PERSPECTIVES
in genetic counseling

Volume 19, Number 1 Spring 1997

Marketing Plan Unveiled: Funds Available for Members' Projects

by Edward Kloza, MS & Beth Balkite, MS
Co-Chairs, Marketing Task Force

After over a year of research, planning, creative brainstorming and extensive member input, the long-awaited Marketing Plan is here.... and the emphasis is on action! Project GeneAMP—for Applied Marketing Project—aims to establish genetic counselors as integral, valued participants in every health care system.

Research documented that genetic counselors need to heighten their visibility—many see us as playing a limited role and having only routine, team-dependent responsibilities. We need to document our value, demonstrating cost effectiveness as well as our potential contributions in the expanding marketplace.

■ Do you have a great marketing idea? NSGC wants to support it! One of the plan's innovative components is funding for project(s) that focus on marketing the genetic counseling profession. Up to $30,000 has been budgeted to finance this effort—but hurry, the deadline to apply for funds is ***May 1.***

■ Want to participate in the plan's implementation? Join one of the five project teams, targeting Primary Care Providers, Managed Care Organizations, Medical Professional Organizations, Consumers/Employers and Law/Policy Makers. Activities will occur at many levels—national, state, regional and local—so there are plenty of ways you can contribute. We need everyone's help.

To find out more about GeneAMP and how you can get involved, see the Marketing Supplement on pages 9-12.

Regional Leadership Honorees... Could You Be Next?

What makes an outstanding volunteer? Tireless hard work, dedication to the profession, respect for colleagues and... chocolate? Learn more about applied leadership qualities from the six recipients of the 1996 Regional Leadership awards, profiled on pages 14-15. The awards recognize one member from each region for outstanding regional achievements and/or volunteer activities on behalf of NSGC and the profession.

■ The Nominations Committee is looking for the leaders of the future. Do you know someone with appropriate skills/experience who should be on the next NSGC ballot? The nomination deadline is ***Friday, April 4.***

■ Or perhaps it's time to transform your inspiration into a reality. Applications for the NSGC Special Projects Fund are due ***May 15***—read about application and selection criteria on page 5.

national society of genetic counselors, inc.

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

ON THE INSIDE

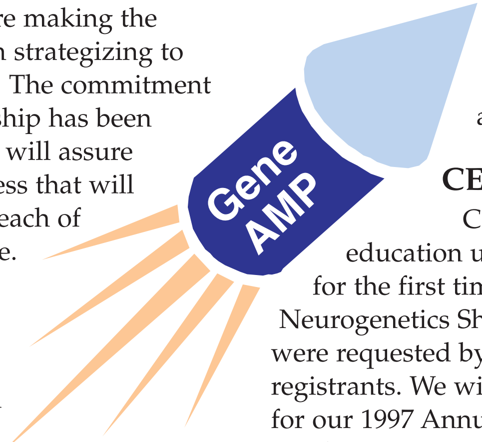
NSGC acknowledges Genzyme Genetics for a grant to support this newsletter.

Genzyme Genetics,
committed to providing quality DNA-based, cytogenetic and prenatal biochemistry testing, service and education.

Presidential Remarks

Countdown Toward the Future: Ready to Blast Off!

What an exciting time for NSGC as our Applied Marketing Plan—Gene AMPlification—enters a new phase. Under the leadership of co-chairs Beth Balkite and Ed Kloza, we're making the transition from strategizing to implementing. The commitment from membership has been incredible and will assure success—success that will be tangible to each of us in the future. *(See marketing supplement, pages 9-12.)*



In line with our marketing objectives, I've appointed a Cancer Genetics Task Force—Maureen Smith (chair), Barbara Biesecker, Bonnie LeRoy, June Peters, Rob Pilarski, Kathy Schneider, Charlene Schulz, Jill Stopfer, Amy Strauss Tranin, Vickie Venne and Cate Walsh Vockley—to be a think tank and propose an action plan to the Cancer Special Interest Group. Their goals include assuring genetic counseling services are included in all cancer genetic centers, educating the oncology communities and exploring funding opportunities for education and research.

CEUs Launched

Continuing education units—available for the first time at our March Neurogenetics Short Course—were requested by 20% of registrants. We will offer CEUs for our 1997 Annual Education Conference and Cancer Short Course as well. Although the ABGC has not yet determined whether CEUs will be required for recertification, they are an excellent way to demonstrate professional credibility.

NSGC Leads the Way

The demand for NSGC input and expertise is increasing, as illustrated by these recent requests:

■ Senator Pete Domenici asked for NSGC input as he reintroduces the Genetic Confidentiality & Nondiscrimination Act of 1996.

■ Kathy Schneider was appointed NSGC representative to the CDC's Task Force on Genetics in Disease Prevention.

■ Marlene Huggins, Jennifer Fitzpatrick and Robin Bennett critiqued ACMG's draft document regarding the duty to recontact.

■ Ed Kloza, Bonnie LeRoy and Maureen Smith will represent NSGC at the Human Genetics Workforce Assessment meeting in Tucson AZ, April 28-29.

■ A Medical Director in Louisville KY requested our input regarding genetic testing policy guidelines for his HMO.

■ I testified before the Indiana State Senate Health Committee regarding a bill addressing Genetic Nondiscrimination and Health Insurance.

Ann Boldt, MS
President

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Deadline for submissions: May 10

The opinions expressed herein are those of the authors and do not necessarily reflect those of the editorial staff or NSGC.

Celebrate Ourselves!

■ Devoted to genetic screening, the December issue of *Clinical Obstetrics & Gynecology* featured articles by **Sharon Aufox, Myrna Ben-Yishay, Barbara Bernhardt, Brenda Finucane, Joan Hogge** and **Mona Stadler.**

■ "Genetics 1997: We're Not in Kansas Anymore" was the title of **Beth Balkite**'s address to the National Medical Cost Containment Association Meeting in February. The audience was primarily nurses and doctors responsible for monitoring the bottom line in managed care organizations.

■ But genetics is still in Kansas, too! **Debra Collin's** web site—http://www.kumc.edu/gec—was selected Medsite of the Week by Medsite Navigator for the week of February 5.

■ **Liz Stierman** was awarded an Outcomes Assessment Grant from California State University, Northridge to develop evalution tools based on the 27 Practice-Based Competencies for Genetic Counseling Training.

■ In "Your Medical Heritage," the eighth episode of *Ancestors*, a PBS television series produced by KBYU, **Vickie Venne** discusses the value of medical information in a family history search, showing how medical records can help confirm a particular diagnosis.

In Memorium

Every now and then you meet a person who changes your life forever—someone whose unique approach to the extraordinary and the mundane make life just seem more fun, more meaningful, more colorful. Genetic counselor **Carole McTague** was one of those people.

Carole passed away January 30, of breast cancer at age 56. She leaves her husband, John; four children, Margaret, Maureen, Kathy and Kevin; and numerous friends and colleagues, each more interesting, more colorful and so fortunate just for having known her.

After many years teaching high school biology, Carole decided it was time for something new. As a non-traditional student at the University of Michigan, she formed close, lasting friendships with her classmates. She often hosted functions at her beautiful home, which those living in "student ghetto" housing lovingly dubbed the "McTague resort."

After graduating in 1988, Carole worked as a prenatal genetic counselor at William Beaumont Hospital of Michigan. Her patients and co-workers remember her dignified warmth and wisdom.

Carole had a zest for life and loved to travel. On African safari with her family, she ballooned over the Serengetti and was charged by a band of disgruntled elephants.

A wonderful storyteller, she was also the one "to see through the fog, cut through the bull and help us find our way." Her friends sought her no-nonsense advice about "big life achievements," like getting married, buying houses or having kids. As a schoolmate, colleague and friend of the highest caliber, Carole will be greatly missed.

Jill Stopfer, MS
Kate Sargent, MS
Diane Baker, MS

DNA: The New Frontier

October 25-28, 1997 • Baltimore MD

SPEAKER SPOTLIGHT

R. Michael Blaese, MD, chief of the National Center for Human Genome Research's clinical gene therapy branch, will discuss the latest breakthroughs in this field. His accomplishments include the first gene therapy trial—using gene-corrected T cells to treat two girls with ADA deficiency.

1997 Annual Education
CONFERENCE
nsgc

REGISTRATION:	Deadline without penalty is ***August 15!*** The conference brochure was mailed mid-March. Don't bury it on your desk!
HOTEL & TRAVEL INFORMATION:	Reduced rates will be available at the Baltimore Marriot Inner Harbor Hotel. Special airline rates will also be available.
PROGRAM:	You'll have the opportunity to attend the plenary sessions and may choose from eleven workshops and eight practice-based symposia, all designed to maximize your ongoing professional education.
CEUs:	Continuing education units will be available for the first time at an annual education conference. You will be eligible to earn 2.2 CEUs.
ABSTRACTS:	Postmark deadline is ***Friday, May 9***. Get those ideas down on paper!
WELCOMING RECEPTION:	You have a duty to recontact old friends and make some new ones! This opening evening reception is the time to do it. This year will feature a casino night theme.
ANCILLARY MEETINGS:	All meetings or receptions must be scheduled through the Executive Office. Ancillary Meeting Reservation Forms are due ***July 15***.
HOSTED DINNERS:	We will continue the tradition of having local genetic counselors host dinners at their favorite local spots. Another networking opportunity! Look for sign-up sheets in the registration area for these Saturday night dinners.
ALL CONFERENCE RELATED REQUESTS:	Please contact the Executive Office for any additional information or conference needs. Voicemail 610-872-7608, Mailbox #6 FAX 610-872-1192 E-mail NSGC@aol.com

E-mail/FAX Poll

Nondirectiveness: Where Do You Stand?

