

PERSPECTIVES

in genetic counseling

Volume 22 Number 4

Winter 2000/01

**national society
of genetic
counselors, inc.**

nsgc

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

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NSGC acknowledges
Genetic Health for a generous grant
to support this newsletter.

Genetic Health

See p. 15

ICE Certification: Points to Consider

Janice Berliner, MS

Recently, we learned about a new credentialing exam created by a nonprofit education organization called the Institute for Clinical Evaluation (ICE) in partnership with the American Society of Clinical Oncology (ASCO).

Initially, the exam was intended for individuals who provide risk analysis and clinical cancer genetics services. Much controversy regarding the usefulness of this exam for genetic counselors has ensued. (*See pp. 8,9*)

ABGC and ABMG representatives were invited to attend an ICE Board meeting in November. Concerns were voiced regarding the purpose of the ICE credential and potential for public confusion regarding the differences between this credential

and ABGC/ABMG certification. ICE indicated that their credential is being developed only for health care professionals who provide clinical cancer genetic services but do not have formal training in genetics, and that the exam is not intended to undermine the ABGC/ABMG certification process. For this reason, they have revised their description of who might benefit from this exam to those who provide risk assessment and management services, and have agreed to change the name of this credential to "familial cancer risk assessment and management."

This provides considerable clarity and reflects ICE's willingness to respond to our concerns. Pages 8 and 9 provide you with background. ♦

NEW AND IMPROVED WEBSITE UNVEILED



Liz Stierman, MS

A recent survey reveals that 55% of all Internet users seek health information online, including guidance about when to seek care and how to question health care providers. This underscores the need to strengthen NSGC's web presence. Our completely updated website is now operational at

Stop by for a visit: www.nsgc.org

www.nsgc.org.

See p. 7

TRIAL Members' Corner Entrance
thru 3/1/00, only:
User's Name: nsgc • Passcode: nsgc

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Cindy Soliday, MS

STRATEGIC PLAN AND EXECUTIVE OFFICE SURVEY

Bea Leopold and Angie Trepanier

Bea Leopold reported that she has observed an interesting phenomenon within NSGC. More members have concluded that traveling on a specific course is the key to our success...and they say it with passion. These major, seemingly competing interests are:

- Marketing
- Legislative efforts
- Billing, licensure & reimbursement
- Relocation of Exec Office to DC
- Web site improvements.

She noted that it is important to retain peripheral vision and to notice the interconnectedness rather than the disparity of the issues.

An evaluative survey of emerging issues and member values was

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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 March 15

Submission deadline February 10

BOARD MEETING HIGHLIGHTS: ISSUES ...

The following represents business covered and action items from NSGC's Annual Board of Director's meeting, November 5 in Savannah, Georgia.

performed this Summer. (See p. 5)
Our third strategic plan will be launched in early 2001.

Angie Trepanier reported on options researched for our Executive Office. The Executive Office Committee noted a commitment to expand our office space and staff. Committee recommendations include:

- Increase savings
- Generate money from current NSGC products
- Expand gradually
- Prioritize demands of expenses.

HEALTH CARE CONSULTANTS

Jen Farmer, MS &

Deb Lochner Doyle, MS

The Board previously agreed that hiring professional health care consultants would be important to assist with billing and reimbursement issues, conduct a time study and define the scope of service. Partnership with ACMG was discussed, with emphasis on our complementary, not conflicting, roles. Partnering with ACMG and broadening the scope of the Request for Proposals to include medical geneticists was approved.

STAND ALONE CONFERENCE

Debra Lochner Doyle, MS

When we decided to hold our Annual Education Conference as a stand alone meeting, we determined also to enrich the program with scientific content. A focus of the discussion was pivoted on the quality of abstract submissions.

The Annual Education Conference Subcommittee members assume the challenge of ensuring that scientific content meets the highest expectation level and will present a plan at the Spring Board meeting.

SACGT – FUTURE DIRECTIONS

Debra Lochner Doyle, MS

Should NSGC take a proactive or reactive stance on issues being addressed by SACGT? Ann Boldt, who serves on the Advisory Committee, indicated that SACGT is not seeking input from outside agencies or associations at this time. NSGC's committee chairs will appoint members to check the SACGT website regularly to monitor activities and issues.

BUDGET

Kris Courtney, MS &

Lisa Mullineaux, MBA, MS

NSGC must increase revenue to meet increased current and anticipated expenses as well as pay for large projects.

Recommendations:

- Increase dues (See p. 4)
- Increase conference fees
- Cut executive and standing committee budgets by 5% - 10% to ensure not only a balanced budget, but a surplus, to be used for large projects
- Consider dedicating any excess income realized in 2000 toward large projects.

Large Projects for Financial Consideration in '01:

- Healthcare consultant for Billing & Reimbursement and Time Study @ \$35,000; half if partnered with ACMG
- Marketing to consumers (See p. 3) @ \$60,000
- Charitable Contributions: The Board held a lengthy and lively discussion about a request for a large contribution to Genetic Alliance. The Board

See next page

... DISCUSSION AND DECISIONS

will develop a "Charitable Contribution Policy" for discussion at the interim Board meeting.

Large Projects for Financial Consideration for 2002 and Beyond:

- The *Journal of Genetic Counseling* editor recommended increasing the page budget and online subscriptions beginning in 2002, increasing the cost by \$8/member.
- Executive Office Transition: Preliminary cost estimates project minimum additional overhead of \$100,000/year.

ICE CERTIFICATION RESPONSE

Wendy Uhlmann, MS

Wendy Uhlmann reviewed the issue of certification for cancer

genetics. The discussion revolved around member input and concerns to date.

President Vivian Weinblatt will respond directly to ICE and ABGC about their concerns and present the issues to the membership in a fair and dispassionate way. (*See p 1, 8-9.*)

NEW WEBSITE UNDERWAY

Liz Stierman, MS

Liz Stierman revealed plans for our newly revised and improved website, which will have password protection later in 2001. Beth Billings was acknowledged for her work in bring our site in line with more contemporary sites. (*See p. 1*)

MARKETING UPDATE

Liz Stierman, MS

With extensive member input, NSGC's consultants, Peter Benkendorf and Russ Klettke, have put together a marketing plan. The ultimate objective: raise demand for genetic counseling services. Other goals include increasing consumer awareness and understanding of our work as well as gaining appropriate respect for our expertise within the health care continuum.

After careful consideration, we chose health care consumers as the target for our marketing efforts, recognizing that we hope to influence many others, for example, third party payers and legislators — who are more likely to respond to the wishes of their constituencies than to our direct efforts.

How do we reach consumers? Our first strategy is to gain visibility through frequent exposure in a broad range of media, particularly at the local level. Capitalizing on the media's excitement about genetic research, we aim to educate the public about the relevance of these breakthroughs to their own lives, including the services that are currently available. To this end, over 40 "media ambassadors" were trained at the Annual Education Conference in the art of working with reporters. As spokespersons for our profession in the nation's top 20 media markets, the ambassadors will answer factual questions as well as convey affirmative messages such as "genetic counseling is an integral part of today's health care delivery."

✉ Liz Stierman, Communications Committee Chair, ☎213-365-9266; nsgccomm@earthlink.net ♦

GENEAMP GOES PROFESSIONAL

In 1996, President Ann Boldt launched GeneAMP with the appointment of Ed Kloza and Beth Balkite as Co-chairs. GeneAMP was charged with developing a program to encourage NSGC members to develop projects to market genetic counseling services and genetic counselors. Over the next five years, 42 proposals were received and reviewed and 19 were funded.

Barbara Lerner replaced Beth as Co-chair in 1998, Andy Faucett replaced Ed Kloza in 1999. In 1999, a critical review of the quality and breadth of the incoming proposals was conducted, and in consideration of the external environment, a recommendation was made to hire a marketing consulting firm.

GeneAMP has accomplished its goals, allowing us to move into the next phase of our marketing strategy. To streamline communications, direct contact with our marketing group will be assumed by the Communications Committee Chair and Executive Director, giving the Board ultimate responsibility, accountability and oversight of our marketing endeavors.

NSGC's Board extends appreciation to all members who have helped GeneAMP arrive at this milestone in our growth and visibility. Members wishing to contribute to our marketing effort's success are encouraged to contact Liz Stierman, Communications Committee Chair.

NSGC thanks and acknowledges the following members who played key roles in GeneAMP: Chairs: Beth Balkite, Andy Faucett, Ed Kloza, Barbara Lerner Team Leaders: Lisa Brown, Debra Lochner Doyle, Cindy Johnson, Seth Marcus, Melonie Michelson, Joy Redman, Laura Waldman, Ali Warner. We apologize for omissions. ♦

CALIFORNIA GCs FIRST TO BE LICENSED

Ann P. Walker, MA

California Governor Gray Davis signed Senate Bill 1364, "The Genetics Test Disclosure and Genetic Counselor Licensure Bill," into law on September 30. This new law enables the Genetic Disease Branch (GDB) of the Department of Health Services (DHS) to establish regulations for licensing genetic counselors and PhD medical geneticists.

