PERSPECTIVES
in genetic counseling

Volume 17 Number 2 Summer 1995

Facilitating Research: The Many Roles of the Genetic Counselor

by Allyn McConkie-Rosell, MSW, Duke University and Dorene Markel, MS, MHSA, University of Michigan

Many advances in genetics in the past decade have depended on the participation of families in research projects. Research may benefit a family directly—for example, by providing access to developing tests. Even when a clinical application is distant, participating in research can help restore a family's sense of power and hope as they face the dismal prognosis of untreatable genetic disease. They know their involvement may someday save others from facing a similar fate.

As advocates for our patients and for science, genetic counselors often act as research facilitators, playing many roles. We may track down research projects studying a specific disease at a patient's request. Or we may be approached by investigators trying to locate research subjects. In either case, we must evaluate whether the study is appropriate, adequately designed and ethically conducted.

Families involved in research want to feel they have made a valuable and worthwhile contribution. The genetic counselor—at the referring medical center or as part of the research team—may be the crucial difference between a positive experience and a nightmare.

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Understanding Screening Decisions: The Health Belief Model

by Carolyn Y. Fang, MA, Christine Dunkel-Schetter, PhD, Michelle Fox, MS, and Zina Tatsugawa, MS; Univ of California, Los Angeles

Understanding the process guiding an individual's decisions about carrier screening helps genetic counselors provide optimal information and support. In the field of health psychology, various models have examined both preventive health behavior (e.g. smoking cessation) and disease screening behavior (e.g. mammography utilization). One of these—the Health Belief Model[1]—has documented some of the factors that influence an individual's decision to perform various health behaviors.

The Health Belief Model was originally formulated to better understand why people fail to take action to prevent or detect disease. The model proposes that the likelihood of an individual performing a health behavior is determined by several factors:

- the perceived vulnerability to the health condition
- the perceived severity of the condition
- the perceived benefits of performing the health behavior
- the perceived costs and barriers of performing this behavior.

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national society of genetic counselors, inc.

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

On the Inside

Women's Health

NSGC acknowledges Women's Health Care Services, Wichita KS, providers of late abortion care for fetal anomalies, George R. Tiller, MD, Medical Director, for a grant to support this newsletter.

Spotlight on...

NSGC's Board of Directors: Shaping our Future

Since its incorporation in 1979, NSGC has grown significantly in size and complexity. The Board of Directors oversees the Society's official affairs and promotes our vision: to be the leading voice, authority and advocate for the genetic counseling profession.

All NSGC's elected officials—President, Treasurer, Secretary, and Regional Representatives—are Board members, as are the six standing committee chairs and the editors of *Perspectives* and the *Journal of Genetic Counseling*. To ensure continuity in leadership, the President-Elect and the past two presidents are also members. The Executive Director is a member *ex-officio*.

Following our Vision

The Board has three main roles:

• **Governance and fiscal responsibility.** The Board sets NSGC's goals and objectives, guided by our mission and strategic plan. It monitors the annual budget and sets priorities for allocating funds.

• **Policy making.** The Board helps shape our public image—our statements to the world about our profession and beliefs—through documents such as resolutions and position statements. Directing development of these statements by committees, the Board solicits member input and approval where appropriate.

• **Monitoring our strategic plan.** What issues are likely to be important for genetic counselors in coming years? NSGC's strategic plan—developed largely from a membership survey—helps the Board anticipate and creatively meet members' changing needs.

Issue Oriented Meetings

The Board convenes twice each year. To keep each other informed in the interim, Board members submit written quarterly reports.

Board meeting agenda items reflect the issues facing genetic counselors—now or in the future. Issues are carefully deliberated before being brought to a vote. Often, more information or exploration is needed—a standing or ad hoc committee may be assigned to draft a recommendation for later consideration.

☛ The Board values member input—let them know what you're thinking. Leave a message on NSGC's voicemail: 610-872-7608, Mailbox #7.

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Send articles, reviews, correspondence to the Editor-in-Chief; address changes, subscription inquiries, advertisements and classifieds to the Executive Director. Contact any Editorial Board member with ideas or suggestions.

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Deadline for Submissions: August 10

Social Issues Committee

Requests for NSGC's Support

Our profession is becoming more publicly visible, as evidenced by two recent requests for support from Washington DC. We evaluated both requests in light of NSGC's mission statement, resolutions and code of ethics.

■ The American Society for Reproductive Medicine (formerly the American Fertility Society) sought our support for NIH-controlled research of early stage human embryos. Subcommittee chairs from the Social Issues Committee and Board members reviewed background information accompanying the request. After considering NSGC's resolution on Fetal Tissue Research, we agreed to sign a very general supporting letter to NIH Director Harold Varmus.

We chose not to accept the Reproductive Medicine Society's request to appoint and fund a liaison to their working group. The group is developing strategies in case the NIH budget is jeopardized due to the funds allocated for embryo research. If you are interested in this issue, contact me for more information about the working group—you can communicate with them via phone or fax.

■ We decided not to endorse "The Preserving Family Health Care Choice and Provider Fairness Act of 1995." This bill had not yet found a sponsor at the time of the request. Those reviewing the act were concerned that the bill's language would actually exclude genetic counselors; there were other reservations as well.

Lori Williamson-Kruse, MS
Chair, Social Issues Committee

Highlights of the Board of Directors' Meeting

On April 22-23, the Board of Directors convened in Chicago for their interim meeting—here are some of the issues that were on the table.

Sections are Coming

Special Interest Groups. Sections. Professional Networks. Now that NSGC is growing, we need to address this emerging member need. Quite simply, a section is a subgroup of members who meet or communicate regularly to address shared professional interests or concerns.

Charles Mahaffey, Director, Chicago Society of Association Executives, educated Board members about sections—an exciting member benefit and one way the NSGC is looking to the future.

Why should we care about sections? We recognize many members have a special focus in their work, like cancer risk assessment, or unique professional issues, like those of veteran counselors. They may unite into a formal or informal network.

NSGC can serve as an umbrella for these emerging groups. The section may sponsor educational meetings or workshops, sharing its expertise to benefit the membership at large. The section benefits as well: in return for nominal dues, NSGC provides low-cost administrative and other services.