THE QUESTION:
How would you describe your counseling objectives? Nondirective? Promoting autonomy? Working alliance? Personal decision making?

Nondirectiveness is a technique, like any other, to be used at the proper time. This thought first arose when dealing with perinatal deaths—parents often don't know about the grief process; it's our job to gently introduce knowledge we've gained from other parents in similar circumstances.

This belief has grown over time, as I encounter other situations where frank directiveness or at least a lack of non-directiveness has seemed appropriate—such as managing genetic diseases, promoting health in BRCA1 counseling, exploring family communication, promoting decision making.

My own counseling agenda is to educate and/or counsel clients about what I think they should know—like the "reasonable person" standard in court, what a reasonable person would want to know.

I don't agree with the assumption made in many recent discussions/papers that most of us uncritically accept nondirectiveness as the core counseling tenet. Most senior counselors can put nondirectiveness in proper perspective, as an important technique, not a first principle.

Bonnie Jeanne Baty, MS
Salt Lake City UT

I see my role in prenatal diagnosis counseling as primarily education in a supportive environment. Pregnancy, family and life histories create a unique situation in every case. To this I bring experience from many families who have been through similar experiences. For example, whether a woman has had successful pregnancies influences her view of amnio-related risks. I can help her give shape to her feelings by sharing that other people have felt the same. Then I get feedback to see if this fits. Is this directive?

Is "empowering" more specific than "promoting autonomy"? I see the counseling I do as client-centered and non-judgmental rather than nondirective. I will support whatever they decide to do—as long as it is the decision that works best for them.

Beth Conrad Billings, MS
Indianapolis IN

My objectives are to forge a working alliance with my client. I will use any and all tools available to me to do so. It doesn't help me to classify my style as directive or nondirective; I am both if and when appropriate.

Deborah de Leon, MS
New York NY

As Seymour Kessler suggested in San Francisco about the directiveness debate, move on... let's not get hung up on one issue, let's analyze exactly what we ARE doing in sessions where there is education and counseling.

Betsy Gettig, MS
Philadelphia PA

My counseling objectives are extremely complex and vary greatly from case to case. My main goal is to correctly identify the patient/family's needs and then meet those needs with a variety of methods—in some cases promoting autonomy, in others developing a working alliance and in other situations, deliberative counseling to work together towards a decision that fits. I am sure it's even more complex than this; I'm excited we're exploring the issue again.

Bonnie LeRoy, MS
Minneapolis MN

My goals as a genetic counselor are to participate in a working alliance and promote appropriate personal decision-making. I find I've become very irritated by the phrase "non-directiveness" after hearing Seymour's talk!!!

Aida Metzenberg, MA, PhD
Northridge CA

I have counseled scores of individuals from other countries and cultures. The concept of patient autonomy was quite foreign to many; in fact, some felt the lack of guidance meant they were being rudely ignored and that the provider was incompetent. Try a nondirective approach with a newcomer from Southeast Asia, who believes man lives in harmony with nature and is unable to control life's events. Asking her to make an informed decision about prenatal diagnosis without any guidance is unrealistic.

Nondirectiveness, *continued*

Nondirective counseling most likely was developed by Anglo-Europeans without taking into consideration the needs, expectations and cultural beliefs of non-Whites. The little data that we have is based mostly on Caucasian clients. We need to use client-centered evaluation tools to understand the impact of interventions on counselees of all backgrounds. The bottom line is to provide meaningful interventions and stay away from categorizing what we do.

Ilana Mittman, MS
Baltimore MD

I vote for "working alliance" in order to facilitate "the good decision" as discussed at the NSGC meeting. Autonomy and informed consent are two aspects to the good decision, but there are others which are more or less salient at different moments in the counseling process.

June Peters, MS
Bethesda MD

I personally welcome the "what would you do" question. It shows we've built a rapport of trust with the client. It's a good opening to talk about the decision making process and to use examples to demonstrate that no decision is right or wrong. I agree with Sonia Suter that nondirectiveness is sometimes not consistent with beneficience. Shouldn't beneficience be then more important?

Cecile Skrzynia, MS
Chapel Hill NC

My answer to the poll question: promoting autonomy.

Louise Staley-Gane, MS
Denver CO

I think of what I do as informational guidance. I guide the couple to the decision they are comfortable with by providing information, discussing various scenarios and identifying areas where they have the most concerns. Of the options listed, I would probably choose "working alliance."

Since the discussions at the NSGC meeting, I have become less stringent about making trying to be nondirective, and I feel my counseling has improved. I am better able to guide the couple to a decision by pointing out which way they are leaning.

Janet Ulm, MSSW
Charlotte NC

The debate continues: look for articles on nondirectiveness in upcoming issues of the ***Journal of Genetic Counseling****.*

Special Projects Fund: Call for Proposals

The Special Projects Fund, established as a result of a 10-year anniversary fundraising effort conducted in 1988, provides an annual $3000 competitive award to conduct projects that focus on the future of the genetic counseling profession and/or improving the provision of genetics services. The fund is an opportunity to enhance professional development; past projects have provided high-quality professional resources.

Project proposals must be submitted by ***May 15*** by an NSGC member in good standing. Awards are based on the proposal's strength and merit, as judged by the Special Projects Fund Committee. Winners are announced at the Annual Education Conference and their names inscribed on a perpetual plaque.

☛ For more information, contact Committee Chair, Angela Tutera Trepanier, 803-779-4928, atutera@richmed.medpark.scarolina.edu

1998 Special Projects Fund Committee

Angela Tutera Trepanier
Stephanie Cohen
Jamie Israel
Stephanie Kieffer
Susan Creighton
Janice Berliner (ex officio)

Past Recipients of Special Projects Fund Awards

1992 **Beverly Tenenholz**: Brochure series: *Now That You've Been Told Your Baby Has...*

1993 **Vivian Ota Wang:** *Training Handbook of Cross-Cultural Genetic Counseling*

1994 **Kathleen Delp & Molly Minnick:** *Manual for Conducting Support Programs For Parents Who Have Interrupted Pregnancies Secondary to Fetal Anomalies*

1995 **Jamie Israel:** *An Introduction to Deafness: A Manual for Genetic Counselors*

1996 **Diane Baker, Jane Schuette, Wendy Uhlmann, Tim East:** Defining the Elements of Patient Letter Writing for Genetic Counseling Students

1997 **Jennifer Fitzpatrick & Marlene Huggins:** The Duty to Recontact: A Survey of Attitudes of Genetics Service Providers nsgc

Committee Activities, SIGs...

Practice Guidelines

■ The **Genetic Services Committee** is developing practice guidelines, statements outlining appropriate health care for specific clinical circumstances. These written guidelines will help maintain our high standards and further define our role, particularly with those outside the profession who influence employment and practice milieu. They will aid in professional training, quality assurance, patient education and reimbursement. And guidelines may be influential in establishing minimum qualifications for practitioners as more non-geneticists enter the field of genetic testing and interpretation.

Subcommittee members Rebecca Anderson, Nathalie McIntosh and Dale Lea have drafted a worksheet for systematically developing practice guidelines based on the protocol of the Agency for Health Care Policy and Research. At least three authors will collaborate to draft each guideline, following a literature review to outline both the medical synopsis and the counseling practice methodology.

A typical guideline will include objectives, guideline methodology, clinical synopsis, primary counseling considerations, resources for families, atypical legal or ethical issues, documentation and patient correspondence, communications with referral source, summary and recommendations, reference citations, triggers for review of the guideline and a standard boilerplate disclaimer.

The guideline will undergo an internal review by at least three qualified peers and the Genetic Services Committee, then an external review by the ACMG Clinical Services Committee, expert reviewers and consumers. Completed guidelines will be published and authorship will be acknowledged.

The Subcommittee seeks nominations of qualified individuals willing to serve on one of the working groups tackling specific guideline to help professionals and patients make informed choices in specific clinical situations. In our areas of proficiency, we sometimes don't appreciate how much we know and how well we know it. Developing guidelines is an opportunity to crystallize our learning and make it available to others.

☛ To nominate a colleague or get involved, contact Rebecca Anderson, 402-354-4773, randerso@umnc.edu

New Jersey Seeking Licensure

■ The *Billing, Licensure & Reimbursement Subcommittee* reports that New Jersey legislation sponsoring licensure for genetic counselors has passed the Assembly Consumer Affairs and Regulated Professions Committee. Next, the bill needs to be sponsored in the State Senate.

