PERSPECTIVES in genetic counseling

Volume 20 Number 2 Summer 1998

national society
of genetic
counselors, inc.

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

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NSGC acknowledges GeneLink, Inc. for a generous grant to support this newsletter.

BIRTHING A FOUNDATION: A LABOR OF LOVE

Lisa Amacker North, MS

Are we old enough to have a child? Recent discussions about the responsibility of genetic counselors to expand research and educate others about the profession sparked my concern about how these activities might be funded.

TAKING OUR TEMPERATURE

NSGC is a non-profit tax exempt 501(c)(6) organization whose mission is to promote the genetic counseling profession as a recognized and integral part of health care delivery, education, research and public policy. NSGC can accept individual and corporate donations, but these monies are not tax deductible to the donor as charitable contributions. Donations may be deductible as a business expense on an itemized return. NSGC, as a 501(c)(6), is also prohibited from receiving private foundation and government grants.

NURTURING A FOUNDATION

Foundations are tax exempt 501(c)(3) organizations that are, according to the IRS code, “organized and operated exclusively for charitable, scientific or educational purposes.”

Foundations can accept tax deductible donations from individuals, corporations and other foundations and can use the income to further their missions. Many non-profit organizations have related foundations which

- Accept and award research grants
- Provide public and professional educational opportunities (brochures, books, seminars) and
- Make charitable donations.

ARMS LENGTH “PARENTING”

The original organization and its supporting foundation are separate and must have independent administration and leadership. They have a common vision but different approaches to achieving their missions.

NSGC does not yet have a related foundation, but several issues have raised interest in this option.

- Maureen Smith recently had to turn down an opportunity for NSGC to apply for a federal

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STRATEGIC PLAN UNVEILED

Bea Leopold, MA, Executive Director

The success of our first strategic plan, created in 1993, prompted Board action to initiate our second. In keeping with NSGC’s culture, we began the process with an educational review of the creation of our first plan (*PGC* 19:1), followed by a membership survey (*PGC* 19:2) and evaluation and analysis (*PGC* 19:3). To achieve consistency, the survey closely followed the original

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UPDATE: THE FUTURE OF GENETIC COUNSELING CPT CODES

Debra Lochner Doyle, MS

It has been nearly a year since I shared through *Perspectives* the decision of the American Medical Association not to accept the American College of Medical Genetics (ACMG) proposal for a Genetic Counseling CPT Code.

UPDATE ON EFFORTS

Fortunately, David Flannery, MD, co-chair, ACMG's Economic of Genetic Services Committee, served on the AMA CPT Editorial Review Panel to educate panel members about genetic counseling and billing issues. Dr. Flannery also participated in a Work Group on Patient Education that was convened to address the issue of CPT codes for Patient Education. According to Dr. Flannery, managed care organizations were instrumental in encouraging the AMA to consider issues surrounding disease management and patient education. The working group developed two proposals for the CPT Advisory Committee:

- Change the description of the Counseling and/or Risk Reduction/Intervention codes (99401-99404) to allow them to be used for patients with symptoms or diagnosed illnesses.
- Create new codes for Patient Education/ Counseling performed by non-physicians under the direction of a physician. These codes would have 15 minute time intervals.

'Efforts are ongoing, although the wheels of change are slow…'

LIMITATIONS

Risk Reduction/Intervention codes require that each service be a "separate encounter." Therefore, genetic evaluations could not be performed on the same day as genetic counseling — even if the physician conducted the evaluation and the genetic counselor performed the counseling.

It is unclear, however, how the second proposal would impact genetic counselors in private practice. It is possible that these counselors would need to be sponsored by a physician (i.e., demonstrate that they have medical back-up when needed).

REVISION OF CPT CODES

The CPT codes were revised extensively for 1997. Great emphasis was placed on determining the level of evaluation and management (E/M) services. Historically key components of E/M services were:

- Obtaining a family history
- Conducting a physical examination
- Facilitating medical decision making

However, in 1997, an exception was recognized in cases in which the medical visit consists predominantly of counseling or case management. In these circumstances, time is the key factor.

The difficulty of determining the level and complexity of service resulted in significant physician outcry. As a result, the AMA and the Health Care Financing Administration (HCFA) held a meeting in Chicago last April to discuss changing these guidelines. According to George Robert Kim, American Academy of Pediatrics, revising the E/M guidelines will be postponed pending physician input. January 1999 will be the earliest possible date for the publication of revised guidelines, which would then be pilot tested. Until that time, HCFA will allow the use of either the 1994/1995 or 1997 CPT guidelines.

The issue of fraud and abuse in relation to these guidelines was also addressed. Concerns were raised in light of the Health Insurance Portability and Accountability Act of 1996 (HIPPA) that refers to sanctions for coding errors. Nancy-Ann DePearle, HCFA Administrator, emphasized that sanctions were created for physicians who show a pattern or practice of improper billing. This was distinguished from practitioners who make honest coding mistakes.

RESOLUTION NOT ON HORIZON

Efforts are ongoing, although the wheels of change are slow given the multiple governmental and professional organizations involved. Although NSGC is not formally at the table for many of these discussions, we are being represented by our colleagues through the ACMG who are equally as committed to resolving these billing and reimbursement issues. ❖

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

*Next issue **September 15***
*Submission deadline **August 11***

Membership Satisfaction Survey to rank and compare our current members' beliefs and the values we place on our membership features and benefits. Also in that issue were the results of several Board sessions which focused on deter-mining where our future emphasis must lie.

FINE TUNING OUR VISION AND MISSION

Board discussions clearly supported our vision. We eliminated the words "will be" to state that we *are* the leading voice, authority and advocate for the genetic counseling profession. We revised our mission statement to read: "NSGC will promote the genetic counseling profession as a recognized and integral part of health care delivery, education, *research* and public policy.

PLAN EMPHASIS

This second strategic plan clearly emphasizes the importance of retrenching to gather important data and forging ahead toward accomplishing our vision and mission. We created this plan to address both external and internal issues. The main categories deemed of highest priority in the next two years are:

- Billing and Reimbursement
- Expanded Roles/Increased Jobs in New Markets
- Perception of Increased Training Programs in Relation to Job Opportunities
- Communications (This category clearly holds the most crossover between internal and external.)

Categories and strategies follow.

Request a complete copy of our new strategic plan with assigned responsibilities and timelines by fax: 610-872-1192 or by e-mail: nsgc@aol.com. ❖

HIGHLIGHTS: 1998 STRATEGIC PLAN

I. BILLING AND REIMBURSEMENT

DATA COLLECTION
- Conduct survey of billing & reimbursement practices
- Assess average time involved to complete GC evaluation
- Encourage HCFA to assign Provider Number

VISIBILITY
- Gather data for "How to Approach…" Manual
- Create packet of marketing materials directed at B&R
- Increase networking to encourage reimbursement for services
- Conduct pilot study to increase networking with health care purchasers

II. EXPANDED ROLES/INCREASED JOBS IN NEW MARKETS

RESEARCH AND DEVELOPMENT
- Dispel myth of inadequate number of GCs (supply v. demand)
- Conduct human resources study
- Create "How To" manuals: entrepreneurship; specialty starter packets
- Create brochures with customized inserts for targeted audiences
- Create new web links
- Develop practice guidelines
- Encourage diversity

OUTREACH
- Incorporate Genetic Counselors into new fields, e.g., pharmaceutical industry; insurance industry as case managers; voluntary organizations; medical/legal field; consultant to related fields: infertility, forensics, egg/sperm banks, education: curriculum development
- Market services to traditionally underserved & rural populations

III. PERCEPTION OF INCREASING NUMBER OF TRAINING PROGRAMS V. JOB AVAILABILITY

DATA COLLECTION
- Obtain data from job search results of new graduates
- Conduct exit interviews
- Survey geneticists and other physicians re: past, present, future needs for genetic counseling services, e.g., hiring practices
- Review human resources studies
- Solicit feature stories about how new jobs have been created

IV. COMMUNICATIONS: INTERNAL AND EXTERNAL

INTERNAL
- Make highlights of quarterly reports available to membership
- Reach out to members not on listserv
- Create standardized regional welcome packet
- Encourage attendance at annual and regional business meetings

EXTERNAL
- Create "Rapid Response" team for public relations
- Write regular media releases
- Explore lobbying efforts

Plan approved by Board of Directors, April 1998

YOUR BOARD AT WORK FOR YOU — LET'S MAKE A DIFFERENCE!