Regulations were developed and revised over about a year by the GDB and an advisory committee comprised of geneticists and representatives of other potentially affected groups (e.g. the California Medical Association, nursing groups, etc.). The regulations spell out the qualifications for licensure, license renewal and the mechanics of obtaining a license.

Licensure applications are expected to become available later this winter.

EFFECTS OF LICENSURE

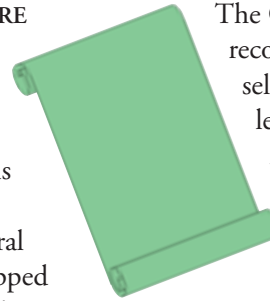
Because many hospitals and labs have advised against unlicensed professionals seeing patients with no physician present, several genetics units have stopped billing on MediCal patients altogether. Licensure should reassure hospital compliance officers.

The GDB is submitting an amendment to the MediCal regulations that will recognize licensed genetic counselors so that their services will be covered under California's MediCal program.

Licensure may also make it easier

for counselors to be credentialed by their hospitals or recognized as legitimate healthcare providers.

The California legislature's recognition that genetic counselors have a specialized expertise legitimizes our profession and means that unlicensed individuals will not legally be able to represent themselves as "genetic counselors."



CHANGING CLIMATE

Being licensed does not affect reimbursement for genetic counseling services directly because insurance companies rely on CPT and ICD-9 codes. Since the AMA must approve new CPT codes, the ACMG has been working to develop CPT codes that describe distinct components of the genetics evaluation and genetic counseling processes.

MORE INFORMATION

Efforts to educate the public and third party payors to lobby for change continue to be crucial. These efforts are being made by NSGC, the ABGC and the ABMG, but they must also come from each individual counselor.

The 'meat' of licensure criteria is in the regulations that are currently being finalized by the GDB. Sara Goldman may be willing to provide the most recent draft to counselors who are actively exploring licensure in their states.

✉ Sara Goldman ☎510-540-3041;
sgoldman@dhs.ca.gov ♦

MEMBERSHIP DUES: VALUE FOR YOUR DOLLARS

Kristine B. Courtney, MS &
Vivian Weinblatt, MS

Recently, all NSGC members received a bill for 2001 dues. This bill reflects a dues increase, which was approved by the Board of Directors at their fall meeting in Savannah.

Your membership dues are the lifeblood of NSGC. They underwrite many of the services you receive, such as *Perspectives*, the NSGC ListServ, the Professional Status Survey, the *Journal of Genetic Counseling*, the NSGC Website and our Executive Office, to name a few. NSGC's annual budget has grown 36% in the last three years, and inflation has occurred at approximately 3% per year, but NSGC dues have not increased since 1998.

The Board felt a dues increase was necessary to continue to provide the quality services you expect while addressing the important issues you have raised, including marketing our profession and billing and reimbursement. A large part of the additional revenue will help to fund a professional Time, Billing and Reimbursement survey in 2001 and will enable expansion of our marketing efforts.

Without your continued support and generous time spent on the activities of this Society, NSGC could not exist. Please keep in mind the benefits of membership in the organization that is the leading voice, authority and advocate of the genetic counseling profession.

✉ Vivian Weinblatt, President,
viweinbl@earthlink.net

✉ Kris Courtney, Finance Chair,
kcourtney1@mindspring.com ♦

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FULL TEXT OF SB1364

✉ www.senate.ca.gov. Follow the "Legislation" section link and enter bill number SB1364. Section 124981 pertains to licensure of genetic counselors. ♦

MEMBER INPUT ON STRATEGIC AND EXECUTIVE OFFICE PLANNING

VISION: The National Society of Genetic Counselors...the leading voice, authority and advocate for the genetic counseling profession.

MISSION: The National Society of Genetic Counselors promotes the genetic counseling profession as a recognized and integral part of health care delivery, education, research and public policy.

*Bea Leopold, MA &
Lisa Amacker North, MS*

INTRODUCTION

In 1991, NSGC initiated the process of creating a strategic plan — beginning with the creation of a vision and mission. As part of the planning process, a membership survey, designed to determine emerging issues, perception of member benefits and value and member satisfaction, was conducted.

| Survey Date | Total# Mailed | Response # | Rate % |
|--------------|---------------|-------------|-----------|
| 1993 | 1096 | 427 | . . . 39% |
| 1997 | 1476 | 310 | . . . 21% |
| 2000 | 1765 | 512 | . . . 29% |

TRENDS IN EMERGING ISSUES

Billing and Reimbursement (B&R) remained at the forefront of emerging issues, ranking first in all three surveys. Marketing and Licensure, terms not included in

the 1997 survey, were ranked second and fourth, respectively, in 2000. It could be surmised that the second highest ranking issue in 1997, Expanded Roles/Jobs in New Markets, would be a partner of Marketing; B&R may be perceived as a partner of licensure.

The four issues receiving the least value of importance are consistent in both 1997 and 2000:

- International voice and leadership
- Issues of identity/identification
- Competition for jobs
- Expanded alliances.

The most significant downward trend was Need for Outcome-based Research, dropping from third ranking to eighth.

MEMBER BENEFITS AND VALUE

In the member benefits section, the top rated benefits in 2000, in

rank order, were:

- Membership Directory
- Professional Status Survey
- Annual Education Conference
- *Perspectives in Genetic Counseling*
- General/Student ListServ.

In the Product category, the Annual Education Conference has experienced the greatest degree of improvement as a benefit. Services and Professional Development categories remain stable, with little shift among them.

Few “negative value” rankings were given. Of that category, the most often indicated were CEU opportunities (13 of 513 respondents) and website (11 of 519 respondents).

MEMBER SATISFACTION

In both 1993 and 1997, members were asked: “Are you satisfied with... your membership in NSGC?” ...information from the Executive Office?” ...the *quality* of materials from NSGC?” ...*quantity* of materials from NSGC?”

In 2000, the following questions were added to provide information to the Executive Office Committee: “Are you satisfied with ...the service from the Executive Office staff?” ...the accessibility of the Executive Office staff?” and “Are you receiving fair value for the price of your current membership?”

The satisfaction scale *See p. 13*

EXTERNAL EMERGING ISSUES RANKED BY 2000 SURVEY RESULT

| EXTERNAL EMERGING ISSUES | Rank | 1997 | | 2000 | | |
|------------------------------------|-----------|-----------|--------|----------|-----------|--------|
| | | N | Points | Rank | N | Points |
| Billing & reimbursement | 1 . . . | 234 . . . | 585 | 1 . . . | 362 . . . | 894 |
| Marketing genetic counseling/ors* | | | | 2 . . . | 215 . . . | 402 |
| Expanded roles/jobs in new markets | 2 . . . | 163 . . . | 329 | 3 . . . | 193 . . . | 355 |
| Licensure* | | | | 4 . . . | 182 . . . | 348 |
| Career autonomy | 5 . . . | 70 . . . | 128 | 5 . . . | 112 . . . | 233 |
| Public health policy | 4 . . . | 80 . . . | 138 | 6 . . . | 86 . . . | 150 |
| Quality assurance of GC services | 6 . . . | 69 . . . | 118 | 7 . . . | 64 . . . | 111 |
| Need for outcome-based research | 3 . . . | 88 . . . | 157 | 8 . . . | 60 . . . | 110 |
| Expanded alliances | 9 . . . | 24 . . . | 37 | 9 . . . | 26 . . . | 43 |
| Competition for jobs | 8 . . . | 32 . . . | 47 | 10 . . . | 26 . . . | 37 |
| Issues of identity/identification | 7 . . . | 35 . . . | 60 | 11 . . . | 20 . . . | 34 |
| International voice and leadership | 10 . . . | 8 . . . | 12 | 12 . . . | 19 . . . | 29 |

* not included in '97 survey

THE LARGER GENETICS COMMUNITY

Rosalie Goldberg, MS

The National Advisory Council for Human Genome Research was convened for its 30th meeting on September 11 at the Natcher Conference Center at the National Institutes of Health. Dr. Francis Collins, Director, National Human Genome Research Institute, presided.

RECENT ACCOMPLISHMENTS

On June 26, the Human Genome Project Public Consortium announced that it has assembled a working draft of the sequence of the human blueprint. The overlapping fragments cover 97% of the human genome, and sequence has already been assembled for approximately 85% of the genome. Dr. Robert Waterston, a Council member, Director, Washington University Sequencing Center and member, National Academy of Science, confirmed that 25% of the sequence is in finished form and 97% to 98% is in draft form. The predicted target date for finishing all of the genome is 2003. Of interest, the Y chromosome will be ready in the year 2000, chromosome 7 in the year 2001, chromosome 2 in the year 2002 and chromosome 4 in the year 2003. Publications on this work will be in the scientific literature by the end of this year.