Ethics Consults Available

■ The Ethics Subcommittee is available to any NSGC member for confidential consultations on ethical issues confronting you or your institution. Consults can delineate the role of the counselor as outlined by the Code of Ethics and clarify what at first appear to be conflicts within the code. The Ethics Subcommittee does not serve as a regulatory board or ombudsman.

☛ To request a consult, contact any of the Subcommittee members listed below.

Karen Eanet, MS, Subcmte Chair	410-328-3335
Linda Nicholson, MS, MC	302-651-4234
Robin Gold, MS	313-493-6060
Barbara Bernhardt, MS	410-955-7894
Deborah Holsinger, MS	714-456-5791, x6681
Katherine Hunt, MS	314-862-6148
Lorna Phelps, MS.	804-828-9632
Kevin Fitzgerald, PhD, SJ *(ex officio)*	708-327-3167

Building Bridges: Counselors Promoting Diversity

■ Established to provide culturally diverse genetic counselors and counseling students the support they need to succeed in the profession, this new Special Interest Group offers a culturally appropriate and safe forum to voice thoughts about training and career issues. It will encourage minority recruitment and assist counselors who feel culturally displaced within our profession. Mentoring, help with job searches/negotiation and assisting members who feel they've been treated unfairly are a few of the possible projects the SIG will undertake. Bridging cultural differences, this new group is open to all genetic counselors, not just individuals representing racial/ethnic minorities.

☛ For more information, contact Ilana Mittman, 410-601-5853, imittman@sinai-balt.com

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Liaison Reports & More

Letter to Down Syndrome Group

■ A recent fundraising letter from the National Down Syndrome Society included this statement, "Imagine further the feeling an expectant parent has when a geneticist advises her to carefully consider her life with her new child with Down Syndrome, because he'll never accomplish anything."

Recognizing a golden opportunity to initiate a dialogue with support organizations, the Down Syndrome Special Interest Group sent a letter to the NDSS to educate them about the genetic counselor's role, at the same time acknowledging the need to improve sensitivity and awareness among health care professionals about Down syndrome.

Responding to the letter, NDSS President Elizabeth Goodwin apologized for the generalization: "Many physicians and geneticists have responsibly kept themselves informed, and treat families with care and sensitivity....We should have qualified our description by including a mention of the many responsible professionals in the field.

"I am very grateful for professionals such as you and your colleagues, who have dedicated their lives to many of the same causes to which I have dedicated mine. You are certainly leading your peers by example, and I offer you the National Down Syndrome Society's fullest support."

Breast Cancer Summit

■ Jill Stopfer, liaison to the **National Action Plan on Breast Cancer**, attended the Consumer's Leadership Summit: Preparing for the New Era of Genetics and Medicine, a meeting to educate consumer advocates about the risks/benefits of genetic susceptibility testing and to learn how to shape public policy on its use.

NCHGR Transformed

■ Rosalie Goldberg, NSGC liaison to the **National Center for Human Genome Research** reports a significant milestone—as of January 13, the NCHGR has been renamed to the National Human Genome Research Institute (NHGRI) of the National Institutes of Health. There will be no difference in functioning with the name change.

An exciting initiative is in progress to establish a National Coalition for Health Professional Education in Genetics. At the first meeting on March 10, NSGC will join 100 diverse health care professional organizations, and will include consumer and voluntary groups, government agencies, industry, managed care organizations and genetic professional societies.

Co-chairs Anne Spence and Mark Rothstein have prepared a committee report of the group convened to evaluate the Ethical, Legal and Social Issues Program of the NHGRI. Addressing the future dilemmas to be addressed in the next phase of Human Genome Research, "Genome 2," Dr. Spence remarked, "the public does not view which computer chip we use as a threat; however, they do view genetic testing as a threat."

NSGC Milestones

■ We now have members in all 50 states with the acceptance of Mary Ebertowski, RN, BSN, of Grand Fork ND. And in January, University of California, Irvine graduate student Laurie Chen became the 1500th NSGC member. Membership surpassed the 1000 member mark in 1990. Can you predict when it will reach 2000? Visit the "Guess that Date!" table at the welcoming reception this year's Annual Education Conference in Baltimore.

AMA Reminded of Our Role

■ In its February 3rd issue, the *American Medical Association Newsletter* published a letter from President Ann Boldt and Past-President Karen Greendale responding to a December article entitled, "AMA, NIH want to raise physician literacy." Under the headline, "Genetics counseling help is available," the letter supports increasing physician involvement in caring for patients affected by genetic disease but decries the failure to mention genetic counselors. It concludes, "Although we wholeheartedly agree that primary care providers and non-genetics specialists must therefore be enlisted into the process, we feel that some situations demand the time-intensive combination of art and science that has always been the hallmark of the genetic counselor."

In the News

■ Last quarter, the NSGC Executive Office was contacted for information or referrals by *Nature, Wall Street Journal, Parade Magazine, Miami Herald, Cleveland Plain Dealer*, KABC-TV, ESPN-TV, *Men's Fitness, Men's Health Newsletter, UC Berkeley Wellness Newsletter* and received 40 consumer requests for information generated by media articles.

Social Issues Committee

Communicating with Lawmakers: A Simple Guide

"Legislative Process & the Genetic Counselor," was the title of the Social Issues Committee workshop at the recent Annual Education Conference. Speaker Lyle Dennis summarized the insider's view of lawmaking. A key take home message was the important role individual constituents play in influencing the outcome of legislation. Communicating with your representatives—with personal visits, telephone calls, letters and faxes—is critical!

Writing letters is the simplest way for you—a voting constituent—to let lawmakers know your views, encourage them to vote your way and to remind them you're watching how they vote. Here are some quick tips to use when drafting letters:

- ■ Address your letters to "The Honorable _____;" the correct salutation is "Dear Representative _____" or "Dear Senator_____" (or "Madame Chairman" or "Mr. Speaker," if applicable). Mailing addresses for state/federal officials are available from the Internet or the local chapter of the League of Women Voters.
- ■ Be specific. State your purpose in your first paragraph. If your concern is a particular bill, identify it by name or congressional record number.
- ■ Tell your lawmaker how the issue affects you personally and professionally. Point out that you live in his/her district. Make it clear these are your views; NSGC cannot lobby for a particular position.
- ■ Be courteous, even if you disagree with your representative's position.
- ■ Be brief and accurate! Aim for one page. Never make statements you can't support with evidence; give just enough facts and figures to justify your views.
- ■ Ask for a reply; it notifies you that your letter was received and provides your legislator's viewpoints.

Alysia Bemus Spear, MS
Social Issues Committee

— SAMPLE LETTER —

Your Name
Address
City State Zip

Date

The Honorable _____
United States House of Representatives
Washington DC 20515

Dear Representative ______:

As someone who lives and votes in your district, I strongly urge you to support/oppose (specific bill).

1-2 paragraphs detailing your opinion.

Again, I encourage you to support/oppose (specific bill). Thank you for your time. I would appreciate it if you would send me information relating to your position on this issue/legislation.

Sincerely,

Your Name

Broadening Genetic Counseling Horizons

Minority Student Recruitment

■ Graduate students **Stacey Wong** and **Arlyn Tanega** from the California State University, Northridge have developed a slide presentation to encourage minority students to consider a career in genetic counseling. The 15-minute talk uses case scenarios depicting the range of activities genetic counselors encounter in their work, supplemented by statistics on professional status. They have arranged to meet with several local undergraduate minority organizations and will next target biology/science clubs.

Australian Report

■ The largest ever contingent from Australia attended October's Annual Education Conference —six genetic counsellors (it's spelled with two "l"s Down Under) contributed 6 posters plus a platform presentation.

After recovering from the sheer numbers—there were more people at the meeting than total members in the Human Genetics Society of Australasia—it became obvious that we experience similar frustrations and dilemmas in formulating and executing our roles as genetic counsellors. We also realized that Australians are not so far behind in our progress as a profession. Like you, we are considering a standards of practice document and a Code of Ethics, based on NSGC's, is already in the works.

We all left the meeting convinced of the benefits of attending—the opportunity to find out what others are doing and to exchange names/e-mail addresses with those with similar interests.

Anne Timko, MS
Bronwyn Butler, MS
Australia

Project GeneAMP (Applied Marketing Project)

Project Objective

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

Purpose

For the next three years, GeneAMP will provide funding support to project(s) that focus on marketing the genetic counseling profession. Project Teams will respectively target: Primary Care Providers; Managed Care Organizations; Medical Professional Organizations; Consumers and Employers; and Law and Policy-makers. Projects will be reviewed on the basis of their merit and strength as well as on their applicability to the GeneAMP objective.

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Request For Proposals

Procedure for Submission & Approval

Applications for funding will only be accepted through the GeneAMP Project Team Leader(s). Approval will be made by a committee composed of the GeneAMP Co-Chairs, NSGC Executive Committee and Finance Committee Chair.

