PERSPECTIVES in genetic counseling

Volume 19 Number 4 Winter 1997/1998

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.

RECERTIFICATION: NO EXAM REQUIRED

Jacquelyn Krogh, MS

A HOT PROFESSIONAL ISSUE in the past few years has been recertification. To examine this issue, ABGC appointed an ad hoc Committee for Recertification to summarize mechanisms used by other professional organizations. They reviewed information compiled by the Citizens Advocacy Center, which had performed a detailed survey of several professional groups.

COMMITTEE RECOMMENDATIONS

- ➢ Certification and recertification should be utilized to assure continued competency of genetic counselors.
- ➢ Voluntary recertification of ABMG certified individuals should be strongly encouraged. *(The ABGC cannot require recertification of professionals already certified by another board.)*
- ➢ ABGC should offer a variety of pathways for certification renewal.
- ➢ ABGC should adopt certification renewal practices that:

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LICENSURE: TWO SIDES OF THE COIN

Is licensure in the best interest of the majority of genetic counselors? In discussions over the past few years, licensure is often included with the issues of billing and reimbursement. Public policy, and economic factors must also be considered. Two NSGC members discuss their views of licensure.

ON THE 'HEAD' SIDE…

Susan Schmerler, MS, JD

PUBLIC POLICY ISSUES

It is a disservice to the public for unqualified, untrained individuals to provide genetic counseling. There is established criteria for genetic counselor certification by voluntary examination. Without some mechanism to require certification, an individual does not have to comply with the American Board of Genetic Counseling (ABGC) prerequisites for education and training. Licen-sure would allow states to require individuals using the title "genetic counselor" to be ABGC board certified/eligible.

Qualified practitioners need to maintain a high

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ON THE 'TAIL' SIDE…

W. Andrew Faucett, MS

PUBLIC POLICY ISSUES

Historically, a profession requests licensure when there is an issue of public harm. This is why licensure requires action of the state legislature. If licensure is pursued, would the public perceive that there is potential for harm?

Licensure for genetic counselors would neither stop other recognized medical professionals from providing genetic counseling services, nor would it assure that the actual quality of genetic counseling was high.

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GENETIC COUNSELORS HOLD THE KEY

Maureen E. Smith, MS, President

SINCE I WAS A CHILD, I have dreamed of being a pioneer, of being a part of something larger than myself — something of meaning. Our work as genetic counselors allows us to be a part of the bigger picture — one that involves the social and ethical issues surrounding human genetics. While we are part of the bigger picture, we are also cognizant of the profound impact of genetic information and testing on the private lives of our patients and their families.

Genetic counselors hold the key to making genetic technology meaningful. We empower our patients with the ability to use information, take action, make appropriate decisions for themselves and feel supported and understood. However, we also understand that technology cannot replace human compassion and our skills as counselors.

With increasing trends toward managed care and fiscal accountability in health care, there is greater attention by policy makers on the regulation of medical care. We must use our communication skills to develop a working dialogue with policy makers to influence decisions regarding the use of genetic information and public policy.

NSGC possesses the collective capabilities of its members and a reputation for excellence. We are recognized by our colleagues and by policy makers as authorities in genetics. We are developing our own body of research and we are telling the world about genetic counseling through GeneAMP. We are training more and more genetic counselors each year to meet the growing demand for our services. Our membership is comprised of self starters and risk takers who have ventured much and placed NSGC in its current position of leadership in genetics. Our greater independence and the increasing specialization of our membership foster a view of ourselves which is less often as team members and more frequently as private contractors with a unique specialty.

These forces will continue to shape NSGC in the years to come. We must each think carefully about where we want our profession to be and how we can best concentrate our energies. With our focus on being the leading voice, authority and advocate for the genetic counseling profession, NSGC will become *your* vision for the future. ❖

MEMBERSHIP DUES

YOU GET MORE THAN YOU PAY FOR!

EVER WONDER WHERE your NSGC dues go and why you are being asked to pay an additional $10 in 1998?

Our $½ million operating budget provides you with valuable membership services each year. Our budget supports GeneAMP, the *Journal, Perspectives,* the Professional Status Survey and the Executive Office. Consider the annual cost of these major benefits per member:

Journal of Genetic Counseling	$26.75	*Perspectives in Genetic Counseling*	$6.25
Special Projects Fund	1.90	Committee expenses	11.25
Liaisons to Key organizations	3.50	GeneAMP	18.75
Web Project	3.75	List Serv	4.75
Membership Directory	9.50	Job Connection	.50
Career Packets	4.50	Regional Newsletters	3.00
Professional Status Survey	4.50	Strategic Planning	6.25
Executive Office	27.00		

Membership mailings *(annual dues, elections, Fall and Winter mailings, etc)*4.50
Board of Directors support (legal fees, insurance, interim mtg,etc) 13.75

TOTAL: $150.40 worth of membership services and benefits — $40 over the cost of full membership!

Other valuable benefits come with your membership: the annual education conference, short courses, regional conferences, continuing education units (CEUs) and a network of colleagues and friends who provide an immeasurable amount of professional and personal support.

The 1998 dues increase, the first in four years, was approved by the Board of Directors to meet the growing financial needs of NSGC. Without your support and generous time spent on the projects of this organization, we simply could not exist. We estimate that the cost of paying professionals to do all the jobs you undertake would double our budget.

Consider the benefits of belonging to the organization which *is* the leading voice, authority, and advocate for the genetic counseling profession. If you have any questions, please contact us or any other NSGC Board member. ❖

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INTERNATIONAL VOICE: GENETIC COUNSELORS IN GREECE

Loukia Katsichti-Loukas, MS, and Marietta Hadzipetrou-Bardanis, MSc

AS THE ONLY TWO graduate-trained genetic counselors in Greece, we came together to provide each other with support and strength to begin to develop a more accepted place for ourselves within the genetics community and by the public. We both trained and worked for a number of years as genetic counselors in the US and Canada. For personal reasons, we each moved to Greece, knowing it would be difficult to find satisfying employment and challenging to break into the field of genetic counseling.

We both currently work on a part-time basis, one of us in an academic hospital, the other in a private clinic setting. Our salaries do not cover our financial needs and certainly do not include "perks" such as professional dues. It has taken us some time and convincing to become recognized members of the Hellenic Association of Medical Geneticists. Our acceptance into the Association has generated some negative reactions among the elders of the well-established genetics community, since membership has traditionally been available only to PhDs or MDs.

Through the Association we have attempted to heighten our visibility and open the dialogue on genetic counseling as a profession. The genetics community has moved slowly to acknowledge our potential contributions to health care and this has made it increasingly difficult to approach other specialties or medical professional organizations.

The first genetic centers in Greece appeared in 1960 and offered cytogenetic services. Soon after, neonatal screening was established. Amniocentesis and CVS have been available as prenatal diagnostic tests since 1976 and 1983 respectively. Pregnant women are offered "genetic counseling" by their obstetricians as part of their routine care. This does not typically include discussing testing options, collecting a family history or providing follow up. Doctors are directive, and patients expect to be directed whether or not to undergo invasive procedures. Misinformation is endemic as people tend to seek answers to their medical problems through the highly sensationalized media or their neighborhood rather than the medical community. We see this as one area where our experience and training could provide invaluable assistance.

For genetic counseling to be established as a profession in Greece, significant changes must be made in the ways physicians think, the Ministry of Health perceives the need for genetic counseling and in the general population's views of their medical care, including options for genetic testing. The large private OB/GYN centers show absolutely no interest in our genetic counseling services and refer patients to us with great hesitation. Thus, we have not been given the opportunity to prove the quality and value of our services. Establishing a private practice has its own difficulties, particularly if physicians are reluctant to refer patients to us.

Getting the media's attention in Greece is not easily achieved unless you know the right people or have a lot of money. We have noticed that news about our availability is spread among our patients' families and friends by word of mouth. This may be another route to reach the public, although relying on it would not be the most effective or efficient way.

A graduate introductory genetic counseling course is offered every second year at the University of Athens Faculty of Nursing. The same course will be offered to undergraduate students at the University next fall. Our goal, to create a graduate genetic counseling program, is supported and spearheaded by Professor C. Bartsocas at the University of Athens. The question then remains whether graduates of such a program would be able to find a job!

