415-356-8280; jhinshaw@genesage.com; www.genesage.com.

FARMINGTON/NORWICH CT: Immediate opening for BC/BE PT (2 days/wk) Genetic Counselor. Ability to work independently & strong writing skills essential. Exp pref. Spanish helpful. Provide peds/PN GC at outreach clin (Norwich) & Pregnancy Riskline coverage (Farmington). Potential for expansion.
☞ Robert Greenstein, MD, The Exchange, 270 Farmington Ave, Ste 160, Farmington CT 06032; ✆860-679-1502; Fax 860-679-1531. EOE/AA

FARMINGTON/HARTFORD CT: Immediate opening for BC, Masters or PhD, min 3 yrs exp, demonstrated ldrshp skills req. Prenatal Service Coordinator. Join active svc providing PNDx, CVS, amnio, new Quad Scrn in academic div. S'vise 2-3 BC GCs, med students, residents, fellows, GC students; coord activities between genetics & MFM svcs. Academic appt.
☞ Mail resumes to: Robert Greenstein, MD, Director, Div Human Genetics, University Connecticut Medical School, Farmington CT 06030; rgreens@ccmckids.org. EOE/AA

GAINESVILLE FL: Immediate opening for BC/BE Genetic Counselor. Exp desired, not req. High motivation, independent, good commun skills pref. Newly created position in growing univ-based reg'l genetics program wkg primarily w/ peds population to coord onsite and satellite clins.
☞ Heather Stalker, MS, University of Florida, Div Pediatric Genetics Box 100296, Gainesville FL 32610; ✆352-392-4104; Fax 352-392-3051; stalkhj@peds.ufl.edu. EOE/AA

CHICAGO IL: Immediate opening for BC/BE Director, Chicago Center for Jewish Genetic Disorders, a newly-funded info, educ & referral ctr w/ solid funding for 3 yrs. Ctr is collaborative effort among major federations, medical centers, foundations, religious orgs, professionals & volunteers svg populations at risk. GC w/ 3-5 yrs exp req; capable of functioning independently & coordinating a new ctr. Salary: mid $40s + benefits.
☞ Send ltr, resume & 3 ref to Pat Yuzawa-Rubin, 1 South Franklin St, Chicago IL 60606; ✆773-880-3709 (Terri Hadro, MS). EOE/AA

PEORIA IL: Immediate opening for 2nd BC/BE Genetic Counseling Specialist in academic position svg 16 counties in N. Central IL. Coord on-site & satellite general genetics clins: peds, adult onset, preconception, PN cases. Opptys to partic in specialty clins w/ inpt consults at Level II tertiary care hospital. Prof tchg & pt educ.
☞ John H. DiLiberti, MD, PhD, William H. Albers Professor and Chair, Dept of Pediatrics, University of Illinois College of Medicine Peoria, 530 NE Glen Oak Ave, Peoria IL 61637; Fax 309-655-2565. EOE/AA

NEW ORLEANS LA: Immediate opening for Genetic Counselor w/ Master's in GC or related field or BC in GC. ≥3 yrs exp if not BE/BC. Assist medical geneticist in all phases of clin efforts in peds, OB/GYN & path; initiate inpt/outpt genetics consults & provide GC, educational suppt & follow-up.
☞ Chris Atkinson, Ochsner Clinic Employment, 1514 Jefferson Hwy, New Orleans LA 70121; ✆800-313-7812; Fax 504-842-7811; catkinson@ochsner.org. EOE/AA

BOSTON MA: Immediate opening for Genetic Associate w/ Masters in GC or related field. Some exp pref, not req. Join busy PNDx & molecular DNA diagnostic programs; MSAFP, rsrch oppty available.
☞ Aubrey Milunsky, MD, Ctr for Human Genetics, Boston Univ School of Medicine, 80 E. Concord St, Boston MA 02118; ✆617-638-7083; Fax 617-638-7092; amilunsk@bu.edu.. EOE/AA

BOSTON MA: *See Pasadena CA*

WALTHAM MA: Jan '00 opening for PT faculty member to teach 2 GC courses. Degree in clin psych, clin SW or equivalent training req; exp in tchg & issues of disability pref. 1st course covers counseling theory & technique in individual, fam & crises counseling; 2nd uses case presentation method with theories as framework for u'stndg GC issues. Work closely w/ students & faculty. Opptys for prog devel, rsrch & writing. Time commitment approx 1 day/wk for a 3 yr renewable contract.
☞ CV & 2 ltrs: Judith Tsipis, Director, Genetic Counseling Program, Brandeis University, MS 008, Waltham MA 02454; ✆781-736-3165; tsipis@brandeis.edu. EOE/AA