Funding Resources Available

Total amounts of project funding in any given year will be based on the current year's GeneAMP budget. Proposals may be funded in whole or in part.

Acceptable budget items include: consulting fees (for non-NSGC members), printing, postage, phone, travel expenses to non-genetic professional meetings.

Unacceptable budget items include: salary, costs related to genetics professional meetings, costs of patient or client services, indirect costs.

Time Table

Proposals are to be submitted to one of the GeneAMP Co-Chairs by September 1 for the following fiscal year, with the exception of the start-up year (1997), in which May 1 has been designated as the date of receipt. Notification of project funding will be made by January 1, with the exception of the start-up year, which shall be May 20.

Because the GeneAMP effort is beginning mid-way through fiscal 1997, this year's time table will be compressed. Proposals are due May 1 for implementation of projects funded from June 1 through December 31, 1997. Proposals for projects to be funded for the fiscal year beginning January 1, 1998 will be due September 1, 1997. Requests for renewals or extensions will be judged with other proposals in the year of application.

Ownership

Any tangible results of any project are the sole property of National Society of Genetic Counselors. Any publication, exhibit or materials produced shall carry a credit line reading: "Funded by National Society of Genetic Counselors."

INSTRUCTIONS

- Each proposal must be limited to two (2) pages. More than one proposal may be submitted to the same project team.
- Project Team Leaders will submit eleven (11) typewritten copies of each proposal to the Executive Office or e-mail nsgc@aol.com.
- The proposal should include the following:
  - Name, address and daytime phone, FAX, e-mail for Project Leader(s)
  - Name(s) of Team Members
  - Project Title
  - Target Audience
  - Statement of Need & Relevance to GeneAMP objective
  - Program Plan, including strategy and timeline
  - Evaluation Process, including projected outcomes
  - Itemized Budget and Total Amount Requested, including in-kind contributions, if applicable
- Do not include CVs or other supportive documentation, with the exception of non-NSGC use of consultants.
- Submission deadline is ***May 1, 1997.***

Long-Awaited Marketing Plan Unveiled

Plan Objective

To establish genetic counselors as integral, valued participants within every health care delivery system.

Background

Through external research and membership input, NSGC has identified key areas that need attention. Research consisted of interviews conducted by consultants at the Center for Applied Research and members of the appointed task force, a literature search, review of the 1996 Professional Status Survey results and reviews of student theses related to this topic. Interviewees included managed care directors, geneticists, clinical specialists, primary care physicians and academicians. These interviews were structured to learn who the decision-makers and influencers are in their respective fields. Internal information and perceptions were obtained from a membership survey, focus groups and feedback from regular articles in *Perspectives in Genetic Counseling*.

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Marketing
Plan

Findings

- **Genetic counselors** need to increase their visibility both as a professional group and individually with primary care physicians, managed care organizations, other third party payors and medical schools. Although some geneticists, perinatologists, obstetricians and oncologists are aware of genetic counselors' roles, they differ in how they perceive genetic counselors' responsibilities as members of a health care team. Most have a limited view of this role; some provide these services themselves.

- **Research concluded** that genetic counseling is perceived by most of the professionals who were interviewed as not being autonomous, but rather as a component of the genetics team effort. Furthermore, this group of interviewees perceived genetic counseling as comprising the more "routine" responsibilities in the genetic evaluation process.

- **Documentation** of cost benefit/cost effectiveness and outcome studies of genetic counseling services do not appear to exist. The research pointed to the need for definitions, tools and practice guidelines. The research also pointed to the impending demand for counseling in certain patient populations as a result of the availability of a large number of presymptomatic genetic tests.

- **Existing tools** directed to the unique strengths of the genetic counseling profession need to be evaluated and adapted or built upon for more generalized use. Others will need to be devised for new markets.

- **Efforts targeting** any broad, national audience may heighten public awareness; however, educating managed care directors, health care providers, etc, will require customized local strategies.

- **A strong willingness** exists in the membership to support the strategic level of marketing on all coverage levels. 80% of NSGC full members currently present, publish or have assumed leadership and advocacy roles.

Recommendations

The plan needs to target primary care physicians and managed care organizations and other third party payors. Relationship building with decision-makers and influencers through education; development of definitions, tools and practice guidelines; research and publications on the cost effectiveness of genetic counseling services must be developed. Educational messages must be clear, consistent, simple and targeted to the audience's level. Educational and other activities need to develop as a process, or cycle, rather than a one-time event, incorporating a sense of developing relationships with the targeted audiences.

Priorities were defined as follows:

Tier I: Primary Care Providers
Tier II: Managed Care Organizations
Tier III: Medical Professional Organizations
Tier III: Consumers and Employers
Tier IV: Law and Policy Makers

Geographically, priorities were defined as follows:

Level I: National
Level II: State and Regional
Level III: Local

Activities in these levels may be developed and conducted simultaneously.

Implementation

The Marketing Co-Chairs have appointed Team Leaders for each Tier who are responsible for the project activities, setting the goals, a budget and a timeline for each project. Members of each Project Team will include volunteers identified through the Membership Marketing Survey, Standing Committee Chairs and Regional Representatives.

Monitoring and evaluation will be incorporated to maintain quality control and assure each project's success.

Evaluation

The Project Team Leaders will apprise the Marketing Co-chairs of the progress of each project on a quarterly basis. The plan will be monitored and evaluated by the appointed Marketing Co-Chairs who will, in turn, report to the Executive Committee. The Co-Chairs have been appointed by the President for a three-year term; the plan's progress will be evaluated annually by the Board of Directors.

MARKETING PROJECT TEAMS

Primary Care Providers

Primary Care Providers: This team targets physicians, midwives, nurse practitioners or other providers of health care who are not highly specialized and who are considered to play "gatekeeper" roles in managed care.

PROJECT TEAM LEADERS:

Lisa Amacker North	Seth Marcus
☎ 704-355-3159	☎ 847-723-7705
enorth@carolinas.org	

Managed Care Organizations

Managed Care Organizations: This team targets one of the major payor groups responsible for determining patient access to & reimbursement for genetics services. MCOs need to understand what genetic counseling contributes to patient care and cost containment.

PROJECT TEAM LEADERS:

Debra Lochner Doyle	Amy Cronister
☎ 206-464-7752	☎ 602-945-4363
dld2303@hub.doh.wa.gov	ext 150

Medical Professional Organizations

Medical Professional Organizations: This team targets the medical professional academies, colleges, societies and associations whose members need to understand who we are and what we do.

PROJECT TEAM LEADER:

Betsy Gettig
☎ 412-624-9951
bgettig@helix.hgen.pitt.edu

Consumers & Employers

Consumers & Employers: This team targets the public at large and other direct consumers of genetic services, as well as those elements of industry (such as labor unions) responsible for purchasing or negotiating group health care.

PROJECT TEAM LEADERS:

Melonie Michelson	Joy Redman
☎ 216-379-8792	☎ 713-798-9500
	joyred@juno.com

Law & Policy Makers

Law & Policy Makers: This team targets legislative groups at state and national levels who influence regulations and pass laws to enforce policy.

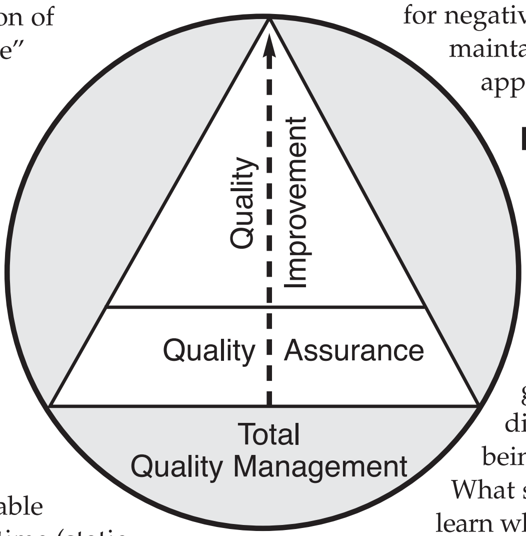
PROJECT TEAM LEADER:

To be announced

Professional Issues Committee

Total Quality Management in Genetic Services

Beginning in 1996, the Professional Issues Committee focused efforts on describing quality assurance, quality improvement and total quality management in genetic counseling. Members of the committee felt this was a timely endeavor in light of the society's development of a marketing plan. In addition, we feel it's vital that we begin to build a collection of literature that supports the "value" of our services.



Learning the Language

A Quality Assurance Subcommittee was formed. Through an initial literature review, we learned the philosophy and jargon of total quality management. These include concepts such as

- **Quality Assurance (QA)**, obtaining an acceptable measurable level of performance at a given time (static measurement)
- **Quality Improvement (QI)**, the ongoing process involving incremental increases in performance
- **Total Quality Management (TQM)**, the whole process of evaluation encompassing both QA and QI practices.

These concepts helped us to consider a starting block for the further pursuit of information specific to our field.

A QA Survey

In the summer of 1996, each of the QA Subcommittee members was asked to identify which type of institution they work for (health maintenance organization, university, private hospital, etc) and to describe any measures they routinely use to evaluate the quality of services provided by genetics professionals in their centers. They were also encouraged to collect similar information from neighboring clinics or institutions.