We are trying to implement changes in Greece by offering genetic counseling services, informing the public and creating a genetic counseling training program. These are not easy tasks, and we face great resistance in each of these areas. We welcome any support or advice our NSGC colleagues have to offer. ❖

EDITORIAL NOTES

Stephanie Cohen, MS

YOU MAY HAVE NOTICED a change in the style of *Perspectives.* Liz Stierman has made the difficult decision to step down as editor following her diagnosis of breast cancer. Liz has done a fabulous job over the past 4 years.

I have been appointed Guest Editor for this issue. Many thanks to Ann Boldt for this privilege and to Bea Leopold for holding everything together during this time of transition.

☞ Please forward submissions for the next issue to the Executive Office. ❖

GENETIC COUNSELING DEFINED BY CARE

THE GENEAMP MANAGED CARE TEAM composed a marketing message defining genetic counseling. Although the original target audience was managed care, the hope was that a simple message could be developed for all audiences. To present a concise, informative and appealing message, the project team's research included:

- ➢Literature reviews compiled on patient satisfaction, cost effectiveness and medical liability as they pertain to genetic services.
- ➢Information gathered on the portrayal of genetic counseling in journals and the popular press.
- ➢Surveys of genetic counselors in managed care organizations (MCOs) regarding their role within the organization and their perceptions of the MCO's views of genetic counseling.
- ➢Surveys of case managers in MCOs to define quality health care and the potential value of genetic counseling.
- ➢Interviews of directors of genetic counseling training programs about their views on the roles and value of genetic counselors within MCOs.
- ➢A review of credentialing processes to glean consistent terminology.
- ➢A review of varied definitions of genetic counseling .

Although many of us value psychosocial assessment and counseling skills, research indicated that these are the least valued aspects by MCOs. Terms such as quality, cost effectiveness and preventive strategies are far more appealing.

A draft statement was developed and distributed to five MCO directors. They were asked to comment whether the statement accurately reflected the roles, credentials and importance of genetic counselors in health care delivery. The feedback generated helped refine the draft to the final statement. The team believes this is a visually appealing, simple, succinct message encompassing the buzz words that managed care organizations notice.

The GeneAMP Managed Care Team for this project included: *Retired Co-Chairs:* Deb Lochner Doyle & Amy Cronister, *Current Chair:* Lisa Brown, *Team Members:* Kristen Baker, Kelly Jackson, Janet Ulm, & Robin Schwartz. ❖

ONE VOICE, ONE MESSAGE

Genetic counselors are nationally certified health professionals who:

Can interpret complex family histories and genetic test results for patients and their health providers

Access and provide up-to-date information

Review and select the most appropriate quality, cost effective care

Educate families and facilitate decision making about reproductive options and preventive strategies

1998 GENEAMP AWARDS

Ed Kloza & Beth Balkite, GeneAMP Co-Chairs

GeneAMP projects are member-driven marketing projects aimed at establishing genetic counselors as integral, valued participants in every health care system. Of the 21 proposals submitted to GeneAMP this cycle, 11 were awarded funding. While all noteworthy, the following proposals were awarded a total of nearly $30,000, our annual budgeted allotment for 1998.

PRIMARY CARE • Seth Marcus and Ali Warner

- *Genetic Counseling Contract Services: A Model for Expanding the 4 P's (Product, Place, Price, Promotion) of Marketing by Genetic Counselors in Private Practice.* D. M. Eakman, B. Lerner, A. Warner
- *Primary Care Slide Show.* J. Farmer, J. Stopfer
- *Genetic Risk Screening Office Guide: A Tool for NSGC Members.* A. Faucett

MANAGED CARE ORGANIZATIONS • Lisa Brown

- *Measurable Outcomes of Genetic Counseling: Counselor and Consumer Assessment.* B. Bernhardt, B. Biesecker, C. James, Y. Kemel, E. Rosenthal, L. Pike Buchanan
- *Policy Statement: Genetic Counseling and Genetic Testing for Managed Care Organizations.* C. Josephson, L. Cohen, C. Dickerson, A. Fishbach, P. Levonian, J. Williams, C. Bellcross
- *Marketing Presentation to Health Care Purchasers.* L. Brown, K. Baker, S. Munawar, A. Musial, K. Wcislo, D. L. Doyle

CONSUMERS AND EMPLOYERS • Melonie Michelson & Joy Redman

- *A Marketing Survey on the Current Status of Genetic Counseling at NCI-designated Cancer Centers.* M. Alvarado, K. Johnson, A. Wonderlick, G. Reiser

MEDICAL AND PROFESSIONAL ORGANIZATIONS • Cindy Johnson & Laura Waldman

- *Cancer Genetic Counseling Packets for Professional Meetings and Public Relations.* J. Peters, E. Knell, C. Bellcross, M. Smith & Cancer SIG
- *NSGC Exhibits at 1998 Oncology Meetings.* J. Peters, E. Knell, C. Bellcross, M. Smith (Cancer SIG Liaison Contact Committee)
- *Professional Education Exhibits.* K. Johnson, J. Peters, B. Gettig

LAW AND POLICY MAKERS • TBA

- *Chance's Choices for Law and Policy Makers.* S. Au

JOIN A SIG

Now in their 3rd year as a membership benefit, Special Interest Groups (SIG's) are involved in a variety of activities ranging from list serv discussions to conference presentations to newsletter production.

The following is a list of 1998 chairs and co-chairs for each SIG:

- ART/Infertility — Jill Fischer
- Cancer Risk Counseling — Cate Walsh Vockley & Stephanie Kieffer
- Clinical Supervisors — Liz Stierman *(if interest continues)*
- Connective Tissue — Leah Hoechstetter
- Diversity — Ilana Mittman
- DNA Diagnostic Labs — Barbara Pettersen & Amy Cronister
- Down Syndrome — Cam Knutson *(if interest continues)*
- GC Training Program Directors — Judith Tsipis
- Legal Issues — Sue Schmerler
- Neurogenetics — Deborah DeLeon & Chris Sauer
- Pediatrics — Julie Rutberg
- Prenatal — Melissa Kershner & Renee Laux
- Private Practice — TBA
- Psychotherapy and Expanded Counseling Skills — Luba Djurdjinovic
- Public Health — Sylvia Au
- Research — Kim Wentzlaff

…and, new in 1998

- Psychiatric Disorders — Beth Rosen

Now is the time to join a SIG that meets your interests and needs, or consider starting your own. Benefits are many. Meet colleagues who have similar interests. Share materials, support and knowledge.

Sign up for SIG membership with your dues or anytime during the year. ❖

NIH CONSENSUS ON CF SCREENING

Virginia Corson, MS

A FOLLOW UP WORKSHOP to the NIH Genetic Testing for Cystic Fibrosis Consensus Development Conference was held to discuss implementation of the consensus statement. A variety of genetics, medical and consumer groups were invited to send representatives. Findings included:

- ➢ A discussion about birth defects/genetic conditions, freedom of choice, reasons to consider testing, the spectrum of tests available and the risks for various conditions should be presented to patients seen for preconceptual consultation, infertility evaluation and prenatal care.
- ➢ Further information could be provided by the medical care provider or genetic counselor for those interested in testing.
- ➢ Existing consumer materials related to CF screening should be reviewed and updated.
- ➢ Materials for education of the medical care providers need to be developed.

There was agreement that CF carrier screening is not currently standard practice and should not be considered as such until the various components of screening can be developed and disseminated. ❖

ABGC POLICY DECISIONS ANNOUNCED

Virginia Corson, MS

IN A RECENT POLICY DECISION, new graduate programs *must* achieve "Recognized New Program" accreditation status *before* they admit students, thus ensuring that their graduates will be eligible to apply for the Certification Exam. New programs needing a Board decision by next year's May 1 universal acceptance date must submit applications to the ABGC office by the end of January.

To take the 1999 Certification Examination, students currently enrolled in non-accredited programs must achieve Active Candidate status as a Special Consideration applicant. Early application is strongly suggested. *This category will be eliminated after 1999.*

Reexamination will not be required for diplomates holding time-limited certifications. *(See Recertification article on page 1.)*

In other business, new Board members Lorraine Suslak and Michael Begleiter replace Beth Fine and Helen Travers. Nomina-tions for next year's Board are being accepted through Feb 6. ❖

☞ABGC 1999 Exam information: ✆301-571-1825.

RECERTIFICATION: NO EXAM REQUIRED

…from p. 1

- recognize the diversity of genetic counselors
- provide validation of various professional activities
- promote professional development by encouraging both novice and veteran genetic counselors to expand their roles.