EAST LANSING MI: Immediate opening for temp, PT, BC/BE Genetic Counselor to provide coverage for maternity leave. GC in genrl & PN genetics clins; PN & DNA tstg programs.
☞ Michael L. Netzloff, MD or Linda Wolf, MS, Dept Peds /Human Development, Michigan State University, College of Human Medicine, B-240 Life Sciences Bldg, East Lansing MI 48824-1317; ✆517-353-2030; Fax 517-353-8464; wolfl@pilot.msu.edu. EOE/AA

EMPLOYMENT OPPORTUNITIES

MOUNTAIN VIEW MO: Immediate opening for BC/BE Genetic Counselor. Employer is Div Medical Genetics, Univ of Missouri-Columbia, but work setting is in rural Ozarks. Coord outreach clins, commun betw PCP & tertiary ctr, public/prof educ. Primarily peds w/ some adults & PN.
☞ Lori Williamson, MS, Southern Missouri Regional Genetics Svc, PO Box 718, Mountain View MO 65548; ✆417-934-5605; williamson-krusel@missouri.edu. EOE/AA

HELENA MT: Immediate opening for BC/BE Genetic Counselor. Peds & adult genrl genetics, fetal path, PN, cancer. Act as liaison to pts & prof for cyto, molec & maternal serum scrng labs. 25% in clin & educ FAS Program. Outrch clin, travel, & prof, public educ.
☞ Submit resume, Shodair app, transcripts & supplemental questionnaire: Gary Willis, Human Resources, Shodair Hospital, PO Box 5539, Helena MT 59604; ✆800-447-6614; Fax 406-444-1035. EOE/AA

BROOKLYN NY: Immediate opening for PT (3 days/wk) BC/BE Genetic Counselor. Exp pref; Spanish a plus. Join busy team of 2 perinatologists, 1 medical geneticist & GC to provide PN GC. Opptys incl counseling for U/S abnormalities, amnios, CVS, PUBS, in addition to lectures, writing for hosp publications & s'vision of GC interns.
☞ Michael F. Cabbad, MD, Reproductive Genetics, The Brooklyn Hospital Center, 240 Willoughby-3rd Fl, Brooklyn NY 11201; ✆718-250-8000; Fax 718-250-8660. EOE/AA

NEW YORK NY: Immediate opening for BC/BE Genetic Counselor in new affiliated cancer GC program. Exp in cancer GC pref, not req. High motivation, ability to work independently, excellent commun & org skills req. Provide GC & tstg for cancer predisposition; assist in prog development. Opptys for tchg & clin rsrch.
☞ Karen Brown, MS, The Mount Sinai School of Medicine, Dept Human Genetics, Box 1497, One Gustave L. Levy Place, New York NY 10029; ✆212-241-6947; Fax 212-860-3316; karen_brown@smtplink.mssm.edu. EOE/AA

NEW YORK NY: Immediate opening for BC/BE Genetic Counselor. Spanish pref. Join comprehensive genetics svc in tertiary care ctr. All aspects of PN & Peds genetics; coord amnio program; oppty to work w/ multidisc OBs & Peds teams. Culturally diverse pt population; prof & community tchg oppty.
☞ Karen L. David, MD, Metropolitan Hospital Center, Dept Peds-Genetics, 1901 First Ave, Rm 523, New York NY 10029; ✆212-423-6452; Fax 212-423-6183; oakd97@pol.net. EOE/AA

NEW YORK NY: Immediate opening for Clinical Research Coordinator. Masters pref; 5 yrs exp in clin trials or equiv & PC skills req. Highly motivated w/ abil to independently manage multi tasks, strong team & organizational skills all req. Oversee clin trials for 1st trimester PN scrng: ID potential pts, assist in recruiting, maintain scheduling, explaining study, provide care, educ & GC, assist in all aspects of data management. Conduct inventory and other admin tasks. Partic in all staff mtgs.
☞Sara Tucker, Administrator, MFM Division, Columbia University, 622 W 168th St, New York NY 10032; No calls! Fax 212-305-3869. EOE/AA