Elaine Sugarman, MS, Secretary & Denise Tilley, MS, Region III Representative

The first day of the Spring Board meeting focused on how we, as a society and group of constituents, can make a difference in Washington with the genetic discrimination bills. Many of the congressional bills addressing genetic discrimination in the workplace and through insurance coverage were reviewed including the Daschle bill (HR2275, S1045) and the Snowe/Slaughter bill (HR306, S89). One important way for everyone to get involved and support these bills is to educate your congresspeople. A visit is the best way to let them know your feelings. Plan your point and know how to express it. Lyle Dennis, a lobbyist who spoke to the group, said that personal letters are more effective than form letters. Stress why NSGC and you support these bills. To learn if your congressperson has signed onto the bill, call your state office.

STRATEGIC PLANNING

With our areas of focus defined at previous Board meetings and by a membership survey, time was spent finalizing our society's strategic plan to carry us into the year 2000. *(For more on Strategic Planning, see p. 1.)*

THE WEB

The Computer Users Group (CUG), a subcommittee of the Education Committee, made a proposal for review of material submitted for the web page. A CUG subcommittee will be created for review of material, and the Education Committee Chair, Executive Director and President will be responsible for final approval. A submission form is being finalized for use by those wishing to post material on the website. Any public item could potentially go on the site, so start thinking of what you'd like to post or see! This group will also be investigating the possibility of creating a restricted area on the NSGC webpage that would be password protected. Abstracts, *Perspectives,* the JobConnection and archives of the listserv were discussed as possible protected materials.

CF — WHERE DO WE STAND?

As many know, the NIH has developed a consensus statement which mandates that genetic testing should be offered to adults with a positive family history of CF, to partners of people with CF, to couples currently planning a pregnancy and to couples seeking prenatal care. There are many concerns surrounding this statement, so an ad hoc committee was asked to prepare a position statement for the NSGC in response. The initial draft was discussed and suggestions were made. *(For more information and commentary on this issue, see p. 7.)*

MEMBERSHIP ISSUES

There is an interest in revising the current membership application to request more detailed information, such as a letter of recommendation and documentation of an applicant's degree/experience. Such supporting documentation is common in other professional societies. There will also be a committee review of NSGC by-law Article 1, which addresses membership status and the interpretation of "broad range of genetic disorders." ❖

ABGC UPDATE

Virginia Corson, MS, ABGC President

ACCREDITATION DECISIONS

The American Board of Genetic Counseling is pleased to announce that the University of California at Irvine, the University of California at Berkeley and the University of Wisconsin-Madison have completed their self-study appraisals and site visit team evaluations and will achieve Full Accreditation status effective July 1, 1998. They join Sarah Lawrence College, University of Pittsburgh and University of Colorado, the first training programs to achieve Full Accreditation status in July 1, 1997. This accreditation process is being conducted in the order in which programs were established.

Case Western Reserve University recently received Recognized New Program accreditation status.

CERTIFICATION EXAMINATION

Next year's examination will be the last opportunity to sit under the Special Consideration category. All new applicants for the 2002 exam must have graduated from a genetic counseling graduate program accredited at the time applicants are accepted. The 1999 Bulletin of Information and Application is available from Sharon Robinson, ABGC Administrative Office, 9650 Rockville Pike, Bethesda MD 20814-3998; ✆301-571-1825; Fax: 301-571-1895; srobinson@abgc.faseb.org. ❖

ANNUAL EDUCATION CONFERENCE: IS IT TIME TO STAND ALONE?

by Cindy Soliday, MS, Chair, Annual Education Conference Subcommittee

A hot topic at the April Board of Directors meeting was the timing of future Annual Education Conferences (AECs).

BACKGROUND

Traditionally, AECs have been held either immediately before or after the American Society of Human Genetics (ASHG) annual meeting in the same location. Membership preferences in the past have supported the continuation of this practice. However, NSGC has experienced increasing difficulties securing space for these dates due to the growth of both the NSGC and ASHG conferences.

HISTORY OF CONFERENCE GROWTH

We started with great ambitions in 1981. Our first two day conference featured three invited speakers, five workshops, seven contributed papers and 123 registrants. Our most recent conference in Baltimore featured 12 plenary speakers, 11 workshops and eight practice-based symposia. In addition, 34 papers were chosen for presentation from a record 111 submissions. The number of registrants topped 800.

We have truly come a long way!

As we look forward to our 20th anniversary, the AEC Subcommittee, at the request of the Board, is taking time to reflect on our conference's quality and growth.

CHALLENGES OF CONTINUING TO MEET WITH ASHG

In recent years we have experienced the following difficulties when planning our conference:

- Finding a hotel site. ASHG reserves large blocks of hotel rooms prior to their conference to accommodate pre-conference committee and ancillary meetings. This makes it difficult to book a hotel with sufficient meeting and room space.
- Selecting date options. October, whether we meet before or after ASHG, is one of the most competitive convention months.
- Maintaining reasonable hotel room rates. Cities able to accommodate ASHG's growing projected number of registrants tend to be high-price sites.
- Growing feedback that attending back-to-back meetings has become intellectually, physically and emotionally draining.
- Scheduling short courses. Given the above, identifying dates for our increasing need for short courses has presented a challenge.

ADVANTAGES OF REMAINING WITH ASHG

Clearly, there are advantages to retaining our policy of meeting alongside of ASHG.

- Meeting separately would require additional money and time away from work for those attending both meetings.
- Funding for some members includes only one meeting each year. When held together, the conferences may be considered as one meeting.
- Interviewing for jobs has enjoyed a better reputation at ASHG than at our conference.
- Continuing to meet with ASHG fosters positive relations, camaraderie and visibility with our fellow geneticist colleagues.

ACCOMMODATIONS MADE

Concessions we have been forced to make recently include:

- Holding our 1999 AEC in Oakland due to the lack of available space in San Francisco, ASHG's meeting site. Our conference will be held immediately prior to ASHG.
- Moving our 2000 AEC to another time because ASHG's meeting is sandwiched between Rosh Hashanah and Yom Kippur. Holding our AEC either before or after ASHG would result in a conflict that would be disrespectful to our Jewish colleagues.

BOARD TAKES OWN PULSE; SEEKS MEMBER VIEWS

In straw polls of its members after a lengthy discussion, your Board voted unanimously on the following issues:

- Against meeting with the American College of Medical Genetics, because NSGC's conference is larger and more established. If we make a change, we want autonomy.
- For a Fall stand-alone conference, beginning in 2000.

Now is the time for you, the membership, to take a balanced look into our conference's future. Weigh the pros and cons and let us know what you are thinking. A LILAC card is enclosed with this issue to take your pulse. ❖

DON'T BE LATE!

The deadline for registration without penalty for our 18th Annual Education Conference in Denver, October 24 - 27, is Friday, August 14.

Avoid the extra charge… remit your registration fees on time! ❖

DIVERSITY SIG ACTIVITIES ABOUND

Ilana Mittman, MS, Diversity SIG Chair, and Karen Potter, MS

The Diversity Special Interest Group is composed of 21 members and has a three-member steering committee to organize SIG activities. The goal of the Diversity SIG is to embrace issues of human diversity as they pertain to the genetic counseling profession.

One of the primary ways this SIG hopes to achieve this goal is through education. The SIG has been active, sponsoring workshops for the general membership as well as participating in public discussion.

Members are organizing a workshop for the Annual Education Conference in Denver, "Genetic Counseling in a Multi-Cultural Society: Recurring Challenges and Potential Approaches." In addition, the SIG may organize a future short course on cross-cultural counseling.

Genetic counseling students also stand to benefit from this SIG's activities. The group is planning a breakfast for minority genetic counseling students at the Denver meeting. This will hopefully create a bond between students and established genetic counselors within the SIG. In addition, a mentorship program is in the works for racial/ ethnic minority genetic counseling students. As in all mentorships, students with diverse backgrounds will have access to a group with whom they can discuss cultural issues and barriers.

The largest activity to date is the major role the Diversity SIG had in facilitating a national dialogue between diverse communities and genetic professionals. "The National Dialogue on Genetics" took place in March at the University of Maryland. More than 100 scholars and community leaders from around the nation participated, representing many ethnic and minority groups, as well as genetic and health organizations. This dialogue educated scientists and federal health agencies about the needs of genetic services in diverse communities. While the clinical application of genetics has the potential for stigmatization and discrimination, this dialogue of diverse groups accentuated human similarities and celebrated the enriching differences that make up the American tapestry.

