PERSPECTIVES in genetic counseling

Volume 16:2 Summer 1994

Innovations in Genetic Education

Teaching about Ethical, Legal and Social Issues through Live, Interactive Television

Robin J. R. Blatt, RN, MPH, Boston MA

The revolution taking place in genetics today will have its greatest impact on society during the next decade and next century. Today's high school students will be making decisions that will dictate social action and govern legal rights concerning the ethical, legal and social implications of genetic research and testing. By enhancing genetic literacy and sensitizing students to these issues, they will be better prepared to help usher in this new era of genetics in a responsible way.

With the advent of interactive telecommunications, a national learning environment could be created whereby the latest scientific information and social controversies in genetics could be brought to numerous individuals at once and where members of society could share a diversity of thoughts and opinions. In 1990, I met with administrators at the Massachusetts Corporation for Educational Telecommunications (MCET) to discuss the concept of bringing

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Board Actions Enhance Society Activities

Nancy Callanan, MS, NSGC Secretary,
University of North Carolina, Chapel Hill

Several issues of emerging importance to NSGC were discussed at the Interim Board of Directors meeting in Chicago in April.

Andy Faucett (Treasurer) and Linda Lustig (Finance Committee) educated the Board about the need for financial planning, setting financial goals and considering investment options. Along with the Finance Committee, they will be considering options and will make further recommendations to the Board at their next meeting.

Bea Leopold (Executive Director) reported on the potential impact of a new law (PL#103-66) that imposes a tax on non-profit organizations for lobbying expenses. While monitoring legislation is not considered lobbying, any call to action is and would result in a tax on all expenses related to lobbying. Vivian Weinblatt (Social Issues) and the Committee will work with Leopold to develop a plan for tracking expenses related to monitoring legislation and will keep the membership informed about this issue.

Karen Greendale (President) reported that NSGC was invited to exhibit at the Latin American Society of Genetics. The Board discussed this and other opportunities to promote the profession of genetic counseling and NSGC. Greendale and the Executive

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national society
of genetic
counselors, inc.

nsgc

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

ON THE INSIDE

NSGC acknowledges our following corporate friend for a grant to support this newsletter.

Women's Health Care Services, Wichita KS, providers of late abortion care for fetal anomalies. George R. Tiller, MD, Medical Director

Interim Board Meeting Focuses on Business, from p. 1

Committee will develop a plan to increase international awareness of NSGC. The Board approved a statement regarding NSGC liaisons with other professional organizations:

> "The NSGC Board of Directors will communicate to members of the Council of Medical Genetics Organizations (COMGO) that NSGC encourages its own members to be active on committees of other genetic organizations to which they belong. However, NSGC disclaims formal representation on a board or any committee of any other organization unless so stipulated by the NSGC president."

Bonnie LeRoy (President Elect) has been working closely with the Education Committee to develop a proposal for continuing education units. In preparation for her tenure as President, she will visit the Executive Office in July.

Betsy Gettig (Past President I) continues to monitor our strategic plan. The Nominating Committee, chaired by Gettig, has added leadership development to their responsibilities. Ed Kloza (Past President II) is our liaison to COMGO and reported that they now have approved Operational Guidelines.

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

Publication Date, Next Issue: September 15
Deadline for Submissions: August 10

GUEST FROM ABGC

Beth Fine, representing the American Board of Genetic Counseling (ABGC), was invited for part of the meeting. Fine reported that ABGC's current focus is to develop certification eligibility and application procedures as well as guidelines for accreditation of Graduate Training Programs. Certification applications will be available in June. The ABGC membership meeting will take place in October in Montreal in conjunction with the NSGC Annual Education Conference.

COMMITTEE ACTIVITIES

- EDUCATION (MAUREEN SMITH)

The Cancer Genetics Short Course received favorable evaluations, and another is planned. The committee is developing a proposal regarding continuing education units and plans to survey the membership regarding their educational needs.

- PROFESSIONAL ISSUES (ANN BOLDT):

The 1994 Professional Status Survey will be sent to Full members this Spring. The committee has selected variables to be monitored over time.