The five largest sequencing centers, known as the G-5, meet every Friday by conference call and joined the G 16, The International Sequencing Consortium, at a meeting to resolve differences. Disagreement occurred because certain researchers have been working for many years on specific regions and diseases and want to be included in

the international effort.

RELATED RESOURCES

The Human Genome Central website contains a brief listing of links to some of the most useful public resources and a demo multimedia education kit.

The Department of Energy Genome Initiative has a new publication entitled *Bringing the Genome to Life*.



On January 16-18, 2001 a symposium, "A Decade of ELSI Research - A Celebration of the First Ten Years of the Ethical, Legal, and Social Implications" (ELSI Program) will be held.

☞ Conference: www.tech-res-intl.com/ELSI

☞ Human Genome Central: www.ncbi.nlm.nih.gov/genome/central

☞ Publication: www.science.doe.gov/ober/berac/genome-to-life-rpt.html ❖

NSGC INVITED TO ATTEND SFN BREAKFAST

Julie Lovell, MS

Making Strides Through a Unified Voice: 2000 Advocacy Group Breakfast was an interactive session held in conjunction with the recent Society for Neuroscience (SFN) Annual Conference. Representatives from numerous patient advocate groups were paired with SFN members who shared similar interests. The session allowed for direct conversation between the researchers working on unlocking the mysteries of neuroscience with those who work on behalf of individuals affected by neurologic disease. Recognizing the important role genetic counselors play as patient advocates, the SFN invited the NSGC to send a representative to the event.



ON THE ROAD

I was paired with SFN member Rudolph Tanzi who is the Director of the Genetics and Aging Research Unit at Massachusetts General Hospital, Harvard Medical School. Dr Tanzi studies the genetics of Alzheimer's disease, and he recently co-authored a nonfiction detective style novel, *Decoding Darkness*, that details the search for the genetic cause for Alzheimer's disease.

I was impressed that most of the individuals I spoke with at the event were familiar with genetic counseling as a profession. One individual even commended genetic counselors as being "some of the most informed people in the trenches."

One patient advocate expressed his frustration with what he perceived as the increasing distance between patients and families and the basic scientists who actually engage in research. He painted a literal image of large pyramids being built tall and steep. He described the scientists as positioning themselves at the tops of the pyramids while the families affected by neurologic disease wandered about in the sand between the bases of the pyramids. This image prompted me to share my belief that genetic counselors are in a unique position to act as liaisons between the families and the researchers. We are often the ones who help to build the ladders out of the sand and help the families navigate their way to the peaks of the pyramids. ☞ Society for Neuroscience, ©202-462-6688; www.sfn.org/ ❖



'01 CONFERENCE UPDATE

November 4 - 7, 2001 (Registration begins Nov 3)

20th Annual Education Conf: *Current Advances — Anticipating Change*

OVERVIEW:

The much anticipated completion of the Human Genome Project promises to alter our understanding of disease etiologies, processes and consequences dramatically. Genetic counselors can anticipate that new directions will impact changes in roles, patient care, education, legislation and research while creating interesting ethical dilemmas. This conference will provide learning opportunities that address these recent and anticipated advances in genetics and prepare the genetic counseling community for what has yet to be discovered. The conference will provide learning opportunities in didactic lectures, workshops, practice-based symposia and 4-hour intensive mini-courses, which allow for greater depth into select topics.

ABSTRACT DEADLINE: All abstracts for the Annual Education Conference must be submitted electronically by Friday, June 15, 2001 at 11:59pm EST. Notification regarding acceptance will be sent by e-mail (or letter if e-mail is not available) by July 16. Visit www.nsgc.org and then click on "About NSGC" or "Members' Corner" then "Educational Programs." Click on the Abstract Submissions Online link. Abstract submissions will be accepted *after February 15*.

✉ Susan Estabrooks, MS, ☎919-684-4996; sestabrooks@chg.mc.duke.edu or Liz Melvin, MS, ☎919-684-4787; emelvin@chg.mc.duke.edu

November 7-8, 2001

Short Course: *Counseling and Management of Metabolic Disorders*

OVERVIEW:

This conference will provide a comprehensive review of a variety of inborn errors of metabolism, such as the leukodystrophies, fatty acid oxidation disorders, peroxisomal disorders, lysosomal diseases, organic acidurias and amino acidemias. An emphasis will be placed on understanding the status of current biochemical and molecular testing options for diagnosing these conditions. Recent advances and protocols for testing during pregnancy, the newborn period and post-mortem screening and medical management and treatment for these conditions will be covered as well as counseling strategies aimed at assisting families in coping with the medical implications and psychological impact of metabolic diseases. ♦

NEW WEBSITE *from p. 1*

Designed with ease of navigation in mind, different sections target consumers, students interested in a genetic counseling career, reporters and those seeking general information. A password-protected area just for NSGC members where we can share resources and have private communications among ourselves will be activated later this Spring.

The site features state-of-the-art design features, including searchable databases to help access ResourceLink, to locate services or, for students, to learn about training programs.

Now that the infrastructure is in place, the next step will be to add content. The Online Communications subcommittee will assist committees, SIGs and members with ideas for additions to the site.

PASSWORD PROTECTION

On or about March 1, all members in good standing will be mailed a personal ID#, required to access the Members' Corner.

WEB EDITOR APPOINTED

Acknowledging that our website is a critical and dynamic communications tool, we have created the position of Web Editor, responsible for soliciting and editing web submissions, setting policies and developing content criteria. Our first editor is Beth Billings who spearheaded the web upgrade and has already dedicated countless hours toward the site's success.

✉ To help replace those "Coming Soon" notices with actual content, contact: Beth Billings ebillings@yahoo.com ♦

POINT: Is Taking the Exam in Our Best Interest?

*Beth N. Peshkin, MS,
Ellen T. Matloff, MS &
Deborah A. McDermott, MS*

The ICE credential in Clinical Cancer Genetics poses a serious threat to the future of the genetic counseling profession. We believe that it is unnecessary, and potentially harmful, for genetic counselors to acquire this credential for the following reasons:

- We already possess the 'gold standard' training and credentialing. Genetic counselors who hold a master's degree from an ABGC accredited program and are ABGC board-eligible/certified have undergone comprehensive, diverse training in genetics that includes participation in clinical cases under the supervision of a certified professional.
- ICE has stated that their credentials are designed to "set clinical performance standards" and to "identify competence," but this is the role of ABGC. We do not want an external organization to set standards for our profession; to do so is a dangerous precedent.
- We do not need additional credentials for specializing. The ABGC has not yet indicated that further credentials are needed to demonstrate competence in genetic counseling specialty areas. If subspecialty credentials in genetic counseling do become warranted, the ABGC should develop them. If we take exams

offered by other organizations, and this becomes a professional standard, those of us who have diverse practices will be forced to spend a lot of time and money obtaining many credentials. To pursue the ICE credential and others like it would completely erode and undermine the value of ABGC training and board certification.

We must have a unified stand on the value of our training and certification. It is critical that consumers, colleagues and employers understand the standards they can expect from those who call themselves genetic counselors. The ICE credential short-changes us by lowering those standards.

It is very possible that genetic counselors may be denied jobs or referrals (whether they have this credential or not) because physicians and other health care professionals without training in genetics will obtain the ICE credential and will no longer feel the need to refer to genetic counselors.

We need to send a clear message that training and credentialing by the ABGC are the only acceptable genetic counseling standards, and we can only do this if our Society stands together and does not endorse exams such as this.

Finally, we hope that genetic counselors who decide not to pursue this credential realize that they are in fact sending a larger message: that maintaining the integrity of our profession is of the utmost importance to us, our Society and the patients whom we serve. ♦

COUNTERPOINT: ...

Vickie L. Venne, MS

The purpose of this exam, according to the ICE website, is "to evaluate the skills obtained through continuing education and practice experience." All exams that ICE has developed cross provider domains and speak to the issue that the best patient care is often provided by a knowledgeable health care team.

In a rapidly advancing and multidisciplinary medical field such as cancer risk assessment and counseling, it makes sense to develop a method of identifying competence in a clinical specialty area. The inclusion of genetic counselors in this process is a tribute to our importance in providing this health care service.

- The purpose of this examination is not to sanction other professionals as genetic counselors. However, it recognizes the essentiality of genetic counseling as a component in the provision of this medical service and could offer benefits to genetic counselors who pass the examination. Also, passing the same examination as physicians may enhance and not detract from the credibility of genetic counselors.
- In the future, this exam may be used for credentialing cancer risk assessment programs or for employment reasons. It provides a way to assess some knowledge base across disciplines. This credential may help payors recognize a level of competence when making reimbursement decisions, although that would most likely not happen until a critical number of providers are credentialed.