The final outcome of this effort will include meeting proceedings, which will be published and made available to all individuals with input on genetic policy. National Dialogue on Genetics can be found at: http://mchneighborhood.ichp.edu/geneticlink/materials/893253084.html ❖

ACTIVITIES OF OTHER SIGS

ASSISTED REPRODUCTIVE TECHNOLOGIES (ART) • **Jill Fischer, Marilyn Ray and Niecee Singer facilitated a workshop on genetic counseling in the field of assisted reproductive technology at ACMG last February.**

PUBLIC HEALTH • **Members exhibited at the Center for Disease Control's 1st annual conference, "Genetics and Public Health: Translating Advances in Human Genetics into Disease Prevention and Health Promotion" in April.**

DOWN SYNDROME • **Unfortunately, the Down syndrome SIG has officially folded due to lack of members this year. However, Cam Brasington is still available as a Down Syndrome resource. ❖**

MEMBERS SPEAK OUT ON GENETIC DISCRIMINATION

On May 21, Jodi Rucquoi represented NSGC before the senate committee on Labor and Human Resources. At the invitation of Sens. Dodd (CT) and Jeffords (Chairman, VT), she presented testimony concerning the prevention of genetic discrimination in health insurance. "This was an exciting experience. Committee members asked several questions which indicated to me that my points had been well taken," she said. Sen. Frist (TN) asked, if given the projections of genetic counseling needs in the future, our current 1600 membership would be adequate. This gave her the opportunity to talk about the myriad of services genetic counselors provide.

After her testimony, Sen. Dodd's office called to express interest in visiting Jodi at her Yale office to witness just what a genetic counselor does.

On incredibly short notice, Shirley Jones, RN, PhD, agreed to represent NSGC at a June 5 information gathering session hosted by Sen. Ted Kennedy's staff on this same topic. The definition of genetic information was the core concept tackled in this meeting and on which the Snow/Slaughter bill will live, die or be significantly altered. According to Shirley, NSGC was the only professional membership organization present. "The Democrats' definition of genetic information," she said, "is inclusive and multifaceted, while the Republican definition is DNA test-based. Both have rather profound implications."

In either case, lobbyists from the insurance, pharmaceutical and medical industries will assuredly be rolling up their sleeves. Thanks, Jodi and Shirley, for being wonderful spokespersons and advocates. ❖

GENETIC TESTING AT A CROSSROAD

Rosalie Goldberg, MS, Liaison to National Human Genome Research Institute Council

The NIH Consensus Conference on Genetic Testing for Cystic Fibrosis concluded that mutation screening should be offered to all pregnant couples. I recently attended a Council meeting, and regardless of our opinion about the nuances of this recommendation, it has been mandated to happen.

> ***'We have two choices: we can complain, or we can speak out with a strong voice.'***

Colleagues, we have our work cut out for us! And our response to this mandate may set the stage for our role in the future of genetic medicine. CF has been touted as the "model disorder" for the future of population genetic testing. Although the CF statement nicely delineates the components of a pre-test education session in utopia, the application will be staggering. The CF test has only 80% sensitivity in the Caucasian population and less (30%) in the Chinese population. Other populations range between these two values. The implementation of policies regarding insurance or Medicaid coverage, privacy, partner testing and a host of other issues has not been addressed.

SETTING PROFESSIONAL STANDARDS OF CARE

But the reality is that Cystic Fibrosis is just the beginning. Very soon, other genetic tests determining predisposition to disease will follow. Let us take a leadership role and understand that the NIH does not set professional standards of care. The NSGC, ACMG and, probably most significantly, ACOG, will ultimately determine the standards of practice. We have two choices: we can complain, or we can speak out with a strong voice. How do we want to use this experience to support our vision as the leading voice, authority and advocate for the genetic counseling profession?

Eventually, genetic tests will become integrated into mainstream medicine during the treatment and intervention phase of health care in a way that is not currently possible. When this happens, issues of informed consent and counseling needs will change.

What will this change mean for the role of genetic counselors and the services that we are able to provide? Our future rests on our ability to counsel, our skills in facilitating difficult decision-making and our willingness to specialize or integrate ourselves into new markets.

OUR ROLE

Providers who eventually use new genetic tests will not be providing genetic counseling or the expanded follow-up services that we are trained to offer clients. We can play a major role in providing professional genetic education, training additional counselors, conducting research and upgrading our expertise in short-term counseling interventions. Such activities can elevate our status.

While none of us has the crystal ball to predict the future, considering innovative and creative ways to enhance our profession will make it more likely that we will be an important part of the changes ahead. Let our voices be heard, and let us continue to market ourselves as experts.❖

FOUNDATION, *from p. 1*

workforce assessment grant because our tax status would not allow us to accept a federal grant.

- Having a foundation would enable individuals to make tax deductible donations to NSGC in the names of members.

An NSGC Foundation would help solve these issues and would allow us to increase the educational and research opportunities for the genetic counseling profession.

An NSGC Foundation would need a well defined mission, coordination between its activities and those of NSGC, a separate Board of Directors and a separate administration not affiliated with our current Executive Office. Although a significant amount of work would be required on the part of committed volunteers, the benefit would be the growth of our profession.

MAKING ROOM FOR BABY

In April, the Board of Directors voted to appoint an *ad hoc* committee to investigate the development of an NSGC Foundation. Strong fund raising, financial management, grantwriting and communication skills are needed to make this dream become a reality. ❖

E-mail/ FAX Poll

Is NSGC Ready to Create a Foundation? Are You Willing to Help?

Fax or EMail your thoughts, comments and opinions or offer your help to: Lisa Amacker North, Fax#: 704-355-8700; enorth@carolinas.org

LETTERS TO THE EDITOR

RESPONSE FROM "ONE VOICE; ONE MESSAGE" TEAM

TO THE EDITOR:

The GeneAMP Managed Care Team is writing in response to the Letter to the Editor printed in the last issue of *Perspectives* (20:1, p7) which raised two key issues regarding the managed care marketing message. The first relates to the format, the second to the process.

The member-driven GeneAMP marketing project, "One Message for Managed Care," was developed because we felt managed care organizations (MCOs) did not understand the role of genetic counseling and how it supports their objectives. To this end, the team felt strongly that one message which would grab MCOs' attention would be critical to our future marketing ventures.

Our goal was to define and articulate the aspects of who we are, what we do and why it matters to MCOs. *(See Perspectives, 19:4, p4.)* From literature reviews and by surveying directors of genetic counseling programs and primary care physicians, definitions and perceptions of genetic counseling were gleaned. We documented quality, cost and benefits.

We conducted a survey of genetic counselors working within MCOs and managed care case managers. Specifically, we asked which elements of genetic counseling were important to the respondents' organization. Psychosocial aspects of counseling all scored predominantly at the "not important" level. We acknowledged that although this element of the genetic counseling process is fundamental to what we provide to patients, its value is not recognized by MCOs. Thus, we felt we should not draw attention to this aspect of the genetic counseling process. Instead, the message was composed of words that have meaning to MCOs with the expectation that once in the door, the value of psychosocial counseling would be demonstrated.

The managed care medical directors interviewed felt the message reflected the "who we are, what we do and why it matters," themes we were trying to project.

We disagree with the authors who state we have omitted "counseling" from the message. We submit that the concept is sewn throughout the message. How can we educate families and facilitate decision making without calling upon the most basic counseling skills? We chose not to use the word in the message but it is the thread that ties it all together.

When we composed this message, we were clear that it would not satisfy all 1600 NSGC members. The final phase of our plan is to use this year to pilot the message further. If upon piloting we find that the message is not suitable for all audiences and/or does not readily identify our profession, the message may be revised.

The Board of Directors has recently approved a process that will require GeneAMP products to be reviewed and approved *(See sidebar, p. 9.)* The Managed Care team has voluntarily submitted the managed care marketing message for review.

Inherent in the promotion and expansion of our profession is an audience who will listen to what we have to say. With this, the dialogue begins. The managed care message was designed to be the first message; it was never intended to be the last. ❖

1997 Managed Care GeneAMP Team: Debra Lochner Doyle and Amy Cronister, Co-chairs, & Kristin Baker, Lisa Brown, Kelly Jackson, Sandra Marchese, Robin Schwartz and Janet Ulm

EVALUATION EXCERPTS

The following excerpts represent the GeneAMP Review Committee's appraisal of the Managed Care project, "One Voice, One Message."

The goals of the evaluation process are:

- to determine if the project met its stated objectives in a manner consistent with the NSGC vision and mission *and*
- to establish the parameters on how and when a product may be utilized.

The committee felt the project met its stated objectives and was consistent with NSGC's vision and mission.