Information was collected from 21 institutions, reflecting practices within private hospitals and universities. Of note, all except one of the centers contacted measured quality of services. The most common measurement was a patient survey or a letter/chart review. Several centers collected CVS or amniocentesis follow-up/outcome information. Fewer centers utilized a QA committee, peer review practices, surveyed referring physicians, held case conferences or participated in a formal QA program. Only one center indicated that it collected follow-up information for ultrasound findings, maintained a formal logbook of cases, filed incident reports for negative feedback received and maintained records of cancelled appointments.

Did You Know You Were Doing QA?

The Subcommittee was pleasantly surprised to learn just how many sites had QA measures in place. But it was also clear that many of the genetic counselors questioned didn't perceive these activities as being QA activities or part of TQM! What started as a fishing expedition to learn what, if anything, genetic counselors were doing to assess the quality of their services taught us that many QA activities are going on but individual sites are not publishing their data. This may largely be due to the fact that it is not perceived as valuable to the rest of the genetics community.

The QA Subcommittee would like to encourage those of you collecting these types of data to write about your findings and what you've learned! Submit articles to the *Journal of Genetic Counseling*—they could be invaluable to those seeking to negotiate managed care contracts or enhanced benefits packages.

So what's next for the QA Subcommittee? We will be focusing our 1997 efforts on another pilot study looking at documenting activities genetic counselors bring to a center that measures cost benefit. Watch for a report in a later edition of *Perspectives!*

Kelly Connerton-Moyer, MS
Debra Lochner Doyle, MS

The Quality Assurance Subcommittee:

Lisa Andres
Kelly Connerton-Moyer
Jacky Dailey
Debra Lochner Doyle
Karen Eanet
Bonnie Liebers
Kristen Mahoney
Cindy Malin
Alexis Poss
Denise Tilley
Sivya Twersky

ABGC Update

Logbook Revision

The American Board of Genetic Counseling logbook for the 1999 examination cycle is now undergoing final editing. It is quite similar in format to that used in 1996, but there are some changes as well as important points to remember.

The logbook's purpose is to document *face-to-face* evaluation and counseling of 50 different patients/families with a wide variety of genetic conditions. At least 15 of the cases must involve evaluation and/or counseling of a patient/family affected with (i.e. showing symptoms of) a genetic disorder. No more than half the cases (25 cases) can be of the same service type. Telephone counseling and group counseling cases are not acceptable as logbook cases.

The clinical supervisor for each case must have been certified by ABGC or ABMG at the time the case was seen. For at least half the cases (25 cases), this supervisor must be a genetic counselor.

All cases must be seen at ABGC approved training sites—those approved though an ABGC accredited training program or sites for which the candidate has received specific ABGC "ad hoc" approval prior to beginning the rotation.

All cases for the logbook must have been undertaken after July 1, 1991. Cases may not be included if they were seen while the individual was an employee of the training site.

The logbook should be finalized by early April; it will be distributed to all genetic counseling training program directors as soon as it is available.

Helen Travers, MS
Chair, ABGC Credentials Cmte

CYBERGENES

Cyber Odds & Ends

LISTSERV OFF TO A GREAT START

Well the listserv—known as NSGCLIST—is up and running, very successfully I might add. The 500 current participants already know how helpful and educational it has been. For those of you who are not participating—and that would be about 1000 of you—what are you waiting for? You can subscribe from any computer, home or work, by sending a message to LISTSERV@SJUVM.STJOHNS.EDU; leave the subject blank and type subscribe NSGCLIST firstname lastname in the body of the message. After you have been added you will receive all the instructions you will need.

JOIN THE RESOURCELINK

The Computer Users' Subcommittee is currently working on another great member benefit—the ResourceLink, an addition to NSGC's web site. Full and associate members will be listed by city/state and area(s) of specialization. To be included on the initial listing, you should have already completed and returned the form included in the recent member mailing. I want to encourage everyone to participate. This will not only allow visitors to the NSGC web site to locate genetic services throughout the country but will allow us to locate each other. Think of it as free advertising for the genetic counseling profession!

Since addresses and phone numbers change frequently, the ResourceLink directory will be updated bi-monthly. Contact the NSGC Executive Office to be added/deleted from the list or to change your listing.

ACCESSING THE INTERNET

There are so many Internet service providers to choose from I don't know where to start! Some options include: America Online, CompuServe, Prodigy, AT&T, MCI and I bet your local phone company has one too. Many companies will offer a free introductory period. They all charge about $20 a month or less for unlimited access, so if you are paying more you might want to switch. And for those of you who still need to buy a modem to access the Internet, I recommend at least a 28.8K speed modem. You do not have to know what it means—just remember, faster is better!

SEEN ANY GOOD WEB SITES LATELY?

Funny you should ask. I just happen to know of a terrific web site for your perusal. Called the Rare Genetic Diseases in Children Support Resources Directory, the address is http://mcrcr4.med.nyu.edu/~murphp01/support.htm. It contains a wealth of links to other sites including support group information, listservs, email discussion groups, web messaging forums and so much more. For information on different syndromes to share with your patients, try the Family Village Specific Diagnoses Card Catalog at: http://www.familyvillage.wisc.edu/specific.htm.

If anyone has questions, or a topic they would like to see covered in a future column, please let me know. The management is always looking for suggestions and I promise to split my fee with you.

Steven Keiles, MS
steven.b.keiles@kp.org

Regional Leadership Award Winners

REGION I

Miriam DiMaio

While winning the 1996 Region I Leadership Award came as a surprise to Miriam DiMaio, it came as no surprise to past and present coworkers. Says one former coworker, "Miriam typifies the dedicated, hard-working genetic counselor who continually strives for excellence and brings out the best in those around her."

Miriam is currently in her 14th year at Yale University, where her position as Senior Genetic Counselor includes coordinating the prenatal diagnosis unit, participating in clinical research and counseling for the Huntington disease presymptomatic testing program. She has been published numerous times, including once in the *New England Journal of Medicine.*

While motivated by her multi-faceted position and the intellectual aspects of genetics, Miriam includes teaching and learning from students as particular highlights. What does this highly regarded genetic counselor see as a major challenge facing genetic counselors today? Providing our services cost effectively.

Joanna Wissler, MS
Dayton OH

REGION II

Lorraine Suslak

Her role in shaping the field of genetic counseling is one of the many reasons that Lorraine Suslak was voted the Region II Leadership Award Winner. Lorraine spearheaded the movement to form the NSGC and she has continued to be involved in addressing pertinent issues affecting genetic counselors. Most recently, she has been working to make licensing a reality in her home state of New Jersey. One of her colleagues describes her as a "quiet and unassuming leader who reinvents and replenishes herself with her own enthusiasm."

Lorraine is currently the Genetic Counseling Supervisor and an Associate in Pediatrics at the University of Medicine and Dentistry of New Jersey. Despite the many aspects of her position, she gets the most satisfaction from one-to-one contact with patients. When asked about the advantages of volunteering, she stresses that getting involved is essential in recognizing the depth and breadth of our unique profession.

Joanna Wissler, MS
Dayton OH

REGION III

Shane Palmer

When Shane Palmer left Sarah Lawrence in 1983, she had no idea she would become a leader in the field with a resume filled with professional activities. Like many new graduates, Shane first focused on developing her own career.

But in 1985, Shane moved to a new job in North Carolina where Sarah Lawrence classmate Ron Cadle recruited her for the NSGC Social Issues Committee. Thereafter, a series of happy accidents (including being elected chair of a committee because she was the only one who showed up for the meeting) led to an ever increasing role within genetics organizations at the state, regional and national level.

Once she began attending board meetings, Shane realized individuals do make a difference. "It's easy to sit back and criticize," she muses, "but unless you get involved you can't influence the process. The NSGC shapes our profession, but it is what it is because of individuals."

She reflects on her tenure as chair of the Social Issues Committee which led to many of the position statements and resolutions adopted by NSGC. Defining positions and reaching a consensus on controversial issues such as fetal tissue research and prenatal substance abuse provided some of the most challenging and rewarding work of Shane's career.

And the work continues. Her next "mission" is to build stronger ties among counselors in Florida. Constantly inspired by the gifted people she meets in NSGC, Shane notes they are the real reward for professional involvement.

Elaine Wu, MS
Ann Arbor MI

REGION IV

Wendy Uhlmann

Wendy Uhlmann's cough rattles the precarious piles of work in her office. Recovering from the flu, she's already back in the office following up on patients, editing slides for a talk and hoping the next phone call doesn't mean her youngest child's sniffles have developed into a full-blown cold.

Wendy coordinates University of Michigan's weekly adult genetics clinic, teaches a course for the UM counseling program and supervises graduate students in clinic. This week she's also writing a textbook chapter, working on an NSGC web site form, supervising an undergraduate and presenting grand rounds at the Cancer Center.