President Bonnie LeRoy created an ad hoc committee to define the structure of special interest groups within NSGC. Maureen Smith and Jill Stopfer are co-chairs.

Role of Liaisons Explored

Our ties with other organizations are particularly important—we receive numerous requests for liaisons or official representatives to other professional societies or projects.

These liaisons, appointed by the President, receive NSGC financial support to attend meetings. The expenses add up—is it worth it? Yes, decided the Board after careful evaluation. They proposed some new guidelines to maximize our liaison relationships:

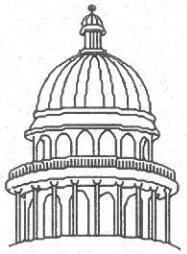
- The Past President II communicates with liaisons to keep them apprised of Board actions and ensure our mission is being met. In the past, this has been informal. Now, we require formal reports, with highlights to be printed in *Perspectives*.
- In appointing liaisons, seek a counselor with appropriate background or experience, who is poised and assertive enough to advocate for our interests. Past Board experience is often helpful.
- In the future, NSGC may sponsor formal training to refine advocacy and leadership skills.

Other Issues Generate Lively Discussion

- **Where shall we meet**—should we continue holding our Annual Education Conference in conjunction with ASHG? The Board reviewed some of the logistical problems involved and raised other options: meeting with another group or on our own. A recently mailed survey solicits member input.
- **NSGC's directory** will not include information about Board certification or eligibility for now, as certification is not a membership requirement.
- **NSGC On-Line?** NSGC is considering creating a "home page" on the World Wide Web—in other words, having information about the Society and genetic counseling available to those browsing the Internet.

Liz Stierman, MS
Perspectives Editor

Legislative Update



- ACOG is supporting a resolution (HR 30/S 85) designating ob/gyns as "primary care" providers. Many health care reform issues—primarily reimbursement and the ability to order tests—revolve around "primary care" status. A resolution is not legislation; it merely promotes the statement.
- HR 1010 (Birth Defects Prevention Act) was voted out of subcommittee with funding. It now must be considered by the full committee and on the House floor, around July 10. The Senate version (S 459) was voted out of committee with additions and is now S 555 (The Health Professions Education Consolidation and Reauthorization Act). Full Senate consideration should occur this summer. Sponsors are Kassebaum (R-KS), Kennedy (D-MA) and Frist (R-TN). Enactment will require consolidation of House and Senate versions and solid funding.

Lee Fallon, MS
Chair, Legislative Issue Subcommittee

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The Genetic Counselor as Research Facilitator

Working with Families

Ideally, a genetic counselor is an integral part of all research projects involving contact with patients and families. There are many ways the counselor can act as an interface between investigator and family.

• **Explaining complex information.** This includes the goals of the study, level of involvement required, type of results expected, how results might impact the family's clinical care and when findings are likely to be available. (Studies often take longer than originally predicted—be conservative when projecting completion dates!)

When families know what to expect, and what they will gain in return, they can make informed decisions about participation. The counselor can also field questions arising during the study and explain findings when available.

• **Fostering realistic expectations.** Families often anticipate they will get clinically-relevant results when, in fact, applications of research findings may be in the distant future. They may be postponing decisions about pregnancy or treatment, awaiting study results. Besides providing factual information, counselors can explore families' hopes and beliefs.

• **Advocating for families.** Some individuals go to extreme lengths to participate in research projects, hoping a treatment or cure will be found in time for them. Some jeopardize their jobs or financial security. Others alienate family members who choose not to participate. An alert counselor will recognize when boundaries are being crossed and help the family maintain a balanced view of research participation.

• **Providing follow-up.** Genetic counselors may contact families with results, although usually there is no formal notification about a study's conclusions. Studies often take several years to complete. Families should be encouraged to contact the genetic center periodically to learn if any new information is available.

Working with Researchers

Genetic counselors play an important investigational role: they can provide the precise pedigrees and clinical histories needed for most studies. Blood or tissue samples may come from many individuals and sites. Often, it is the counselor who coordinates this process. The genetic counselor can also alert the investigator to a family's problems that might interfere with their participation.

Advocating for Ourselves

Finally, we must acknowledge the contributions we make in this arena. Genetic counselors should strive for more defined roles in research projects. Grant applications and other research funding should reflect the time and efforts of the counselors involved, as should the scientific publications which result from their efforts.

Two Research Tales: A Genetic Counselor Makes a Big Difference

■ Family A enrolls in a research study hoping to clarify their Fragile X status—several adult family members are at risk. One brother, familiar with the medical field, is elected to contact the investigator and coordinate blood drawing and shipment to the research laboratory. After many months, many phone calls from anxious family members and many phone calls to the lab, the man obtains results. As best he can, he explains the complex and emotionally-charged findings: several family members are carriers. The family is frustrated and angry—they don't understand the results and have no one to answer their questions. Several years later, the family is still bitter about their experience.

■ Family B has von Hippel-Lindau disease. The proband is a 13 year old boy with kidney and pancreatic tumors; his affected mother died from multiple spinal tumors when he was five. The family is angry at the medical community, who they feel are uninformed and unconcerned about their disease. Through contacts with colleagues and medical literature review, their genetic counselor locates an NIH-supported research project. She contacts the principle investigator, getting details about the study which she then explains to the family. Still in its early stages, the research is unlikely to benefit the family directly, but they elect to participate anyway. Extended family members participate as well, many who were not aware of their risks before. When the gene is identified, the family is notified—they are pleased to have contributed to this scientific breakthrough.

Help for Research Facilitators

Evaluating Research Projects: A New Tool in the Works

Researchers often use NSGC directly or indirectly to solicit genetic counselors to refer appropriate patients: they place announcements in *Perspectives*, send mailings to our members or post signs at our meetings.

Protecting Patients

Genetic counselors have a responsibility to the patients and families we refer to research projects. How can we judge which projects are appropriate and ethically conducted?

NSGC, through the Genetic Research Issues Subcommittee of the Social Issues Committee, is developing a mechanism for counselors to obtain information about research projects. We agreed early in committee discussions that we could not define criteria to select which research projects should have access to our membership.