CURRENT STATUS

Mandatory examination will not be the *only* option for recertification. Over the next year, ABGC will develop a program for recertification based on continuing education and other pathways.

The committee included: Nancy Callanan, Lisa Hillman, Elinor Langfelder and Nancy Steinberg Warren. ❖

A Bill is a Bill is a Bill is a Bill! Right? …Wrong!

Shelly Cummings, MS

Fear of Genetic Discrimination dissuades some who might benefit from genetic testing. Four major developments have taken place since 1995 that provide some level of reassurance for individuals considering predictive testing:

- Laws enacted in many states forbid health insurers from using the results of genetic tests as a factor in deciding coverage. However, private sector employer-sponsored health plans that provide benefits for employees and their dependents through self-funded arrangements are generally exempt from state insurance laws due to the Employee Retirement Income Security Act (ERISA) preemption. This affects nearly half of all working Americans. Another problem is that these state laws focus narrowly on genetic tests rather than more broadly on genetic information generated by family history, physician examination or medical records.
- The enactment of the federal Health Insurance Portability and Accountability Act (HIPAA) forbids group health plans from calling genetic information a pre-existing condition. *(See Table 1.)*
- The Equal Employment Opportunity Commission issued a guideline interpreting the Americans with Disabilities Act to apply to persons suffering employment discrimination on the basis of genetic information.
- President Clinton declared his support for genetic anti-discrimination bills. A recent survey of insurers showed that the majority thought they should not be allowed to use genetic information to decide about coverage.

Congressional interest in securing health insurance protection for genetic information is strong and bipartisan. Three issues are addressed by genetic non-discrimination bills:

- discrimination in health insurance and group provider plans;
- discrimination in life and disability insurance
- discrimination in employment.

For more information, visit http://www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/.❖

Table 1
Pros and Cons of HIPAA

HIPPA Does…

- *Protect* all genetic information
- *State* that genetic information can not be viewed as a pre-existing condition
- *Prevent* charging higher premiums

HIPAA Does Not…

- *Protect* against rate hikes
- *Protect* against unauthorized access to genetic information
- *Provide* coverage outside the group market
- *Prevent* the insurer from demanding genetic testing as a condition of coverage

Congressional Activity in 105th Legislative Session

Bill #	Bill Name • Sponsor	Issue Addressed
S. 89	Genetic Information Nondiscrimination in Health Insurance Act of 1997 • O. Snowe	Discrimination by group health plans
S. 422	Genetic Confidentiality & Nondiscrimination Act of 1997 • P. Domenici	All health insurance, employment, disclosure, research issues & damages for non-compliance
S. 193	Human Research Subjects Protection Act of 1997 • J. Glenn	Research participation protection
S. 1045	Genetic Justice Act • T. Daschle	Group health providers regulation
HR. 306	Genetic Information Nondiscrimination in Health Insurance Act of 1997 • L. Slaughter	Loopholes in HIPAA: Prohibits rate increases in group plans, use of genetic information in individual health plans and restricts collection and disclosure of genetic info
HR. 328	Genetic Information Health Insurance Nondiscrimination Act of 1997 • G. Solomon	Loopholes in HIPPA: Addresses discrim in individual health ins.
HR. 2198	Genetic Privacy and Nondiscrimination Act of 1997 • C. Stearns	Disclosure, all health insurance & employment. Calls for damages similar to Civil Rights Act of 1964
HR. 2215	Genetic Nondiscrimination in the Workplace Act • J. Kennedy	Employment discrimination
HR. 2216	Genetic Protection in Insurance Coverage Act • J. Kennedy	Group health & other health, life & disability insurance
HR. 52	Fair Health Information Practices Act of 1997 • G. Condit	Code of fair practices for health information
HR. 1815	Medical Privacy in the Age of New Technologies Act • J. McDermott	Privacy of health information
HR. 2275	Genetic Employment Protection Act of 1997 • N. Lowey	Employment discrimination

GENETIC COUNSELORS AND MEDICAID: HOW TO APPROACH THE GIANT

Tricia Page, MS

Few populations are more in need of our services than Medicaid recipients. In this time of financial uncertainty, genetic counselors need to understand how Medicaid operates.

Medicaid, created by Title XIX of the Social Security Act of 1965, is jointly funded by federal and state governments. The amount of federal contribution is determined by the Federal Medical Assistance Percentage, which is calculated by comparing each state's average per capita income level with the national average.

Though federally organized, individual states have broad discretion to determine eligibility standards, the type, amount and duration of services and rates of reimbursement. To investigate reimbursement codes and provider qualifications, check with your state health department for a Medicaid provider procedures manual.

As in the private sector, managed care is increasingly pre-sent in Medicaid. Between 1991 and 1996, the number of Medicaid beneficiaries enrolled in managed care programs increased from 9% to 40%, although enrollment varied widely by state.

Genetic counselors need to become involved in protecting the role of genetic services in Medicaid. Some genetic organizations such as CORN-affiliated TEXGENE are already involved. Participation in local organizations is imperative if we are to preserve our role as patient educators and advocates. ❖

Resources:

<http:www.hcfa.gov/Medicaid/pntrtn3.htm>

<http://www.cc.emory.edu/pediatrics/corn/corn.htm>.

GENETICS AND EMERGING PUBLIC POLICY

Kristin Peterson, MS, Legislative Subcommittee, Social Issues Cmte

Interest in genetic issues is developing and growing in several public policy forums. Several pieces of legislation that seek to regulate and control the application of genetic information determined through genetics research, testing or evaluation have been introduced in both Houses of Congress. In many states, legislatures have either passed or are considering similar types of legislation. How can genetic counselors develop and maintain awareness of public policy issues that may affect their practice and/or their patients?

> *'Monitoring emerging legislative policy does not need to be difficult or time consuming.'*

Monitoring emerging legislative policy does not need to be difficult or time consuming. Access to the activities and legislation introduced into the United States Congress can be made via the Federal Legislative Activities website http://thomas.loc.gov. The State Governments website <http://www.loc.gov/global/state/stategov.html> is a gateway to many of the state legislatures, state laws and statutes.

Currently, there are at least ten bills in Congress that, if passed, would affect the practice of medical genetics. Several of the legislative initiatives being considered address the use of genetic information in accessing or maintaining health insurance or employment. The Genetic Information Nondiscrimination in Health Insurance Act of 1997 was introduced by Representative Slaughter and Senator Snowe as H.R. 306/S.89 and has received widespread support in both Houses and from the Clinton Administration.

H.R.306 and S.89 have identical language and seek to "prohibit discrimination against individuals and their family members on the basis of genetic information or a request for genetic services." Genetic information is defined as "information about genes, gene products, or inherited characteristics that may derive from an individual or a family member of the individual." The bill seeks to regulate disclosure of genetic information by health plans and issuers. It provides for punitive and compensatory damage if these guidelines are violated.

If passed, this legislation would provide the first explicit protection from genetic discrimination in health insurance at the federal level. However, there are some concerns about this bill. The strong provisions for privacy included in the bill may hamper the collection of public health data. Also, the scope of this legislation is limited to health insurance and does not address issues related to employment.

It is important that genetic counselors monitor these issues and that we build expertise in reading, understanding and critiquing the merits and deficits of emerging public policies. If you have comments, thoughts or questions on any bills currently in Congress or are aware of other public policy issues related to genetics that our Society should be monitoring, please contact me: ✆612-623-5268 or kristin.peterson@health.state.mn.us.❖

GENETIC COUNSELORS' VOICES REPRESENTED...

PSYCHIATRIC GENETIC CONFERENCE EXPLORES RESEARCH ISSUES

Beth Rosen, MS

MANY of us regularly encounter family histories of schizophrenia, major depression and bipolar disorder. Psychiatric illnesses are common, yet most of us know little about the genetics of psychiatric illness. We are able to give empirical risk figures, explain that mendelian inheritance does not appear likely and state that predictive testing is not available. To better educate myself about the field of psychiatric genetics, I recently attended the 5th World Congress of Psychiatric Genetics in Santa Fe in October. To my great surprise, I was the only genetic counselor present.

In his opening address, the President of the Congress predicted that genes will probably soon be identified for schizophrenia, bipolar disorder, autism, attention deficit disorder, hyperactivity, adolescent depression and personality traits. This research and its subsequent media coverage will lead to an increasing number of questions to which genetic counselors will need to respond.

