PERSPECTIVES
in genetic counseling
Volume 19, Number 2 Summer 1997

NSGC's Evolving Strategic Plan: Survey Probes Future Direction

by Bea Leopold, MA, Executive Director

Our Strategic Plan was developed as a structure for guiding us into the future. Committed to multifaceted levels of member involvement, we interviewed leaders from within and outside NSGC's infrastructure, held focus groups, surveyed members and detailed progress in *Perspectives.* In an intense year-long process, we defined our vision, mission and the steps needed to achieve our many lofty goals. The final Strategic Plan document reflected NSGC's top priorities, assigned responsibilities to specific committees or individuals and ranked objectives into three levels based on a time-determined priority: immediate response necessary; intermediate response planning required; and ongoing monitoring required. Outlines of our accomplishments have been highlighted in each Annual Report since 1993. Our Strategic Plan has, over the past four years, helped guide our decision making and position NSGC as a major recognized force in the genetics community.

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NHGRI: Past and Future Support for Genetic Counseling

by Barbara Biesecker, MS, Don Hadley, MS, Elizabeth Thomson, RN, MSN; NHGRI, Bethesda MD

The National Human Genome Research Institute (NHGRI) has demonstrated a longstanding commitment to the genetic counseling field. Congress established the Center—originally the National Center for Human Genome Research—in 1990. In January 1997, the Center became the newest member of the National Institutes of Health.

From the beginning, NHGRI has offered numerous professional opportunities for genetic counselors. Many activities of particular interest occur within its Ethical, Legal and Social Implications (ELSI) Program, which consists of three components.

- **The Extramural ELSI Research Program** funds basic and applied research and education projects at Institutions throughout the US. These projects are designed to examine and distribute information on various genetics topics and related ELSI issues.
- **Intramural ELSI Activities** occur on the campus of NIH. This includes activities of the Office of Genome Ethics, a number of education activities and certain research components of the Medical Genetics Branch which directly support genetic counseling research.
- **The Office of Policy Coordination** in the Director's Office provides information and analysis on ELSI policy issues.

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national society
of genetic
counselors, inc.
nsgc

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

ON THE INSIDE

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

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Strategic Planning: A Guide to the Future

Strategic vs Long Range Planning

Long range planning assumes existing trends will continue and forecasts the future straight ahead from a set vantage point. Strategic planning, a more complex process, helps an organization:

- Identify its focus
- Operate efficiently, effectively and responsibly
- Respond logically when issues, events and/or problems arise
- Stimulate thinking about the future.

Strategic planning focuses on a big picture vision, answering the question: *Where do we want to be?* It identifies issues and choices and emphasizes both internal and external environments, or current realities, to the organization. Strategic planning considers a range of possible futures, enabling an association to evolve with and maneuver around unpredictable events. If long range planning is linear, a line from here to there, strategic planning is a spiral, moving toward the future and circling round as it addresses issues and events, evolving as it grows.

Which emerging issues do you think will be the most important to the genetic counseling profession?

Respond to the enclosed survey by August 1

How was NSGC's Plan Created?

After we established our vision—*where we wanted to be*—we determined the best way to realize that vision. This included identifying our:

- **Mission**: What we want to do.
- **Current Position**: Internal strengths, weaknesses; external opportunities and threats.
- **Issues and Barriers:** Those obstacles that could make a difference to NSGC's long-term success.
- **Strategies and Goals**: Our options; how we can manage critical issues or overcome barriers.
- **Objectives and Action Steps**: What we must do to achieve our goals.
- **Evaluation and Monitoring Plan:** How we know we are working toward our vision.

Board Initiates Evaluation

At the April Board of Directors meeting, we began evaluating our first Strategic Plan. We discovered we are about one year ahead of schedule toward its completion. We reviewed our vision and mission statement, updating them slightly to reflect where we want to be. We will continue to fine tune the wording of these definitions. Under consideration are the following changes:

- **Vision.** NSGC: the leading voice, authority and advocate for the genetic counseling profession. *(Note: We released the words "will be," taking the stance that we **are** the leading voice…)*
- **Mission.** NSGC will <position> genetic counselors as integral <to all genetic aspects of> health care delivery, education, <research> and public policy. *(Note: Much discussion revolved around changes to the mission to strengthen what we do; thus the change from **promote** to **position.** The addition of the word **research** was resoundingly supported by the entire Board.)*

To complete the evaluation, we participated in a fascinating experiment. Board members were asked to judge the value of each of our member services, personally and then how they believed an unknown demographic equal (perhaps you) might perceive that same benefit. Their answers were compared with the original membership survey.

Emerging Issues

Last, we identified issues likely to affect the profession through the end of this decade. Board members ranked them according to perceived importance. External issues involve the world outside the organization, in particular, the changing market for services; internal issues involve ways NSGC can better serve members. Refer to the survey to learn what issues were identified.

Now It's Your Turn…

In keeping with NSGC's culture and commitment to member inclusiveness, we are now seeking your input. How much do you value NSGC's member services? What do you think will be the most pressing issues in the coming years? Help us plan for *our* future. Respond by completing and returning the enclosed survey. Your opinion matters.

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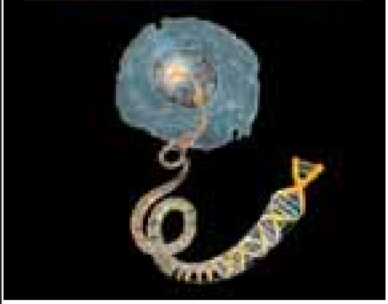
NHGRI: Past & Future Support for Genetic Counseling

ELSI Funds Support Genetic Counseling Projects

Since the establishment of the Division of Intramural Research in 1993, NHGRI has placed particular emphasis on research in genetic counseling.

ELSI has provided funds for a wide range of research and education proposals related to genetic counseling—including an NSGC conference to update recommendations on genetic counseling training curricula, a project to provide genetics education to health professionals and many projects designed to examine issues surrounding genetic testing and counseling for cystic fibrosis and inherited forms of cancer. For example, Barbara Bernhardt recently presented findings from her team's ELSI-funded work on population screening at the NIH Cystic Fibrosis Consensus Development Conference.

National Human Genome Research Institute
at the National Institutes of Health



For more information:
http://www.nhgri.nih.gov

Many ELSI grants include genetic counselors as principle investigators or co-investigators; in fact, NHGRI is one of the most likely Institutes in which non-doctoral level professionals can successfully compete for scarce grant funds.

At this time, the vast majority of ELSI Research Program funds support projects in these highest priority areas:

- Issues surrounding genetics research, such as informed consent and privacy.
- Clinical integration of new genetic technologies.
- Privacy and fairness in the use and interpretation of genetic information.
- Education, particularly of health professionals.

About 20% of the funds support education projects and small amounts of money are available for conferences of national significance.