Instead, we are developing a tool for gathering relevant information about a research project or lab. Thus armed, the genetic counselor can decide individually when to refer. Information can be shared with patients, facilitating informed decisions about participation.

New Questionnaire

The Genetic Research Subcommittee is developing a questionnaire covering all aspects of research projects that may impact families or counselors. Any researcher wishing to contact NSGC members through our publications or mailing list will first be required to complete the questionnaire, to be kept on file in the Executive Office. Interested counselors can obtain a copy of the completed form, or use the questions to gather information from researchers approaching them by other routes.

Input Welcomed

The questionnaire—which should be completed by Fall 1995— will cover a broad range of topics. We hope it will inspire researchers to reevaluate their procedures if their answers do not win the approval of genetic counselors.

☛ Do you have ideas for the questionnaire? Fax your comments to Dorene Markel at 313-763-8135.

Dorene S. Markel, MS, MHSA
Chair, Genetic Research Issues Subcommittee

Look Before You Leap: What Counselors and Families Should Know about Research Projects

Project Goals and Status
- What are the project's purpose and its long-term goals?
- Is the project clinically relevant (e.g., a direct mutational study allowing future prenatal diagnosis)?
- Is the lab collecting samples for a future study or an ongoing project?
- What happens if investigators leave or transfer to another institution, or if funding is lost?

Involvement Required
- Must the patient be clinically evaluated or simply provide blood or other tissue to the laboratory?
- Can the evaluation be done locally or must it take place at the research center?
- Which family members need to participate?
- Who arranges and coordinates clinical evaluation or collection and transporting of samples?
- Will the family be reimbursed for their participation costs (such as specimen shipping charges)?

Patient Safeguards
- Will results be shared with other collaborators without further explicit consent from the patient?
- How will the identity of research subjects be protected?

Results
- When will the project be completed?
- Will participants be notified of the study outcome and findings? When and how?
- Will individual results be reported to the family? To the referring counselor? When and how?
- Who is available to interpret or explain results, or answer the family's questions?

CyberGenes

Use E-Mail to Access Internet

Electronic mail (e-mail) is the most commonly used Internet feature—for many, it's the only feature they use. E-mail is extremely fast and easy and much cheaper than snailmail (the US postal service).

E-mail Addresses

First, find out how to access your e-mail program from your system. Next, determine how people should address e-mail to you—if the address is not exact, e-mail cannot be delivered. All dots and symbols must be entered correctly.

Are you having trouble receiving e-mail? Sometimes the Internet changes addresses in strange ways. If you are having problems, e-mail me; I will send back a note telling you how your e-mail address appears on the Internet.

One way to ensure your mail is delivered correctly is by requesting a return receipt. There should be a simple way for your system to request a receipt with every mailing. You will also be notified when mail is successfully received. If the address is incorrect, your letter will come back stamped "Return to Sender, Address Unknown, No such person, No such zone." *Sorry, too much Elvis :-)*

Sending Files Via E-mail

E-mail is not word processing—you will not be able to format your message. However, some systems allow you to attach a file to your e-mail as a separate enclosure. The receiving party transfers the file with formatting intact to their own computer.

Accessing Other Features of the Internet via E-mail

If you can send e-mail to addresses outside your own organization, you can access files from all over the world. I recommend sending for "Doctor Bob's Free Guide to Accessing the Internet by E-mail." It contains helpful hints and several addresses for easily requesting files. To retrieve this guide, send e-mail to one of these addresses:

To: mail-server@rtfm.mit.edu
Leave Subject blank, and enter this line only in the body of the note:
send usenet/news.answers/Internet-services/access-via-email

To: listserv@ubvm.cc.buffalo.edu
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If your system won't allow you to leave the subject line blank, type a period instead. When you receive the guide, it may be too large to be displayed on your system; you can still print it even though it doesn't appear on your screen.

I expect you to give this a try—send for it even if you do not feel comfortable using your computer! If you can receive this guide, you will know you can do anything using e-mail. Good luck!

Next time: more about e-mail, Listserv, and translations of these terms: imho :-) lol ymmv <g> otf

Steven Keiles, MS
pokeilss@scpmg.com

Research Update

Predictive Testing in Families with Childhood Cancer

Parents of children with cancer are known to suffer psychological distress at various stages in the illness. Knowledge of disease risk gained through genetic screening tests may also cause psychological distress. Do parents of children with cancer suffer more psychological distress if predictive genetic testing for cancer is available? A multidisciplinary team from genetics, oncology and psychology has been funded by the Canadian Genome Analysis and Technology Program to study this question.

Three different groups are being studied. Parents in the first group have children diagnosed with familial or non-familial cancer at The Hospital for Sick Children. Parents in the second group have children with the Beckwith-Wiedemann syndrome (BWS), ascertained through the pediatric oncology clinic or the genetics clinic. A control group consists of parents of children with a chronic medical condition.

Groups are subdivided according to the cancer screening or predictive testing approaches used in each case. Some of the familial cancer cases segregate like the Li-Fraumeni syndrome; they are eligible for predictive genetic testing for germline mutations in the p53 tumor suppressor gene. Children with BWS have ultrasounds and AFP testing every three months.

Parents of the children affected with cancer or BWS are interviewed about their understanding of cancer causes and the impact

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Understanding Screening Decisions: The Health Belief Model

The model predicts that health behaviors will be exhibited when perceived vulnerability and perceived severity are high and the benefits of the proposed behavior outweigh the costs or barriers.

The health belief model has been studied in many contexts: HIV prevention, mammography use, vaccination behavior and even carrier screening for Tay-Sachs disease.[2] In general, these studies have shown that perceived barriers, perceived benefits and perceived vulnerability play the largest role in determining health behavior.[3]

Health Beliefs and Cystic Fibrosis Carrier Screening

The health belief model may be a useful tool to help understand why individuals do or do not desire to undergo carrier screening. We recently conducted a study examining the role of the health belief model factors in cystic fibrosis carrier screening.