...Reasons to Warm to ICE Exam

- As genetic counselors struggle to identify mechanisms to develop a revenue stream, passing such an exam could help with reimbursement.
- Although the ABMG and ABGC certifications evaluate our genetic and counseling knowledge, this exam would *credential* specific knowledge in the highly public cancer genetic field. And for those of us who became boarded prior to 1996 and are not required to recertify, passing this exam is another way to demonstrate a commitment to staying current.
- Consider that the issue is quality patient care and not whether genetic counselors are the only ones who could possibly provide cancer genetic services. In that light, there are other benefits to our patients. As our families identify members who do not have easy access to major medical centers, but still deserve quality care, the exam could help identify clinicians motivated enough to learn this information and sit for an exam to demonstrate competence — as well as the converse. Many providers will learn the limitations of their knowledge.

Promoting multidisciplinary knowledge will not diminish the necessity of skilled genetic counselors and may, in fact, increase the demand for our services. Sometimes the more you know, the more you realize when it is time to refer. ♦

ICE Website: www.icemed.org
ABGC Newsletters (for ICE Updates) www.faseb.org/genetics/abgc/news/news-menu.htm

EXCERPTS: NSGC'S OFFICIAL RESPONSE ICE

November 27, 2000

Dear Dr. Norcini:

...I would like to take this opportunity to reply to your invitation to "develop a working relationship" with regard to your clinical cancer genetics credentialing examination.

As the leading voice, authority and advocate of the genetic counseling profession, representing over 1800 genetic counselors, students and other genetics professionals, NSGC supports ICE and ASCO in their efforts to improve the knowledge and skills of health care providers. The NSGC shares this commitment to continuing education by providing high-level national and regional education conferences ...designed to support the education needs of our membership, keeping them current and competitive in the ever-changing world of human genetics.

The NSGC recognizes the American Board of Genetic Counseling (ABGC) as its certifying organization, and the vast majority of our membership both seeks and achieves this certification. ...ABGC is considered the gold standard for certification for the genetic counseling profession.

Many members of the NSGC membership have raised concern regarding the ICE clinical cancer genetics credential, specifically with regard to consumer/patient confusion between those health care providers with the ICE credential and those with ABGC certification, particularly when considering the similarity between the CGC and CCG designations.

Members are also unclear regarding the significance of this credential within their own cancer genetics units and worry about the possible erosion of the value of ABGC certification.

Other members are less concerned about the impact of the ICE cancer genetics credential. However, in light of the concerns raised by a significant segment of our membership, we do not anticipate seeking a formal working relationship with ICE on this issue at this time. As a result of the absence of consensus among our membership, we cannot endorse the ICE credential, and we do not anticipate offering the exam in conjunction with NSGC annual or regional conferences. Individual genetic counselors will make their own determinations with regard to the value of this credential and will act according to their own professional ethics.

The ABGC has also raised concern with ICE's credentialing process, and we support its efforts to raise these issues to your Board of Directors. We hope an understanding can be reached which results in the continued provision of quality cancer genetics services for our patients.

Finally, the NSGC would like to express its concern that ICE chose to proceed with this credentialing process without the active involvement of the professional genetics organizations in the early stages of its development. We suspect that at least some of the discord generated by this exam might have been ameliorated by collaboration from the outset. That said, we remain available for further discussion and comment regarding this issue and look forward to the outcome of your Board of Directors meeting later this month.

Vivian J. Weinblatt, MS, CGC
President

Note: Dr. Norcini is Executive Vice President of ICE. ♦

Perspectives in Genetic Counseling
22:4 — Winter 2000/01



Psychosocial Genetic Counseling

Author: Jon Weil

Publisher: Oxford University Press,
198 Madison Avenue, New York
NY, 10016

Cost: \$49.95; 297 pp

Reviewer: Lisa Andres

Finally the field of genetic counseling has a book that not only provides readers with an important theoretical background to psychosocial genetic counseling, but also provides practical tools that help implement what they have learned. The author offers many examples of specific counseling situations throughout the book as well as examples of dialogue between genetic counselors and counselee(s). In doing so the author provides the reader with some powerful intervention strategies.

The first few chapters focus on the psychological issues faced by a counselee as an individual and in the broader social context. These chapters are followed by a focus on the techniques and structure of psychosocial genetic counseling.

The next section addresses risk assessment and decision-making in the context of a non-directive approach to genetic counseling. The reader is then provided with practical approaches to specific counseling situations including cancer risk counseling and genetic counseling of children and adolescents.

The next chapter, "The Ethnocultural Imperative" first provides us with a background, which helps

RESOURCES • RESOURCES • RESOURCES •

us to understand ethnic and cultural differences and the potential ethnocultural barriers to genetic counseling. This chapter then provides us with practical cross-cultural genetic counseling perspective and looks at genetic counseling in the larger social context. The author examines existing sociological research into the resistance to reproductive genetic screening, testing and counseling and explores the perspective of individuals affected by genetic birth defects and disabilities.

The author has written this book with a wealth of experience. He holds PhDs in Genetics and Social-Clinical Psychology, and he also has a private psychotherapy practice which focuses on the psychosocial impact of genetic diseases and birth defects on individuals and families.

Dr. Weil has utilized his experience as the Director, UC Berkeley Genetic Counseling Program, to provide an excellent teaching tool for genetic counseling students.

This book's appeal, however, is not limited to students since even genetic counselors who have been practicing for many years could benefit immensely from a thorough review. This book is an excellent resource for all medical professionals who deal with patients and families who are impacted by genetic testing, genetic conditions, birth defects and disabilities. ♦

GENETICS IN PRINT



Kathryn Peters, MS, Betty Alvarado, MSW, & Stacy Schmidt, MS

Got some extra time? A recent ListServ query uncovered the following fiction and non-fiction books featuring characters with

genetic conditions. An asterick (*) indicates that the book is fiction.

Down Syndrome and Other Forms of MR or Developmental Disabilities

- *Another Season*, G. Stallings
- *Expecting Adam: A True Story of Birth, Rebirth, and Everyday Magic*, M. Beck
- *Before and After Zachariah: A True Story about a Family and a Different Kind of Courage*, F. Kupfer
- * *Don't Call Me Marda*, S.K. Welch
- * *Flowers for Algernon*, D. Keyes
- * *Jewel*, B. Lott
- *My Journey With Jake: A Memoir of Parenting and Disability*, M. Edelson
- *The World of Nigel Hunt*, N. Hunt
- * *Tru Confessions*, J. Tashjian

Autism

- *A Child Called Noah*, J. Greenfield
- *Family Pictures*, S. Miller
- *Nobody, Nowhere: The Extraordinary Autobiography of an Autistic*, D. Williams

Cancer

- *Autobiography of A Face*, L. Grealy
- *It's Always Something*, G. Radner
- *Second Act*, B. Barrie

Huntington disease

- *Mapping Fate*, A. Wexler
- *Faces of Huntington's*, C. Leal-Pock

Cystic Fibrosis

- *Alex, the Story of a Child*, F. Deford
- *Stevie's Secret*, D. Shader Smith

Achondroplasia

- * *Mendel's Dwarf*, S. Mawer
(author is descendent of Gregor Mendel)

See next page

RESOURCES

from previous page

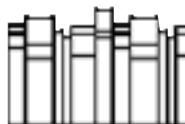
* *Stones From the River*, U. Hegi

Mental Illness

- *The Diminished Mind*, H. Anifantakis (Alzheimer disease)
- *The Man Who Mistook His Wife for a Hat*, O. Sacks
- *An Unquiet Mind*, K. Redfield Jamison (bipolar disease)

Other Themes

- * *Fear Nothing* and **Seize the Night*, D. Koontz (xeroderma pigmentosa)
- * *Herman*, L.S. Christensen (alopecia areata)
- *Intensive Care: A Family Love Story*, M. Weisman (DMD)
- *Kara Mia*, M. Anglim and W. Allan, MD (long Q-T syndrome)
- *Journey*, R. & S. Massie (hemophilia)
- *Ordinary Daylight: Portrait of an Artist Going Blind*, A. Potok (RP)
- *Searching for the Stork: One Couple's Struggle To Start a Family*, M.L. Wasserman (reproductive difficulties)
- *Swimmer in the Secret Sea*, W. Kotzwinkle (stillbirth)
- *The Broken Cord*, M. Dorris (fetal alcohol syndrome)
- *The Child Who Never Grew*, P. Buck (PKU)
- *The Silents*, C. Abrams (deafness)
- *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures*, A. Fadiman (epilepsy)
- *Ten Years to Live*, H. J. Schutt (inherited ataxia) ❖



Media WATCH



Roxanne Ruzicka, MS &
Angela Geist, MS

NPR and CBS News' *The Early Show* (August 7) discussed the variability among state newborn screening programs. The American Academy of Pediatrics is lobbying the federal government for uniform testing standards. The report correctly mentions that all states have mandatory newborn screening for PKU and hypothyroidism and that tests are available for about 30 inherited diseases, but few states require full newborn screening.