Counselors Contribute to NHGRI Activities

From 1989-1996, the ELSI Working Group guided the establishment and development of the ELSI Program of the Human Genome Project. Genetic counselors were very prominent members of the working group—which included Beth Fine, Joe McInerney and Vivian Weinblatt, the NSGC liaison. From the beginning, virtually all the ELSI review groups (which review grant applications) have included at least one genetic counselor as a member.

Formal appointments will likely continue for genetic counselors to serve on such national deliberative bodies addressing implications of genome research. Never before in our profession's history have we been invited to participate in such authoritative policy, educational and research activities.

On-Site Research and Education

The Intramural NHGRI also sponsors genetic counseling research activities. A diverse group of studies are underway at the intramural NHGRI, focusing on hereditary cancers, the psychosocial aspects of Marfan syndrome and client interest in prenatal diagnosis for achondroplasia. Collaborative efforts with Howard and Georgetown Universities involve psychosocial and ethics research focused on cross-cultural issues and informed consent.

1996 marked the inception of a new graduate program in genetic counseling—a collaboration between The Johns Hopkins University and NHGRI's Medical Genetics Branch—emphasizing research in genetic counseling. Graduates receive an ScM degree in Health Policy and Management. Four students per year attend the 2 $^{1}/_{2}$ year program featuring a curriculum rich in ethics, policy, health education, counseling and research methods.

Genetic counselors at NHGRI have many diverse roles—Principal Investigators on research projects, Program Director of Extramural research efforts, Director of Family Studies Core. They also helped to develop and teach a recently designed research ethics course. Expert counselors from other institutions have contributed to specialty workshops/clinics on conditions such as Smith-Magenis and X-SCID syndromes.

These and future on-campus and extramural efforts will contribute to furthering our understanding of the impact of genetic conditions and the process of genetic counseling.

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From the Leadership

Presidential Remarks

Full Speed Ahead!

The past few months have been a whirlwind of NSGC activity and the summer promises to not let up! My daunting challenge is to adequately summarize our progress and outline some exciting opportunities just ahead for us.

- Seven GeneAMP Projects are underway. We were all impressed at the creativity and thoughtfulness of the proposals which will increase our visibility in the target markets! *(See page 12 for a list of awardees.)*
- Bonnie LeRoy, Ed Kloza and Maureen Smith represented NSGC during the Workforce Needs Assessment meeting in Tucson AZ this April. A Request for Proposals was written as a result of this meeting; currently the sponsors are trying to secure funds (about $250,000) for this endeavor.
- I've had discussions with the leaders of other genetics and professional organizations—ACMG, ASHG, AMA, NHGRI, ISONG, CORN and the Alliance of Genetic Support Groups—about issues such as joint committee activities, workforce issues, the 1998 American College of Medical Genetics Conference (all four NSGC workshop proposals were accepted), licensure, Senator Domenici's bill, informed consent consensus statements and a potential genetic testing services accreditation program.
- NSGC and other genetic organizations recently shared concerns over misuse of genetic information—a non-genetics professional is offering "confidential" genetic testing on the Internet (www.confidentialgenetest.com). In a letter outlining NSGC's concerns based on our Code of Ethics, Position Statements and Resolutions, I stated that "given the complexities of genetic conditions/ molecular analysis, it is imperative that the limitations, implications, risks and benefits be fully disclosed to an individual prior to genetic testing. Accurate risk assessment is based on a complete pedigree, confirmation of the suspected/known genetic diagnosis within a family and experienced judgment of the health care provider." Since this is only the tip of the iceberg, NSGC will initiate dialogues with appropriate persons at the Department of Health and Human Services. If you are aware of similar situations, please let me know.
- On June 18th, Bea Leopold, Maureen Smith, Chantelle Wolpert and I visit Washington DC to meet Dr. Mary Kay Pelias in Senator Domenici's office to discuss the Genetic Confidentiality and Nondiscrimination Act of 1997. Next we'll meet with leaders from the National Human Genome Research Institute. Our goals include developing an effective working relationship between NHGRI and NSGC as well as seeking NSGC representation on genetic advisory committees and grant review committees.
- Beth Fine, Karen Greendale and I met with international colleagues at the European Society of Human Genetics Conference in Genoa. Look for a full report in the next issue of *Perspectives.*

I continue to be impressed with the commitment and dedication of NSGC members to our profession and have appreciated my many conversations with members regarding issues of membership criteria, social issues policy, NIH consensus statements and SIG activities. This continued dialogue is invaluable for the future advancement of our society!

Ann Boldt, MS
President

Board of Directors Meets in Chicago

The Board of Directors gathered for a weekend this April to discuss current issues and plan our future. With the cool, gray Chicago skies looming outside, the meeting took place in a nondescript conference room over many long hours. But the topics of discussion—the hard work of many members and committees, our organization's accomplishments and our plans for the future—added excitement and warmth to the room.

- Monitoring the Strategic Plan, the Board of Directors considered our progress in reaching the goals set in 1993, and the internal and external factors of current and future importance. To develop a strategy for the coming years, we first created a list of emerging issues affecting NSGC and the genetic counseling profession. The Board has continued to prioritize this list since the meeting and now seeks member input and feedback. *(Be sure to fill out the survey mailed with this issue!)*

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■ The GeneAMP project and the marketing task force will play an important role as we become proactive in promoting our profession. Beth Balkite, co-chair of the Marketing Task Force, gave the Board an overview of the marketing effort. She proposed a new definition of genetic counseling—initiated by Ed Kloza, Beth Balkite, Ann Boldt and Bea Leopold—to help us present a unified message. The simple, one sentence description is designed for easy recall. Together with a fuller explanation of each component mentioned in the one sentence, the definition seeks to paint a picture of genetic counseling. The marketing task force will continue to oversee the definition's development.

■ NSGC-sponsored short courses have been tremendously successful in recent years. In looking forward to future short courses, guidelines for short course proposals and planning have been formalized and were accepted at the Board of Directors meeting. *(See article on page 6.)*

■ Anticipating future requests, the Board approved an interim memorial funds policy. These guidelines are designed to meet the needs of those wishing to establish such funds and to address NSGC's fiscal responsibilities. The Finance Committee will examine the issues in further detail and draft a plan for consideration at the Fall Board of Directors meeting.

Elaine Sugarman, MS
Secretary

Position Paper Approved

"Predisposition Genetic Testing for Late-Onset Disorders in Adults: A Position Paper of the National Society of Genetic Counselors" has recently been finalized by the Social Issues Committee and was approved by the Board of Directors at their April meeting. The article—crafted by Wendy McKinnon, Bonnie Baty, Robin Bennett, Monica Magee, Whitney Neufeld-Kaiser, Kathryn Peters, Jill Sawyer and Katherine Schneider—will be submitted to *JAMA* for possible inclusion in a late 1997 issue devoted to genetics. Comments are welcome—please provide input before the ***July 1*** submission date.