We measured participants' perceptions using an agree/disagree scale of 1-5 with statements such as these:[4]

- **Perceived vulnerability:** "There is the chance that I have a cystic fibrosis gene."
- **Perceived severity:** "Cystic fibrosis is one of the worst diseases there is." "If I had a CF gene, I would be concerned about what others would think of me."
- **Perceived benefits:** "Knowing if my partner and I each have a CF gene is valuable information." "Knowing my cystic fibrosis genetic test result will help me make better decisions about having children in the future."
- **Perceived barriers:** "It is inconvenient for me to have a test for the CF gene today." "I am uncomfortable about being tested to see if I have a CF gene."

Barriers, Benefits and Vulnerability

We found women's perceptions play strong roles in predicting their intentions to be screened for CF mutations. Those perceiving fewer barriers and more benefits to screening, believing themselves to be somewhat vulnerable to carrying the CF gene, were more likely to desire carrier screening.

Understanding the decision making process and the factors that influence carrier screening choices help genetic counselors better tailor the information and support they offer clients.

References

[1]Rosenstock IM (1966). Why people use health services. *Millbank Memorial Fund Quarterly*, 44(Suppl), 94-127.

[2]Becker MH, Kaback MM, Rosenstock IM, & Ruth MV. (1975). Some influences on public participation in a genetic screening program. *Journal of Community Health*, 1(1), 3-14.

[3]Janz NK, Becker MH (1984). The health belief model: A decade later. *Health Education Quarterly*, 11(1), 1-47.

[4]Tatsugawa ZH, Fox MA, Fang CY, Novak JM, *et al* (1993). Education and testing strategy for large-scale cystic fibrosis carrier screening. *Journal of Genetic Counseling*, 3(4):279-289.

The Health Belief Model in Practice

- Women perceiving fewer barriers were more likely to desire screening. Make testing convenient and keep costs affordable.
- Ascertain if the client perceives other barriers to testing.
- Explore the perceived benefits of screening. Does the client feel carrier status information would be helpful in making reproductive decisions? How would she use this information?
- Educate the client about the likelihood of being a carrier. How does she perceive her risk? Women feeling somewhat vulnerable are more likely to desire testing.

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Childhood Cancer

and implications of predictive testing for cancer. Parents ascertained through the oncology clinic will be followed for one year with three interviews.

Understanding attitudes about genetic testing in families dealing with childhood cancer or tumor risk will be an essential component in developing appropriate and acceptable predictive testing programs.

Karlene Australie, MS
Cheryl Shuman, MS
Toronto Canada

Letter to NSGC Members

AAAS Fellowship Now Open to Genetic Counselors

■ *In December, ASHG announced a new fellowship program open only to its MD and PhD members. Responding to letters from genetic counselors and discussion with NSGC President Bonnie LeRoy, ASHG reviewed the application criteria and elected to open the fellowship to Masters level professionals as well. Applications will be mailed to ASHG members in early August; the deadline is* ***November 15, 1995.***

THE AMERICAN SOCIETY OF HUMAN GENETICS

9650 ROCKVILLE PIKE / BETHESDA MD 20813-3998 / (301) 571-1825 / FAX: (301) 530-7079

Dear Colleagues:

I would like to address the issues raised by previously published communications concerning the new American Association for the Advancement of Science (AAAS) Congressional Fellowship program and be sure that we have a good and open dialogue about them.

The fellowship program is jointly supported by the ASHG and the Department of Energy. The Society is pleased at the opportunity to be present at the interface of science and government. The AAAS program has been in place for the past 20 years and is designed for professional scientists to advise Congress on matters of theoretical and applied technology and investigational research.

The program places highly qualified scientists and engineers in the offices of individual members of Congress and committees for one-year assignments. Although the major benefit accrues to the Society which selects the fellow, the Congress is extremely appreciative of the scientific and technical expertise which has traditionally characterized the fellows.

The goal of the Society in initiating this fellowship is to create a nucleus of knowledgeable professionals to serve as a resource for consultation in the development of public health policy as it relates to all phases of human genetics—laboratory and clinical research and the practice of medical genetics. We hope a byproduct will be to educate the Congress about human genetics.

The program was expanded several years ago to include international participants whose degrees might not coincide with US doctoral degrees, and although the program description technically does not require a PhD or MD, the fellows have been drawn almost entirely from postdoctoral candidates. This program was developed and guided by the AAAS orientation which presumed that the highest achievement in a scientific field would be accompanied by a doctoral degree. Because some ASHG members raised a concern about this qualification, the matter was pursued and further reviewed, and it became apparent that a reinterpretation of the guidelines was appropriate. The decision has been made to remove the restriction of having a doctoral level degree so that the opportunity to compete for the fellowship would be available to all ASHG members.

We hope that genetic counselors will consider applying for the fellowship. All members of ASHG who have demonstrated through their scientific achievements that they possess the appropriate scientific background based on training, experience and productivity will be considered for the fellowship and should apply if interested. The opportunity for application will be repeated each year for the next four years with November 15, 1995, being the next deadline for receipt.

Sincerely yours,

Judith G. Hall, MD
President, American Society of Human Genetics

ABGC Update

Training Program Accreditation Results Announced

The Board of Directors of the American Board of Genetic Counseling met in Philadelphia on April 7-8, in conjunction with examination preparation sessions held with the National Board of Medical Examiners staff.

Training Program Accreditation

The Accreditation Committee presented its reviews of training program applications for Interim or Recognized New Program Status. Sixteen programs were granted Interim Accreditation. This status is valid for one year and can be renewed annually until a program is eligible for Full Accreditation. Two programs were approved as Recognized New Programs. This status is also time-limited, as new programs are expected to apply for full accreditation within three years of graduating their first class.

New Process for Approving Training Sites

With the implementation of this new accreditation process, ABGC will discontinue its old system of approving clinical training sites (for logbook cases) on June 30, 1995. After that, clinical training sites will be reviewed and approved only as part of training program accreditation applications.

To request ad hoc approval of a clinical training site not affiliated with a counselor training program (for example, a summer placement), submit an agreement form documenting clinical experience and supervision to the Administrative Office for review. (Request forms from program directors or the Administrative Office.)

1996 Certification Exam

The Credentials Committee discussed criteria and logistics for reviewing applications for the 1996 examination. Two completed applications were received prior to the meeting. The application deadline for the next exam is December 31, 1995.

☎ For ABGC for Board exam information or applications: 301-571-1825.