Regional Leadership Award Winners

How does she manage to juggle the various roles of clinician, teacher, supervisor, speaker, writer, wife and mother? "CHOCOLATE!" laughs Wendy without hesitation. But a serious devotion to the profession and a personal commitment to excellence form the real foundation of Wendy's accomplishments.

Wendy cites Program Director Diane Baker as the ultimate role model for professional involvement. Following Diane's example, Wendy joined the Professional Issues Committee (which she eventually chaired) immediately after graduating in 1987. She's served on many other committees, co-authored booklets and co-chaired the 1995 Annual Education Conference. Wendy's most lasting legacy to the profession may be the Professional Status Survey, which she revamped into a workable instrument for longterm, longitudinal data analysis.

"I love what I do," says Wendy simply. "And I love the people in this field. Learning and sharing with colleagues at meetings is something I look forward to every year. Part of why I stay active in NSGC is so I can justify my attendance at meetings," Wendy confides with a smile. "They can't say no if I'm involved in the conference!"

Elaine Wu, MS
Ann Arbor MI

REGION V

Bonnie Baty

Longtime volunteer Bonnie Baty's first NSGC activity was co-organizing a regional conference in Salt Lake City in 1981. The satisfaction of meeting and talking with other counselors in the small region inspired her to continue to stay involved.

Even though she has been at her job for many years, the position has changed considerably and stayed interesting. The people she has met through her career and the feeling of doing something worthwhile keep her motivation high.

Being elected Regional Representative and sitting on NSGC's Board of Directors gave Bonnie the stimulating opportunity to interface with a wide range of members and to influence the profession at a national level. Currently Bonnie is involved with policy making as a member of the Social Issues Committee.

In all her volunteer roles, Bonnie has never felt discouraged. "NSGC involvement is what you make of it," she says, and you don't need an elected position to be involved. Three things keep her motivated: change, camaraderie and a feeling of achievement. She feels her greatest professional accomplishment is helping to develop the field through her work on the American Board of Genetic Counseling; she is chair of the Accreditation Committee.

On the personal side, Bonnie and her husband perform Hungarian dance music semi-professionally across the nation. Recently they traveled to eastern Europe to learn more about its people and culture.

Bonnie feels the biggest challenge genetic counselors face is ensuring that we are the ones doing the counseling in the future. She would like to see the profession explode by aggressively marketing ourselves. "There are many niches—we would be foolish to limit ourselves."

Karen Potter, MS
Ann Arbor MI

REGION VI

Bill Herbert

Bill Herbert was involved with NSGC even before it formed. An early experience was helping to organize the first national education conference in San Diego in 1980.

This initial experience began a path that ultimately led to being elected Treasurer and then Finance Committee Chair. Though both positions created a lot of work, however, Bill found them rewarding. On a local level, he's helped organize quarterly meetings among Southern California's genetic counselors. He also acts as a local job referral service, linking job seekers to hiring institutions.

He reports never feeling discouraged, just tired. His motivation comes from knowing what he does is worthwhile. It also stems from change. Many have asked how he can still enjoy the field after 20 years. Doing a variety of things keeps him interested... and drives him crazy! He feels burnout comes from limiting yourself.

When asked about his greatest accomplishment, Bill immediately replies, "My children." Extremely proud of them, he insists that family is what it's all about.

What is the biggest issue genetic counselors face? "Reimbursement," says Bill. "This will define our field and determine whether it will expand. Many issues accompany this, including licensing and CPT codes. But until we can find reimbursement for the valuable services we provide, we will be limited."

Karen Potter, MS
Ann Arbor MI

Bulletin Board

Memorial Lectureship

■ Friends and colleagues are establishing a lectureship at the University of Michigan in memory of Carole McTague *(see page 4)*. The fund will sponsor an annual lecture on a clinical genetics topic.

☛ To make a donation, contact Diane Baker, 313-763-2933. Make checks payable to the University of Michigan.

Is Your Set is Complete?

■ Back issues of the *Journal of Genetic Counseling* are available for $5 each. Entire volumes can be purchased for $20, including postage and handling. Requests will be filled based on availability, but most issues are in stock.

☛ Contact the NSGC Executive Office, 610-872-7608, mailbox 8, FAX 610-872-1192 or nsgc@aol.com.

Upcoming Meetings

April 18-19 • Chicago IL
"The New Genetics in Primary Care," sponsored by the University of Chicago. Contact: 773-702-1056

April 24-25 • Washington DC
"Practical Applications of Genetic Testing in Managed Care," sponsored by International Business Communications. Contact 508-481-6400, inq@ibcusa.com

April 26-27 • Chicago IL
NSGC Region IV Educational Meeting. Contact Mary Ahrens, 612-625-2134, ahrens@lenti.med.umn.edu

May 2-3 • Denver CO
NSGC Region V Educational Meeting. Contact Christine Barth, 303-861-3128

May 18-20 • Genoa Italy
29th Annual Meeting of the European Society of Human Genetics. Contact: 011-39-10-5704092, http://www.unige.it/ESHG97

June 16-17 • Rockville MD
Frontiers in Breast Cancer: Research, Diagnosis & Therapy. Contact: 212-737-3091, GeneQuest@concentric.net

June 22-26 • Minneapolis MN
Midwest Intensive Bioethics Course. Contact: 612-626-9756,holmb006@maroon.tc.umn.edu

June 25-29 • Washington DC
5th International Conference on Grief & Bereavement in Contemporary Society. Contact: 860-586-7503, ADECOffice@aol.com

Cancer SIG Directory

■ The Cancer Genetic Counseling Special Interest Group is offerring its referral directory to all NSGC members. The directory—available around April 15—will list SIG members who are accepting patients for cancer risk counseling and testing.

☛ The directory will be broadcast on the NSGC Listserv; others members may obtain a hard copy from the NSGC Executive Office, 610-872-7608, mailbox 8, or nsgc@aol.com.

Malpractice Insurance

■ NSGC has a cooperative agreement with the American Counseling Association to offer liability insurance for genetic counselors at group rates. The ACA has just changed insurance carriers; the former carrier has contacted policyholders directly, creating some confusion. Counselors choosing individual coverage will not have the rate advantage, access to ACA materials or ACA's backing in case a lawsuit is filed.

Cancer Internship Opportunity

■ The Clinical Genetics Service at Roswell Park Cancer Institute in Buffalo NY has received an NIH grant for educational programming in cancer genetics. They have designed an intensive 2-week clinical internship focusing on oncology and genetics for practicing genetic counselors and nurses. Training will include education in the biology/genetics of cancer; clinical experience in cancer risk assessment, genetic testing and counseling; and discussion of psychological, legal and ethical issues.

Internships will be offered in June and September, 1997. Stipends are available to cover travel and rooming expenses of up to $1000. All other expenses will be the participant's responsibility.

☛ For more information or an application, contact Carolyn Farrell, MS, CNP or Mary-Jo Rosenblatt, MS, at 716-845-8400, farrell@sc3103.med.buffalo.edu.

LGS/NSGC Travel Fund Eliminated

■ Due to the low number of applications, the Laboratory for Genetics Services/NSGC Speakers Travel Fund was discontinued January 1, 1997. LGS has enjoyed helping the genetic counselors who sought funding and is committed to continued support of NSGC.

What has NSGC Done for You Lately?

■ Where should NSGC be going in the future? What are your needs—current and longterm—from the Society? These are the kinds of questions the Board of Directors will consider as it begins to evaluate and possibly update our Strategic Plan.

☛ Share your thoughts/opinions with your Regional Representative or other Board member before the Interim Board of Directors meeting, April 11-13.

Book Reviewers Sought

■ The *Journal of Genetic Counseling* is looking for members interested in reviewing recently published books on a variety of genetics/genetic counseling topics.

☛ For more information, contact Christina Palmer, PhD, Dept of Psychiatry & Biobehavioral Sciences, UCLA School of Medicine, 760 Westwood Plaza, Los Angeles CA 90024; 310-825-8660; FAX 310-206-4446; cpalmer@npih.mednet.ucla.edu.

Educational Materials Available

■ Two new resources are available to educate families about folic acid and neural tube defects. The first, a pamphlet written with a GLaRGG grant, is designed for parents who have had a child with neural tube defects. The March of Dimes funded development of the second, a bookmark for the general public discussing folic acid. Both have space for you to stamp your institution's address.

☛ For more information, contact Connie Motter, 330-379-8792.

Welcome to Cyberspace!

■ Did you just get e-mail access? We don't want to be the last to know! Please inform the NSGC Executive Office (nsgc@aol.com) when you go online. This will help expedite communications from the Listserv and Special Interest Groups.

■ Interested in joining the Computers Users Group of the Education Committee? Contact Jill Fischer, 616-391-3068, jfischer@bw.brhn.org.

Call for Abstracts

■ Deadlines are creeping up quickly. Submit abstracts for poster or platform presentations for NSGC's 16th Annual Education Conference in Baltimore by ***Friday, May 9.***

☛ For information about submitting or developing abstracts, contact Laura Thomson, 315-464-7610.