ROCHESTER NY: Immediate opening for PT, BC/BE Genetic Counselor in only Repro Genetics svc in the Finger Lakes Reg of Upstate NY. Exp desired, not req. Join multidisc team of 3 GCs, 7 perinatologists (1 BC in genetics) & 2 ped geneticists to provide broad range of svcs: maternal serum scrng, high resolution U/S, amnio, CVS & umbilical blood sampling. Teratogen info svc.
☞ Devereux N. Saller, Jr, MS, MD, Director, Reproductive Genetics, Div Maternal-Fetal Medicine, University of Rochester School of Medicine & Dentistry, 601 Elmwood Ave-Box 8668, Rochester NY 14642; ✆716-275-3297; Fax 716-256-1416. EOE/AA

ASHVILLE NC: Immediate opening for BC/BE Genetic Counselor in Public Health Genetics Network svg 11 counties in Western NC. Self-motivated, organized, creative & team player req. Some travel. Coord w/ 2 medical genetic ctrs, Wake Forest Univ & Fullerton Genetics Ctr; coord genetic satellite clins; prepare family pedigrees, provide GC & community educ.
☞ Elizabeth G. Moore, Director, Genetic Health Care Program, Div of Public Health, PO Box 29597, Raleigh NC 27626-0597; ✆919-715-3411; Fax 919-715-9633. EOE/AA

COLUMBUS OH: Immediate opening for BC/BE Genetic Counselor. Enthusiasm, self motivation desired. Some cancer GC exp pref, not req. Join active, growing clinical cancer genetics svc; rsrch and educ oppty.
☞ Charis Eng, MD, PhD, Director, Clinical Cancer Genetics Program, James Cancer Hospital and Solove Research Institute, Ohio State University Comprehensive Cancer Ctr, 300 W 10th Ave, Ste 519, Columbus OH 43210-1240; ✆614-688-4508; Fax 614-688-4245; eng-1@medctr.osu.edu. EOE/AA

PHILADELPHIA PA: Immediate opening for BC/BE Genetic Counselor. Exp in cancer pref, not req. Prefer applicants w/ good writing skills, public speaking abil, interpersonal skills and abil. to work independently. Work in cancer risk assmt programs for br, ov, GI & prostate cancers, providing genetic risk assmt, educ, GC. Strong emphasis on rsrch.
☞ Marianne Green, Human Resources, Fox Chase Cancer Center, 7701 Burholme Ave, Phila PA 19111; ✆800-325-4145; Fax 215-728-4061; J_Costalas@fccc.edu. EOE/AA

RAPID CITY/SIOUX FALLS SD: Immediate opening for BC Genetic Counselor/ Research Associate. Significant related exp pref. Equivalent combination of educ & exp will be considered. Assist in operation of statewide Birth Defects Genetics Clinic, serve as information resource, assist in rsrch projects, assist in developing educ materials & workshops.
☞ Virginia P. Johnson, MD, University of South Dakota School of Medicine, Dept OB/GYN , 414 E. Clark St , Vermillion SD 57069; ✆605-677-5623, TDD 605-677-6389; Fax 605-677-5778; vjohnson@usd.edu. EOE/AA

See next page

national society
of genetic
counselors, inc.

nsgc

233 Canterbury Drive
Wallingford PA 19086-6617

Employment Opportunities, from p. 15

Amarillo TX: Opening for Masters-prepared Genetic Counselor; faculty position. Join clinical team incl: MD faculty, residents, ultrasonographers, NPs in start-up OB/Pediatric GC program providing only high-risk PN care in TX Panhandle. Pt base draws from W. OK, E. NM & SW KS. Comp. salary and moving exp.
☞ Steve Eldridge, Administrator, Texas Tech School of Medicine, Dept OB/GYN, 1400 Wallace, Amarillo TX 79106; ✆806-354-5500x232; eldridge@cortex.ama.ttuhsc.edu. EOE/AA

Fort Worth TX: Immediate opening for BC/BE Genetic Counselor. Join busy private practice of 4 perinatologists, 1 perinatologist/BC med geneticist. All aspects of PN GC. Some travel; outreach clinics a possibility.
☞ Mark Maberry, MD, Kim McMillen, office manager or Heather Powers, Yvonne Hulsebos, Sarah Jane Tew, genetic counselors, Obstetrix, 1325 Pennsylvania Ave, Ste 690, Fort Worth TX 76104-5298; ✆817-878-5298; Fax 817-878-5289; EOE/AA