Ann P. Walker, MA
Ginny Corson, MS

Approved Training Programs

The following programs were granted Interim Accreditation:

University of California, Berkeley
Brandeis University
University of Cincinnati
University of Colorado
Howard University
Indiana University
University of California, Irvine
University of Michigan
University of Minnesota
Northwestern University
Sarah Lawrence College
University of South Carolina
University of Texas, Houston
Medical College of Virginia
University of Wisconsin
University of Pittsburgh

These programs were granted Recognized New Program Status:

Beaver College
Johns Hopkins University/Natl Ctr for Human Genome Research

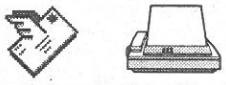
E-mail/FAX Poll

Do you use CGC?

Many counselors now use the letters CGC (for Certified Genetic Counselor) after their names. Are you one of them? Why do you use it (or why not)?

Let us know your experiences. The next issue of *Perspectives* will explore the pros and cons of CGC.

☛ Contact Liz Stierman
FAX 213- 380-7344
e-mail LStierman@aol.com



Celebrating Ourselves

LGS/NSGC Award Winners

Congratulations to the recipients of the LGS/NSGC Speakers' Travel Fund Awards for the past quarter:

Kathleen J. Delp, MSW, for her presentation, "Nature Plus Nurture," at the 21st Annual Training Conference, North American Council on Adoptable Children, in Norfolk VA, August 3-6.

Katherine A. Schneider, MPH, for her presentation, "Genetic Testing Advances: Primary Health Care Applications," at the National Primary Care Nurse Practitioner Symposium, July 21 in Keystone Resort CO.

Funding application forms can be obtained by calling the Executive Office, 610-872-7608, Mailbox 8.

Bulletin Board

Research Network

Couples who learn that their fetus is affected with metachromatic leukodystrophy or Krabbe disease at 10-12 weeks gestation and who decide to continue the pregnancy are eligible for a newly-approved fetal treatment research protocol at the Johns Hopkins Hospital and the Kennedy Krieger Institute.

Bone marrow cells from the father will be injected into the fetus to determine if healthy cells can survive and function in the baby after birth. Although experience with *in utero* bone marrow transplantation is very limited, treatment before 14 weeks using a new bone marrow cell-sorting technique may be more effective than previous attempts.

☛ For more information, contact Ginny Corson, 410-955-3091.

Are you an Expert?

The Genetic Services Committee seeks "experts" to draft practice guidelines in well-defined areas of clinical practice. Drafts will serve as models for future efforts as well as providing fodder for discussion at a workshop in Minneapolis. Potential topics: counseling for advanced maternal age, serum markers, ascertaining trisomies pre- and postnatally, NTDs, selected cancers, teratogens and single gene disorders such as CF, NF, DMD. Interested?

☛ Contact Becky Anderson, 402-354-4773 (mornings) or e-mail: RANDERSON@UNMCVM.UNMC.EDU

Register Now!

August 15 is the deadline for registering without late fee for NSGC's 1995 Annual Education Conference in Minneapolis.

Upcoming Meetings

July 23-28	Short Course on Molecular Diagnostics, Genetic Counseling, and the Human Genome Project, Ann Arbor MI. Contact: Amy VanSlambrook Pott, 313-747-1827.
September 19	MARGHN Fall Education Meeting: "Health Care Reform: Where Are We Now?" Philadelphia PA. Contact: Gail Chiarello, 215-983-6760.
October 17-20	Genetic Mechanisms of Cancer, Houston TX, Contact: 713-792-2222.
October 21-24	3rd International Meeting of the Society for Neonatal Screening, Boston MA. Contact: 617-647-5530.
October 29-November 1	NSGC 14th Annual Education Conference: "Conditions that Affect Adults: Implications for Genetic Counseling, Testing and Public Policy," Minneapolis MN. Contact: 610-872-7608, Mailbox #6.
March 11-14 1996	Joint Clinical Genetics Meeting of the American College of Medical Genetics and March of Dimes, San Antonio TX.
August 1996	9th International Congress of Human Genetics, Rio de Janeiro, Brazil. Contact: Congress Secretariat 55-21-286-3536.

Ethics Subcommittee Vacancies

The Ethics Subcommittee is recruiting two members to begin three year terms this fall. The requirements: full NSGC membership, an interest in bioethics and availability for conference calls as needed.

☛ To apply, send your CV and a letter detailing your interest and experience in bioethics to:
Sandra Peacock, MS
7730 Meadowvale
Houston TX 77063.
Deadline: **July 15, 1995.**

Ethics Consults Available

The Ethics Subcommittee is available to NSGC members for confidential consultations on ethical issues confronting you or your institution. Consults clarify conflicts about the role of the counselor as outlined by NSGC's Code of Ethics. We are not a regulatory board or ombudsman.

☛ To request a consult, contact a subcommittee member:

Sandra Peacock 713-781-1680
Beth Balkite 800-848-4436
Anne Matthews 303-837-2760
Linda Nicholson . . .302-651-4234
June Peters 602-834-8979
Karen Supovitz 410-706-3815
Vivian Wang 212-362-2330
Kevin Fitzgerald . . .202-687-6425

Free Birth Defects Poster

The California Birth Defects Monitoring Program is offering posters promoting birth defects research. The color posters show newborns of all races with the message, in English or Spanish, "1 in 33 is one too many...especially when it's yours."

☛ Free. Phone 209-224-2212 or FAX 209-224-0252.

Bulletin Board

Editorial Board Opening

In 1996, *Journal of Genetic Counseling* editorial board members begin a term rotation system which will create vacancies on the board each year. Editorial board members are expected to have experience in writing for publication, manuscript review and interest in developing a literature in genetic counseling. A minimum commitment of three years is required.

☛ Interested NSGC members should submit a letter of interest and CV to:
Deborah Eunpu, Editor-in-Chief
PO Box 2145
Jenkintown PA 19046.
Deadline: **July 15, 1995.**

Changes in your Life?

NSGC's new membership directory will be published soon. Do you have a new name, address, phone or fax number? A different work focus? Have you added e-mail?

☛ Copy page 70 of the current directory, note any changes and FAX to the Executive Office, 610-872-1192.
Deadline: **July 15, 1995.**

Check your Mailbox...