The approval committee was very clear in its concern that the message be used *only for managed care organizations,* as stated in the original design. There was consensus that while the message may be appealing to medical providers, there is no data to suggest this message is appropriate for other medical audiences. Some reviewers expressed concern that the message left out the most vital aspect of our profession, counseling. Many believe this is what distinguishes our role from other [genetic] health care providers.

We encourage you to educate the membership further on this issue and to monitor the reaction and understanding of those groups to whom it will be presented. ❖

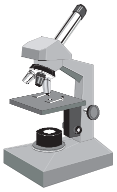
Maureen Smith, MS, President, on behalf of the GeneAMP Review Committee

RESEARCH NETWORK

The Mount Sinai Medical Center, in conjunction with the Metropolitan New York Registry, is seeking male and female volunteers for family studies of inherited and non-inherited factors associated with breast and ovarian cancer risk. The study includes free genetic counseling and testing for three common Ashkenazi mutations in BRCA1/2 genes. Participants are required to complete a series of questionnaires on lifestyle, medical and environmental factors.

Eligible candidates must be at least 25% Ashkenazi Jewish and have a family or personal history of breast and/or ovarian cancer. Both affected and unaffected individuals from qualifying families can receive genetic counseling and testing; testing is not required.

☛ Ruth Ann Denchy, MSW, ✆800-865-3803; ruth_denchy@smtplink.mssm.edu



A long term study at the National Cancer Institute has studied families with an inherited predisposition to develop kidney tumors. Studies of families with von Hippel-Lindau disease have identified the VHL gene responsible for this disorder. Recently, studies of families with two or more members with renal oncocytomas and a predisposition to develop papillary renal carcinomas [hereditary papillary renal carcinoma (HPRC)] have identified the MET proto-oncogene as being responsible for this disorder.

NCI is now interested in studying families with three or more members with renal tumors. Individuals with bilateral, multiple renal tumors without a family history of renal tumors are also of interest.

The evaluation includes a complete history and physical, an abdominal CAT scan and an ultrasound examination. Other clinical studies are tailored to the particular disorder being studied. Affected family members are tested for possible mutations in the VHL gene and the MET proto-oncogene.

☛ Berton Zbar, MD, National Cancer Institute, ✆301-846-1288; Fax: 301-846-6145; zbar@ncifcrf.gov. ❖

GENEAMP REVIEW PROCESS DEVELOPED

How are GeneAMP marketing products evaluated for use by members?
Since the marketing proposals and products are funded and produced by NSGC, the Board determined that formal accountability and ownership by NSGC was necessary.

What action was taken for appropriate review?
All GeneAMP products must be endorsed by NSGC *prior* to use. A GeneAMP Approval Committee was assigned responsibility for reviewing all marketing products to determine whether they met their original objectives in a manner consistent with NSGC's vision and mission. The Board also charged the committee with establishing parameters for how and when the products may be utilized.

Who serves on the GeneAMP Approval Committee?
Committee membership consists of the two GeneAMP co-chairs, the President-elect, President, Past President I, Past President II and the six standing committee chairs: Education, Finance, Genetic Services, Membership, Professional Issues and Social Issues. Any committee member who has participated in the development of a marketing product will be excused from the approval process for that product.

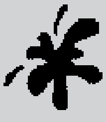
When does the Approval Committee process go into effect?
Immediately! In fact, several products are currently in the review process. Starting in 1999, GeneAMP proposals will be awarded from January 1 to November 30. This will allow the GeneAMP Approval Committee time to review the products in December, before the start of the next cycle, facilitating committee review on projects requesting an extension or further development. The exact approval process will be developed by the Approval Committee and will be included in the policies and procedures for all GeneAMP proposals.

What happens if the Approval Committee does not approve a product?
The Committee may suggest acceptable revisions, may withdraw funding or may specify limited use for the product. Unapproved products may not be distributed. ❖

— Ann Boldt, Past President I, and
Beth Balkite, MS & Ed Kloza, MS
GeneAMP Co-Chairs

IN ERROR

The contact number for linkage studies on Alzheimer and Parkinson diseases and age-related macular degeneration being conducted at Vanderbilt University listed in the last issue of *Perspectives* (V20:1) was incorrect.



☛ Amy E. Bazyk, MS ✆888-717-4319.

What's On the Web?

Shelly Cummings, MS

I am always looking for suggestions or recommendations on interesting websites. Please send them to me for publication in this column so we can all share your surfing experiences! Below are a few sites I found to be fascinating.

- The Mountain States Regional Genetic Services Network (MSRGSNet) contains valuable information, services and support for health care practitioners, patients, families and their caregivers who are confronted with a rare condition or a possible genetic diagnosis. This site focuses on services in Arizona, Colorado, Montana, New Mexico, Utah and Wyoming. http://www.ahsc.arizona.edu/msrgsn/msrgsnhp.htm
- The Magellan Internet Guide has a homepage that can serve as a tremendous resource on a number of levels: from basic facts about diseases to the latest research and support groups for various conditions. Examples of sites included: the Ataxia Telangiectasia Children's Project, Dystrophic Epidermolysis Bullosa Research Association, The Fragile X Listserv, Chromosome 18 Registry and Research Society and the Xeroderma Pigmentosa Society. This page should definitely be bookmarked! http://www.mckinley.com/magellan/Reviews/Health_and_Medicine/Diseases/Genetic_Disorders/index.magellan.html
- The National Organization for Albinism and Hypopigmentation (NOAH) is a nonprofit organization that offers information and support to people with albinism, their families and the professionals who work with them. http://www.albinism.org/aboutnoah.html
- University of Kansas Medical Center is a great resource if you need to contact a genetics professional society either by phone, mail, e-mail or by accessing their Internet site. http://www.kumc.edu/instruction/medicine/genetics/prof/soclist.html
- The Unknown and Rare Disorders Website is designed to bring together those "in the know" with those who are looking for answers. Case histories are listed where a diagnosis has not been made and the condition is considered unknown. If you have insight, information or suggestions regarding these disorders, contact the party involved or leave a message in the form provided with each case file. http://www.dubuque.net/~manemann/

Meeting Manager

July 9 - 11 • Delevan WI

"The Future is Ours," National Down Syndrome Society, for professionals and families. Kay Marshall, ☎212-460-9330x112

July 24 - 26 • Aspen CO

"Genetics & Ethics in the 21st Century," The Given Institute of University of Colorado, ☎800-882-9153 or 303-372-9050

August 9 - 14 • Atlanta GA

"Principles and Practice of Cancer Registration, Surveillance and Control," Metropolitan Atlanta Seer Registry in conjunction with the Rollins School of Public Health and Winship Cancer Center at Emory University. A five day training program in cancer registry methodology and utilization. Dr. John L. Young, Jr: ☎404-727-8487; Fax: 404-727-7261

August 17 - 19 • Atlanta GA

"Genetics in Population-based Cancer Research," 32nd International Association of Cancer Registries. A one-day optional course, "Genetics and Cancer Epidemiology Workshop," precedes the conference. Patti Long, ☎404-727-9271; Fax: 404-727-8737; iacr98@sph.emory.edu

August 22 • Costa Mesa CA

"Genetic Medicine: Into the 21st Century — A Public and Professional Dialogue," Pacific Northwest Regional Genetics Network. Pam Cohen, ☎510-540-2852; pam@psrgn.org

August 26 - 28 • San Antonio TX

"To Test or Not to Test, Issues in Genetic Screening," Texas Genetics Network. Judith Livingston, ☎512-458-7111x2129

September 11 - 13 • Arlington VA

"Forging Genetic Partnerships: Researchers, Policymakers and Consumers" Alliance of Genetic Support Groups. Mary Ann Wilson, ☎202-966-5557x206

DUTY TO WARN THIRD PARTIES: PRACTICAL CONSIDERATIONS

This article is the second in a three-part informational series about an emerging policy and legal issue that may affect clinical genetic counseling practice. The information included in this article and the previous article is intended to provide background information, not legal advice. The Social Issues committee sincerely thanks all those members who sent comments and supplemental information.

Chantelle Wolpert, MBA, PA-C

Since there are limited examples of applications of the duty to warn third parties, each case must be evaluated for applicability. In general, there are three elements that may help genetic counselors assess when a duty to warn third parties is necessary.

First, there is probably a duty to warn a third party if the genetic counselor has a *special relationship* with the patient and the risk to an identifiable third party is a direct result of this relationship.

A special relationship refers to the patient/genetic counselor relationship. When a genetic counselor works with a patient, the criterion of a special relationship will typically be met. Exceptions occur when a genetic counselor gives an informational talk to a group of patients or performs task-specific contract work like notifying other medical professionals of genetic testing results. In those situations, limited patient contact prevents the genetic counselor/patient relationship from being established. As a result, risks to third parties would not be disclosed.