Science (Sept 15) "Genetic Testing - Present and Future" discusses the merits and problems inherent in genetic testing. The article states that "because of these complex psychosocial and technical issues, it is clear that genetic testing should never be offered to patients without appropriate genetic counseling."

More (Oct) featured an article on genetic testing for cancer. Several genetic counselors were quoted, including Jill Stopfer and Helen Hixon, and the article promoted genetic counseling before testing. *The Best of Health: 275 Questions You've Always Wanted to Ask Your Doctor*, by Marvin Lipman, MD, contains a helpful section on genetic testing. Readers are advised to take the initiative to discuss family history concerns with their physicians since "not all doctors nowadays have the time or the interest to review their patients' family history." The authors advise anyone interested in genetic testing to see a genetic counselor with "at least a master's degree in genetic counseling, plus certification by the American Board of Medical Genetics or the American Board of Genetic Counseling." Readers are

asked to "be prepared to do your own legwork rather than count on your doctor for a referral" since "according to a recent survey, 20 percent of internists in one state weren't even aware whether genetic counseling was available in their area." NSGC is mentioned as a referral source, and reasons for seeking genetic counseling as well as some of the possible benefits/drawbacks of testing are discussed.

"ER" (Nov 2) presented a boy with end stage Niemann-Pick disease type A. The doctors argued the value of giving hope for a treatment that may delay death only slightly.

Parents (October) In "Saying Good-Bye to Vincey," an Irish couple's one-year-old son is diagnosed with Tay Sachs disease. The disease and its inheritance are accurately described and a genetic counselor is mentioned in the role of discussing the natural history of the disorder. Another couple used amnio for prenatal diagnosis for Tay Sachs. ❖

IN MEMORIUM

Evelyn Lilienthal (SLC'78) died on December 13 of lung cancer. She was NSGC's first Membership Committee Chair and worked for many years at Stamford Hospital, in Stamford CT and Westchester County Medical Center in Valhalla NY. She mentored many who entered the profession in its early years. She will be deeply missed by those who knew her.

Genetic Counselors wishing to acknowledge Evelyn's life to her family may write to Peter Lilienthal and Family, 34 Duncan Dr, Greenwich, CT 06831. ❖

Perspectives in Genetic Counseling
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BULLETIN BOARD

NEW JOURNAL EDITOR NAMED

Allyn McConkie-Rosell, PhD, has been appointed Assistant Editor of the *Journal of Genetic Counseling* and will assume the Editor-in-Chief position in January 2002. Board Certified by the American Board of Medical Genetics in 1984, she holds a PhD in social work with a minor in health behavior.

Allyn envisions the *Journal* as representing the diversity of the profession in the 21st century.

Allyn, and of course Bob, continue to encourage the membership to not only submit manuscripts, but also to alert the *Journal* Editorial Board about timely topics for review, articles and interesting research. ♦

RESEARCH NETWORK

NEUROFIBROMAS IN NF1

We are conducting a genetic study to determine whether alleles of DNA repair or cell cycle checkpoint genes affect the rate of neurofibroma formation in NF1 patients. For the purpose of this study, we are specifically looking for patients in the following categories:

- 18 - 20 years old with fewer than 5 or more than 30 neurofibromas
- 20 - 30 years old with fewer than 10 or more than 100 neurofibromas
- 30 - 40 years old with fewer than 20 or more than 200 neurofibromas.

✉ Dr. Andre Benards,
©617-726-5620;
abernard@helix.mgh.harvard.edu ♦

Perspectives in Genetic Counseling
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SUBCOMMITTEE TO DRAFT POSITION PAPER ON PATENTING AND DNA SEQUENCES

A subcommittee of the Genetic Services Committee will generate an NSGC position paper on the patenting of DNA sequences. Interested members are invited to participate.

✉ Nathalie McIntosh,
©617-355-7311;
mcintosh@rascal.med.harvard.edu ♦

NEW NSGC PUBLICATIONS

Working with Women who have Mental Retardation, by Brenda Finucane, is available to members for \$15, including postage and handling fees. The book, funded by the Jane Engelberg Memorial Fellowship, addresses the complexities and

challenges genetic counselors face.

Another new publication, *Genetic Counseling Casebook*, is a compilation of 22 cases gathered by the Education Committee. The price is \$8.00, including postage and handling fees.

Both are available by sending a check, payable to NSGC, to the Executive Office. ♦

SB BROCHURE AVAILABLE

A new brochure tailored for women at higher risk for NTDs, *Plan Ahead - Do What You Can*, is available through the Spina Bifida Association of America (SBAA), National Information and Resource Center. Organizations or clinics may order the first 50 copies at no charge.

✉ ©800-621-3141; www.sbaa.org ♦

ENGELBERG FELLOWSHIP ENTERS 10TH YEAR

The 10th Jane Engelberg Memorial Fellowship (JEMF), an annual \$50,000 grant of the Engelberg Foundation to NSGC, will be awarded for 2001-2002 to one or more genetic counselor(s) for study, research, writing or exploration of new interests to enhance present skills, develop new skills, contribute to the body of knowledge in the field of genetic counseling or expand professional roles.

JEMF invites proposals from genetic counselors who are full members in good standing of NSGC and are certified in genetic counseling by the American Board of Medical Genetics or the American Board of Genetic Counseling. Individuals who have been granted active candidate status by the American Board of Genetic Counseling also are eligible to apply. Applicants may elect to pursue fellowship work on a part-time or full-time basis for a maximum of one year. The award will be presented at NSGC's Annual Education Conference in 2001 in Washington DC. Applications are due May 1. A Program Application and Guideline Booklet will be mailed to all Full members in January.

✉ Robin Bennett, Medical Genetics, University of Washington Medical Center, Box 357720, Seattle, WA 98195, ©206-616-2135,
fax: 206-616-2414, robinb@u.washington.edu

✉ Joan Scott, Gene Logic, 708 Quince Orchard Rd, Gaithersburg MD 20878; ©240-631-7477, fax: 301-926-6125, jscott@geneologic.com ♦

COMMITTEE AND SIG UPDATES

NEW TELEGENETICS SIG

Becky Butler, MSSW

The Telegenetics SIG has been formed to reflect emerging telecommunications technologies that include both telemedicine and distance education. The group will serve as a resource to NSGC and to each other on issues related to telegenetics, including updates on new technology, clinical services, billing and reimbursement, licensure, educational modes (for genetic counselors, health professionals and

consumers) and ethical issues.

The Telegenetics SIG is developing a position statement as well as articles for the *Journal of Genetic Counseling and Perspectives*. A list of existing telemedicine and web guidelines from outside groups is being gathered and circulated. An ongoing activity will be the identification of telemedicine and distance education web sources, grant sources and identification of genetic counselors who are doing telegenetics and what they are

doing. A proposal will be developed for an educational session at the 2002 Annual Education Conference.

☎ Becky Butler, 501-296-1736;

ButlerBeckyB@exchange.uams.edu

☎ Robin Bennett, 206-616-2135;

robinb@u.washington.edu ♦

'01 SIG CHAIRS

The following listing represents changes in Special Interest Group (SIG) leadership. If a SIG is not noted, please refer to your 2000 Membership Directory for current chairs of each SIG.

DIVERSITY

Barbara Harrison

..... bfwillis@howard.edu

Nisha Isaac. . . danisaac@starpower.net

FAMILIAL CANCER RISK

Jill Brensinger brensji@jhmi.edu

Susan Manley . . smanley@myriad.com

PEDIATRICS

Helga Toriello

..... helga.toriello@spectrum-health.org

PRENATAL

Renee Chard . . . chardr@poa.mmc.org

Molly Carpenter

..... carpem@poa.mmc.org

PRIVATE PRACTICE

Barb Pettersen BarbPett@bendcable.com

PSYCHIATRIC DISORDERS

Beth Rosen-Sheidley

..... bsheidley@lifespan.org

Chantelle Wolpert

..... chantell@chg.mc.duke.edu

New SIGs in '01

INDUSTRY

Heather Brown.

..... hbrown@genesage.com

Kathleen Fergus . kfergus@dhs.ca.gov

TELEGENETICS . (See article, col 1) ♦

STRATEGIC, EXECUTIVE OFFICE SURVEY RESULTS, fr p. 5

was rated from 1 (most satisfied) to 4 (least satisfied). To determine highest value by the membership, only the first and second ranks were tallied.

Member satisfaction is indicated in percentage on the chart, "Comparison of Membership Satisfaction," on this page. Member *dissatisfaction* indications were ≤4% for each of the first four categories.

Regarding Executive Office service and accessibility, only 4 of 485 respondents indicated "least satisfied" with service from Executive Office staff and 15 of 488 (3%) indicated "least satisfied" with staff accessibility.