You should have already received two important questionnaires:

- **Cancer Network Survey** will be the basis of a comprehensive directory from the Familial Cancer Risk Counseling Alliance.
- **Education Committee Poll** will help guide planning for future conferences. Share your views on short courses, CEUs and meeting logistics.

A Plea for Help!

Do you know of videos, slides, statistical packages, student curricula, questionnaires or cross-cultural A-V materials for sale or loan? The Media Resource Center Committee for the 1995 Annual Education Conference wants to:

- Distribute a list of resources available to NSGC members.
- Continue with the annual "slide swap."
- Have videos available for scheduled previews.
- Display any other relevant items.

Call Lyn Hammond if you can contribute descriptions or reviews of A-V materials you have previewed for the resource list.

If you have materials to loan for display at the conference, please contact a committee member listed below. Materials are needed by **September 22, 1995.** Thank you!

Slide swap:	Denise Tilley, MS	704-355-3159
Videos:	Lisa Wisniewski, MS	503-413-4726
	Mimi Rietsch, MS	607-724-4308
	Bonnie Epstein, MPH	800-955-4363 x203
Curricula/Other:	Lyn Hammond, MS	803-792-2620

In this mailing

Everything you wanted to know about a molecular test, but...

A subcommittee of the Genetic Services Committee just completed a tool to save time (and therefore $) and increase your appearance as a savvy consumer. The Molecular Genetics Laboratory Questionnaire, accompanying this mailing, was created to obtain consistent and complete information about DNA labs and testing.

The expectation is that labs will complete and maintain the information themselves, to be sent as requested. Labs registered with Helix received copies in early June, so may not have fully completed forms for all the diseases. Feel free to fax blank copies to labs to which you are considering sending specimens, but which have not received or completed the forms.

Next project: define our role as research broker with these labs...

Resources

■ Video ■

Life and Death Before Birth—Evaluation of the Stillborn

Produced by: The Wisconsin Stillbirth Service Program (1995).

Cost: $90/set. To order, contact Catherine A. Reiser, MS, (608) 262-9722.

It has been said the stillborn infant is "nobody's patient"—however, the parents may become our patients some day. This video series emphasizes the rationale for a complete and detailed stillborn evaluation: to help answer the parents' questions. It is designed to educate health care providers and hospital staff; it is not for families.

The series consists of five videos, approximately 20 minutes each. Information is conveyed in easily digestible increments. As a self-paced learning module, the series is logically constructed and well supported by the accompanying manual. The segments, which are focused and short so viewers will not lose interest, cover parents' needs, the justification for a full assessment, practical steps for fetal evaluation, outcome in the center's first 1000 referrals and interesting cases.

Bolsters Staff Education

This up-to-date video set is designed for the community served by the Wisconsin Stillbirth Service Project but can clearly benefit other areas as well. It could be helpful to counselors planning inservices to staff when a new stillbirth protocol is being promoted or where a current one needs re-vamping. The pre- and post tests for each segment allow educators to apply for CMEs. The protocols provided make a useful starting point for the discussion of individual hospital procedures.

Useful Techniques Offered

The presentation style is confident and caring. The first segment focuses on patient grieving responses during and after hospitalization. Specific, practical suggestions help hospital staff truly make a difference for the family. The 21 page bibliography should satisfy anyone interested in learning more.

Honest sharing of personal experience and techniques demystifies the rationale for each recommended test in the protocol. Especially helpful is the segment showing an actual physical exam of a stillborn infant. Examples showing how the complete evaluation leads to specific diagnoses will encourage medical personnel to follow the practical instructions.

Empiric Data

The segment presenting data gathered from 1000 cases justifies having and following a full stillbirth evaluation protocol at every hospital where births occur. The data will be useful in counseling families who have experienced a fetal demise. The fascinating segment on unknown cases is will be interesting for most genetic counselors.

If we need a reminder of why a stillbirth evaluation protocol should be implemented, or if we need to develop inservices for such a protocol, this videotape series is a useful educational tool.

Susan A. Demsey, MS
Bellflower CA

■ Support Groups ■

CHERUBS
The Association for Congenital Diaphragmatic Hernia Research, Advocacy and Support

c/o Dawn M. Torrence
3671 Bruce Garner Road
Franklinton NC 27525

Information, support and parent-to-parent match-ups. Newsletter offers practical information about surgery and beyond.

Mitochondrial Disorders Foundation of America

Lynnie Morgan, Founder/Director
5100-1B Clayton Road, Suite 187
Concord CA 94521
(800) 838-6332
(510) 798-8798 Office/FAX

New organization with a biannual newsletter, regular updates on mitochondrial research and access to support services. They are developing a database for matching families with similar clinical symptoms. $20 basic membership.

Support Group Directory

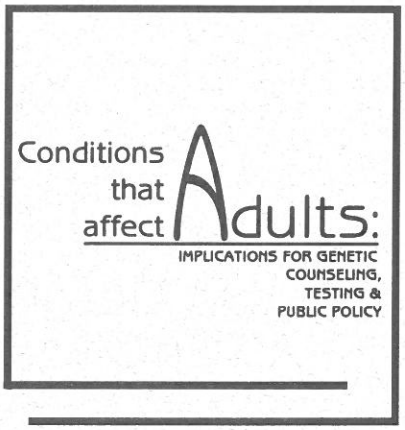
Alliance of Genetic Support Groups
35 Wisconsin Circle, Suite 440
Chevy Chase MD 20815

The revised and expanded *Directory of National Voluntary Organizations and Related Resources*, supported in part by an NSGC grant, lists support groups and other resources for specific genetic conditions. Cost is $12 for full NSGC members; $22 for all others.

Book Review

Facing Life-Threatening Illness: Does Living Better Mean Living Longer?

■ *Dr. David Spiegel, known for his work with breast cancer support groups, will be a keynote speaker at October's Annual Education Conference in Minneapolis.*



Living Beyond Limits

By David Spiegel, MD

New York: Fawcett Columbine (1994). 316 pages, including readings, references and index, $12.50.