Second, the third party who is at-risk must be *identifiable.* Medical information about biological family members is routinely supplied to genetic counselors. This information is critical for performing certain aspects of risk assessment and would enable one to identify at-risk family members easily.

Many genetic counseling situations may meet the first two elements. However, to meet the third element of duty to warn, the harm to the third party must be *foreseeable.* The crux will be: “What constitutes foreseeable harm?”

Some professionals may feel that there is a duty to warn if a family member is found through carrier screening to have a disease-causing gene. Other colleagues may decide that the duty to warn third parties applies to future offspring and, therefore, individuals at-risk for having a child with a severe disability or lethal disorder should be informed of their risk. Advances in medical genetics technology will undoubtedly alter views of foreseeable harm.

Medical genetics professionals also need to review their personal and ethical beliefs, professional guidelines and department or institution policies. In large medical organizations, there are a variety of other resources that genetic counselors can access for guidance, such as an ethics committee or medical legal staff. Finally, it is advisable to become familiar with state statutes or state court decisions that might alter or expand how the duty to warn may be applied.

Genetics health professionals need to decide if the concept of duty to warn third parties should be incorporated into genetic counseling practice. Discussing this issue with patients during the informed consent process could potentially protect other family members from harm. ❖

A GENETIC COUNSELOR ATTORNEY’S RESPONSE TO PART I

Tracy Field, MS, JD

After reading your column in *Perspectives* (20:1) I feel compelled to advise you regarding cases which you should review before concluding that the courts have not addressed issues directly relevant to genetic counseling.

In *Pate v. Threlkel,* (661 So. 2d 278 Fla, 1995), the child of a patient brought a medical malpractice action against a physician who failed to warn the patient that her child might have inherited a genetically transferrable disease. The Florida Supreme Court held that the physician owed a duty to warn the patient of the hereditary nature of the disease.

The plaintiff alleged that the physician who performed surgery for medullary thyroid carcinoma (MTC) on the plaintiff’s mother knew or should have known the likelihood that the plaintiff could have inherited this condition from her mother. The plaintiff asserted that the physician had a duty to warn her mother about the importance of testing her children for MTC and that if he had, her children would have been tested immediately. The plaintiff then would have been able to take preventative action and, more likely than not, her condition would have been curable. The plaintiff argued that as a direct result of the physician’s failure to warn her mother, the patient sustained advanced MTC with resulting pain and suffering, the shortening of her life expectancy, loss of enjoyment of life and other damages. ❖

CORD BLOOD BANKING AS ENHANCEMENT FOR BMT

by R. Nathan Slotnick, MD, PhD,
Director, Reproductive Genetics,
Eastern Virginia Medical School,
Norfolk VA

The therapeutic value of stem cells has long been realized via their use in bone marrow transplantation (BMT). BMT has proved helpful to treat pediatric marrow malignancies, such as leukemia and aplastic anemia, when unresponsive to chemotherapy or radiation. In genetics, BMT is used in the treatment of erythrocyte disorders (hemoglobinopathies), lymphocyte disorders (Severe Combined Immune Deficiency syndrome), granulocyte disorders (chronic granulomatous disease and Chediak-Higashi syndrome) and pure metabolic disorders (mucopolysaccharidoses, osteoclast disorders and mucolipidoses).

BMT is also applied to adult oncology and hematology, particularly in treatment of metastatic breast and ovarian cancers.

The National Marrow Donor Program is limited in its ability to provide appropriately matched bone marrow donors to recipients because of:

- The high cost of haplotyping potential marrow donors
- The dramatic underrepresentation of certain ethnic groups
- The significant time delay in identifying, typing and harvesting donors
- The high rate of attrition — roughly 25-30% per year.

Due to these obstacles, an estimated half of the patients seeking a donor match die waiting.

From the roughly 3,800,000 deliveries in the United States this year, obstetricians will discard placenta and cord blood as they have always done. Within this discarded blood are millions of pluripotent hematopoietic stem cells, the progenitor cells of the blood system. International clinical research shows that these cells can potentially revolutionize pediatric care, oncology and genetic medicine. The business of harvesting, isolating and storing these cells, however, is fraught with complicated legal and ethical issues.

> ***'International clinical research shows that these [cord blood] cells can potentially revolutionize pediatric care, oncology and genetic medicine.'***

The power of hematopoietic stem cells lies in their ability to regenerate and differentiate into the range of human blood cells. These cells arise in the fetal yolk sac 3-4 weeks after conception, migrate to the fetal spleen and liver and then at 12-14 weeks begin to move to the bone marrow spaces where they reside.

The first clinical trials employing cord blood as a source of transplantable stem cells began in Europe 10 years ago. Since then, over 500 cord blood transplants have been performed, with impressive long term, disease-free survival. A large scale collection of cord blood from U.S. births could greatly enhance ethnic representation in the national donor program.

With 1:185-200 pregnancies in the U.S. at risk for marrow immunodeficiency or metabolic disorders, cord blood harvesting and processing may offer a route to early treatment and disease amelioration. Equally exciting are efforts examining cord blood stem cells as vectors for gene therapy.

Surrounding this promise though, is the growing "business" of cord blood collection. While the harvesting and storage of cord blood has grown at academic centers, regional American Red Cross blood banks and other not-for-profit organizations, a small number of private cord blood banks comprise the primary repositories. These can be expensive and difficult for physicians to deal with. Patient access is also limited. Most patients learn of cord blood banking through the lay press, since caregiver knowledge is frequently limited.

Often, cord blood collection services are presented as an "insurance policy" for unborn children, possibly coercing susceptible parents to "do the best thing for the baby" when in fact the child has only a small likelihood of requiring a BMT. Patients looking to store cord blood from their pregnancies may have unequal access to these services due to laboratories' high prices. These issues merely skim the surface of further ethical and legal considerations, such as:

- Is there conflict of interest if an obstetrician charges for cord blood collection?
- Is there potential for discrimination and misuse of genetic information?
- How should access to cord blood be regulated after divorce?
- How can we regulate informed consent for cord blood donation?

While recommendations from ACMG and ACOG remain unclear, the future of cord blood transplantation seems bright. ❖

NEW MEMBER BENEFIT

NSGC FORMS NEW LIABILITY INSURANCE LIAISON WITH ACAIT

Debra Lochner Doyle, MS, Janice Berliner, MS, Kathy Valverde, MS & Bea Leopold, MA

At the conclusion of the April Board of Directors meeting, we met with Paul Nelson, Executive Director, American Counseling Association Insurance Trust (ACAIT). Paul had requested time to meet with us to propose a new mechanism for offering genetic counselors malpractice insurance.

UNDERSTANDING THE FINER POINTS OF INSURANCE

Some interesting points arose as we discussed our own awareness of our coverage. Can you answer these questions?

- Are you currently covered by your employer? If so, is it occurrence based or claims made? What is your coverage?
- Would you be covered if you left your current position and a suit was filed after your departure? Could you purchase a rider to extend your current plan?
- What if you agree to fill in for a colleague on maternity leave at a separate institution? Will your current coverage apply should a suit occur?
- If the hospital provides insurance and both you and the physician(s) are named in a lawsuit, must you accept whomever the hospital selects to represent you?

CURRENT SYSTEM OF COVERAGE

Currently, any NSGC member who has graduated from a genetic counseling training program *or* is Board certified may apply for insurance coverage through ACAIT for about $416/year for $1-$3 million worth of coverage (i.e., $1 million per occurrence, $3 million aggregate). Currently, it appears that only 30 genetic counselors have applied for coverage.

NEW PROCEDURE PROPOSED

ACAIT proposed that NSGC purchase a Master Policy. Members could apply for coverage under the Master Policy at the same rate schedule. Some benefits:

- All members would be eligible; ACA membership not required
- Students could receive coverage for approximately $30/year during rotations
- Members are invited to recommend their own counsel and may choose an attorney in the event of a licensing board complaint
- Board certified members would receive a 5% discount. Further discounts would be offered should more than 20% of the membership receive coverage
- ACAIT could provide us with educational materials or a one day workshop covering the legal aspects of counseling

A Master Policy would be responsive to potential needs of the membership for relatively little cost to NSGC — a great new benefit for our members. ❖

PRIMER ON LIABILITY INSURANCE

Why do I need professional liability insurance?

In practice, fewer than 1:100 genetic counselors will ever be sued. However, costs associated with a lawsuit could easily ruin your professional and personal life. The cost of legal defense alone in medical cases often exceeds $100,000.