☛ To request a copy of the manuscript or provide feedback, contact Wendy McKinnon, 802-658-4310, FAX 802 860-7542, mckinnon@salus.med.uvm.edu

Celebrate Ourselves!

■ The January 1997 issue of *Health Psychology*—devoted to psychological aspects of genetic testing—includes an article co-authored by **Bonnie Baty.**

■ Speaking out on a timely issue, **Cecelia Bellcross** testified as an expert witness for a hearing on a "partial birth" abortion bill proposed by the Wisconsin State Assembly.

■ A recent broadcast by the Seattle NBC affiliate packed a lot of information about genetic testing's pros and cons—most coming from interviews with **Robin Bennett** and **Stefanie Uhrich**.

■ Look for a May *JAMA* article on informed consent in cancer susceptibility testing—its co-authors include **Barbara Biesecker** and **Katherine Schneider**.

■ **Ginny Corson** and **Ilana Mittman** spoke to 23 senior journalists from across the US as part of a four day genetics course by the Knight Center for Specialized Journalism at the University of Maryland, College Park.

■ **Stephanie Kieffer** and **Katherine Schneider** were awarded a special projects grant by the New England Regional Genetics Group to study the role of support groups in a BRCA1 testing program.

■ The American Association for the Advancement of Science has elected **Joe McInerney** to the rank of Fellow, recognizing his "national leadership in the development of innovative curricula in science education and his vigorous defense of scientific integrity in the teaching of science."

■ Busy **Christina Palmer's** work on risk perception and worldview is being noted—her article on the topic appeared in journal *Risk Analysis* last year; the National Science Foundation has funded a further study which will also look at ethnicity.

■ **Julie Rutberg** presented on the management of maternal PKU at the International Society of Inherited Metabolic Diseases meeting in Austria. **Linda Cooper** is one of the abstract's co-authors.

■ **Cecile Skrzynia** was prominently featured in a local newspaper story about the new cancer clinic at the University of North Carolina Chapel Hill Medical Center, which she is setting up.

■ **Vivian Weinblatt** was interviewed for an *Inside Magazine* article on the "Jewish" genetic diseases. And she spoke to the Pennsylvania Biotechnology Association conference on "The Relevance of the Human Genome Project."

NSGC Short Course Guidelines

With the first NSGC-sponsored short course, the *ABC's of Cancer Genetics*, the Education Committee established a tradition of offering high quality educational programs on specific topics of interest to members. The second NSGC-sponsored short course, *Unlocking the Secretes of Neurogenetics,* was so successful that the American College of Medical Genetics invited the program chairs to offer the course in March at their annual conference. The third short course, *Cancer Genetic Counseling: A New Era Unfold*s, promises to uphold the established tradition of excellence.

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Committees,
Liaisons,
SIGs...

To encourage development of high quality educational programs, the **Annual Education Conference Subcommittee** has developed guidelines for submitting short course proposals. Approved by the Board of Directors this spring, these guidelines take effect immediately.

Any NSGC member or Special Interest Group wishing to offer a short course in conjunction with the 1999 ACMG meeting or the 1999 NSGC Annual Education Conference is encouraged to obtain a copy of the guidelines and an application from the Executive Office. Applicants will be asked to provide the title of their program, a statement of purpose, three learning objectives, the proposed number of contact hours and a list of participants in the planning process.

The deadline for receipt of proposals for short courses to be offered in conjunction with the 1999 American College of Medical Genetics conference is ***August 1, 1997***. If you are interested in offering a short course in conjunction with the 1999 NSGC Annual Education Meeting, your proposal should be postmarked no later than ***January 1, 1998***.

Applications will be reviewed by the members of the Subcommittee; proposed program chair(s) will be notified of their decision approximately 16 months before the meeting date.

Carol Christianson, MS
Annual Education Subcommittee

☛ For more information about coordinating a short course, contact Annual Education Subcommittee Chair, Lisa Amacker North, 704-355-3159, enorth@carolinas@org. For an application and guidelines, call the NSGC Executive Office, 610-862-7608, #6.

Find Your Role in NSGC

Follow-the-Leader—a child's game my daughters love to play. Follow-the-Leader—the organizational structure that allows NSGC to move forward.

In a previous issue, we presented some qualities of leaders. But just as in the game, having leaders implies there will be followers. What is their role? Leaders, followers—the relationship between the two is not as polarized as the words suggest. In reality, it is a partnership. Just as leaders inspire followers, followers inspire and encourage leaders.

Much of NSGC's work is accomplished through committees—our organization's success reflects the success of the committees in reaching their goals. The leadership structure—including the committee chairs—provides a framework through which activities are coordinated. But it is only through the ideas and hard work of the committee members that goals are reached.

How can you be an effective committee member? Be an active participant in all stages of the group's work. Committees set goals and outline objectives and projects to accomplish. Bring your ideas and contribute to this goal-defining process. Don't forget to set personal goals—identify what you can offer and what you will get from participating. And bring your commitment to work! Part of the leader's role is to hold committee members accountable; followers must see that their tasks get done.

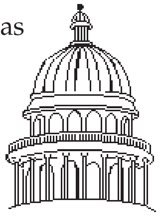
Do you have the qualities to be a leader or a follower? (Most people have some of both.) Either way, we want you to be involved—both roles are needed to accomplish our goals. As in the game, leaders change. Followers step forward to become leaders and leaders step back to become followers. This infuses NSGC with new ideas and direction.

Step forward and get involved—either as a leader providing guidance and inspiration or as a follower accomplishing tasks.

Kevin Josephson, MS
Nominating Committee

Remember to vote! ***August 1*** *is the deadline to cast your ballot for President and three new Regional Representatives.*

Legislative Update



- The Genetics Confidentiality and Nondiscrimination Act of 1997 (S.422) has met with some opposition. Introduced by Senator Domenici (R-NM), it strives to strengthen the informed consent process for research subjects and prohibit employment/health insurance discrimination. Some feel it is not possible to distinguish genetic information from any other medical information; others feel it may hinder legitimate research. The language of this bill is still being revised—look for floor consideration this fall.

- Introduced by Senator Bond (R-MO), the Birth Defects Prevention Act (S.419) remains very similar to the legislation introduced and passed in previous sessions of congress which never received appropriations funding. Consideration expected this fall.

- Legislation restricting the availability of late pregnancy intact D&E ("partial birth abortion") except to save the life of the mother has passed both Houses and been sent to the White House. At press time, the President has taken no action—he has previously indicated he would veto if the language was too restrictive.

Lee Fallon, MS
Social Issues Committee

Billing & Licensure Update

- The California legislature is considering regulations to license genetic counselors and provide standards for genetic services. Ann Walker testified in February, advocating adoption of certification as the standard for licensure.