Living Beyond Limits describes how individuals and their families can live fully in the face of life-threatening illness by supplementing standard medical care with social and emotional support. The book is based on Dr. Spiegel's 20 years of clinical practice and scientific research, including a study which showed the positive effects of group support on quality and quantity of life.

"Limits" in the title refers not only to living life to its fullest despite the limitations of serious illness but, in some cases, to living beyond the quantitative limits of such illness due to the psychological benefits of a supportive and caring environment.

Diagnosis and Beyond

Spiegel takes the reader through the initial stage of diagnosis (primarily metastatic breast cancer, the focus of his work) with chapters titled "Weathering the Diagnosis" and "The Lull After the Storm." Other chapters deal with specific themes and issues, including personality and coping, "detoxifying" dying, revising relationships with family and friends, developing a life project and communicating with doctors.

The chapter "Does Living Better Mean Living Longer?" tells of Dr. Spiegel's involvement in the late 1970s with breast cancer patients randomized to a support group as an adjunct to their cancer care. These women scored better on standard measures of anxiety and depression when compared to a control group receiving only routine cancer care. Several years later, when Dr. Spiegel collected follow-up on these patients, he discovered the average survival time among patients participating in the support group was twice that of non-participants.

Taking Control

The book's recurrent themes are finding networks of support, facing one's illness and fears of dying, controlling those aspects of life within one's control and strengthening relationships with family and friends. This is contrasted to other psychotherapeutic interventions that focus on controlling the course of the disease by denying illness, wishing or visualizing it away, or maintaining a positive attitude. Dr. Spiegel states, "It is not simply that mind can triumph over matter, but that mind matters."

Compassionate, Practical Advice

Throughout the book, Dr. Spiegel shares anecdotes and excerpts from patient interviews and support groups, making his account of his work experience with cancer support groups extremely personal and meaningful. His tone is caring and his description of his patients extremely compassionate.

He takes a very practical approach to many issues, often itemizing his recommendations. For example, he advises:

- choosing the right time and place for talking
- stating feelings, not conclusions
- listening and restating what you hear
- admitting when you have had enough when talking with family and friends about emotional difficulties.

Relevant to Genetic Disease

Living Beyond Limits is highly recommended to health professionals working with patients facing cancer and other life-threatening illness. It is also recommended to those facing such an illness in themselves or in a family member or friend—this is likely to include all of us at some point. The book may be difficult to read for someone with less than a high school education.

Many parallels can be drawn between Dr. Spiegel's patients and patients (and their families) who have genetic disorders; particularly important is the immense benefit of support groups. Dr. Spiegel describes support groups as a "powerful antidote to the toxin of social isolation."

Jane Schuette, MS
Ann Arbor MI

Student Page

Graduating Counselors: Are they finding jobs?

Bea Leopold recently asked training program directors if new graduates were having a hard time finding jobs. Here's what they had to say:

■ Students free to move to have no problems getting jobs. Those students who must stay in a particular area may have more difficulty—especially where there is a training program, because there are so many counselors in that area already.

■ The competition for jobs seems to be increasing—the job market does not appear to be keeping up with the number of graduating counselors.

■ There seems to be very few jobs listed with only one [local] opening since January. One hospital just decreased the number of genetic counselors hired by 1/2. I don't know why—it doesn't make sense. Is it managed care?

■ Yes, it is a tougher market. Students no longer get interview travel expenses covered, more positions seem to be part-time rather than full-time, funding for positions is less certain or of limited duration.

■ My students are experiencing difficulty. I wonder if this is because the traditional job market is saturated and the trend toward developing inroads into non-traditional sites is just being launched—HMOs, oncology clinics, etc. These may need to be developed by more experienced counselors thus freeing traditional jobs for new graduates.

■ Like last year, it seems slower... less jobs to interview for and more competition for those jobs. If this is a national trend, we may take fewer students.

■ Geographical constraints are a factor. At least seven jobs are available [locally]; not all are ones I've encouraged students to pursue (i.e. jobs are there, but not all are desirable).

■ My students are finding jobs.

■ Slower than recent years but 50% of our class is settled and the rest are negotiating. I do think managed care problems and fall out may have affected the market adversely—too soon to tell for sure.

■ Getting tighter but jobs are still available—I think students are *very* picky and not very resourceful. I think the job market will open up more over the next five years when hospitals figure out how to pay for services with changes in the health care system.

■ Definitely tighter—fewer positions, less $—concerns re: managed care, etc??? (a guess).

■ The students all state that there appear to be few jobs available—most of my students do anticipate relocating. I have heard of a number of experienced counselors changing jobs this year—I wonder if this is having an impact on what is available to new grads.
I am concerned!

■ Our students have had no problems. They have found positions before they graduated.

■ The fiscal reality is that this is a relatively new discipline which can't always demonstrate—secondary to billing issues, turf, etc.—that counselors "make" their own salary.

Have you helped a student lately?

Joan Marks interviewed about 100 students for the Sarah Lawrence genetic counseling training program this year. She estimates that 20% of these candidates had asked a genetic counselor to observe a genetic counseling session and were denied the opportunity.

Student Research Projects

Students from the Northwestern University training program share their thesis projects. Contact them directly for more information.

Katherine Hunt: "The meaning of genetic counseling services to women receiving public assistance." 314-367-9515.

Tina Bartell: "Epilepsy and pregnancy: what women know about their risks." 909-799-6044.

Joanna Zeiger: "The impact of genetic counseling on knowledge about prenatal diagnosis in women of advanced maternal age." 410-614-1749 or e-mail: jzeiger@welchlink.welch.jhu.edu.

Charli Loebl: "The evaluation of a proposed screening protocol: multiple marker screening as an indication for prenatal diagnosis in women of advanced maternal age." 312-567-2427.

Shelly Cummings: "DNA testing: a comparison of opinions between the public and health providers." 312-362-9706.