Does my genetics department professional insurance cover me, in the event of a liability suit?

Check to determine precisely what your institution covers. The fact that your department holds insurance does not necessarily indicate that you are fully covered.

How much insurance is recommended?

Usually, a policy with limits of $1 million per occurrence and $3million aggregate is needed to be acceptable for hospital accreditation. This amount is recommended for all professionals in medical settings.

How long does it take to be covered?

Because of the liaison between NSGC and the ACA Insurance Trust (ACAIT), proof of insurance can be obtained within 7 - 10 days from the time ACAIT receives the application and payment.

What is the cost for $1m/$3m coverage?

This will vary, depending on the number of hours worked, whether you are institution-based or self-employed and the limit chosen. The price can range from $68 to $489 annually. Also, there is a 5% discount for genetic counselors who are Board certified.

What if I'm threatened with a potential lawsuit? Where can I turn?

The NSGC insurance program will be coordinated through the ACA Insurance Trust. Their risk management attorney will speak to you confidentially and free of charge. Even if you are not currently insured, the staff at ACAIT is available to speak with you.

Simply call: ✆800-347-6647x284. ❖

BULLETIN BOARD

WORKSHOPS SOLICITED FOR '99

Submissions for workshops for our 18th Annual Education Conference in Oakland CA, October 1999, "Life Cycle Genetics — From Preconception to Adulthood," are being accepted through August 15. Ideally, workshops will support the conference theme.

We also invite members to serve on our committee — a great way to become involved!

Lyn Hammond, MS
✆843-792-7541; hammondl@musc.edu
Kelly E. Ormond, MS
✆312-926-6478; kormond@nmh.org

BETH FINE

1956 - 1998

It is with profound sadness that we mourn the loss of Beth Fine, who died on May 12 of breast cancer. Her contributions to NSGC, to the genetic counseling profession and to the many lives she touched so deeply will be everlasting.

A special memorial service at the Annual Education Conference in Denver is being coordinated by Bonnie LeRoy. Karen Greendale is creating a scrapbook of members' personal experiences with Beth to give to her sons at the service. Please send your special memories to Karen c/o NYSDOH, Wadsworth Center, Empire State Plaza, Rm E-299A, Box 509, Albany NY 12201-0509.

To honor Beth's life, NSGC will establish a memorial in her name. Make checks payable to: NSGC c/o the Executive Office. Announcement of the fund dedicated to Beth's memory will be made in Denver. All contributions will be acknowledged to the donor and to Beth's husband and sons. Members wishing to write condolence notes to her family may write to: Dan, Josh and Aaron Kaplan, 2441 Oak, Northbrook IL 60062. ❖

NSGC TO CELEBRATE 20th YEAR

Our 20th anniversary celebration will be held at our 18th Annual Education Conference in Oakland California, October 1999. If you are interested in serving on this exciting anniversary committee, contact either Luba Djurdjinovic ✆607-724-4308 or Ann Boldt ✆317-338-6725 *by July 15.*

NEW CONNECTING LINKS

A new Connecting Links category has been added to our roster. Members with expressed interest and/or expertise in "Assisted Reproductive Technologies/ Preimplantation Genetic Diagnosis" may be listed. To be listed, you are *not* required to belong to the ART SIG. However, every member of that SIG will be automatically listed. Simply contact the Executive Office by fax, e-mail or voice mailbox #3.

WANTED: OPINIONS AND MENTOR PARTICIPATION

WOULD YOU PAY MORE FOR ENHANCED, HANDS-ON EDUCATION?

- Three optional "hands-on" wet-labs, to run simultaneously during an "on your own" afternoon, have been proposed for our 1999 Annual Education Conference. A charge beyond the conference registration fee would be assessed. Help us plan by completing and returning the enclosed poll indicating your interest in this concept. Look for the **YELLOW CARD** inserted in this issue.

MENTOR SIGN-UP

- It's that time again! We are again matching students and new grads with veteran counselors in our successful Mentor Program. Look for the **BLUE CARD** inserted in this issue.

STATUS QUO OR CHANGE: TAKE YOUR (CONFERENCE) PULSE!

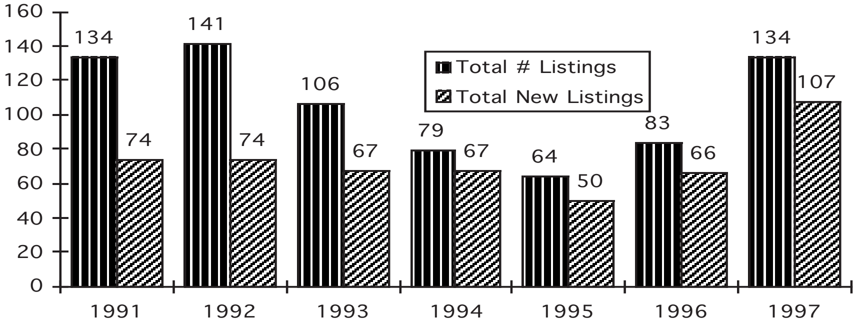
- Don't miss this opportunity to voice your opinion about the sites of future Annual Education Conferences. Look for the **LILAC CARD** inserted in this issue.

We rely on your opinions to make NSGC work for you! ❖

FAST FACTS

TOTAL JOBS LISTED COMPARED WITH NEW JOBS LISTED

Have you noticed the increase in job listings lately? We have! To prove that more jobs are available, we conducted a retrospective analysis based on information the Executive Office has compiled since 1991. As of June 1, 52 new jobs have been listed in 1998.



EMPLOYMENT OPPORTUNITIES

■ **Little Rock AR:** Immediate opening for BC/BE Genetic Counselor. Org & partic in wkly ped adult & satellite genetic clinics.
Contact: Susan Hassed, MS, UAMS-Arkansas Children's Hospital, 800 Marshall St, Little Rock AR 72202; ✆501-320-2966; Fax#: 501-320-1564; sjhassed@exchange.uams.edu. EOE/AA

■ **Little Rock AR:** Immediate opening for BC/BE Genetic Counselor. Join statewide PN genetics svc. GC for wide variety of indications; case mgmt & follow-up; involv w/ Teratogen Information Svc, MSAFP/Double scrng prog, med student educ, Fetal Boards conf & rsrch.
Contact: Barbara Karczeski, MS, University Arkansas for Medical Sciences, Arkansas Genetics Program, Dept OB/GYN, 4301 W. Markham, Slot 506, Little Rock AR 72205; ✆501-296-1700 or ✆800-358-7229. EOE/AA

■ **Berkeley CA:** Civil Svc Exam: Aug/Sept '98. 2 Genetic Disease Program Specialists (GDPS IV & GDPS III) *GDPS IV:* [$4139-4994/mo] 4 yrs admin in PH genetic prog w/ rsrch, couns or tchg in genetics, genetic disease or closely related field; *GDPS III:* [$3770-4547/mo] 3 yrs exp in same. IV: Section Chief of major prog: s'vise staff, plan, implement genetic disease control prog of 1 major or lower incident level disease groups; plan, org, direct & coord activ of prevent & control prog; assist GDB Chief to develop, implement & eval prog & policies. III: consult & devel hereditary & congenital disease preven prog; devel prog objectives/stds, eval proj effectiveness; liaison & coord lab svcs.
Contact: Maxie Spears, Genetic Disease Branch, Berkeley CA 94704; ✆510-540-2613; (TDD 916-657-3042). Apps postmarked by 7/17. EOE/AA

■ **Los Angeles CA:** Immediate opening for Genetic Counselor. Nursing; public health background considered. Conduct case follow up for abnorm preg or live births. I'view male applicants for anonymous semen donor prog: obtain detailed info re medical & fam hx.
Contact: Marilyn Ray, MPH, California Cryobank, Inc, 1019 Gayley Ave, Los Angeles CA 90024-3425; ✆800-231-3373x21; Fax#: 310-443-5258; mara@cryobank.com. EOE/AA

■ **Pasadena CA:** Immediate opening for motivated, BC/BE Genetic Counselor. Spanish a plus. Some local travel. Join busy PN team w/ oppty for some cancer GC. Diverse prof growth.
Contact: Melissa K. Crane, MS, Alfigen, 11 W Del Mar Blvd, Pasadena CA 91105; ✆626-356-3432 x4118. EOE/AA

■ **Sacramento CA:** Temp full time BC/BE Genetic Counselor for maternity leave coverage 8/1-10/31/98 in busy, diverse genetics dept. Join 9 GCs & 2 MD geneticists: PN, Expanded AFP, Peds, Adult & Cancer couns in HMO setting.
Contact: Bonnie Leonard, MS, Kaiser Permanente, Genetics, 1650 Response Rd, Sacramento CA 95815 ; ✆916-614-4781; Fax# 916-614-4768; Bonnie.Leonard@ncal.kaiperm.org. EOE/AA