Most of the research groups have been performing genome-wide screens with samples obtained from multiplex families. Much of the meeting, therefore, was devoted to sharing data on significant linkage findings for individual chromosomes. Unfortunately, one walked away with the impression that almost every chromosome had been implicated, though LOD scores were typically on the order of 1.0 to 2.5.

When applying linkage analysis principles to psychiatric disease, several difficulties have arisen:

- Investigators have been forced to select a "most likely" mode of inheritance to perform analysis using existing linkage software.
- Because of difficulties in the classification of psychiatric disease, as well as the frequency of different diagnoses within a family, it is difficult to know which diagnoses to include when performing linkage analysis.
- Few researchers are distinguishing along ethnic lines. As is the case with other disorders, such variations may be partly responsible for the lack of consensus in results obtained thus far.

ETHICAL ISSUES

Several speakers focused on the need to address ethical issues in psychiatric genetic research, to develop informed consent guidelines and to refer to genetic counselors. But as a counter address asserted that the "ethics industry" interferes with psychiatric research and warned that "too much sensitivity about ethical issues will put barriers in the way of future research." There seemed to be much agreement from the audience, and I was left with the impression that many of the researchers regard ethics as an impediment to their research.

Genetic counselors offer unique perspectives. We know all too well the consequences of technology that outpaces public understanding, legislation and ethical guidelines. Not only can we offer psychiatric genetic researchers greater insight into the intricacies of providing genetic testing, we can also share a comprehensive understanding of genetics. I was surprised to learn that of the principal investigators awarded NIMH grant money for psychiatric genetics research, 41% have no formal training or degree in genetics. If these individuals can educate themselves about genetics, we should make a similar effort to educate ourselves about psychiatric disease.

Abstracts of sessions and posters can be found in the *American Journal of Medical Genetics* (74:6) Oct 1997. ❖

PSRGN TACKLES BRCA TESTING ETHICS

Pam Cohen, MS

"GENETIC TESTING for Hereditary Breast Cancer: Should We Stop It?" was the topic of the Pacific Southwest Regional Genetics Network (PSRGN) conference held in San Diego last August.

The conference began with the video, "Genetic Testing for Cancer Risk: It's Your Choice," produced by the National Action Plan on Breast Cancer. The featured families outlined the pros and cons of testing within the context of their personal circumstances and beliefs.

Minimum standards for offering BRCA1/2 testing, including limiting testing. State-approved health facilities were proposed. The next several speakers reviewed epidemiological questions, pre-test genetic counseling, post-test options and laboratory issues.

One panelist argued that BRCA1/2 testing is premature given the current lack of knowledge about the implications of gene positive and negative results. She argued that more resources need to be devoted to preventing breast cancer rather than to predicting its potential occurrence.

...and Heard at Multiple Meetings

A lively open microphone discussion brought a wide spectrum of reactions. While some agreed with the proposal to restrict BRCA1/2 testing, others viewed this as paternalistic. The majority of participants' comments reflected concern about taking extreme measures on either side. ❖

Human Genome Research Advisory Counsel Report

Rosalie Goldberg, MS, Liaison to National Advisory Council for Human Genome Research

The National Advisory Council for Human Genome Research convened its 21st meeting in September. Dr. Francis Collins, director, highlighted both scientific and legislative issues. Donna Shalala presented "Health Insurance in the Age of Genetics."

A 2½ day meeting, "Genetic Medicine and Primary Care: The New Era," March 13-15 in New Orleans, is designed to educate practicing physicians about recent genetic advances.

An open session was largely devoted to the ethics of the patenting and commercialization of technologies funded by NHGRI grants.

The next Council meeting is scheduled for February 12 -13. ❖

Second Cancer Short Course A Huge Success

Melisa Siegler, MS

In 1993, many of us were introduced to the "ABC's of Cancer Genetics" in Atlanta. Four years later, 400 registrants gathered at NSGC's Short Course to explore "Cancer Genetic Counseling: A New Era Unfolds." Lectures, a lively panel discussion and workshops held the interest of "veteran" cancer counselors, those new to the specialty and many trying to bring cancer counseling into their daily practices.

The point/counterpoint panel raised many issues pertinent to cancer counseling, including the psychological impact of genetic testing, the role of the counselor in decision-making, ethical and legal considerations and the distinction between research and clinical programs. Six workshops met the needs of all attendees, despite our diverse experiences in cancer counseling.

Thanks to the hard work of Co-Chairs Ellen Matloff, Beth Peshkin, and their committees, this short course was a huge success. ❖

Meeting Manager

February 27 - March 1 • Los Angeles CA

March of Dimes Birth Defects Foundation and American College of Medical Genetics 5th Joint Clinical Genetics Symposium. NSGC's ART/Infertility SIG will conduct a workshop. Contact: ACMG: ✆301-530-7127 or March of Dimes ✆914-997-4511

March 20 • Auburn MA

Region I Meeting, Ramada Inn. Contact: Ali Warner; ✆Fax: 508-832-8711

March 19 - 22 • Chicago IL

Annual Conference, Association for Death Education and Counseling. Contact: ADEC 1998 Conference HQ; ✆860-586-7503

April 3 • Princeton NJ

Region II Meeting, "What Do We Do in Region II?" Robert Wood Johnson Jr Education Center. Contact: Kathy Valverde; ✆215-572-4058; valverde@beaver.edu

April 19 - 20 • Lisle (Chicago) IL

Region IV Meeting. Contact: Mary Ahrens; ✆612-625-2134; ahrens@lenti.med.umn.edu

April 23-24 • Cambridge MA

"The Human Genome Project: Science, Law and Social Change in the 21st Century," sponsored by the Whitehead Institute for Biomedical Research in association with the American Society of Law, Medicine & Ethics. Contact: Gus Cervini; ✆617-258-0633; cervini@wi.mit.edu

May 15 - 16 • Ann Arbor MI

"Genome Horizons: Public Deliberations and Policy Pathways" sponsored by University of Michigan School of Public Health. Contact: Tahnee C. Hartman, MPH; ✆313-647-8304 jhanschu@sph.umich.edu

May 28 - 31• Pacific Grove CA

Region VI Meeting: "Genetic Counseling: Introduction to the Next Millenium," Asilomar Conference Center. Contact: Andi Fishbach; ✆415-202-2993; andrea.fishbach@ncal.kaiperm.org

Oct 24 - 27• Denver CO

NSGC 17th Annual Education Conference, "Back to the Future: Genetic Counseling in the 21st Century."

In Our Own Words

NSGC's ResourceLink At Work!

Lyn Smith Hammond, MS

"I feel that ResourceLink is a great way for interested individuals to explore the genetic counseling profession and connect with genetics professionals who are willing to share their experiences… ."

— Marilyn Ray, MPH

"I have received calls and questions regarding the genetic counseling profession. We need to be available to the community we work in."

— Debra Han, MPH

"I think [ResourceLink] will prove to be a valuable way of reaching future generations of genetic counselors."

— Pam Cohen, MS

ResourceLink, our web-based directory of full and associate members needs you! It is accessible on NSGC's homepage. Entries include the same information as our printed directory and are updated regularly. ResourceLink exists to help people find us and find out about us. As a courtesy to our members, listings are not automatic. To be listed, you must take action. Obtain an application from the NSGC Executive Office ✆610-872-7608 mailbox#8 or http://members.aol.com/nsgcweb/signup.htm.

From a marketing perspective, we want students, consumers and professionals who visit the ResourceLink to have local access to our members. We need more representation to adequately reflect who, what and where we are. Let our voices be known! ❖

Practice Guidelines for Genetic Counseling: A Success Story

Debra Lochner Doyle, MS

As I shared with the membership at the Annual Education Conference, for the past two years many genetic counselors, medical geneticists and perinatologists in Washington State have been developing practice care guidelines that we call "Critical Elements of Genetic Counseling and Evaluation."

These CE's have been shared widely with managed care organizations throughout the state. Recently, I had the opportunity to meet with the human resouces manager at Weyerhaeuser Corporation. I explained genetic counseling, genetic testing and how most companies fail to recognize the benefits of these services for their employees. I shared the CE's, along with other published guidelines and a draft of a medical policy. I also informed them of the significant work that the genetic service providers had accomplished in producing the CEs.

Recently, the Medical Director for Weyerhaeuser telephoned me regarding their decision to revise their employee benefits policy to include genetic counseling, testing and evaluation. Furthermore, they will recommend that genetic counseling be provided by a "trained" genetic counselor before and after any testing. Clearly, this is a direction I hope other large companies will want to emulate. ❖

Awards Honor…

National Achievement Award

Elaine Wu, MS

Virginia Corson was awarded the prestigious Natalie Weissberger Paul National Achievement Award for outstanding service to the genetic counseling profession.