The committee received a good response to the call for nominations for the Natalie Weissberger Paul Outstanding National Achievement Award and Regional Leadership Achievement Awards.

Robin Bennett reported that the Pedigree Standardization Project is nearing completion.

- SOCIAL ISSUES COMMITTEE (VIVIAN WEINBLATT)

The Board is in final stages of approving a position statement and, subject to membership vote, a resolution. (See p. 8.) Weinblatt presented a proposal to streamline the review process for position statements and resolutions. Two subcommittees, Legislative and Genetic Research Issues, have been formed.

This committee will work with Leopold to establish a Legislative Hotline.

- MEMBERSHIP (KAREN COPELAND)

The Board approved funding for a college-level career recruitment poster. The Committee is exploring the creation of NSGC rolodex cards.

- GENETIC SERVICES (REBECCA ANDERSON)

This committee has several agenda items: the development of practice guidelines; a survey of labs performing AFP tests; and the creation of a tool to be used when selecting DNA laboratories.

- REGIONAL REPRESENTATIVES (MARY-FRANCES GARBER, JILL STOPFER, SHANE PALMER, KATHY DELP, AMY CRONISTER AND ROBIN BENNETT)

The Regional Representatives have developed plans to enhance communication among members in their respective regions. They have established a network within each region and have identified State Representatives. Each region will have a newsletter to keep members informed about the activities of their colleagues. ■

HUMAN GENOME PROJECT

OUTSTANDING CONCLUSION OF COUNSELOR TRAINER COURSE

The final phase of the NCHGR-ELSI grant entitled "Genetic Counselors and Educators on Human Genome Issues" was completed on April 20-24 in Chicago when 20 genetic counselors participated in a training session.

The grant had three phases:

- develop the curriculum for a course aimed at familiarizing non-genetic health professionals about health care issues related to DNA-based testing and the HGP
- implement an educational program to address the human resources and quality control issues raised by the introduction of new genetic information into mainstream medical practice and
- train 20 genetic counselors to present a course, *Humanizing Genetic Testing: Clinical Applications of New DNA Technologies,* to non-MD health professionals.

LEARNING BY OBSERVING

This grant represents a crucial first step in training other health professionals about the importance of education in the DNA test process, the meaning of informed consent and the relevance of ethical, legal and psychosocial issues raised by such testing.

On the first day and a half, grant co-investigators Beth Fine and Marci Koblenz presented the course to a small group of non-MD health professionals. This allowed the genetic counselors to observe the experiences of the health care providers. Over the next two days, the counselors reviewed course materials, critiqued the presentation and discussed training issues. They worked diligently with Marci and Beth to explore ideas for funding, guest speakers and the logistics of running the course in their respective regions.

Each counselor committed to present the course at least two times per year for two years.

QUALITY PACKAGE SUPPORTS TRAINING

The professionally designed material is educational, visually pleasing and easily understood. Each counselor/trainer received a full set of training materials which included the manual, print materials, slides and videotape. Each health professional participant will receive a comprehensive set of printed education materials.

The 20 counselors left Chicago energized and committed. This educational effort should promote liaisons between genetic counselor educators and health professionals throughout the country. By serving as educators, consultants and supervisors for health care providers, genetic counselors will help ameliorate the shortage of appropriately trained professionals.

HOW YOU CAN PARTICIPATE

This exciting project is designed to ensure that information generated by HGP research is communicated in a responsible manner.

If you are interested in helping with the course in your area, contact one of the following professionals who attended the course: Janice Bach, Beth Balkite, Michele Brennan, Karen Albiez Brooks, Lola Cartier, Amy Cronister, Jo Cope, Debra Lochner Doyle, Robin Gold, Jana Hall, JoAnn Inserra, Gabi Jervis, Hillary Lipe, Maria Mascari, Elizabeth Otto, Mimi Rietsch, Christine Sauer, Ellen Simpson, Stephanie Smith, Chantelle Wolpert. ■

JoAnn Inserra, MS
Norwalk Hospital
Norwalk CT

Celebrate Ourselves

Because many genetic counselors wear several hats, the Board resolved to communicate more clearly about situations in which NSGC is formally represented. Following are reports of meetings in which our organization was present in policy making environments.