Ulnar-Mammary Syndrome

■ A research group in the Boston area seeks families in which two or more individuals have the ulnar-mammary syndrome, also known as Schinzel syndrome. The main features of this autosomal dominant condition are absence of breast tissue (with uni- or bilateral absence of breasts in females) and abnormalities of ulnar or fibular aspect of the extremities. It is a rare condition with variable expressivity.

☛ For more information, contact Marisa Ladoulis, 617-724-9004, ladoulis.marisa@mgh.harvard.edu.

Schizophrenia and Obsessive Compulsive Disorder

■ The Rockefeller University in New York is recruiting participants for a genetic study of Schizophrenia and Obsessive Compulsive Disorder (OCD) under the direction of Dr. Maria Karayiorgou. The investigation hopes to identify susceptiblity genes for these illnesses.

The study psychologist will conduct telephone interviews with family members having either schizophrenia or OCD. Affected and unaffected family members need to provide blood samples, which may be drawn at sites convenient for them.

The study seeks trios—an affected adult plus both biological parents—OR sibling pairs with the same or similar type of illness.

☛ Contact Maude Blundell, MS, 212-327-8335, blundem@rockvax.rockefeller.edu. Individuals wishing further information may call collect.

Hirschsprung Disease

■ In its sixth year, a study directed by Dr. Aravinda Chakravarti at Case Western Reserve University is investigating the genetics of Hirschsprung disease. Families with multiple cases OR individuals affected with Hirschsprung disease and other anomalies are invited to participate.

☛ Contact Jennifer Scott, MS, 216-368-1814, jas43@po.cwru.edu.

Cancer Genetics: A Guide for Families

Cancer Genetics: A Guide for Families, 55-page counseling guide by Gwendolyn Marie Reiser, MS & Bradley Schaefer, MD; produced by Meyer Rehabilitation Institute and Eppley Cancer Center; $45.

Resources

edited by Karen Copeland

Meyer Rehabilitation is offering a cancer genetics guide "... to aid health care providers in counseling patients and their families." The preface encourages users to arrange pages based on personal preference, make the contents patient specific and add their own pages with information unique to their settings. The format of the guide, a three-ring easel binder, makes it easy to customize and update. The eight topic areas cover cancer statistics, basic cancer principles, hereditary cancer, hereditary cancer syndromes, breast and ovarian cancer, colon cancer, gene testing and cancer cytogenetics.

Photographs are among the guide's most useful aspects; they include mammograms, colonoscopies, five karyotypes (46,XY, 46,XX, AML, ALL and CML) and a FISH study for BCR/ABL. There are several excellent sample pedigrees covering hereditary cancer syndromes as well as breast and colon cancer. The section covering hereditary cancer illustrates sporadic, familial and hereditary cancer with great example pedigrees. Several sections provide syndrome features, empiric risk figures, tables and pie charts. The page layout was generally easy to understand.

The cancer statistics section includes interesting information, such as 1996 estimated new cancer cases and cancer deaths. The basic cancer principles section discusses oncogenes, tumor suppressor genes and mismatch repair genes, as well as Vogelstein's model of carcinogenesis for colon carcinoma. These sections contain too much information to use as an introduction for patients but provide useful background if needed.

Breast and ovarian cancer is the longest section, covering 15 pages, but the Gail Model is missing from the discussion on calculating breast cancer risk and there is a notable absence of specific information on ovarian cancer, including ovarian cancer risk factors, suggested protective factors and heterogeneity of ovarian cancer. Gene testing covers dominant, recessive and X-linked inheritance, linkage and protein fragment test. Two pages discuss the potential benefits and risk associated with cancer gene testing. This section especially needs to be tailored for individual needs.

Notable absences from the guide are general population data for specific cancers (such as risk and age of onset to compare with various cancer syndromes), surveillance options (for individuals at general risk or increased risk), prophylactic surgical options and pages to promote a healthy lifestyle regardless of cancer risk.

COMPARING TO MY CUSTOM-BUILT GUIDE

I held onto the advertisement for this book for many months, unsure if I should order it. There are probably as many variations of customized counseling aids as there are genetic counselors—I had already created my own since there was not one available when I started cancer counseling. My personal book cost approximately $40 for materials, not including my time. My final, but constantly changing book, is also a three ring binder with 50+ pages divided into six not-so-clearly defined sections.

I was initially disappointed when I first reviewed the guide. There are only two color pages and many other pages could be easily reproduced with word processing or slide-making programs. However, looking over it again as I composed this review and comparing it to my custom-built notebook, I feel it is worth the $45 cost, especially for individuals new to cancer risk counseling. This product is both an organizational and topic guideline; even if all of these pages are not used, you may get ideas to customize your own. This guide begins to fill the void of a counseling aid for cancer risk counselors.

Sheri Babb, MS
St. Louis MO

Dwarfism Web Site

For those interested in short stature disorders, a visit to the Dwarfism Home Page is a must: http://www-bfs.ucsd.edu/dwarfism. Click on Frequently Asked Questions for a wealth of information written in a wonderful conversation style. The site has scores of links to mailing lists, support organizations, medical information, doctors and product resources. Read the Little People of America's position on genetic testing, bone-lengthening procedures and the portrayal of dwarves in the cinema.

Angela Grace, MS
Hazlet NJ

Job Listings

Oakland CA

■ Immediate opening for BC/BE Pediatric Multispecialty Clinic Assistant Supervisor at large HMO. Masters in GC, nursing or clin health-related degree w/ 3 yrs clin exp in maternal-child-ped and/or genetic + 1 yr s'visory, mngmt or prog admin req. S'vise prof & clerical staff to coord KP Northern Calif Reg'l Ped spec clins: metabolic, lipid, craniofacial, skeletal dysplasia, SB, etc. Develop/implement/monitor systems for high quality care.
Contact: Susan Dewey, RN, Genetics Dept, Kaiser Permanente, 280 W MacArthur Bl, Oakland CA 94611; 510-596-6779. EOE/AA

Orange CA

■ Immediate opening for BC/BE Genetic Counselor. Exp & computer skills pref. PNDx: amnio, CVS, AFP, & terat coun. Wide variety subspec & satellite clinics.
Contact: Khalil Zadeh, PhD, Genetics Center, 1000 W La Veta Ave, Ste 9, Orange CA 92868; 714-667-1965; FAX 714-667-1106; nzadeh@aol.com. EOE/AA

Pasadena CA

■ Immediate opening for 2 BC/BE Genetic Counselors w/ MS from GC Program req. #1 Baldwin Park Med Ctr; #2 Panorama City/Woodland Hills Med Ctrs. Exp in PN, peds & cancer coun; devlpmt of educ programs in genetics req; fluency in Spanish; org, oral & written commun skills pref. PN coun: expanded AFP, peds.
Contact: Kermit Anderson, MA, MEd, Perinatal Screening, Kaiser Permanente, 393 E Walnut Ave, Pasadena CA 91188-8026; 818-564-3320; FAX 818-564-3311; kermit.anderson@kp.org. EOE/AA

Pasadena CA

■ Immediate opening for BC/BE Genetic Counselor w/ min 2 yrs exp in PN/clin genetics req. Biling Eng/Span pref. Send CV + 2 ref. Join perinatologist in priv practice couns for variety of perinatal indications: MS scrng, AMA, Fam hx.
Contact: Bharat Shah, MD, 50 Alessandro Dr, Ste 150, Pasadena CA 91105; 818-449-8706; FAX 818-449-3464.

Denver CO

■ Immediate opening for part-time BC/BE Genetic Counselor/ Professional Research Asst. Exp in molec lab setting or cancer genetics helpful. Exclnt org/computer skills req. Identify & recruit families to partic in: linkage analysis for lung cancer suscept genes, familial cancer registries & other rsrch studies. Intake fam hx; environ exposures, educ re: cancer risk factors & prevention. Work closely w/ clin investigator/data mgr, other prof. Perform GC in genr'l hereditary cancer clin setting.
Contact: Respond by 4/4 to: Robin Hohsfield, RN, Coordinator Clinical Investigations Core, Univ Colorado Cancer Center, Campus Box B-189, 4200 E Ninth Ave, Denver CO 80262; Robin.Hohsfield@UHColorado.edu. EOE/AA

Honolulu HI

■ Immediate opening for BC/BE Genetic Counselor. Highly motivated, flexible, comfortable in multicultural setting. Exp pref, not req. Join large multidisc team: All aspects of PN coun: amnio/CVS/PUBS, terat, U/S, outpt diabetes prog, triple marker scrng, bereavement & family histories.
Contact: Albert Mossman, Human Resources, Kapi'olani Medical Ctr for Women & Children, 1319 Punahou St, Honolulu HI 96826; 808-973-8208; FAX 808-973-3125. EOE/AA