- Wisconsin attempted licensing through the Social Work, Family Therapist and Professional Counselor Licensing Act. This law requires certification to use the term "counselor" professionally. A petition to the Professional Counselor Section and seven individual applications were unsuccessful; two genetic counselors were certified by this board. An exemption to the law is being sought.

- In Illinois, Leslie Cohen reports that genetic counselors have dropped their pursuit of licensure due to the low numbers and high expenses involved. They are looking into the state's managed care setup for public aid recipients, hoping to ensure that genetic services, testing and counseling will be covered under these new plans.

LuAnn Weik, MS & Angela Musial, MS
Billing, Licensure & Reimbursement Subcmte

SIG Announcements

- Do you have an interest in conditions such as Marfan syndrome, osteogenesis imperfecta or skeletal dysplasias? The **Connective Tissue Disorders** SIG is recruiting members. Contact Leah Hoechstetter, 513-559-4351, or Melanie Pepin, 206-543-5464.

- The **Gay, Lesbian and Friends** SIG is looking for new members. For more information, contact Bruce Haas, 212-639-6760.

- The **Psychotherapy and Expanded Counseling Skills** SIG is sponsoring case study groups at the Annual Education Conference. Professionally led, there will be 6-8 people per group. For more information, contact Luba Djurdjinovic, 607-724-4308.

- The **Prenatal Diagnosis SIG** has published two newsletters to date. Beth Balkite from Genzyme will be giving a talk at the Annual Education Conference on Prenatal FISH. Renee Laux is a new co-chair.

compiled by Karen Potter, MS,
Cathy Wicklund, MS

Human Genome Project Update

- To date, 54.2 megabases of DNA have been sequenced, representing 1.8% of the human genome. By 1998 7.2% will have been completed.

- Implications of discovering the gene for hereditary hemochromatosis were discussed at a March meeting, "Iron Overload, Public Health and Genetics." The consensus: population screening is premature.

- According to the recently-issued statement from the NIH Consensus Panel on Genetic Testing for Cystic Fibrosis, it is appropriate to offer CF carrier testing to the prenatal population and couples planning pregnancy, regardless of family history or ethnicity. The Statement includes recommendations about informed consent and education/counseling. It endorses insurance coverage for genetic testing but doesn't address genetic counseling costs.

- Culminating two years of work, Tony Holtzman and Michael Watson presented the final report of the Task Force on Genetic Testing with consensus conclusions. It recommends "the College of Pathologists and American College of Medical Genetics seek advice and input from consumer groups... as well as from the NSGC, on educational, psychological and counseling issues in pre- and postanalytic components of genetic testing that are of direct concern to consumers."

Rosalie Goldberg, MS, Liaison
Nat'l Advisory Council for Human Genome Research

The American College of Medical Genetics: Perspectives from the New President

■ *In January, genetic counselors on the NSGC Listserv debated the merits of membership in the American College of Medical Genetics. Some balked at the $100 dues, citing limits on our role in the College. Others stressed the value of being in the loop and influencing policy. This interview with College President Reed Pyeritz explores the role of genetic counselors in the organization.*

Reed Pyeritz ("Peeritz"), MD, PhD, a member of the College's Founding Board of Directors, began a two year term as President in January. An internist specializing in Marfan syndrome, he now focuses on the genetics of common disease. He is Chairman of Human Genetics at the Allegheny University of the Health Sciences in Pittsburgh and Philadelphia.

The American College of Medical Genetics was created by a committee of the American Society of Human Genetics in 1991 to represent genetic service providers and their patients and "...to elevate the rapidly emerging specialty of Medical Genetics to full representation within the established medical service, certification and regulatory organizations."

Genetics lacked recognition as a full-fledged medical specialty then. Membership in the American Medical Association House of Delegates was a key goal of the College, achieved in June 1996. That body requires that only doctoral level, certified geneticists be Fellows of the College and that 51% of the physician Fellows be current AMA members.

Only Fellows can vote for officers or hold office. Board-certified genetic counselors may be Associate Members, with all other member privileges including serving/voting on committees. Physicians in NSGC are also Associate Members, with similar restrictions.

How do ACMG and NSGC overlap? How do they work together?

"Clearly, both have a responsibility to their voting members and to advance and protect their professional standing," says Pyeritz, "but both have a commitment to all their members. Medical genetics can only be done effectively as a team. Genetic counselors, whether members of the College or not, are members of the team; their professional stature needs to be maintained and enhanced just as the Fellows' needs to be."

Counselors have had input on almost every issue: Ann Smith served as advisor to the founding board. We have periodic meetings between NSGC and College leaders, open lines of communication—I talk with Ann Boldt or Maureen Smith whenever there's an issue that requires advice or joint action; we share copies of important correspondence. We're working together on the billing issue....

About the American College of Medical Genetics

Mission Statement: The College "is committed to making genetic services available to the American public without regard to age, race, national origin, gender, sexual orientation, disability or ability to pay. The College will foster the development and implementation of methods of diagnosis, treatment and prevention of genetic disease in order to generally improve the public health. It will sponsor educational programs for geneticists, the medical community and the public at large."

Membership: 1006 paid members including 93 genetic counselors

For more information: Contact the ACMG office, 301-571-1825, or http://www.faseb.org/genetics.

How can counselors become involved, be heard?

Committees are where much of the College's work is done. Counselors now sit and vote on nine of the College's committees or subcommittees (13 seats), influencing activities, policy and more.

"While I'm President, any time a clinically-oriented position paper is written, a genetic counselor will be involved just as a clinical or laboratory geneticist would be involved. We go to great pains to make sure that all constituencies of the College and the field are represented."

If interested in working on a committee, contact one of the College's leaders so they can notify you when an opening arises or a new committee forms. We encourage new people to become involved and would appreciate input to the Program Committee so the Annual Meetings are valuable for counselors.

Can the College's voice really be heard in the AMA?

It has already. Recently, we modified or defeated three AMA initiatives that would have affected genetics negatively. The AMA is very enamored with genetics right now—they've hired two geneticists and are undertaking to bring genetics to primary care physicians. Pyeritz admits the AMA

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Letters to the Editor

Nondirectiveness

This past Thanksgiving my 9-year-old son was playing Jenga with a rather arrogant 40-year-old trauma surgeon. The game of Jenga begins with a tower of blocks; the opponents take turns removing the blocks, one-by-one, and putting them on the top of the tower. The player who knocks down the tower loses. The otherwise bored holiday guests gathered around the two players with building excitement as the tower grew higher and higher and more precarious. Admittedly I was the proud father watching my son take on the surgeon all on his own. At one point, after many anxious turns, my son looked at me, and for the first time asked me which block he should pull from the tower. I hesitated, and then suggested a particular block. He pulled it. The tower came tumbling down.