LOCATION, LOCATION, LOCATION

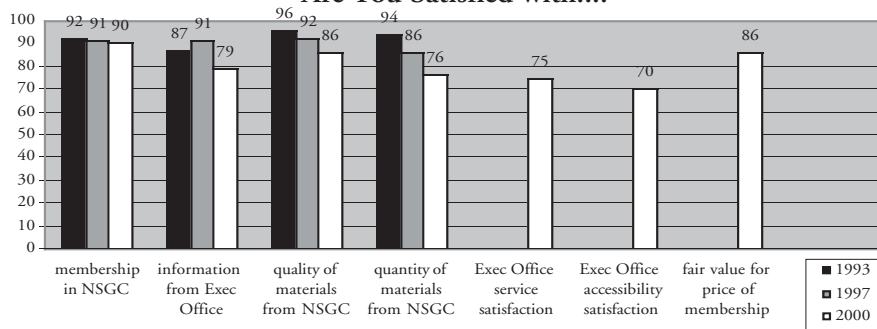
Lastly, the issue of the location of the Executive Office in relationship to the impact on services and/or visibility yielded an 82% negative (location does not matter) and 18% positive (location does matter) response. Of the responses, 89% of each value represents the perceptions of Full members.

WHERE TO GO FROM HERE

This report will be the foundation for NSGC's 3rd Strategic Plan. Copies of the complete survey results are available by contacting the Executive Office.

☎ fax: 610-872-1192; nsgc@aol.com ♦

Comparison of Membership Satisfaction.
Are You Satisfied with....



EMPLOYMENT OPPORTUNITIES

■ **HOLLYWOOD CA:** Immediate opening for BC/BE Genetic Counselor. Join 1 GC in OB/Gyn dept for primarily PN GC on temp, maternity leave cvg assignment.
 ☞ Send ltrs rec & CV: Stephanie Morton MS or Jeffrey Greenberg, MS, Kaiser Permanente, OB/Gyn Dept, Hollywood CA; ☎323-783-5756; Fax: 323-783-5208; stephanie.w.morton@kp.org, jeff.d.greenberg@kp.org. EOE/AA

■ **LOS ANGELES CA:** Spring 2001 opening for BC/BE Genetic Counselor. Motiv, independent & excellent comm & orgskills req. Exp in cancer genetics and/or Span desired. Abil to work well w/ diverse pt & prof grps essential. Join GC, medical geneticist & world-renown team of cancer & chemopreven specialists at ldg clin & rsrch fac. Counsel clients w/ hered suscep to BR, OV, colon & other cancers. Partic in rsrch protocols, develop public & prof educ progs in cancer genetics & provide clin trng to GC students.
 ☞ CV & 2 ltrs of rec: Monica Alvarado, MS, Cancer Genetics Unit, USC/Norris Comprehensive Cancer Center, 1441 Eastlake Ave-M/S 34, Los Angeles CA 90089. EOE/AA

■ **LOS ANGELES (AREA) CA:** Immediate opening for FT or PT Genetic Counselor. Korean/Chinese or Spanish pref. Respon: PN GC.
 ☞ Maria Ochoa, Maternal Fetal Medicine, 330 W. Las Tunas Dr, PNDx Ctr at San Gabriel Valley Medical Ctr, San Gabriel CA 91776; ☎626-282-9250; Fax: 626-282-9953; akarimi@chw.edu. EOE/AA

■ **ORANGE CA:** Immediate opening for BC Genetic Counselor w/ Faculty appointment. Exp in peds & adult genetics, excellent clin, i'personal & org skills, computer proficiency essential. Span desired. Respon:GC pts in non-PN settings; tchg & clin s'vision for GC students; med student, resident & other health prof educ; commun outreach; new prog devel; clin rsrch.
 ☞ CV & 3 ref: Suzanne B. Cassidy, MD, Director, Div Human Genetics, Dept Pediatrics, UCI Medical Center, 101 The City Dr, Bldg. 2, 3rd Fl, ZOT 4482, Orange CA 92868; ☎714-456-6873. EOE.

■ **SACRAMENTO CA:** Immediate opening for BC/BE Genetic Counselor. Travel to satellite clins in Stockton & Modesto. Span desired. Work w/ 3 GCs & Repro Geneticist in busy PNDx priv prac. PN GC for all aspects of PNDx: AMA, abn U/S, + Exp AFP, + fam hx, terat. Oppty to partic in 2 multi-ctr NIH trials; 1st trimester scrng & random study of transabdom CVS & early amnio.
 ☞ Diana Stultz, Practice Manager, Prenatal Diagnosis of Northern California Medical Group, 1315 Alhambra Blvd #210, Sacramento CA 95816; ☎916-736-6708; Fax: 916-731-5569; ADMPNdx@aol.com. EOE/AA

■ **SAN FRANCISCO CA:** Immediate opening for BC/BE Cancer Genetic Counselor. Cancer GC exp pref. Full gamut of GC, risk asmt & genetic tstg svcs to indiv & fam at risk for BR & OV cancer, CHR-approved BRCA1 & 2 tstg protocols.

☞ Beth Crawford, MS, UCSF Cancer Risk Program, 1600 Divisadero 2nd fl, San Francisco CA 94115-1714; ☎415-885-7779; Fax: 415-885-3787. EOE/AA

■ **SAN JOSE:** Immediate opening for FT/PT BC/BE Genetic Counselors. Independent & team player work style req. Provide GC for PN & preconcep pts.
 ☞ Elaine Palome, Staffing Consultant, Genzyme Genetics, 15 Pleasant Street Connector, PO Box 9322, Framingham MA 01701-9322; Fax: 508-872-2460; elaine.palome@genzyme.com. Electronic communications pref. EOE/AA.

■ **SAN JOSE CA:** Immediate openings for BC/BE Genetic Counselors. Independent work style pref. Join team of 4 GCs & 5 perinatologists to provide PN GC at state-approved PNDx ctr: AMA, triple marker scrng, fam hx, terat, & U/S abnorm. Potential involv in bereavmnt supt grp.
 ☞ Cover ltr & 2 ltrs of rec: Kim Rittenhouse, MS, PhD, Perinatal Practice Management/Obstetrix, 2520 Samaritan Dr, San Jose CA 95124; ☎408-358-7127; Fax: 408-358-8264. EOE/AA

■ **NEW HAVEN CT:** Summer 2001 opening for Cancer Genetic Counseling Internship. 3-month paid summer internship avail. Min 1 yr grad work in GC from ABGC-accred prog. Respon: clin cancer genetics & research proj.
 ☞ Apps must be received by 2/1. Send resume, 2 ltrs of rec & a 300-400 word personal stmnt re: interest in this oppty to: Ellen T. Matloff, MS, Director, Cancer Genetic Counseling, Yale Cancer Center, Box 208028, New Haven CT 06520-8028; ellen.matloff@yale.edu. EOE/AA

■ **NEWARK DE:** Immediate opening for BE Genetic Counselor. GC to persons or families w/ hx of certain cancers or known risk factors.
 ☞ Attn: KSGC/PR99, Christiana Care Resume Service, PO Box 549251, Suite 200, Waltham MA 02454-9251; Job Hotline: 800-999-9169; christianacare@hiresystems.com. For immediate processing, www.christianacare.org to apply on-line. EOE/M/F/D/V

■ **MIAMI FL:** Immediate opening for FT/PT BC/BE Genetic Counselors. Independent & team player work style req. Provide GC for PN & preconcep pts.
 ☞ Elaine Palome, Staffing Consultant, Genzyme Genetics, 15 Pleasant Street Connector, PO Box 9322, Framingham MA 01701-9322; Fax: 508-872-2460; elaine.palome@genzyme.com. Electronic communications pref. EOE/AA.

■ **SOUTH FL:** Immediate openings for Genetic Counselors for Sheridan Healthcorp, a natl grp practice management co. Opptys for exp GCs in Fort Lauderdale, Weston & Boca Raton perinatology practices.
 ☞ Karen Block, Sheridan Healthcorp, Inc, ☎800-437-2672 x7674; Fax: 954/964-5461; kblock@shcr.com. EOE/AA

■ **TAMPA FL:** Immediate opening for FT/PT BC/BE Genetic Counselor. Join growing cancer GC & tstg prog at NCI-designated Cancer Ctr. Clin & rsrch incl variety of cancer suscep syndromes. Respons: GC at cancer ctr & area MD offices under clin & rsrch-driven protocols.

Prof & commun educ.