Galveston TX: Immediate opening for BC/BE Genetic Counselor. Oppty to join rapidly devel academic fetal dx & therapy team; oversee large NIH PNDx project comparing 1st US/PAPPA/HCG & 2nd [Quad tst] trimester scrng.
☞ Jeri Nichols or Radek Bukowski, University of Texas Med Branch Galveston, Dept OB/GYN, 301 University Blvd, Rte 0587, Galveston TX 77555; ✆409-772-3466 or 409-772-0216; Fax 409-772-5297; jrnichol@utmb.edu or rkbukows@utmb.edu. EOE/AA

Houston TX: Immediate opening for Genetic Counselor. Exp in cancer genetics desired, not req. Join multidisc team of physicians & biostatistician in comprehensive breast care ctr w/ clin rsrch focus. Assess risk, offer GC & tstg, & risk reduction strategies to persons at high risk for br/ov & other cancers.
☞ Richard M. Elledge, MD, Baylor-Methodist Breast Care Center, 6560 Fannin St, Ste 1558, Scurlock Tower, Houston TX 77030; ✆713-798-1600; Fax 713-798-8884; relledge@bcm.tmc.edu. EOE/AA

Houston TX: Immediate opening for BC/BE Genetic Counselor. Req: high motivation, abil to work independently, flexible, adaptable, abil to work in fast paced, high growth environment. Some travel req. GC & case mgmt: PNDx, cancer risk & peds. Tchg: short courses & lectures for nurses, med students, genetic lab trainees & community groups.
☞ Katherine Thompson, MD, Center for Medical Genetics, PA, 7400 Fannin St, Ste 1150, Houston TX 77054; 713-790-1990; Fax 713-790-1903. EOE/AA

Lubbock TX: Immediate opening for Cancer Genetics Counselor. Join multidisc team at major tertiary care facility in the South Plains of W. Tx Panhandle & E. NM w/ large population base. Help estab high risk CA evaluation program. Clin and rsrch functions for GC & tstg, scrng for STAR trials.
☞ Charles E. Geyer, Jr, MD, Joe Arrington Cancer Research & Treatment Center, Covenant Health System, 4101 22nd Pl, Lubbock TX 79410; ✆806-725-7934; cgeyer@covhs.org. EOE/AA

Madison WI: Spring '00 opening for BC/BE Genetic Counselor. Exp pref. Join 4 Perinatologists (1 BC in med genetics) & 1 GC. All aspects of PN svcs in a joint Univ/ community hosp clin. GC: AMA, CVS, amnio, teratogens, mult. marker screening, fam hx & emphasis on abn U/S findings. Oppty for cancer GC, GC student s'vision & med student/resident tchg.
☞ Margo Grady, MS, Meriter Hospital Perinatal Clinic, 202 S. Park St, Madison WI 53715; ✆608-267-6261; Fax 608-267-5928; mgrady@meriter.com. EOE/AA

Marshfield WI: Immediate opening for Family Collection Leader. Masters in GC pref; RN w/ exp considered. S'visory, basic computer exp req, phlebotomy & lab exp desired. Phlebotomy trng req, if no exp. Lead team of specialists to obtain DNA, pedigree, med info from families; use knowledge of genetics, computers, linkage mapping, medicine as well as ethical, legal, social implications of genetics. Large sampling, in 10s of 1000s to be recruited.
☞ Jill Kupfer, Human Resources, Marshfield Clinic, 1000 N Oak Ave, Marshfield WI 54449; ✆800-782-8581x75341. EOE/AA

Opportunity Outside US

Toronto, Ontario Canada: Jan 15 opening for Genetic Counselor to join very active univ hospital clinical genetics team w/ wide variety of pt referrals: PN (not LMA), peds, adult and spec clins. Tchg & rsrch.
☞ Nancy Taylor, The Hospital for Sick Children, Div Clinical and Metabolic Genetics, 555 University Ave, Toronto, ON M5G 1X8 CANADA; 416-813-6386; 416-813-5345; nancy.taylor@sickkids.on.ca. Canadian immigration requires Canadian citizens considered first.

Norway: Second opening for BC/BE Cancer Genetic Counselor. Working knowledge of a Scandinavian language req. Join multidisc team to partic in all aspects of cancer GC svc. Clin rsrch oppty.
☞ According to local regulations, former applicants must reapply. Pal Muller, MD, PhD, The Norwegian Radium Hospital, Unit Medical Genetics, Montebello 0310 Oslo, Norway; ✆011-47-2293-5675; Fax 011-47-2293-5219; pmoller@ulnk.uio.no.