Ginny, an assistant professor at Johns Hopkins, holds joint appointments in the Departments of OB-GYN and Pediatrics. Her CV abounds with published papers, chapters and abstracts, as well as numerous leadership positions in NSGC, ASHG, ABGC and ACMG.

A former NSGC president, Ginny recalls, "It was different in the early days. NSGC was much smaller so getting involved was just a matter of someone asking you to do something." With characteristic modesty, this current ABGC president attributes her achievements primarily to "an inability to say no."

"That's not so far off," laughs Linda Cooper, a friend and former colleague. "Ginny really can't say no and everyone knows it! But they also know that she'll meet each challenge thoroughly, thoughtfully and on time. She's great to work with — so warm, generous, unpretentious, intelligent, articulate and organized."

Ginny is deeply committed to the genetic counseling profession and encourages young members to get involved in their professional organizations. "It's a great way to expand your professional identity both by doing something outside your usual job and by meeting people who work in different roles," she suggests.

"The annual meeting has gotten bigger and busier," she admits. "But it's still just a matter of showing up, standing up and saying 'yes'." ❖

…MEMBERS

REGIONAL AWARDS

EACH YEAR, NSGC recognizes a member in each region for work on behalf of NSGC and the profession. This year's awardees:

Region I	Dale Lea
Region II	Judith Benkendorf
Region III	Ron Cadle
Region IV	Carol Christianson
Region V	Amy Cronister
Region VI	Susie Ball

Profiles of regional award recipients will appear in the next issue of *Perspectives.* ❖

ENGELBERG FELLOWSHIP FUNDS SOCIOLINGUISTIC STUDY IN THE GENETIC COUNSELING SETTING

THE 1998 recipients of the Jane Engelberg Memorial Fellowship, Judith Benkendorf and Michele Prince, will be studying "Genetic Counseling as Discourse: A Sociolinguistic Approach."

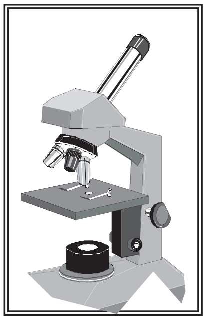
The goal is to gain a better understanding of how genetic counseling works by studying discourse analysis and utilizing these methods to analyze tapes and transcripts of genetic counseling sessions and to demonstrate how genetic counseling principles are achieved through conversation.

Two products will be developed: a manual, the genetic counselors guide to discourse analysis as it relates to our practice and professional principles, and an accompanying audiotape, which will be distributed to genetic counseling training programs and NSGC members.

Both Judith and Michelle hold positions in the Department of Obstetrics, Georgetown University, Washington DC. ❖

RESEARCH NETWORK

DYSTONIA SUBJECTS NEEDED



WE are searching for non-DYT1 genes responsible for adult onset forms of dystonia-like torticollis, spasmodic dysphonia, blepharospasm and Meige syndrome. Families with at least two or three living affected relatives are needed. In addition, we recently mapped a gene, DYT6, to chromosome 8. This occurs in Mennonites with a mixed dystonia phenotype, including early and late onset, generalized and focal forms in the same family. Please refer anyone of Mennonite/Amish ancestry with any form of dystonia, regardless of a known family history.

Contact Deborah de Leon, MS, Department of Neurology, Beth Israel Medical Center, PACC Suite 2R, 10 Union Square East, New York, NY 10032; ✆212-844-8719; Fax: 212-844-8710; ddeleon@bethisraelny.org ❖

IMPACT OF PREGNANCY ON PRENATAL COUNSELORS

PREGNANT or recently pregnant (within the last six months) genetic counselors are needed for a student master's thesis. The project studies the impact of pregnant counselors on the prenatal genetic counseling session. Interviews will be approximately one hour and will be conducted by telephone or in person.

Contact Shelley Mueller, Brandeis University, Department of Biology, Waltham MA 02254; ✆617-441-9660; mueller@ccnmr.mit.edu. ❖

STUDENT CORNER

Cathy Wicklund, MS

STUDENTS MATRICULATED in the University of Texas-Houston Genetic Counseling Program, a joint endeavor between the University of Texas Medical School and the Graduate School of Biomedical Sciences, spend their first year in classroom study and introductory clinical rotations. Graduate requirements include a thesis. Each student is expected to propose a laboratory or clinically oriented research question that includes study design, collection of data where applicable, and analysis. An oral defense is required. The following represent topics by UT-Houston's current 2nd year students.

- Erika Martin: "Etiologic Study of Adolescent Idiopathic Scoliosis." To determine factors contributing to the etiology of idiopathic scoliosis in three ethnic groups: African American, Caucasian and Hispanic.
- Melissa Trant: "Characterization of Maturity Onset Diabetes of the Young in Mexican-American Youth." To ascertain gene mutations causing MODY1, MODY2 or MODY3 in Mexican American families in Houston, and identify an association with their regional point of origin in Mexico.
- Jolynn Swantkowski: "Use of a Retrospectively Identified Cohort of Children with Thrombosis to Assess Underlying Genetic Predispositions for Future Adverse Clotting." To offer free genetic testing for six known risk factors associated with thrombosis to a random cohort of children. ❖

RESOURCES

WHAT'S ON THE WEB?

Shelly Cummings, MS

These selected sites are relevant and may be worth bookmarking.

http://www-unix.oit.umass.edu/7Efholmes/
Facilitates participation of women regarding social and ethical issues raised by human genome research.

http://www.medicinenet.com/MAINMENU/news/nov0797.htm
Lists sites about medical gneetics that are intelligible, generally sound and useful.

http://www.tchin.org
Provides information and resources to families and professionals about congenital and acquired heart disease.

http://www.mic.ki.se/Diseases/index.html
Lists disorders from bacterial and fungal to behavioral and mental — with hotlinks to research articles on the various topics and links to professional society homepages.

http://www.healthnet.ivi.com/ivi/hnews/bites/htm/bites.htm
Provides brief glimpses of recent medical advances and journals where more information can be found.

http://www.hhmi.org/GeneticTrail/start.htm
Explains the impact of genetic discoveries and research on families. This Howard Hughes Medical Institute page boasts exquisite graphics not to be missed!

http://www.faseb.org/genetics/mainmenu.html
Supplies a listing of the major genetic societies with hotlinks. Search features include topics or areas of interest.

http://medaapos.bu.edu/AAPOS/Lawyers.html
Tickles your funny bone. Read some of the Lawyers Best Questions and Answers. ❖

GATTICA: A DANGER TO SOCIETY?

Katherine Hunt, MS

"Gattaca" is Hollywood's interpretation of where the genetic revolution will lead us in the not too distant future.

The story takes place in a world divided into two groups: the 'valids' and 'invalids.' 'Valids' are engineered for physical and intellectual perfection; 'invalids' are created naturally with their genetic code left to chance. The movie follows an 'invalid' as he attempts to defy his fate and successfully incorporate himself into the genetically superior race.

I walked away from "Gattaca" feeling unsettled and frustrated. The line from this movie 'myopia is a sure sign of the disadvantaged' coupled with references made to visiting the local geneticist to ensure a genetically superior child, take us back in time to the eugenics movement. This is a dramatic digression which does not accurately portray the direction those of us in the field forecast the genetic revolution will take us in the next decade.

My fear is that this movie will reinforce a mistrust of genetics and alter any current understanding of genetic professionals' roles. ❖

NEW TOOL PROMOTES FAMILY HISTORY AND GENETIC COUNSELING

Jessica Mandel, MS

Growing Your Family Medical Tree. Fran Carlson; Keep it Simple Solutions. Lafayette Hills PA. 1-888-385-KISS

THE NEWEST TOOL in promoting patients' awareness of their family histories is a self-help kit, *Growing Your Family Medical Tree.* Resembling a card game, the Deck Of Life "plays out" major health concerns, physical traits, ethnicity, occupation, skills and lifestyle behaviors. The handbook explains how to collect medical data and family history. Stickers identify medical risks as a color pattern emerges in the family. The goal is to empower individuals to recognize their medical needs, understand the role of genes in their daily lives and explore prevention with the help of a doctor or genetic counselor.

The tool is best suited for those with a general interest in their family history or with a known medical history that they have time to investigate. When recommended by a medical professional who can assist with information gathering and serve as a resource, this tool has the potential to identify real health concerns in families, particularly factors beyond biology, e.g., behavior, lifestyle and personality.