■ KAREN GREENDALE represented NSGC at a three day meeting sponsored by the March of Dimes comprised of international organizations. The participants drafted a manifesto advocating for birth defects prevention efforts including surveillance and epidemiologic research and for an organization of advocacy groups to oversee this effort worldwide.

■ ANDY FAUCETT represented NSGC at an international workshop convened by the CDC to discuss their soon to be released research on CVS and congenital limb deficiencies. The article reports a 1: 2900 risk for limb abnormalities with CVS after 10 weeks gestation. The group applauded the role that genetic counselors play in disseminating this information to prenatal patients and the general public.

Innovations in Genetic Education: …

continued from page 1

genetics education to television. Located in Cambridge, Massachusetts, MCET is a not-for-profit organization dedicated to improving the quality of education in grades K-12 by using the most advanced technology for the delivery of distance learning. A six month pilot project was initiated, resulting in the submission of a grant to the National Center for Human Genome Research (NCHGR), ELSI Program.

In 1991, ELSI awarded MCET a three year grant to fund a national genetic educational telecourse and public outreach effort. Now in its second year, this program, *The Human Genome Project: Exploring the Scientific and Humanistic Dimensions,* is a national interactive telecourse and outreach effort for use by high school classrooms and the general public. Carefully designed to complement existing biology, social studies, or health curricula, this interdisciplinary series provides an opportunity to prepare today's students as tomorrow's leaders and to inform the public of genetic research underway.

PROGRAM GOALS

The overall objectives of this effort are to:

- enhance public awareness of the Human Genome Project
- increase scientific literacy
- foster sensitivity to disabilities
- encourage critical thinking and ethical decision making
- promote public participation in the formation of public policy and
- expose students to new career opportunities.

The telecourse modules are based on case studies involving:

- Huntington disease
- fragile-X syndrome
- cancer and
- cystic fibrosis.

For each module there is a preproduced 10-15 minute videotape dramatizing the scientific and bio-ethical issues raised by new developments in human genetics. These teleplays, designed as "interest grabbers," constitute the core of each topic discussion and set the stage for the live, interactive broadcast.

> **…opportunity to prepare today's students as tomorrow's leaders and to inform the public of genetic research underway.**

INTERACTIVE COMPONENT

Following each tape there are three live, interactive broadcasts. Students are exposed to experts in ethics, law and public policy, as well as to consumers living with genetic conditions. These broadcasts enable students to ask questions of the studio guests as well as each other and discuss the individual, family and societal issues raised by the teleplay.

In addition to teaching about genetics, a main focus in each module is to provide the students with a bioethical framework (developed by The Hastings Center) along with the necessary tools to work through the many dilemmas posed by the case study. Thus far, the case study methodologies appear to be encouraging discussion and new understandings of the issues associated with genetics and the Human Genome Project. Currently, there are over 100 school sites (rural, urban and suburban) nationally that receive the modules.

EXCITE THE STUDENTS

This program is designed to guide students through the process of discovery. Instead of *telling* students what information they need to know prior to previewing the case study, the goal is to excite the students about the concepts and issues raised, begin to ask questions of interest and pursue further information on their own.

Materials accompanying each of the modules include:

- instructional objectives
- a synopsis of the case study
- background information to complement the teleplay
- vocabulary
- current articles
- references and resources
- suggestions for preparation for the live broadcast and
- follow-up activities.

SELF DISCOVERY

Students are encouraged to obtain answers to their questions through independent research, group discussion and during the live broadcast. Students are also provided with a *Genome Journal,* and they are encouraged to write after viewing the preproduced tapes and live broadcast. This provides a creative way for students to think about the information covered and

...Interactive Television and Science Theater

thoughts that emerge after the broadcasts. Throughout the program, students are expected to work with teachers to obtain materials about current events which are then displayed in a Genetic Resource Center for the classroom.