Guess who felt like an ass? Me. Guess who my son looked at with eyes of disappointment? Me. This was an important parenting lesson but I also believe it to be a glaring lesson of the value of nondirectiveness. When that tower falls for the counselee and you've been directive, be prepared to be blamed. When you feel compelled to put in your own "two cents," you are partially responsible for the actions taken. By telling the client what you would do, you are clearly affecting the outcome; you are an authority figure. Ask yourself: Why do I want responsibility for the outcome? Why shouldn't the client take responsibility for the decision making? Don't be scared to cut the cord and release yourself from paternalism. Nondirectiveness is liberating for both counselor and client.

Seth Marcus, MS
Park Ridge IL

Survey Advice

Students and others writing surveys on professional topics, let me suggest one way to keep your next mailing out of my trash can. (As the numbers increase and I become more pressed for time, this is where many surveys land.) Please think carefully about the demographic data you request. We're still a relatively small profession and there are many of us who can be identified by one or two demographic questions. As Idaho's only genetic counselor, I give up my anonymity when I disclose which state I practice in. Others—ethnic minorities, men, counselors practicing for many years and people with unusual jobs—may also be easily identified.

When queried about my state, I ask myself: Who might see this survey? How personal are the questions? Are there knowledge questions I'll be embarrassed to answer incorrectly? How important is the information to our profession's development? Depending on my my mood, I leave some questions blank, am less than candid or trash the survey entirely.

The demographic questions are not just throw aways—they matter to those filling out the survey and they should be as carefully thought out as the content questions. Consider whether you need this information at all. Will other, less identifying data suffice? Rather than asking in which state a person practices, for example, you may ask for NSGC region or whether their clients are primarily urban or rural. You may actually save yourself time analyzing data you don't need and get a higher return rate.

Anne C. Spencer, MS
Boise ID

***Pyeritz**, continued from previous page*

isn't perfect. Witness how they handled the partial birth abortion issue. "But regardless of what any of us think about the AMA politically, they are a major force in American medicine and we have to learn to use that position to our collective advantage."

What about genetic counselors and billing?

"We all recognize the problem of a genetic counselor not being able to bill and get reimbursed. That's a problem we all face. Given that [NSGC has no] seat at the table of national discussions, the College has to be the one who takes up the banner." Despite recent setbacks, this is still being pursued by the College's Economic Services Committee, which includes two genetic counselors. How these "major policy decisions get made is totally political."

What do you think is the greatest challenge facing genetics right now?

"How to provide high quality services to an increasing number of people, largely due to the Human Genome Project. There aren't enough genetic counselors or medical geneticists in the world to do that. We have to decide as a profession, collectively, what we're going to give away and what we're going to retain and, having done that, what we'll be left with economically."

Linda Whipperman Bendor, MS
Stanford CA

Bulletin Board

Resource Guide Available

A *Guide for Developing Community-Responsive Models in Health Professions Education,* written by the Community-Campus Partnerships for Health and the Health Professions Schools in Service to the Nation Program, helps readers improve community-campus partnerships, better prepare students and promote healthier communities. Chapters in the 190-page guide address such topics as curriculum development, interdisciplinary collaboration, cultural competence, faculty development, student leadership and program evaluation; it also includes information about model programs.

☛ The resource guide is available for $15 (includes shipping) from the Community-Campus Partnerships for Health, 1388 Sutter Street, Suite 805, San Francisco CA 94109. For more information, contact Alisa Holmes, 415-502-7979, ccph@itsa.ucsf.edu or visit their web site, www.futurehealth.ucsf.edu.

Hispanic Prenatal Hotline

It's up and running and already very popular! The National Hispanic Prenatal Hotline provides culturally appropriate, bilingual information and local referrals to Hispanic callers. The hotline, part of the Maternal and Child Health Bureau's campaign to promote early and regular prenatal care, is operated by the National Coalition of Hispanic Health and Human Service Organizations.

☛ The Hotline number is 1-800-504-7081.

Online Cancer Counseling Directory

A directory of genetic counselors, physicians, geneticists and nurses with expertise in familial cancer risk counseling and genetic susceptibility testing is available on CancerNet™. The National Cancer Institute's International Cancer Information Center developed and maintains this online cancer information service, located at http://cancernet.nci.nih.gov.

Free Science Education Materials

The National Cancer Institute has free science education materials available, including the latest cancer rates/risks, an information kit to increase public understanding of recent scientific discoveries and a slide lecture called *Understanding Gene Testing.*

☛ For more information, contact Jana Johnston, Health Promotion, 301-496-6667, johnstoj@occ.nci.nih.gov.

Expanded AFP Testing Materials

Linda Robinson of the California Genetic Disease Branch has developed a 4-hour presentation on the State's Expanded AFP Screening Program, detailing counseling issues and testing protocols. The presentation includes an extensive packet of information compiled on the subject.

☛ For more information, contact Linda Robinson, 510-883-6027, Mondays & Wednesdays.

Update Your Listing

NSGC members! Review the information on the back cover to ensure a correct listing in the 1988 Membership Directory. To be included in this edition, changes are due ***August 29.*** But to keep those lines of communication flowing all year round, be sure to inform the Executive Office of changes whenever they occur.

Get Ready for Baltimore!

■ Start gearing up for the Annual Education Conference—it promises to be worthwhile. Abstract Chair Laura Thomson reports that an unprecedented number of abstracts were received—105! The deadline for registering without penalty is ***August 15.***

■ Hosting a reunion or other gathering? To request a room or equipment for an ancillary meeting, contact the Executive Office by ***July 15.***

■ Accommodations sought: Are you able to share a room with an international genetic service provider—at no cost to the visiting colleague? Contact Lavanya Misra, Chair, International Issues Subcommittee, 212-523-3112, FAX 212-523-1839.

Share Your Treasures!

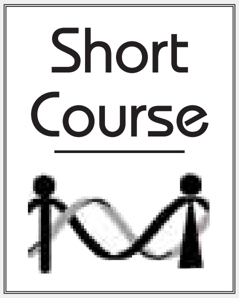
The Resource Room—a place to preview slides, videos, written materials and other genetic counseling aids—is a popular feature of the Annual Education Conference.

■ Do you have materials or information for display? Let us know by ***September 15.***

■ Would you like to help with a "Students' Corner"? Current students or recent graduates are both welcome—volunteer before ***July 31.***

☛ Contact Rhonda Schonberg, 202-884-4166, FAX 202-884-2390.

Cancer Genetic Counseling: A New Era Unfolds



The NSGC-sponsored short course on cancer genetic counseling—to be held Friday, October 24 at the Marriott Inner Harbor in Baltimore—will address general concepts as well as late breaking developments. The case-oriented, concept-driven approach to the course is designed to challenge both new and experienced counselors. Plenary sessions and diverse workshops will help individuals meet their own learning needs. Participants will be able to:

- Apply principles of pedigree analysis, cancer biology and epidemiology to cancer risk assessment.
- Evaluate the appropriateness of various testing strategies.
- Consider screening and prevention options in high risk individuals.
- Explore the ELSI issues germane to cancer risk notification.