■ **San Fernando Valley CA:** Immediate opening for BC/BE Genetic Counselor. Fluency in Spanish. Prog encompasses med genetics & all aspects of PNDx: amnio, CVS, newborn hemoglobinopathy scrng, terat couns, expanded AFP screening, DNA dx & cancer couns. Work closely w/ BC med geneticist & other GCs.
Contact: Christine Ruyfrok, RN, Kaiser Permanente Medical Center, OB/GYN Dept, 13652 Cantara St, Panorama City CA 91402-5497; ✆818-375-4320. EOE/AA

■ **San Francisco CA**: Immediate opening for BC/BE Genetics Studies/Clinical Coordinator. Rsrch exp pref. New Human Genetics facility in the Genrl Clin Rsrch Ctr at UCSF. Coord clin aspects of genetic rsrch studies (recruit families, maintain compliance w/ IRB stds, etc) for wide range of diseases in rapidly developing prog. Interact w/ faculty scientists, families & staff.
Contact: Nelson Freimer, MD [postal]: UCSF Box F-0984, [courier]: Neurogenetics Lab, Rm 68, 401 Parnassus], San Francisco CA 94143; ✆415-476-7864; Fax#: 415-476-7389; nelson@ngl.ucsf.edu. EOE/AA.

■ **Southern CA:** Immediate opening for part time, per diem BC/BE Genetic Counselor. Poss future expansion. MS from ABGC-approved prog; exp pref; will consider new grads. Bilingual Eng/Span & computer exp pref. Motivated, work well w/ multidisc team, excellent commun skills; limited travel. Join active multidisc team: all aspects of PN GC: XAFP scrng, AMA, fam & preg hx, terat, multiple SAB, newborn scrng, preconceptual & cancer couns. Some med providers; student educ.
Contact: Wendy Sutherland, ✆714-279-6066 Ref: Position #OC98150. Send CV & 3 written ref to: Joan Wetzel, MS, Kaiser Permanente, 1188 N Euclid, Rm 220, Anaheim CA 92801; ✆714-254-2703; Fax#: 714-254-2953; Joan.M.Wetzel@kp.org. EOE/AA

■ **San Jose CA:** Immediate opening for BC/BE Genetic Counselor. Exp pref. Join active team in estab, comprehensive genetics prog in lrg HMO. Broad range of svcs: PN, peds, adult, cancer. Partic in spec clins.
Contact: Cindy Soliday, MS, Genetics, Kaiser Permanente, 5755 Cottle Rd, San Jose CA 95123; ✆408-972-3332; Fax#: 408-972-3298. EOE/AA

■ **Southern CA:** Immediate opening for BC Genetic Counselor. Possible sites: Orange Co & Bakersfield (Kern Co). Exp & computer skills pref. Join comprehensive PNDx ctr; amnio, CVS, AFP & terat couns + wide variety of subspecialty clins & molecular genetics.
Contact: Khalil N. Zadeh, PhD, Administrator, Genetics Center, 1000 W La Veta Ave, Ste 9, Orange CA 92868; ✆714-667-1965 or 888-4-GENETIC; Fax#: 714-667-1106; nzadeh@aol.com. Website: www.geneticscenter.com. EOE/AA

■ **Southern CA:** See Salt Lake City UT

■ **Atlanta GA:** See Salt Lake City UT

■ **Savannah GA:** Immediate opening for BC/BE Genetic Counselor. Exp, i'pendent, self starter, signif respon & autonomy pref. Join busy reg'l PN tstg & high risk OB ctr w/ diverse pt population: all areas of PN; limited peds, tchg, cancer & outrch. Salary Range: $33-45K/yr.
Contact: Andy Faucett, MS, Savannah Perinatology at Memorial Medical Center, 4750 Waters Ave, Ste 202, Savannah GA 31404; ✆912-350-5970; Fax#: 912-350-5976. EOE/AA

■ **Chicago IL:** Immediate opening for BC Genetic Counselor for Director, Graduate Program in Genetic Counseling, Northwestern University. Min 5 yrs exp in clin GC & 2 yrs exp tchg in GC grad prog. Admin & s'visory exp in GC pref. Assume respon for continued devel of prog which focuses on curriculum in genetics, GC & psychosocial development; clin exp (rotations) in variety of acad & hosp settings; orig rsrch proj in GC.
Contact: Eugene Pergament, MD, PhD, Prentice Women's Hospital, 333 E. Superior St, Chicago IL 60611; ✆312-908-4280; Fax# 312-908-0806; epergame@nmh.org. EOE/AA

■ **Indianapolis IN:** Immediate opening for BC/BE Genetic Counselor w/ Masters in GC, human genetics or equiv. Work closely w/ Perinatologists and growing team offering full svc PN svcs: PNDx, GC, U/S & hi-risk preg mngmt. GC to families re: genetic risk, dx, prognosis, diag tstg & options; partic in studies & rsrch proj, conduct educ progs, serve as resource for professionals and commun.
Contact: Ellie Smith, St Vincent Hospital and Health System, Human Resources Dept, 2001 W 86th St, PO Box 40970, Indianapolis IN 46240; ✆317-338-2722; TDD: 317-338-8450; JobLine: ✆317-338-5627; EOE/AA

■ **Louisville KY:** Immediate opening for BC/BE Genetic Counselor. Exp pref, not req. Join 2 geneticists & 1 GC in univ-based clin genetics prog. Provide all aspects of PN, peds & adult genetics. Onsite subspec & outrch clins. Prof & commun educ.
Contact: Send CV & 3 ltrs rec: Katherine M. Christensen, MS, Child Evaluation Center, University of Louisville, 571 S. Floyd St, Ste 100, Louisville KY 40202-3828; ✆502-852-5681; Fax#: 502-852-7886. EOE/AA

■ **New Orleans LA:** Immediate opening for BC/BE Genetic Counselor. Self-starter, ideally w/ 2+ yrs exp & interest in cancer genetics. Faculty position w/ clin & tchg duties; oppty for clin rsrch incl wide range of peds pts; coord several multi-specialty clins.
Contact: Yves Lacassie, MD or Leslie Colvin, MS, Children's Hospital, 200 Henry Clay Ave, New Orleans LA 70118; ✆504-896-9254 Fax#: 504-896-9222; ylacassie@mail.peds.lsumc.edu (YL) or Elaysee@aol.com (LC). EOE/AA

■ **Baltimore MD**: Immediate opening for BC, MS level Genetic Counselor from ABGC-approved prog. Join busy PNDx ctr & Marfan syndrome clin rsrch proj. Tchg & rsrch oppty.
Contact: Send CV & 3 ltrs of rec to: Kristyne Stone, MS, Johns Hopkins Hospital, 600 N. Wolfe St, Blalock 1008, Baltimore MD 21287; ✆410-955-3091; Fax#: 410-955-0484, kmstone@welchlink.welch.jhu.edu. EOE/AA

■ **Bethesda MD:** Immediate opening for BC/BE Genetic Counselor in Ophthalmic Genetics Section of the Ophthalmic Genetics Intramural Rsrch Prog, Natl Eye Inst. Self motivated graduates w/ strong i'personal skills req. Interact w/ clin & lab rsrch re: molec & gene expression of ophthalmic genetic diseases.
Contact: Muriel I. Kaiser, MD, Ophthalmic Genetics & Clinical Svcs Branch, 10 Center Dr, MSC 1860, Bldg 10, Rm 10N226, Bethesda MD 20892-1860; ✆301-496-3577; Fax#: 301-402-1214. EOE/AA

■ **Grand Rapids MI:** Immediate opening for BC/BE Genetic Counselor w/ ability to work i'pendently. Join 3 FT & 1 PT GC & PhD geneticist in growing office: PN, peds, adult, cancer & spec clin couns. 3 days PN GC in new outrch perinatal office ~1 hr from Grand Rapids; 2 days in GR. Oppty for tchg & pub.
Contact: Send ltr, CV & ref: Helga Toriello, PhD, Butterworth Hospital, 21 Michigan St NE, Ste 465-Genetic Svcs, Grand Rapids MI 49506; ✆616-391-2700; Fax#: 616-391-3114; htoriello@bw.brhn.org. EOE/AA