☞ Terry Ferlita, MS, H. Lee Moffitt Cancer Ctr & Research Ctr, Lifetime Cancer Screening Ctr, 4117 E. Fowler Ave, Tampa FL 33617; ☎800-456-3434, x 6981; Fax: 813-632-1769; ferlittm@moffitt.usf.edu. EOE/AA

■ **ATLANTA GA:** Immediate opening for BC/BE Genetic Counselor in private, academic medical genetics ctr. Enthusiastic, dedicated individual w/ excellent verbal & written commun skills, computer-friendly, ability to travel.
 ☞ GeneCare Medical Genetics Center, PO Box 4270, Chapel Hill NC 27515-4270; No phone calls, please. EOE/AA

■ **SAVANNAH GA:** Immediate opening for BC/BE Genetic Counselor. Some cancer exp pref. Join busy MFM prac involv all aspects of PN GC. Join team of 3 MFM MDs & expndg GC dept to provide: AMA, serum scrng (1st & 2nd trimester), terat, family hx, & U/S anom. Possibility of PN/cancer GC job share.
 ☞ Send CV & 3 ltrs of rec: Tahnee Causey, MS, Savannah Perinatology, 4750 Waters Ave-Ste 202, Savannah GA 31404; ☎912-350-5970; Fax: 912-350-3374; causea1@memorialmed.com. EOE/AA

■ **IOWA CITY IA:** Immediate opening for Program Associate I. BC/BE GC or nursing, PH or related field req. BS in nursing & license to practice in IA desirable. Provide genetic eval & GC svcs in Reg'l Genetic Consult Clin, conduct clin, educ, admin, liaison & rsrch activ, as directed.
 ☞ Attn. #54 c/o Janine McBride-Rahn, University of Iowa, 200 Hawkins Dr, Iowa City IA 52242-1083; Fax: 319-356-4855. EOE/AA/ Women & minorities strongly encour to apply.

■ **CHICAGO IL:** Immediate opening for BC/BE Genetic Counselor. Must be independent & motivated. Join active team in PN & PGD setting: Coord 1st trimester scrng prog & GC for CVS & amnio, other PN indications. Potential respon for infertility & IVF pts, assist w/ PGD prog coord. Opptys for publication.
 ☞ Christina Masciangelo, MS, Reproductive Genetics Institute, 836 W Wellington-Ste 4504, Chicago IL 60657; ☎773-296-7095; Fax: 773-871-5221; cmascian@immc.org. EOE/AA

■ **CHICAGO IL:** Immediate opening for PT BC/BE Egg Donor/Pre-conception Genetic Counselor. Interest in ART & pre-conception GC req; must carry liability insurance. Oppty for growth to FT and branch into other areas of pre-conception GC.
 ☞ Nazca I. Fontes, Director, 2835 N Sheffield Ave Ste 237, Chicago IL 60657; ☎773-868-3971; Fax: 773-868-3972; eggdonation@roidonors.com. EOE/AA

■ **BOSTON MA:** Immediate opening for PT (20 hrs/wk) Genetic Counselor. Exp pref. Independent work style req. Join 2 GCs & 1 MD geneticist in busy academic high-risk PN genetics prog. Primary respon: accompany MFM to satellite hi-risk clins in local commun hospitals.
 ☞ Fax resume: Heather Ferguson, MS, Beth Israel Deaconess Medical Center, 330 Brookline Ave, Boston MA 02215; ☎617-667-7110; Fax: 617-667-1551. EOE/AA

EMPLOYMENT OPPORTUNITIES



■ **WALTHAM MA:** Apr 01 opening for BC Co-Director, Brandeis Genetic Counseling Program. Extensive clin exp req. Direct clin internships, plan prof devel, tch couns/preprof courses, advise students, consult on rsrch proj, partic in admission process, prog plng.

✉ Submit CV & draft course outline for "Intro to GC" by Feb 1; Judith Tsipis, PhD, Director, Genetic Counseling Program, Brandeis University, biology Dept MS 008, Waltham MA 02454; ©781-736-3165; tsipis@brandeis.edu. EOE/AA

■ **BALTIMORE MD:** Immediate opening for BC/BE Genetic Counselor. Join multidisc team of clinicians & rsrchrs at Hereditary Colorectal Cancer Program. GC for personal or family hx of cancer in clin & rsrch settings, initiate or assist w/ rsrch or clin projects.

✉ Susan Booker, Program Coordinator, The Johns Hopkins Hospital, 550 North Broadway-Room 410, Baltimore MD 21205; ©410-955-4040; Fax: 410-614-2325; bookesu@jhmi.edu. EOE/AA

■ **BALTIMORE MD:** Immediate opening for Research Program Coordinator w/ MS in related area req. Respon: manage studies of various diseases w/ genetic components.

✉ Send salary history with CV: Attn: Job #MNSG849, Johns Hopkins University, PO Box 3687, Scranton PA 18505; JHU@alexus.com. EOE/AA/D/V

■ **BALTIMORE MD:** Immediate opening for 2 Data Base Manager and Research Analyst. Working knowl of MS Access &/or UNIX; rsrch exp desirable. Join rsrch grp studying genetics & epidem of diabetes, obesity, osteoporosis, other

aging-related disorders.

✉ Mail CV to: Dana Randolph, Human Resources, University of Maryland, 737 W Lombard St, Baltimore MD 21201. Also EM or fax CV to Braxton Mitchell & T. Pollin. Fax: 410-706-1622; tpollin@medicine.umaryland.edu. EOE/AA

■ **BETHESDA MD:** Immediate opening for a BC/BE Genetic Counselor within the Neurogenetics Branch, NINDS/NIH: GC & educ within rsrch protocols for families w/ hereditary neurological diseases. Primary focus: clin care; managing clins; assist w/ devel & admin of therapeutic trials; implement research protocols in GC.

✉ Erica Greene, Bldg.31/Rm 8A23 MSC 2540, Bethesda, MD 20892; ©301-435-5499; lylese@ninds.nih.gov. EOE/AA

■ **ROCHESTER MN:** Immediate opening for BC/BE Genetic Counselor (50%PN; 50% genrl). PN exp pref. Join team of 6 MDs & 3 GCs: varied pt population at lrg tertiary/ref ctr: PN, adult, cancer, others. Oppty for rsrch & educ roles.

✉ Cynthia Scott, Staffing Specialist, Mayo Clinic Staffing Ctr, 200 1st St. SW OE 1-22, Rochester MN 55905; ©507-284-0030; Fax: 507-284-1445; careers@mayo.edu; www.mayo.edu. EOE/AA

■ **COLUMBIA MO:** Immediate opening for BC/BE Genetic Counselor. Join 3 GCs & 3 MD geneticists: Direct PNDx & GC svc & AFP prog; in-house consult rotations. Opptys for prof growth, rsrch & prog devel.

✉ Judith Miles, MD, PhD, Medical Genetics, Dept Child Health, University of Missouri Hospitals and Clinics, Columbia MO 65212; ©573-882-6991; milesjh@missouri.edu. EOE/AA

■ **ST. LOUIS MO:**

Immediate opening for Genetic Counselor in priv prac setting. Enthu-siastic, dedicated, team-oriented individual. MS or RN req, exp in preconcep & PN GC req. ✉ GeneCare Medical Genetics Center, PO Box 4270, Chapel Hill NC 27515-4270; No phone calls, please. EOE/AA

■ **CHAPEL HILL NC:**

Immediate opening for BC/BE Genetics Counselor. Exp pref. Join busy univ-based PNDx Prog w/ 7 perinatologists, 3 GCs & 1 perinatal grief counselor. Svcs incl: all aspects of PN GC, MS multiscrn prog, oppty for tchg, commun

outreach, rsrch avail. Partic in tchg residents, fellows, GC students; interact & collab w/ multiple other genetic specialties.

✉ Rachel Baughman, MS, Prenatal Diagnosis Program, Dept OB/Gyn, University of North Carolina at Chapel Hill School of Medicine, CB#7570, Chapel Hill NC 27599-7570; ©919-966-2229; Fax: 919-966-1999; bour@med.unc.edu.. EOE/ADA

■ **DURHAM NC:** Immediate opening for BC/BE Genetics Counselor. Span spkg pref, not req. Work in hi-volume PNDx clin at tertiary care hosp affil w/ med school. Join 2 GCs, Medical Geneticist & 7 MFMs. Respon incl travel to local satellite clin, resident/GC tchg & s'vision. Tchg, rsrch & lecture opptys.

✉ Resume & 3 ltrs of rec: Kristin Paulyson Nuñez, MS, Coordinator, Prenatal Diagnosis, Duke University Medical Center, Box 3390, Durham NC 27710. EOE/AA

■ **RALEIGH NC:** Immediate opening for BC/BE Genetic Counselor. Some trav req. Self-motivated, org, creative, team player to join Public Health Genetics Network svq 13 counties in Eastern NC. Coord w/ ECUSM genetic satellite clins; prepare pedigrees, provide GC & commun educ.

✉ Elizabeth G. Moore, Director, Div Public Health, Genetic Health Care Program, 1916 Mail Service Ctr, Raleigh NC 27699-1916; ©919-715-3420. EOE/AA

■ **WINSTON-SALEM NC:** Immediate opening for Coordinator, Fetal Alcohol and Drug Program. MA, MS, MEd req. Budget mngmt & grant writing skills pref. Respon: provide info, training & supt for individuals/ agencies re: PN exposures to alcohol & other drugs.