Register now as space is limited!! The deadline is ***August 15.*** Contact the Executive Office for more information, 610-872-7608, mailbox 6.

Upcoming Meetings

July 8-13 • July 29-Aug 3 • Ann Arbor MI
Breast Cancer: Genetics & Risk Evaluation Workshop, sponsored by the Univ of Michigan Comprehensive Cancer Center. Contact: Laurie Blumberg, 313-764-2248

July 18-20 • Aspen CO
Genetics & Ethics in the 21st Century, sponsored by the University of Colorado. Contact: 800-882-9153

August 23, 1997 • San Diego CA
"Genetic Testing for Hereditary Breast Cancer: Should We Stop It?" sponsored by the Pacific Southwest Regional Genetics Network. Contact: Pamela Cohen, 510-540-2852, pcohen@genetic.dhs.cahwnet.gov

Sept 4-6 • Chapel Hill NC
International Symposium on Gene Therapy for Hemophilia. Contact: 919-962-2118, gtmeet@med.unc.edu

Oct 19-22 • Baltimore MD
"Forging New Directions into the Next Millennium," Healthy Mothers, Healthy Babies Coalition National

CyberGenes

ResourceLink & You

What's the most important resource in the genetic counseling profession? OK, time's up: it's ourselves. That's what makes the ResourceLink so important. Now I know what some of you are thinking. What is a ResourceLink? Glad you asked.

Directly linked to the NSGC web site, the ResourceLink is a voluntary online listing of genetic counselors with their most recent addresses, phone/fax numbers and e-mail addresses. It is updated frequently so information can be added or deleted quickly.

ResourceLink Nuts & Bolts

Organized by city/state/province, ResourceLink allows those interested in finding out about the profession as well as those seeking genetic counseling to locate a geographically-suitable counselor. It also gives some background information for searchers—here is some of the introductory text displayed at the site:

- The ResourceLink lists NSGC members who gave their permission to be listed on this web site. Therefore other genetic counselors, who are not listed, may be located at a nearby University medical center or other medical center/hospital.
- Each center varies with regard to referral requirements, payment methods and services.
- Most counselors will perform a brief intake to determine whether or not an appointment for a genetic consultation would be of benefit to you. Longer consultations by phone are usually not possible and a scheduled appointment would be necessary to discuss your concerns.

But I Don't Need to Find Anyone!

What if someone needs to find you? ResourceLink is a great marketing tool for our profession—now it will be easier for the public, the media, prospective patients and interested students to find genetic counselors.

ResourceLink is open to Full or Associate NSGC members. Applications are available online or, if you don't have a computer, contact the Executive Office for an enrollment form. Don't be the last one on the block to sign up!

Steven Keiles, M.S.
steven.b.keiles@kp.org

Project GeneAMP (Applied Marketing Project)

The GeneAMP Proposal Selection Committee received 12 proposals for developing and implementing NSGC's marketing strategies. Ideas were submitted through all five Project teams—Primary Care, Managed Care, Medical Professional Organizations, Consumers & Employers and Law & Policy Makers. The submissions demonstrated creativity, resourcefulness and, certainly, vision. The total amount of funding requested by the proposals exceeded $75,000.

Project GeneAMP

To establish genetic counselors as integral, valued participants in every health care system

The selection committee—comprised of GeneAMP Co-Chairs Ed Kloza and Beth Balkite, the NSGC Board of Directors Executive Committee and the Chair of the Finance Committee—reviewed all proposals and evaluated each on the following criteria: meeting the GeneAMP objective, meeting its own goals, feasibility of timeline, appropriateness of evaluation method, innovation and budget.

The Winning Proposals

After careful consideration, the committee selected the following seven proposals—at least one from each Project Team—for funding:

Genetic Counseling Contract Services Inc: A Model for Expanding the Four Ps (Product, Place, Price, Promotion) of Marketing by Genetic Counselors in Private Practice. Barbara Lerner, Doreen Martis Eakman, Alison Warner

Promotion of NSGC at Professional Meetings 1: Development of a Permanent NSGC Display. Lisa Amacker North, Bea Leopold, Liz Stierman, Seth Marcus, Lori Williamson-Kruse, Cathy Wuchenich

One Message for Managed Care. Debra Lochner Doyle, Amy Cronister, Kristin Baker, Lisa Brown, Kelly Jackson, Sandy Marchese, Robin Schwartz, Janet Ulm

Professional Education Exhibits. Betsy Gettig, Laura Turlington, Karen Johnson, Patrick McNamara

Education of State Legislators Regarding the Importance of Genetic Counseling in Health Care. Aïda Metzenberg, Stacey Wong

The Primary Care Slide Show. Jennifer Farmer, Jill Stopfer

Consumer Groups: Linking to Genetic Counseling Services. Debra Collins

The Next Round is Coming

For the next three years, GeneAMP will provide funding support to project(s) marketing the genetic counseling profession and fulfilling the project's objective—to establish genetic counselors as integral, valued participants in every health care system. Applications for 1998 funds are due ***September 1.***

Applications will only be accepted through the GeneAMP Project Team Leaders *(listed below)*. Proposed projects will be judged on the basis of their merit and strength as well as their applicability to the GeneAMP objective. Proposals may be funded in whole or in part.

More than one proposal may be submitted to the same project team. Proposals are limited to two pages and should include names of project leaders/team members, a statement of need, target audience, relevance to GeneAMP objectives, strategy, timeline, projected outcomes, an evaluation plan and an itemized budget. (Complete proposal guidelines—outlined in the previous issue of *Perspectives*—are available from the NSGC Executive Office.)

For more information or help in developing a proposal, contact a Project Team Leader:

Primary Care Providers:
Lisa Amacker North
☎ 704-355-3159
enorth@carolinas.org

Seth Marcus
☎ 847-723-7705

Managed Care Organizations:
Debra Lochner Doyle
☎ 206-464-7752
dld2303@hub.doh.wa.gov

Amy Cronister
☎ 602-675-0250
ext 12

Medical Professional Organizations:
Betsy Gettig
☎ 412-624-9951
bgettig@helix.hgen.pitt.edu

Consumers & Employers:
Melonie Michelson
☎ 216-379-8792

Joy Redman
☎ 713-798-9500
joyred@juno.com

Law & Policy Makers: To be announced

Ed Kloza, MS & Beth Balkite, MS
GeneAMP Co-Chairs

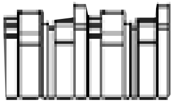
Winding Your Way Through DNA

PROMISES AND PERILS OF BIOTECHNOLOGY; GENETIC TESTING: WINDING YOUR WAY THROUGH DNA. produced by Pyramid Media, 1996; order code 0-05222; 310-828-7577; 25 minutes; $225.00

Resources

edited by

Karen Copeland



This video was produced by the University of California at San Francisco as a collaborative effort between geneticists, educators, bioethicists and historians. It uses real-life situations to illustrate the practical applications and implications of complex genetic testing. It shows, in a very powerful way, how the availability of this testing impacts decision making in real life.