See next page

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nsgc

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EMPLOYMENT OPPORTUNITIES

… from previous page

■ **ST. PAUL MN:** Immediate opening for 2 BC/BE Genetic Counselors (Full & Part Time). MS from ABGC-approved prog, min 2 yrs perinatal exp & high motivation strongly pref. Willingness to assume add'l respon w/ other disciplines. All areas of PN GC.
CONTACT: Send CV & ltr of interest: Kristin Lundberg, Human Resources Dept, Allina Health System, 333 North Smith Ave, St. Paul MN 55102; ☎612-220-5627. EOE/AA

■ **ST. LOUIS MO:** Summer opening for BC/BE Genetic Counselor. Broad range of peds & adult GC in hi volume, multidisc ctr. Involv in cancer genetics prog; partic in professional educ.
CONTACT: Mike S. Watson, PhD or Jennifer Ivanovich, MS, Washington University School of Medicine, Div Medical Genetics, One Children's Place, St. Louis MO 63110; ☎314-454-6093. EOE/AA

■ **LEBANON NH:** Immediate opening for BC/BE Genetic Counselor w/ Masters in med genetics or related field w/ equiv exp. Provide PN & preconceptual evals & GC; coord scrng & dx tstg, follow up couns & svcs; partic on MFM team to couns pts w/ MFM physician or med geneticist incl difficult scrng issues & dx of fetal abnorm; act as lisison w/ other subspec & ref clinicians; partic in tchg med students & residents.
CONTACT: Suzy Blish, Human Resources, The Hitchcock Clinic, 1 Medical Center Dr, Lebanon NH 03756; ☎603-650-8926; Fax# 603-650-8919. EOE/AA

■ **NEWARK NJ:** Immediate opening for BC/BE Cancer Risk Genetic Counselor. Strong writing & verbal skills; rsrch interest essential. Join genrl clin genetics team: clin cancer risk GC svcs, partic in ongoing clin/psychosocial rsrch, play active role in prof & community educ. Some PN & genrl peds GC.
CONTACT: Lorraine Suslak, MS Univ of Med & Denistry-NJ Med School, 90 Bergen St, Ste 5400, Newark NJ 07103; ☎973-972-3311; Fax#: 973-972-3310; Suslaklo@umdnj.edu. EOE/AA

■ **NEWARK NJ:** Immediate opening for BC/BE Genetic Counselor. Partic in building ped genetics prog for hosp affiliates of St Barnabas Health Care System throughout NJ. Some travel.
CONTACT: Shari Fallet, DC, Children's Hospital of New Jersey at Newark Beth Israel Med Ctr, 201 Lyons Ave, Newark NJ 07112; ☎973-926-4021; Fax#: 973-923-0639; SFallet@bethi.com. EOE/AA

■ **ALBANY NY:** Immediate opening for part time BC/BE Genetic Counselor w/ poss exp to full time. Join group of 3 perinatologists: amnio, serum screens, abnorm U/S, preconceptual risk.
CONTACT: Human Resources Dept, St Peters Hospital, 315 S Manning Blv d, Albany NY 12208. EOE/AA

■ **NEW YORK NY:** Immediate opening for part time (12 hrs/wk) BC/BE PN Genetic Counselor. Exp pref; abil to work independently req. Grant funded through Dec '00, renewable.
CONTACT: Elinor Langfelder, MS, St. Vincent's Hospital, Antepartum Testing Unit, New York NY 10011; Fax CV to: 212-604-3899; Info: ☎212-604-8896; ElinorLang@aol.com. EOE/AA

■ **CINCINNATI OH:** Immediate opening for BC/BE Genetic Counselor w/ MS from ABGC-approved prog. Excellent commun, org & follow through skills req. All aspects of M/F dx pre-conceptual couns, serve as resource & educator for pts & staff.
CONTACT: Jenifer Findlow, Good Samaritan Hospital, Human Resources, 375 Dixmyth Ave, Cincinnati OH 45220; Fax#: 513-872-3672. EOE/AA

■ **CLEVELAND OH:** Immediate opening for BC/BE Laboratory Liaison Counselor. I'face between lab, physicians & GCs, both w/in our system & in commun; couns & prov results to pts. Involv in clin lab rsrch progs; train GCs, clin lab fellows, genetics & path resident.
CONTACT: Ltr of interest, CV & 3 ltrs ref to: Stuart Schwartz, PhD, Center for Human Genetics Laboratory, Case Western Reserve Univ School of Medicine, 10524 Euclid Ave, 6th Fl, Cleveland OH 44106-2205; ☎216-983-1134; Fax#: 216-983-1144. EOE/AA

■ **PHILADELPHIA PA:** Immediate opening for BC/BE Pediatric Genetic Counselors. (1) Research & (1) Clinical. Exp pref, not req, exceptional org skills & abil to work w/ team essential, computer exp desired. Provide inpt & outpt peds svcs, partic in all aspects of clin rsrch: recruit, obtain hx, informed consent, handle specimens, commun results, coord follow-up, some data analysis. Oppty in spec clins & tchg.
CONTACT: Send CV & 3 ltrs of rec to: Dian Taylor-Pringle, Children's Hospital of Philadelphia, 34th & Civic Center Blvd, Philadelphia PA 19104- 4399; ☎215-590-4360; Fax#: 215-590-3184. EOE/M/F/D/V

■ **PITTSBURGH PA:** Immediate opening for Genetics Clinical Research Coordinator. Req MS in GC or relevant exp & educ; good commun, tchg & s'visory skills; knowledge of computer db; accurate financial record keeping; rsrch interests. Join human disease gene discovry proj, Div Gastroenterology & Hepatology & Ctr for Genomic Science: identify & recruit families & individuals, coord blood /buccal scraping samples, complete & analyze pedigrees, collect demographics for database; explain results to subjects; summarize data for presentation to Principal Investigators, implement protocols w/ little s'vision. S'vise grad student rsrchrs, process clin fees & procure supplies.
CONTACT: Send ltr of int & CV to: M J Kubiak, c/o Job #D-17863, University of Pittsburgh, 100 Craig Hall, Pittsburgh PA 15260; ☎412-624-8044. EOE/AA

■ **DALLAS TX:** Immediate opening for BC/BE Pediatric Genetic Counselor. Min 1 yr exp pref; Spanish helpful. Motivated, enthus personality pref. Join team at peds tchg hospital: outpt genrl genetics & metabolic clin; DS clin, inpt consults; oppty to partic in support group facil, tchg & public educ.
CONTACT: Gail Brookshire, Children's Medical Center of Dallas, Genetics & Metabolism, 1935 Motor St, Dallas TX 75235; Fax#: 214-640-2567; GBROOK@childmed.dallas.tx.us. EOE/AA

■ **TEMPLE TX:** Immediate opening for BC/BE Genetic Counselor w/ MS in human genetics or equiv. Assist PhD med geneticist w/ genetic evals in peds clin; GC in genrl genetics; cancer couns & spec clins; coord & partic in multidisc DS & NF clins.
CONTACT: Pat Balz, Human Resources Dept, Scott & White Memorial Hospital & Clinic, 2401 S. 31st St, Temple TX 76508; ☎254-724-1632. Fax#: 254-724-1631. EOE/AA

■ **SALT LAKE CITY UT:** Immediate opening for (2) BC/BE GCs (1) in Atlanta GA & (1) in Southern CA. Public speaking & writing skills essential. Abil to work i'pendently; travel req. Provide educ & consult for cancer genetic susceptibility tstg for professionals; help estab new reg'l cancer risk assessment progs.
CONTACT: Susan Manley, MS, Myriad Genetic Laboratories, 320 Wakara Way, Salt Lake City UT 84108; ☎801-584-3505; Fax#: 801-584-3515. EOE/AA.

■ **MILWAUKEE WI:** Immediate opening for BC/BE Genetic Counselor w/ Masters from accredited GC prog & 1-2 yrs exp. Primarily peds: inpt, genrl genetics & new prog dev w/ potential for expansion to PN.
CONTACT: Myra Maltar, Human Resources Dept, Children's Health System, Children's Office Bldg, 9000 W Wisconsin Ave, PO Box 1997 - MS 951, Milwaukee WI 53201. AA/EOE

IN CANADA

■ **TORONTO, ON:** Immediate opening for BC/BE Genetic Counselor. 2 yrs exp highly desirable; 1 yr renewable contract. Pref given to Canadian citizens. Join active Univ Hosp Clin Rsrch Prog in Cancer Genetics; primarily peds; involv w/ coun, rsrch & tchg.
CONTACT: Cheryl Shuman, MS, The Hospital for Sick Children, Dept Genetics, 555 University Ave, Toronto, ON M5G 1X8; ☎416-813-6386.