✉ CV & 2 ltrs rec to Tamison Jewett, MD, Dept Peds, Sec Med Genetics, Wake Forest University School of Medicine, Medical Center Boulevard, Winston-Salem NC 27157-1076. EOE/AA

■ **LIVINGSTON NJ:** Immediate opening for BC/BE Genetic Counselor. 1-2 yr exp pref. High-motiv, independence desired. Join busy MHM prac w/ wide variety of indications, case mngmt & follow up.

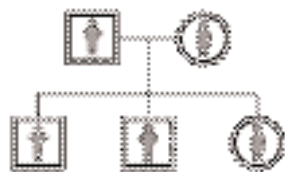
✉ Jennifer Stephenson, Human Resources, St Barnabas Medical Center, Old Short Hills Rd, Livingston NJ 07039; ©973-322-4247; Fax: 973-322-4598; sbmcjobs@sbhcs.com. EOE/AA

■ **PATERSON NJ:** Immediate opening for BC/BE Genetic Counselor. Exp pref, bilingual (Span) desired. Strong verbal & writing skills req. Self-motivated, energetic GC with interest in tchg. Join general genetics team based in an urban tertiary-care hosp providing broad range of svcs.

✉ Susan Schmerler, MS, Section of Genetics, St. Joseph's Hospital, 703 Main St, Paterson NJ 07503; Schmerler@sghmc.org. EOE/AA

See next page

Genetic Health



Genetic Health is a free online resource that helps consumers understand genetic advances to better manage their health.

We invite the genetics community to visit our site and experience TreeBuilder™, a user-friendly tool that enables consumers to build, store and update their family medical tree.

EMPLOYMENT OPPORTUNITIES, from p. 15

■ **ALBUQUERQUE NM:** Immediate opening for BC/BE Genetic Counselor. Join office/hosp-based perinatal practice. Work closely w/ BC MFM physicians & BC Clin Geneticist spec in PNDx, GC & Fetal Therapy progs.
☞ CV & 3 ltrs of rec: Anne Bryarly, Practice Administrator, Perinatal Associates of New Mexico, Ltd, 201 Cedar SE-#405, Albuquerque NM 87106; ☎505-764-9535;
Fax: 505-845-9646; abpanm@msn.com. EOE/AA

■ **BUFFALO NY:** Immediate opening for BC/BE Genetic Counselor. Exp in cancer & genrl genetics pref. Join NP/GC & GC on multidisc teams in various oncology clins & w/ clin/scientific rsrchrs. Partic in & provide clin, educ & rsrch activ & svcs at Comp Cancer Ctr.
☞ Carolyn D. Farrell, MS, CNP, Director, Clinical Genetics Service, Roswell Park Cancer Institute, Elm & Carlton Sts, Buffalo NY 14263; ☎716-845-8400 Fax: 716-845-5720;
Carolyn.Farrell@RoswellPark.org. EOE/AA

■ **MINEOLA NY:** Immediate opening for BC/BE Genetic Counselor. Cancer GC req; abil to work independently pref. Respon: PN & Peds GC
☞ Kathleen O'Brien, MS, Winthrop University Hospital, 120 Mineola Blvd Ste 210, Mineola NY 11501; ☎516-663-2657; Fax: 516-663-3070.
EOE/AA

■ **NEW YORK NY:** Immediate opening for BC/BE Genetic Counselor. Span pref. Self-motiv, org, team-oriented individual, able to work independently & on multidisc team. Excellent commun & writing skills req. Join busy perinatal prac to work in clinical PN genetics & the FASTER Trial, the largest NIH-funded study in obstetrics.
☞ Karla K. Welch, MS, Columbia Presbyterian Medical Center, 622 West 168th St, PH16, New York NY 10032; No calls.. Fax: 212-342-2802; welchk@zeus.cpmc.columbia.edu. EOE/AA

■ **NEW YORK NY:** Immediate opening for BC/BE Genetic Counselor. PN exp pref; self-motivated, energetic; excellent org skills; work independently & on team. Join 2 GCs, 3 MDs

& MFM in hi-volume ctr w/ varied PN pts; s'vise GC students; interact w/ med students, tchg & med fellows.

☞ Heather T. Kamen, MS, Human Genetics, New York-Presbyterian Hospital, 525 E 68th St Box 128, New York NY 10021;
Fax: 212-746-8893; htk9001@nyp.org. EOE/AA

■ **CLEVELAND OH:** Immediate opening for BC/BE Genetic Counselor. Exp pref in all areas of GC, incl cancer genetics & registries. Join 3 GC's working w/ OB/GYN geneticist & MFM specialists in PN & IVF clin to cover all aspects of peds, cancer & adult GC.
☞ Donna Gill, Program Coordinator, Taussig Cancer Center, Cleveland Clinic, 9500 Euclid Ave - T10, Cleveland OH 44195;
☎216-445-1250; Fax: 216-445-6935;
gild@cc.ccf.org. EOE/AA

■ **PORTLAND OR:** Immediate opening for BC/BE Genetic Counselor. Join busy pediatric/adult clinic at univ-affil facility: provide GC in clin setting, some cancer GC, consults.
☞ Karen Kovak, OHSU, PO, Box 574, Genetics & Birth Defects Clinic, Portland OR 97207-0574; ☎503-494-5606; kovakk@ohsu.edu. EOE/AA

■ **PHILADELPHIA PA:** Immediate opening for FT/PT BC/BE Genetic Counselors. Independent & team player work style req. Provide GC for PN & preconcep pts.
☞ Elaine Palome, Staffing Consultant, Genzyme Genetics, 15 Pleasant Street Connector, PO Box 9322, Framingham MA 01701-9322;
Fax: 508-872-2460; elaine.palome@genzyme.com. Electronic communications pref. EOE/AA.

■ **PITTSBURGH PA:** Immediate opening for BC/BE Administrator IV / Genetic Counselor w/ ocular disorders expertise. 4 yrs exp in clin mgmt/rsrch trials. Rsrch exp includes: staff s'vision, rsrch design & outcome assessments, preparation of publications, grants & IRBs w/ OPRR reg knowledge, develop clin protocols, maintain /modify database, Windows/ Mac knowledge; tch, s'vise GC students. Salary range: \$49,346-\$53,880.

☞ Michael B. Gorin, MD, Medical Director, Dept Ophthalmology, Center for Rare & Genetic Disease Disorders, 203 Lothrop St, Pittsburgh PA 15213-2588; ☎412-647-2235;

Fax: 412-647-5880. EOE/AA

■ **PITTSBURGH PA:** Immediate opening for BC Genetic Counselor. Min 3 yrs req. Join Cancer Genetics Program, a joint prog of Univ Pgh Cancer Institute, an NCI-designated Comprehensive Cancer Ctr, & Magee-Womens Hospital, a NIH Ctr of Excellence in Women's Health. Clin position w/ wide variety of consults & rsrch protocols: Breast, Colorectal cancer, von Hippel-Lindau progs, hereditary paraganglioma & endocrine clins. Oppty for acad appt. Work with NSABP STAR trial pts. Tch GC students,
☞ Donna Bushey, Administrator, UPCI/MWH CGP, 300 Halket Street #3522, Pittsburgh PA 15213-3180; ☎800-454-8156; Fax: 412-641-1132; dbushey@mail.magee.edu. EOE/AA

■ **AUSTIN TX:** Immediate opening for FT/PT BC/BE Genetic Counselors. Independent & team player work style req. Provide GC for PN & preconcep pts.
☞ Elaine Palome, Staffing Consultant, Genzyme Genetics, 15 Pleasant Street Connector, PO Box 9322, Framingham MA 01701-9322; Fax: 508-872-2460; elaine.palome@genzyme.com. Electronic communications pref. EOE/AA.

■ **FORT WORTH TX:** January 2001 opening for Genetic Counselor. Primarily peds svc, w/ >2000 new pts/yr. Work w/ clin genetics & other hosp spec clins: muscular dystrophy, spina bifida & orofacial. ☞ Mary K. Kukulich, MD, Cook Children's Genetics Service, 1300 W. Lancaster, Ste. 204, Fort Worth TX 76102;
☎800-266-5514; Fax: 817-335-8277;
MKukulich@CookChildrens.org. EOE/AA

In Canada

■ **TORONTO, ON:** Immediate opening for ABGC or CAGC BC/BE Genetic Counselor. Exp, strong admin/computer skills req. Self-motiv, team oriented, able to work independ & on multidisc team, good verbal/written commun & org skills. Handle adult-related, diverse GC pr pop: assess med, genetic & psychosocial needs, provide approp.GC, educ, tstg option, provide clin tchg for students/prof colleagues at large tchg hosp network. Opptys for clin rsrch.
☞ Fax CV & ltr of interest c/o Dr. K. Siminovitch, University Health Network, Toronto, ON, Canada; Fax: 416-586-8731.