Two scenarios illustrate the decision making process. The first involves a woman named Jennifer who decides to be tested for Huntington disease. Jennifer's story demonstrates testing limitations and the process one goes through to decide whether testing is right for the individual. This is especially relevant when there is no available disease cure and manifestations may not occur for two or three decades.

The second scenario is about Lilly Ann's and Laura's decision to be tested for the gene responsible for hypercholesterolemia, an autosomal dominant condition. This story emphasizes the value of knowledge. In this disorder, health risks can be decreased by changing behavior through exercise, diet and medication. These dynamic real-life situations provide opportunities for thoughtful open-ended decision making and show how genetic information may be applied to personal, career and societal issues.

The graphics are excellent; the information presented on human genetics and genetic testing is up-to-date and very accurate. *Promises and Perils* would be a valuable resource for teaching high school and college biology and science courses. Social work, genetic counseling and science students would be well-educated about the practical applications of genetic testing. There is an excellent supplemental teaching guide with activities and handouts to enhance the learning of human genetics and testing and the ethical, financial and psychological issues surrounding such testing. The real strength of this video is that it demonstrates how the science and medical aspects of genetics must be combined with other forms of knowledge and personal values in order to completely understand the issues and make decisions.

Stefanie Uhrich, MS
Seattle WA

ABGC Update

First Training Programs Achieve Full Accreditation

Establishing accreditation for training programs is a landmark for the genetic counseling profession. The American Board of Genetic Counseling reviewed applications for full accreditation in early 1997. Applying programs conducted an in-depth self-study appraisal and were evaluated by a site visit team.

The Board is pleased to announce that Sarah Lawrence College, the University of Pittsburgh and the University of Colorado achieved full accreditation effective July 1. We extend special thanks to the *ad hoc* site visit committee members who established procedures for the visits, the site visitors themselves and these first three programs, especially the directors and all participants in the accreditation process.

Each year, about three programs that currently have Interim Accreditation will be evaluated, over a six-year cycle. Programs with Recognized New Program status must apply for full accreditation within five years of graduating their first students.

Logbook Forms Available

Logbook forms for the 1999 Certification Examination and instructions for completion are now available from the ABGC Administrative Office. The Bulletin of Information and Application will be available later this year. The next ABGC exam is scheduled for June 23, 1999.

Bonnie Baty, MS, Accreditation Chair
Helen Travers, MS, Credentials Chair

☛ For logbooks or other information, contact Sharon Robinson, ABGC Administrative Office, 9650 Rockville Pike, Bethesda MD 20814-3998, 301-571-1825; FAX 301-571-1895, **robinson@abgc.faseb.org**

Thesis Projects • 1997 Graduates

California State University, Northridge

Wendy Buchanan: The genetics of frontotemporal dementia, a late-onset neurodegenerative disorder.

Jodi Kirsch: Tetrasomy 18p with unusual brain findings: a case report.

Dalia Khoshbakhsh: Nonketotic hyperglycinemia: a case report

Kathleen Blazer: Abnormalities associated with chromosome 15q11-q13 and a case report of an intrachromosomal triplication of this region.

Northwestern University

Pam Clouser: An assessment of the knowledge and attitudes of Wisconsin insurance companies and employers regarding genetic legislation.

Carrie Curell: Attitudes toward predictive testing for Alzheimer's disease.

Lindsay Jordan: Y-me Hotline workers: Assessment of knowledge, interests and need for an educational program about breast cancer genetics and genetic counseling.

Kate Roth: An analysis of Internet-based genetic counseling.

Aimee Tucker: The efficacy of FISH analysis for common aneuploidies in relieving the anxiety of patients awaiting prenatal diagnosis results.

Kara Watson: Prior knowledge among mothers of children with hemoglobinopathies and determination of benefits of genetic counseling.

University of Cincinnati

Annie Fuchs: How does amniocentesis really feel? Comparing patient experience with genetic counselors' descriptions during counseling.

Cindy Hoyle: Discussion of genetic discrimination issues by genetic counselors and their clients: A comparison study.

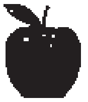
Shelley Kennedy: An assessment of the effectiveness of two brief interventions at training obstetrical nurses and midwives about the maternal serum triple screen.

Peggy Kolodziej: Factors that influence a hypothetical choice between enzyme and gene therapies by adults with Gaucher disease type 1.

Kate Lynch: Communication with first and second degree relatives in familial breast cancer families.

Ingrid Ziebarth: African American and Caucasian client preferences for genetic counselor characteristics.

Student Page



University of Texas, Houston

Ellen R. Friday: The association of nonsyndromic cleft lip/palate with cancer and other birth defects.

Andrea Ybarra: A survey of variable expression in retinitis pigmentosa (RP).

Noelle Kimberly Romaine: Spina bifida: Evaluation of genetic and environmental factors.

University of Wisconsin-Madison

Jessica Dickstein: Creation of the Wisconsin Stillbirth Service Program web site.

Kendall Mockridge: Tandem mass spectrometry for the diagnosis of inborn errors of metabolism: A new era in Wisconsin newborn screening.

Amy Stettner: Familial ovarian germ cell cancers: Does a genetic predisposition exist in some families?

Heidi Nagel: Clinical evaluation of an interactive educational computer program on inherited breast cancer and genetic testing—a preliminary report.

Patricia Leh: Generation of stillbirth education and awareness resources for the community and for newly bereaved parents.

DEADLINES & REMINDERS

- **Provide feedback** on the Predisposition Testing Position Paper *(see page 4)* . . . ***July 1***
- **Return the survey** identifying our profession's most pressing issues *(see Strategic Planning, pages 1-2)* . . . . ***August 1***
- **Vote** in the NSGC election . . . . ***August 1***
- **Register** without penalty for the Annual Education Conference and/or the Cancer Genetic Counseling Short Course . ***August 15***
- **Submit a proposal** for Project GeneAMP funds *(see page 12)* . . . . ***September 1***

Job Listings

San Jose CA

■ Sept 1 opening for BC/BE Genetic Counselor. Exp pref. Join active team in established, comprehensive genetics program in large HMO. Broad range of svcs: PN, terat, triple marker scrng, ped & adult consults.
Contact: Karen Wcislo, Genetics, Kaiser Permanente, 260 International Cr, San Jose CA 95119-1197; 408-972-3300. EOE/AA

Washington DC

■ July 1 opening for BC/BE Genetic Counselor w/trng in cancer genetics or 1-2 yrs exp & min 3 yr commitment req; excellent commun skills, ability to work independently req. Phlebotomy req. Pre- & post-test GC for BRCA 1&2 in context of rsrch protocols; participate in study recruitment.
Contact: Fax cover ltr & CV to Beth Peshkin, MS, Georgetown University Medical Center, 2233 Wisconsin Ave Ste 535, Washington DC 20007; Fax: 202-687-0820. EOE/AA