Fran Carlson, author of the tool and president of Keep it Simple Solutions Healthcare Publications, is embarking on a national publicity campaign and is seeking genetic counselors to help promote the importance of family history and the services of genetic counseling. For more information, call 215-233-2117. ❖

A LAST NOTE: For anyone who requested follow-up information in Baltimore, Fran's list of contacts was stolen. Please recontact her directly.

IN FAVOR OF LICENSURE

Schmerler …from page 1

level of proficiency and knowledge. License renewal could be dependent on recertifica-tion or continuing education.

Genetic counselors are bound by NSGC's Code of Ethics, which is not an enforceable document. However, not everyone who provides genetic counseling services is an NSGC member. A licensing act could provide enforceable, ethical guidelines.

A licensing board could serve as a source of information for the public about the educational background, competency and license status of a genetic counselor. It would also provide a system for receiving and acting on consumer complaints, adding a measure of professional accountability.

ECONOMIC ISSUES

Establishing a Board of Genetic Counseling in each state could be financially prohibitive. Alternatives to separate Boards include coming within the purview of an existing Board. This would necessitate establishing a genetic counseling advisory committee, but at a substantially lower cost.

Fees for licensure can be kept reasonable by using ABGC certification as a prerequisite to licensure, eliminating the need and cost of an licensing examination. Licensing fees also reflect the number of complaints brought against licensed professionals. If these are few, the administrative costs should be modest.

Interstate mobility of genetic counselors would not be constrained if all states have the same basis for licensing, i.e., the national examination.

BILLING & REIMBURSEMENT ISSUES

State recognition through licensure could increase the esteem of the profession and encourage managed care programs to make licensing a requirement for their genetic counselors. This may increase the number of referrals and/or reimbursement for services.

Licensure can help ensure the hiring of qualified genetic counselors.

THE BOTTOM LINE

At this point in the maturation process of our profession, I believe that the reasons for licensing genetic counselors far outweigh the reasons for not pursuing licensure. ❖

IN OPPOSITION TO LICENSURE

Faucett…from page 1

Licensing boards in each state would consist of genetic counselors, medical professionals, government officials and possibly the public, each of whom would have different views of genetic counselors' roles. Harmful restrictions or limitations may be imposed.

ECONOMIC ISSUES

Licensure requires governmental action which involves lobbying. Due to the low number of counselors in some states and high expense of lobbying, this may not always be possible. Once licensure is established, costly yearly fees would be required.

Some states require licensing boards to annually prove they are serving an important role. If convincing evidence is not provided, these boards are disbanded.

States could theoretically require additional recertification or continuing education above the level recommended by ABGC, adding more expense.

BILLING & REIMBURSEMENT ISSUES

Licensure will neither automatically change the ability of genetic counselors to bill, nor increase the level of reimbursement. Nursing is a field that requires practictioners to be licensed, yet most are not able to independently bill. In some states, unlicensed genetic counselors have won the battle to be able to bill. Genetic counselors in states where licensure is not possible may be at a disadvantage with insurance companies.

THE BOTTOM LINE

Licensure is an emotional issue. Many NSGC members believe it would provide improved recognition and prestige. Historically, genetic counseling has been unique in its role in medicine. Recently, medical journals and lay publications have highlighted the importance of genetic counseling by master's-level genetic counselors.

Genetic counseling has established a process of board certification. It is highly regarded that genetic counselors take the same general board exam as other genetic professionals. Promoting the services of only board certified/eligible counselors would solve many of the issues which are prompting the idea of licensure without some of its potential harms. NSGC should promote the idea of certification instead of licensure. ❖

BULLETIN BOARD

FREE FOR THE ASKING…

RESEARCH ISSUES DOCUMENT

GENETIC COUNSELORS are increasingly becoming advocates and conduits for genetic research. As liaisons between patients and research labs, what responsibilities do we have to our patients and their families? What do we need to know about the project or laboratory? Can we present the study in a way that assures informed consent?

The Genetic Research Issues Subcommittee of the Social Issues Committee has created a document that provides a mechanism for genetic counselors to gather information about a research project or laboratory.

For your free copy, contact Judith Miller, MS, ✆309-655-4648; Fax: 309-655-2565; jmiller@uic.edu. ❖

FRAMABLE CODE OF ETHICS

IF YOU MISSED it at the Annual Education Conference in Baltimore, it's not too late to request your free framable copy of the Code of Ethics. The document is set on parchment paper and is ready for your 11x14" frame. Request your free copy from the Executive Office; Fax: 610-872-1192; nsgc@aol.com. ❖

NEW ADMINISTRATOR TO NSGC LIST SERV

LISA BRODEUR became our list serv manager as of January 1. She replaces Kate Dietrich, who single-handedly initiated and has managed our list serv since its inception on January 1 1997. Prior to that, Kate managed the student list serv. All of us who have sent messages or have requested help and resources to our online membership know how diligently Kate has worked to ensure that we could depend on professional online communications. Kate now passes these responsibilities to staff, under the supervision of our Executive Director. Please direct all questions about our list serv after January 1 to Lisa at: nsgclistQ@aol.com.

With our advance training, we hope the impact of this change is minimal. However, you might want to allow extra response time during the transition.

Thank you, Kate, for your singlehanded, professional efforts as we have learned to communicate with each other online! ❖

NEW *JOURNAL* ITEMS

LEARNING MODULES INTRODUCED

DON'T MISS the new "Update and Review" section in the December issue of the *Journal of Genetic Counseling*. Penned by Kelly Ormond, it will update you on the latest in triple marker screening. Each issue will feature a timely review on current issues in genetic counseling. Please consider writing a module or helping review others' works. Contact Janice Berliner, ✆718-494-5369; JLBerliner@aol.com. ❖

CALL FOR CASES

THE *JOURNAL of Genetic Counseling* is seeking case reports for a new section which will emphasize the counseling and psychological aspects of genetic counseling through presentation and analysis of counseling situations.

Dust off your keyboards and write up that fascinating case that you've been thinking about. Manuscripts are needed now for next year's start of this feature. Potential authors, readers or commentators are urged to contact editor Kathryn Spitzer Kim, ✆781-736-3108; kkim@brandeis.edu. ❖

THINK FRESH! THINK BIG!

SHORT COURSES OFFER intensive study in specific areas of genetics. Applications for 1999 are being accepted through March 31, 1998. Guidelines and applications may be requested by contacting Cindy Soliday, Annual Education Conference/Short Course Subcommittee Chair, ✆408-972-3332; Cindy.E.Soliday@ncal.kaiperm.org. ❖

ETHICS DOOR IS OPEN

THE ETHICS SUBCOMMITTEE assists members in making informed decisions about how best to resolve ethical dilemmas. All contact is held in strict confidence. ❖

Robin Gold, Chair, ✆313-493-6060
Lorna Phelps, ✆804-828-9632
Karen Lewis, ✆616-391-8863
Katherine Hunt, ✆505-272-6315
Stephanie Kieffer, ✆617-632-2271
Dan Riconda, ✆407-841-5111 x1050
Julie Rutberg, ✆410-955-3071

LIMITED TIME OFFER

A LIMITED NUMBER of program books from the 16th Annual Education Conference and Cancer Short Course in Baltimore last October are available. Contact the Executive Office for information. ❖

DUES SCHEDULE REVISED

DUES INVOICES were mailed to all members in November. To accommodate the needs of our Special Interest Groups, maintain accuracy of our general and specialty list servs and keep your NSGC information flowing without interruption, we are asking that all dues be paid by the January 15 deadline. Help keep NSGC on the leading edge. Renew your membership on time. You are important to us! ❖

EMPLOYMENT OPPORTUNITIES

■ **FRESNO CA:** BC/BE Genetic Counselor. Exp pref; but new grads encouraged to apply. Exclnt org & interpersonal skills req. Join team at tertiary Genetic Ctr svg wide geographic region w/ diverse population. Provide PN, peds & adult genetics. ☛ Susan Wisniewski, Admin Dir, Valley Childrens Hospital, Dept Genetic Medicine, 3151 N Millbrook, Fresno CA 93703; ✆209-243-6750; Fax: 209-243-6744. EOE/AA