■ EMPLOYMENT OPPORTUNITIES ■

■ *These classified listings represent the most recent additions to the NSGC JobConnection service. Members and students interested in complete or regional information may receive a computerized printout, at no charge, by calling 610-872-7608 Mailbox #2. Printouts are mailed on the first and third Monday of each month. This service is strictly confidential.*

SACRAMENTO CA: Immediate opening for BC/BE Genetic Counselor. Exp & Spanish pref, but not req. Ability to work independently; excellent organizational and interpersonal skills req.
RESPONSIBILITIES: New GC position to join others in full svc PNDx practice: amnio, CVS, abnormal U/S, AFP, teratogens and family hx.
CONTACT: Douglas Hershey, MD, Prenatal Diagnosis of No. California, 1315 Alhambra Blvd #210, Sacramento CA 95816; 916-736-6888. EOE/AA.

SACRAMENTO CA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join 7 GCs & 2 MDs in large, reg'l HMO genetics program: all aspects of PN, ped & adult GC & case mngmt; oppty to partic in rsrch studies & mustidisc specialty clinics.
CONTACT: Mark Lipson, MD, Dept Genetics, Kaiser Permanente Medical Center, 2345 Fair Oaks, Sacramento CA 95825; 916-978-1402. EOE/AA.

SACRAMENTO CA: Immediate opening for BC/BE Genetic Counselor. Exp req.
RESPONSIBILITIES: Join busy private perinatal practice: all aspects of PNDx coun: amnio, CVS, abnormal U/S, terat, AFP and DNA in a Calif State prenatal diagnostic ctr.
CONTACT: Judy Lampe, Practice Manager, Perinatal Associates of No. California, 5301 F St #110, Sacramento CA 95819; 916-733-1755. EOE/AA.

COLORADO SPRINGS CO: Immediate opening for BC Genetic Counselor. Masters in nursing or GC; Exp pref.
RESPONSIBILITIES: PNDx, MSAFP, triple test, community educ, newborn eval, ped & adult genetic conditions.
CONTACT: Annetta Bersche, Human Resources, Memorial Hospital, Box 1326 Colorado Springs CO 80901-1326; 800-523-1225x5577. EOE/AA.

NEW HAVEN CT: Immediate opening for BC/BE Genetic Counselor. Exp req; familiarity w/ cancer genetics & molecular dx desirable.
RESPONSIBILITIES: Counsel & case mngmt for family hx of cancer; coord molecular testing; assist in research protocols. Oppty for research, tchg & developing new strategies for cancer risk assmnt.
CONTACT: M. Stephen Meyn, MD, PhD, Dept of Genetics, Yale School of Medicine, 333 Cedar St, New Haven CT 06510; 203-785-6546. EOE/AA.

FT. LAUDERDALE FL: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join MD geneticist and BC GC to provide comprehensive PN and ped GC for rapidly growing genetic ctr affiliated with several perinatology practices & hospitals. Oppty for rsrch; publications.
CONTACT: Anna Carpenter, MPH or Peter Mamunes, MD, Medical Director, Alfigen Genetics Center of So. Florida, 2700 W Cypress Creek Rd, Ste D-128, Ft. Lauderdale FL 33309; 305-968-3365. EOE/AA.

CHARLESTOWN (BOSTON) MA: Immediate opening for BC/BE Genetic Counselor/Coordinator.
RESPONSIBILITIES: New full-time rsrch position w/ internat'l-recognized neurogenetics team: liaison between pts, families, clinicians, researchers; coord pt and family ascertainment, contact, sample collection, initial & follow-up coun. Field studies; some clin coun possible.
CONTACT: Jonathan L. Haines, PhD, Mass General Hospital, Molecular Neurogenetic Unit, Charlestown MA 02129; 617-724-9571. EOE/AA.

NEW YORK NY: Immediate opening for BC/BE Genetic Counselor. Exp pref; familiarity w/ molec tech a plus.
RESPONSIBILITIES: All aspects of coun/case mngmt for family hx of cancer; coord molec tstg; partic in rsrch protocols in genetic epidemiology; some admin. Oppty for teaching & research, develop multidisc strategies for cancer risk assmnt; atmosphere conducive to professional developmt.
CONTACT: Karen Brown, MS, Program Coordinator, Memorial Sloan-Kettering Cancer Ctr, 1275 York Ave. Box 559, New York NY 10021; 212-639-6760. EOE/AA.

NEW YORK NY: Immediate opening for BC/BE Genetic Counselor. Exp pref; familiarity w/ CF & molecular technology a plus.
RESPONSIBILITIES: All aspects of coun/case mngmt for CF pts & families; coord molecular testing; genrl peds, in-house clin & consulting svcs. Oppty for tchg & rsrch.
CONTACT: St. Vincent's Hospital & Medical Ctr of NY, CF Center, 36 Seventh Ave, Ste 509, New York NY 10011; 212-604-8895. EOE/AA.

STONY BROOK NY: Immediate opening for BC/BE Genetic Counselor/Clinic Coordinator with Masters in GC; 1-2 years perinatal, ped & outreach exp pref.
RESPONSIBILITIES: Join growing clinical genetics div in tertiary care facility: general genetic svc, peds, perinatal, full svc cytogenetic and biochem lab, newly-estab molec dx lab.
CONTACT: Human Resources-Ref# UH-S-5124-95-05-S, University Hospital, HSC, Level 3, Rm 106, Stony Brook NY 11794-8300. EOE/AA.

BETHLEHEM PA: Immediate opening for P/T BC Genetic Counselor; 5 yrs related exp req; must demonstrate active interest in publication & tchg.
RESPONSIBILITIES: Comprehensive pt & family coun: family hx; review diagnosis, prognosis, treatment plans; assist in assimilating genetic info; provide info necessary in decisions re: testing & PNDx.
CONTACT: Human Resources, St. Lukes Hospital, 801 Ostrum St, Bethlehem PA 18015; 610-954-3712. EOE/AA.

HERSHEY PA: Immediate opening for BC/BE Genetic Counselor; cytogenetic exp req.
RESPONSIBILITIES: All aspects of PN and ped coun & case mngmt for flexible GC who likes diversity; work in Univ hospital setting w/ multidisc team: 2 geneticists, genetic associate, molecular biologist and cytogenetic techs in active, well established comprehensive genetic ctr.
CONTACT: Cheryl M. Schmidt, RN, MPA, The Milton S. Hershey Medical Center, PO Box 850, Div Genetics, Dept Pediatrics, Hershey PA 17033; 717-531-8414. EOE/AA.

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Name (please print) _____