Springfield IL

■ Immediate opening for BC/BE Genetic Counselor: coord genetic clins, consult at multiple ped specialty clins, teaching med students & residents, professional & comm educ.
Contact: Catherine O'Malley, SIU School of Medicine, PO Box 19230-MC#1614, Pediatrics, Springfield IL 62794-1614. EOE/AA

Indianapolis IN

■ July 1 opening for Part-time BC Genetic Counselor. Exp req. Join univ-based genetics team: peds, specialty & outreach clins; teach in GC training prog; community educ.
Contact: Marcia Combs, c/o #92-97, Indiana Univ, Human Resources, 620 Union Dr Rm 340, Indianapolis IN 46202. EOE/AA

Baltimore MD

■ July 1 opening for BC Genetic Counselor w/min 5 yrs exp in clin genetics. Grant writing & rsrch exp desirable. Ability in all areas of GC, esp in accredited MGC trng prog. Provide s'vision for house staff, medical & GC students; teaching & admin. Clin respon in busy pediatric clin.
Contact: Submit CV & 2 ltrs recommendation to: Karen Eanet, MS, University of Maryland Hospital, Div Human Genetics, 22 S Greene St-A661, Baltimore MD 21201; 410-328-3335; keanet@peds05.ab.umd.edu. EOE/AA

Rockville MD

■ Immediate opening for BC/BE Genetic Counselor. Start part-time w/possible expansion to full-time. 2+ yrs exp pref. Cancer GC exp & bilingual (esp. Span, Asian) a plus. Ability to work independently req. All aspects of PN GC & follow-up in private PN practice. Some genrl, terat, carrier scrng, cancer couns. Occasional info/educ to health prof, students & support groups. Occasional travel to Baltimore & N. VA ctrs.
Contact: Robin McBride, MS, Genetic Consultants of Maryland, 11125 Rockville Pike Ste 302, Rockville MD 20852; 301-770-5300; FAX 301-770-2005.

Rockville MD

■ October 1 start date for BC/BE Genetic Counselor. Coord studies of genetic factors re: connective tissue disorders: assessment of counseling needs and provision of GC.
Contact: Daniel Wilson, Westat, Dept HS97, 1650 Research Blvd, Rockville MD 20850-3129; 301-251-1500; Fax: 301-294-2040; HR1@WESTAT.COM. EOE/AA

Ann Arbor MI

■ Immediate opening for BC/BE Genetic Counselor. Exp pref. Highly motivated, independent personality req. All aspects of PN GC: amnio, CVS, U/S anomalies, terat, triple marker scrng, bereavement. Oppty for teaching & outreach.
Contact: Send CV & 3 ltrs recommendation to: Clark Nugent, MD, University Michigan, Dept OB/GYN, Fetal Diagnostic Ctr, 1500 E Medical Center Dr, Ann Arbor MI 48109-0264; 313-764-1406; FAX 313-647-1006; nugentc@mailgw.obgyn.med.umich.edu. EOE/AA

East Lansing MI

■ Aug 1 opening for part-time temporary (3 mo w/ possible permanent) for BC/BE Genetic Counselor. Genr'l genetics, PN and satellite clins; partic in triple test/AFP result interpretation, may incl CF & hemochromatosis educ, interpretations of DNA tst results; rsrch & commun/prof educ oppty.
Contact: Michael Netzloff, MD, B240 Life Sciences Bldg, East Lansing MI 48824-1317; 517-353-2030; Fax: 517-353-8464. EOE/AA

Eugene OR

■ Immediate opening for BC/BE Genetic Counselor. Join active, multidisc perinatal GC svc team in tertiary care ctr. Provide GC, coord amnio & AFP prog; assess/respond to needs/inquiries of pts, families, staff and referring physicians. Oppty to work w/families w/variety of unusual dx and long-term follow-up.
Contact: HR/NSGC, Sacred Heart Medical Center, PO Box 1479, Eugene OR 97440; FAX 541-687-6050. EOE/AA

Philadelphia PA

■ Immediate opening for BC/BE Genetic Counselor. Start Part-time w/possible expansion to Full-time. Participate in genrl peds, specialty & local satellite clins. S'vise GC students & residents. Oppty for rsrch, public spkg, teaching exist.
Contact: Jennifer Peet, MS, St. Christopher's Hospital for Children, Section Clinical Genetics & Dysmorphology, Erie & Front Sts, Philadelphia PA 19134-1095; 215-427-8374; peet@allegheny.edu. EOE/AA

Columbia SC

■ Immediate opening for BC/BE Genetic Counselor w/excellent org, interpersonal skills req. Join high risk pregnancy mgmt svc: CVS, amnio, serum screen, abnormal U/S, etc. Oppty for teaching in GC Trng Prog; projects in educ, clin svc & rsrch.
Contact: Send CV & 3 ltrs rec to: Janice Edwards, MS, Ob/Gyn, Univ South Carolina, School of Medicine, Columbia SC 29203; 803-779-4928; Fax: 803-434-7756; jjedwards@richmed.medpark.sc.edu. EOE/AA

Fort Worth TX

■ Immediate openings for 2 BC/BE Genetic Counselors. Join a busy, mustidisc priv practice in Ft. Worth & Arlington. All aspects of PN GC. Add'l outreach clins a possibility; oppty for participate in ongoing support group.
Contact: Mark Maberry, MD or Kim McMillen , Office Manager, Texas Maternal Fetal Medicine, PA, 1325 Pennsylvania Ave, Ste 690, Fort Worth TX 76104-2133; 817-878-5298; Fax: 817-878-5289. EOE/AA

**national society
of genetic
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nsgc

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Perspectives in Genetic Counseling is published quarterly by the National Society of Genetic Counselors, Inc. Send articles and correspondence to the Editor-in-Chief; address changes, subscription inquiries and advertisements to the Executive Director. Contact any Editorial Board member with ideas or suggestions. Editorial Staff:

Next issue ***September 15***
Submission deadline ***August 10***

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"Let's Get It Right!"

We're updating our records for the 1998 Membership Directory, due for distribution this fall. Carefully review your information below for accuracy and completeness.

- Did we "Get It Right?" Then, there's no need to do anything.
- Need some fine tuning or changes? Copy and return this page with corrections and additions marked in *RED*. Need more space? Refer to the form on the last page of the current membership directory.
- See your current directory for letter indicators to general and specialty CONNECTING LINKS.
- To incorporate your new information, mail or fax your corrected profile to the Executive Office: FAX 610-872-1192, no cover sheet needed!
- Work on NSGC's 1998 Membership Directory will begin July 15. All changes or additions must be received in the Executive Office by ***Friday, August 29.***