■ **LOS ANGELES (DUARTE) CA:** Highly motivated BC/BE Genetic Counselor. Exclnt written, oral & interpersonal skills req; cancer genetics exp pref. Join active cancer genetics program; on-site & satellite clinics; clin rsrch; grant writing, tchg; exclnt oppty for growth & educ devlpmt ☛ Jeffrey N. Weitzel, MD, Director, City of Hope National Medical Center, Clinical Cancer Genetics, 1500 E Duarte Rd, Duarte CA 91010; ✆626-359-8111; Fax: 626-930-5495; jweitzel@smtplink.coh.org EOE/AA

■ **LOS ANGELES CA:** BC/BE Genetic Counselor. Join large, active genetic service providing full range of svcs. Primary respon PN w/ oppty to be involved in specialty clins. ☛ Bill Herbert, MS, Cedars-Sinai Medical Ctr, 444 S. San Vicente Blvd Ste 1001, Los Angeles CA 90048; ✆310-855-2211; Fax: 213-655-5381; bherbert@mailgate.csmc.edu EOE/AA

■ **N. LOS ANGELES CO/VENTURA AREA CA:** BC/BE Genetic Counselor. Exp & bilingual (Eng/Span) pref. Primarily PN svcs to diverse pt population: AMA, XAFP (TMS), terat, DNA ref. Back-up to S. CA sites, as needed. ☛ Beth Bronstein, Human Resources, Genzyme Genetics, Box 9322, Dept. BB-A854, Framingham MA 01701; Fax 508-872-5234. EOE/AA

■ **SAN DIEGO CA:** Genetic Counselor I or II. Speak & write Spanish fluently pref, not req. ☛ Send CV & 2 ltrs recommendation to James T. Mascarello, PhD, Children's Hospital-San Diego, Genetic Services, MC 5031, San Diego CA 92123 ✆619-576-5809. EOE/AA

■ **SAN JOSE CA:** Exp BC Genetic Counselor/ Cancer Genetics Reg'l Coordinator. Provide advanced clinical hereditary cancer expertise: prog devel, consult svc, insvcs for genetics staff & other providers, reg'l & inter-reg'l cancer task forces & progs, rsrch oppty, some direct pt care. ☛ JoAnn Bergoffen, MD, Asst Chief Genetics, Kaiser Permanente Medical Care Program of N. Calif, 260 International Cr, San Jose CA 95119; ✆408-972-3300; Fax 408-972-3298 EOE/AA

■ **SAN JOSE CA:** BC/BE Genetic Counselor. Exp pref. Join large, active, estab, comprehensive HMO genetics prog: broad range of PN, cancer, peds & adult svc; partic in specialty clins. ☛ Cindy Soliday, MS, Kaiser Permanente, Genetics Bldg 1, 5755 Cottle Rd, San Jose CA 95123; ✆408-972-3332; Fax 408-972-3298. EOE/AA

■ **BOISE ID:** P/T (60%) BC/BE Genetic Counselor. Exp pref; will consider new grad w/ exclnt clin judgment & substantial exposure to PN, ped & adult GC. Join ctr svg pts in ID, eastern OR & northern NE. Primarily PN w/ some ped, adult & cancer GC; teach med student/family prac residency tchg; oppty for lay/commun outrch. ☛ Anne C. Spencer, MS, St. Luke's Perinatal Svc, 190 East Bannock St, Boise ID 83712; ✆208-381-3088; spenera@slrmc.org. EOE/AA

■ **CHICAGO IL:** Immediate opening for BC/BE Genetic Counselor. Exp & Spanish pref not req. All aspects of PNDx (U/S, terat, dysmorph), perinatal consults, some peds/newborns, occasional genrl/adult genetics; monthly outrch clin; tch residents, lectures to hospital staff ☛ Jar Fee Yung, PhD, Mercy Hospital & Med Ctr, Medical Genetics, 2525 S Michigan Ave, Chicago IL 60616-2477; ✆312-567-2283; Fax 312-567-7619; jfyung@mercy-chicago.org. EOE/AA

■ **BATON ROUGE LA:** BC/BE Genetic Counselor. Exp pref. Join clin & rsrch genetics team w/ growing prog: PN, neonatal, peds, cancer. Provide info/educ to health prof supt grps. ☛ Submit CV & 2 ltrs recommendation: Sue Chenevert, MS, Genetics Coordinator, Woman's Hospital, 9050 Airline Hwy, Baton Rouge LA 70815; 504-924-8378; Fax: 504-231-5380. EOE/AA

■ **BALTIMORE MD:** BC/BE Genetic Counselor. PN exp pref. Univ-based PN tstg ctr team. Partic in all aspects of PNDx: CVS, amnio, fetal anom, AFP, fam hx, terat. Rsrch & tchg oppty. ☛ Jeffrey S. Dungan, MD, OB/GYN Associates of University of Maryland, 405 W. Redwood St, Ste 400, Baltimore MD 21202; ✆401-328-3615; Fax 401-328-2849. EOE/M/F/D/V

■ **CHEVY CHASE MD:** Project Manger Director, Info & Resource Ctr. Provide wide range of info & referral links betwn consumers, public, prof & genetic resources available in supt groups, voluntary health orgs, genetic clins & prof assns. ☛ Mary Davidson, MSW, LCSW-C, Alliance of Genetic Support Groups, 35 Wisconsin Cr, Ste 440, Chevy Chase MD 20815; ✆301-652-5553; Fax 301-654-0171. EOE/AA

■ **BOSTON MA:** 0.8 FTE BC/BE Genetic Counselor. Provide comprehensive clin svcs to members & clinicians of large HMO; clin rsrch & tstg; broad range couns issues; strong PNDx prog; cofacil supt grp; prof educ to HMO clinicians, GC students & med students; outrch to satellite sites. ☛ Martha MacMillin or Susan Mecsas-Faxon, Harvard Pilgrim Health Care, Genetics Dept, 185 Dartmouth St, Boston MA 02116; ✆617-859-5151; Fax 617-267-8203. EOE/AA

■ **BOSTON MA:** Tentative April start for BC Genetic Counselor w/ min 2 yrs exp. Strong GC skills req; cancer exp pref. Self motivated, work well in group, strong interest in rsrch. Active high risk cancer clins & genetic tstg progs; dev & implement clin rsrch projects. ☛ Katherine Schneider, MPH, Dana-Farber Cancer Inst, 44 Binney St, SM206, Boston MA 02115; ✆617-632-3480; Fax 617-632-3161 EOE/AA

■ **KANSAS CITY MO:** BC/BE 2/3 peds & 1/3 PN Genetic Counselor. Join 2 GCs in tertiary care peds facility: Genr'l peds genetics, hemophilia, cleft lip/ palate, hemoglob & NTD, 2 reg'l outrch & PNDx clins. Prof & commun educ. ☛ Dorene Shipley, The Children's Mercy Hospital, Human Resources, 2401 Gillham Rd, Kansas City MO 64108; ✆816-234-3144; Fax 816-855-1989. EOE/AA

■ **ST. LOUIS MO:** BC/BE Genetic Counselor. Highly motivated; independent personality req. Join 3 GCs in busy univ-based PNDx prog: all aspects of tstg; free terat/genetics phone svc. ☛ Send CV & 3 ltrs rec to Heidi A. Beaver, MPH, Barnes Jewish Hospital, Dept OB/GYN, 216 South Kingshighway, St. Louis MO 63110;✆ 314-454-7358. EOE/AA

■ **HELENA MT:** BC/BE Genetic Counselor. Cancer GC exp pref. Ped & adult genrl genetics, outrch clins including svcs to Native Americans, fetal pathology, PN scrng & Dx. Oppty for prof & public educ; contrib to prog development. ☛ Gary Willis, Dept Human Resources, Shodair Hospital, PO Box 5539, Helena MT 59604; ✆800-447-6614; Fax 406-444-7536. EOE/AA

■ **NEW YORK: NY:** BC/BE Genetic Counselor. Spanish pref. All aspects of peds & PN: coord amnio/CVS prog; oppty to work w/ multidisc peds & OB teams; culturally diverse populations; prof & public ed. ☛ Karen David, MD, Director, Clinical Genetics, Metropolitan Hospital, 1901 First Ave Rm 523, New York NY 10029; ✆212-423-6452; Fax 212-423-6183. EOE/AA

■ **SUFFOLK CO/LONG ISLAND NY:** Cancer Risk Genetic Counselor w/ 1-2 yrs relevant exp req. Start part-time w/ poss expansion. Abil to work independently; exclnt commun skills req. Join active, commun-based, multidisc onc group: develop prog & registry for high risk individuals. Oppty for outrch. Prof & commun educ. ☛ H. B. Wodinsky, CEO; NSHOA, 235 N. Belle Mead Rd, East Setauket NY 11733; Fax: 516-751-3366.