Baltimore MD

■ Immediate opening for Genetic Counselor w/ Masters. Part-time/full-time possible. Excellent commun & i'personal skills, familiarity w/ Jewish culture req. Familiarity w/ classification of psychiatric illnesses, exp w/ recruitment for rsrch protocols, public speaking pref. Weekend/evening work req. Research in multidisc rsrch group w/ focus on describing genetic susceptibility of schizophrenia and bipolar illness in Ashkenazi Jewish community.
Contact: Gail Ullrich, MSW, Dept Psychiatry and Behavioral Sciences, The Johns Hopkins Univ School of Medicine, 1615 Thames St Ste 205, Baltimore MD 21231; 410-955-0455; FAX 410-955-0644. EOE/AA

Boston MA

■ May 1 opening for Genetic Counselor. BC + 2 yrs exp pref. Excellent org skills; abil to work i'pendently essential. Primarily PN: Amnio & CVS; coun for abnl U/S, terat, high risk OB pts; coord add'l tstg & follow up; resource to health care prof; partic in monthly tchg rounds; s'vise GC students.
Contact: Betsy Johnson, Human Resources, Beth Israel Deaconess Medical Center, 330 Brookline Ave, Boston MA 02215; 617-667-7110; FAX 617-667-4515. EOE/AA

Boston MA

■ Immediate opening for Genetic Associate w/ MS in GC or related field. Some exp pref, not req. Busy PNDx, molec DNA dx progs, involve in MSAFP. Rsrch oppty.
Contact: Aubrey Milunsky, MD, Center for Human Genetics, Boston Univ School Medicine, 80 E Concord St, Boston MA 02118; 617-638-7083; FAX 617-638-7092. EOE/AA

Helena MT

■ Immediate opening for BC/BE Genetic Counselor. Exp w/ cancer coun & computers pref. Ped & adult genr'l GC: outreach clin, svc to Native Amer, fetal path, PN scrng & cx. Oppty for prof/ lay educ & contrib to program devlpmt.
Contact: Rick Harden, Human Resources, Shodair Hospital, PO Box 5539, Helena MT 59604; 800-447-6614; FAX 406-444-7536. EOE/AA

St. Louis MO

■ Immediate opening for BC/BE Genetic Counselor. CV & 3 ltrs rec req. Highly motivated, i'pendent personality req. Join team of 3 GCs in busy univ-based PNDx prog offering all aspects of tstg; free terat/genetics phone svc.
Contact: Heidi A. Beaver, MPH, Dept OB/GYN, Div Genetics, Barnes Jewish Hospital, 216 South Kingshighway, St. Louis MO 63110; 314-454-7358. EOE/AA

New York NY

■ July 1 opening for Health Policy Analyst w/ MD *or* Masters + 3 yrs related exp. Strong writing skills essential. Send writing sample w/ resume. Join task force to devel recommendations for state law & policy on genetic testing & screening.
Contact: Carl Coleman, NYS Task Force on Life & the Law, 5 Penn Plaza, Rm 301, New York NY 10001-1803; 212-613-4303; FAX 212-613-4351. EOE/AA

Syracuse NY

■ Immediate opening for BC/BE Genetic Associate. All aspects of coun & case mgmt for growing Ped/Adult Genetic Div in tertiary care Univ Hosp. Support svcs: cyto, molec dx labs, secty. PN genetic svc thru OB Dept Public educ & clin rsrch oppty.
Contact: Joe Hoo, MD or Laura Thomson, MS, Div Pediatric Genetics, SUNY Health Science Ctr, 750 E Adams St, Syracuse NY 13210; 315-464-7610; FAX 315-464-7564. EOE/AA

Chapel Hill NC

■ Immediate opening for BC/BE Genetic Counselor. Exp pref. Join large multidisc team: All aspects of PN GC & MSAFP prog; oppty for tchg, commun, outrch & rsrch avail. Interact & collab w/ other genetic specialities.
Contact: Rachel Baughman, MS, Prenatal Diagnosis Program, Dept OB/GYN, Univ North Carolina School Medicine, CB #7570 MacNider Bldg, Chapel Hill NC 27599-7570; 919-966-2229; FAX 919-966-1999; rbaugh.obgyn@mhs.unc.edu. EOE/AA

Cheltenham (Philadelphia Area) PA

■ Immediate opening for BC Genetic Counselor in Family Risk

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of genetic
counselors, inc.**

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Assessment Program. Familiarity w/ cancer genetics pref. Cancer risk coun & case mgmt. Work in multidisc setting to develop new strategies for cancer risk assmt & coun; partic in rsrch studies w/ emphasis on educ, epidem, commun outrch.
CONTACT: Mary B. Daly, MD, PhD, Family Risk Assessment Program, Fox Chase Cancer Center, 510 Township Line Rd, Cheltenham PA 19012.

Philadelphia PA

■ Immediate opening for 2 BC/BE Pediatric Genetic Counselors: #1 Research & #2 Clinical. Exp pref not req, exceptional org skills & ability to work w/ team essential, computer exp desired. Send CV & 3 ltrs rec. Provide inpt/outpt ped svcs; partic in all aspects of clin rsrch: recruit, obtain histories, informed consent, handle specimens, commun results, coord follow up, some date analysis. Oppty in spec clins & tchg.
CONTACT: Regina Harvey, Div Human Genetics & Molecular Biology, Children's Hospital of Phila, 34th & Civic Ctr Blvd, Philadelphia PA 19104; 215-590-3856; FAX 215-590-3764. EOE/AA

Job Listings

Philadelphia PA

■ May opening for Part time (6 month) BC/BE Genetic Counselor. Potential for perm part-time work. PNDx w/possible travel to area satellite clin.
CONTACT: Rose Giardine, MS, Dept Ob/ Gyn, Univ Pennsylvania Medical Ctr, 3400 Spruce St, Philadelphia PA 19104; 215-662-3232; FAX 215-349-5893. EOE/AA

Philadelphia PA

■ Immediate opening for BC/BE Genetic Counselor. Min 2 yrs exp in perinatal setting pref; new grads will be considered. Good clin judgment skills & autonomous personality pref. PN coun at wide variety of satellite sites, in So. New Jersey & Phila. Coun indications: AMA, triple screen, fam hx of wide variety of genetic diseases, abn U/S. Handle pt & client calls, provide staff educ at rounds, clin rsrch oppty avail.
CONTACT: Denise M. Cutillo, MS, Genzyme Genetics, Pine Bldg Basement East, Pennsylvania Hospital, 800 Spruce St, Philadelphia PA 19107; 215-829-3604; FAX 215-829-3553. EOE/AA

Memphis TN

■ Immediate opening for BC/BE Genetic Counselor. Exp pref. Join multidisc Univ based team. Diverse GC oppty in genr'l genetic svc (clin & inpt) in ped, newborn, adult, spec clins, EIM, newborn scrng triage, outrch; PN in collab w/ Repro Genetics. Oppty for clin coord, case mgmt, tchg, rsrch. Collab w/ area hosp & Univ depts. Cyto, metab & molec labs on site.
CONTACT: Jewell C. Ward, MD, PhD, Div Medical Genetics, Dept Pediatrics, University Tennessee Memphis, 711 Jefferson #523, Memphis TN 38105; 901-448-6595; FAX 901-448-4117; jward@utmem1.utmem.edu. EOE/AA

Dallas TX

■ Immediate opening for BC/BE Pediatric Genetic Counselor. Exp pref; Spanish helpful; motivated, enthusiastic personality pref. Join team at peds tchg hosp: outpt genr'l genetics & metabolic clin for adults & peds; DS clin; inpt consults; oppty to partic in multispec & outrch clins; supt grp facil; tchg & pub ed.
CONTACT: Gail Brookshire or Stacie Rosenthal, Children's Medical Center of Dallas, 1935 Motor St, Dallas TX 75235; FAX 214-640-6233. EOE/AA

Houston TX

■ Immediate opening for BC/BE Genetic Counselor. Spanish pref not req; abil to work independently essential. PN coun at 6 satellite clins in Houston, ped coun in spec clins, cytogenetic coun & s'vision/tchg gc & med students.
CONTACT: Dr. Hope Northrup, Dept Pediatrics, University Texas, 6431 Fannin, Ste 3.144, Houston TX 77030; 713-792-5330 x3060; FAX 713-796-9984. EOE/AA

Houston TX

■ Immediate opening for BC Sr. Genetic Counselor. Post-baccalaureate deg, 3 yrs exp (1 yr s'visry pref). Prov risk assessment & GC to hereditary cancer pts & families as part of interdisc team. Prof/public educ, rsrch proj devpmt & mgmt. Partic in growth of human cancer genetic prog in oncology trtmt & research ctrs.
CONTACT: Steve Beck, Mgr, MD Anderson Cancer Ctr, 15154 Holcombe Blvd, Box 205, Houston TX 77030; 713-794-5503; FAX 713-794-5951. EOE/AA

IN CANADA: Toronto Ont

■ Immediate opening for BC/BE Genetic Counselor. 2 yrs exp desirable. Pref to Canadian citizens. Join active clin genetic team for primarily peds pts, some PN, adult & specialty clins; tchg & rsrch.
CONTACT: Cheryl Shuman, Dept Genetics, Hospital for Sick Children, 555 University Ave, Toronto, ON, M5G1X8, CANADA; 416-813-6386.