■ **RESEARCH TRIANGLE PARK NC:** Genetic Counselor w/ min 3 yrs exp. Consult w/ MD's & GC's; develop pt & physician materials; write/edit individ test repts; perform reg'l & natl inservice & sales trng lectures & teleconferences. ☛ Juli Neusch, Human Resources, LabCorp, 1904 Alexander Dr, Research Triangle Park NC 27709; ✆800-833-3984; Fax 919-572-7423. EOE/AA

■ **EUGENE OR:** BC Genetic Counselor w/ min 2 yrs clin exp in GC or equiv MS in Human Genetics w/ ability to maintain long-term follow-up w/ ob pts. Coord peri/neonatal genetic needs of referral pts to the Fetal Dx Ctr. Exp & rsrch; U/S detected dysmorph, MSAFP, amnio, 3-dimen U/S, coord tertiary perinatal care. Multi-disc approach stresses autonomy, tchg & prog devel. ☛ Megan Hough, Fetal Diagnostic Ctr, 2785 Grand Cayman, Eugene OR 97408; ✆541-302-9880; Fax 541-302-9880. EOE/AA

■ **PHILADELPHIA PA:** Genetic Counselor in Prostate & Breast Risk Assessment Programs. Rsrch exp pref. Strong writing skills. ☛ Human Resources-MAM, Fox Chase Cancer Ctr, 7701 Burholme Ave, Philadelphia PA 19111. EOE/AA

■ **PITTSBURGH PA:** BC/ BE Cancer Genetic Counselor & Instructor, Clin Medicine (non-tenure). Hi motivation, min 1 yr CA assessment & GC skills: comprehensive cancer GC & clin care coord; prof, trainees & public educ; clin & rsrch database; contrib to grants, manuscripts, & clin/scientific papers. Oppty to inter-act w/ full spectrum of staff at CA

Continued on next page

national society of genetic counselors, inc.

nsgc

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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.

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*Submission deadline **February 10***

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EMPLOYMENT OPPORTUNITIES

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ctr progs.
☛ Send CV & 3 ltrs rec c/o Wendy S. Rubinstein, MD, PhD, Univ Pittsburgh, Cancer Genetics Program, 3471 Fifth Ave, Kaufmann Bldg, Ste 802, Pittsburgh PA 15213-3221; rubinsteinw@msx.upmc.edu. EOE/AA

■ **MEMPHIS TN:** BC/BE Genetic Counselor. Exp pref, not req. Genrl genetics (clin & in-pt): peds, NB, IEM, NF, Retinal, adult, NB scrng triage, outrch; PN in collab w/ Repro Gen. Oppty for case mgmt, tchg, res. Extensive collab w/ other area hosp & Univ depts. Cyto, metab & molec labs on site.
☛ Jewell C. Ward, MD, PhD or Diana M. Chambers, MS, Univ Tennessee Memphis, Ctr Health Sciences, Dept Pediatrics, Div Med Genetics, 711 Jefferson #523, Memphis TN 38105; ✆901-448-6595; Fax 901-448-4117; jward@ulmem1.utmem.edu. EOE/AA

■ **AUSTIN TX:** BC/BE Genetic Counselor. 2 yrs exp in similar setting req. GC for PN pts in perinatal dx ctr for: AMA, abn serum scrng results, U/S abnorm & family history. Some local travel.
☛ Beth Bronstein, Human Resources, Genzyme Genetics, Box 9322, Dept. BB-A854, Framingham MA 01701; Fax 508-872-5234. EOE/AA

■ **CORPUS CHRISTI TX:** BC/BE Genetic Counselor. Exp pref. Full service PNDx & trtmt in busy growing priv prac. Some ped case mgmt.
☛ Lisa Kelley, MS, Center for Genetic Services, 7121 SPID, #202, Corpus Christi TX 78412; ✆512-985-6600; Fax 512-985-6603; Bayl@Davlin.net. EOE/AA

■ **DALLAS TX:** Research Nurse w/ LVN or RN. Exclnt interpersonal skills & ability to work independently req. Identify pts suitable for specific genetic & clin studies, contact pts, enroll in studies, conduct study protocols, document results. Oppty for interaction w/ diverse pts & professionals. Occasional travel may be req.
☛ Carol Wise, PhD or Susan Iannoccone, MD, Texas Scottish Rite Hospital for Children, 2222 Welborn, Dallas TX 75219; ✆214-559-7861 or 214-559-7830; Fax 214-559-7872 or 214-559-7835; carol@mcdermott.swmed.edu or susani@ix.netcom.com. EOE/AA

■ **DALLAS TX:** BC Genetic Counselor. Will consider BE w/ min 1 yr exp. Abil to work independently req. Join PNDx ctr at private hosp. Tchg oppty w/ OB residents & GC students.
☛ Paula Bogdanow Schmid, MS, Baylor Univ Medical Ctr, 3500 Gaston Ave, Dallas TX 75246; ✆214-820-6015; Fax 214-820-6018. EOE/AA

■ **HOUSTON TX:** 2 BC/BE Genetic Counselors. Independent, self-starter, computer friendly w/ ability to speak Spanish desired. Join preconceptual counseling team: provide educ & counseling to pts w/ genetic & medical risks for pregnancy.
☛ Martha E. Shaw, MS, LBJ Hospital, OB/GYN & Genetics, 5656 Kelley Dr, Houston TX 77026; ✆713-636-5938; Fax 713-636-4521; MShaw@obg.med.uth.tmc.edu. EOE/AA

■ **HOUSTON TX:** BC/BE Genetic Counselor. Motivated, creative, & enthusiastic personality pref. Assist in coordinating a rsrch DNA Dx Lab; provide GC svcs in Dept Ophthalmology & contact pts & physicians involved in studies of inherited retinal diseases.
☛ Stephen P. Daiger, PhD, Univ TX Health Science Ctr, School of Public Health, Human Genetic Ctr, PO Box 20334, Houston TX 77225-0334; ✆713-500-9829; Fax 713-500-0900, sdaiger@utsph.sph.uth.tmc.edu. EOE/AA

■ **HOUSTON TX:** BC/BE Cancer Risk Genetic Counselor w/ exlnt commun skills, self motivation, abil to work well on team; strong rsrch interest. Exp pref; will consider new grads w/ exemplary skills & clin exp in cancer or adult genetics. Join GC, onc/rsrch nurses, oncologists & psychosocial rsrch grp team. Provide cancer risk coun svcs; partic in ongoing clin/psychosocial rsrch projects; play active role in prof educ.
☛ Patricia Ward, MS, University of Texas M.D. Anderson Cancer Center, 1515 Holcombe Blvd, Box 243, Houston TX 77030; ✆713-745-2541; Fax: 713-794-4730; pward@notes.mdacc.tmc.edu EOE/AA.

■ **CHARLOTTESVILLE VA:** BC/BE Genetic Counselor. 2+ yrs exp pref; cancer genetics exp helpful but not req. Clin position w/ occasional tchg and/or rsrch duties.
☛ Susan M. Jones, MS, University of Virginia Health Sciences Ctr, Cancer Ctr, Box #334, Charlottesville VA 22908; ✆804-243-6446; Fax 804-243-6571; smj8d@virginia.edu EOE/AA

■ **YAKIMA WA:** 0.6 FTE BC/BE Genetic Counselor w/ exp. Bilingual (Eng/Span) pref. Join growing rural regl ctr to provide full range of svcs: PNDx, peds, adult, presymp, perinatal loss, outrch,CA, FAS, CL/P team, community & provider education.
☛ Susie Ball, MS, Yakima Valley Memorial Hospital, Central Washington Genetics Prog, 2811 Tieton Dr, Yakima WA 98902; ✆509-575-8160; Fax 509-577-5088; SusieBall@aol.com. EOE/AA.

IN CANADA

■ **TORONTO ONTARIO:** BC/BE Genetic Counselor(s). Min 2 yrs exp highly desirable. Pref to Canadian citizens. Join active univ hospital clin genetics team: primarily ped pts; some PN, adult & spec clins; involvement w/ rsrch & tchg.
☛ Cheryl Shuman, The Hospital for Sick Children, Dept Genetics, 555 University Ave, Toronto Ontario M5G 1X8; ✆416-813-6386.