In addition to reaching students nationwide, MCET plans to broadcast an interactive, televised Community Forum in early Spring 1995 to bring together adults to discuss the Human Genome Project and the impact of the accompanying ethical, legal and social issues on individuals and society. Also, a summer workshop will again be held for teachers interested in becoming involved in this educational, outreach effort. ■

Genetic counselors working with teachers who may be interested in this project can

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Innovations in Genetic Education

Mapping the Soul, A Play about the Human Genome Project

After I finished a presentation on genetics and ethics at the Boston Museum of Science, two sisters strolled onto the stage. They began a conversation that involved a heated debate about one getting pregnant to use the fetal tissue for transplantation that would potentially cure their father's Parkinson disease. Midway through the dialogue, the entire audience was drawn into a discussion about the effects of fetal tissue transplantation. The sisters were actresses. I had just had my first experience with Science Theater.

A year later, I approached the Boston Museum of Science with the idea of using Science Theater to teach about the Human Genome Project (HGP). They submitted a grant application to the New England Regional Genetics Group (NERGG). With direction from the Science Theater staff, the advice of a multidisciplinary advisory board and NERGG funding, a playwright was hired and *Mapping the Soul* developed.

Mapping the Soul is a play about a couple — he, a genetic researcher, and she, an insurance company executive. Her company recently denied health insurance to an applicant because of a genetic predisposition to cancer. She has an inherited visual impairment and realizes the ramifications of this practice. As the storyline gets more complex, it also draws museum visitors into the discussion. Its primary objective is to promote public knowledge, understanding and discussion of the HGP with its associated ethical, legal, social, educational and economic issues.

Science Theater is an unusual interpretive technique that allows subjects to be addressed that ordinarily would be relegated to lectures. Basic science, recent discoveries and current issues are addressed in a multidimensional fashion using actors and actresses. Such plays are an integral part of a Museum's daily programming and center around two general principles: the first, to humanize scientists by examining their discoveries, biographies and accomplishments, and the second, to provide an active forum for the discussion of science related public policy.

Mapping the Soul seems to inspire the audience and provoke thoughts about important scientific and societal issues. In the middle of the play, interaction between actors and the audience occurs as the actors call upon the audience to respond to questions and dilemmas, so there is a natural exchange of ideas and views.

Science Theater provides a new vehicle for genetic education. Traditionally, museums, schools, science centers and professionals have relied on lectures, physical demonstrations and experiments to explain scientific phenomena and theories. Science Theater provides an alternative media that can effectively relay educational messages. Evaluation data from pre and post testing are currently being analyzed to determine the educational implications of this method of public education.

It is critical that the general public be informed about the HGP and participate in the discussion and debate about the related ethical, legal and social implications of genetic research in our lives. *Mapping the Soul* is rich in its portrayal of the scientific and social issues associated with the new genetics. It dramatically reveals that the HGP is a technical exercise; mapping the soul, however, is an experience society must create.

The Boston Museum of Science is interested in collaborating with other museums that would like to perform *Mapping the Soul.* Contact Michael Alexander, Boston Museum of Science, Science Park, Boston MA 02114-1099; 617-589-0100. ■

Robin J.R. Blatt, RN, MPH

SPOTLIGHT ON EDUCATION

VARIETY OF OPPORTUNITIES AVAILABLE FOR MEMBER …

One of NSGC's primary goals is to provide continuing education to the membership and educate the public about genetic counseling. The Education Committee is your Society's means to accomplish these goals. Following are some current activities.

Many of the Education Committee projects require direct input from the membership. If you are interested in learning more about these activities or want to provide input, please contact Maureen Smith, 901-448-6595.

ANNUAL EDUCATION CONFERENCE SUBCOMMITTEE

Historically, the Annual Education Conference (AEC) has been NSGC's most visible activity. The AEC subcommittee, chaired by Barbara Bowles Biesecker, provides advice to AEC chairpersons, picks chairpersons and themes for the conferences, reviews the evaluations, updates the planning manual and develops the budget. This committee is comprised of six members who are appointed by the education committee chair to serve two year terms, plus the Education Committee chairperson as an *ex officio* member.

Current projects of this AEC subcommittee include reviewing information about continuing education units and selecting the 1996 AEC co-chairs and conference theme.

ALTERNATIVE EDUCATION METHODS AND SHORT COURSES

A recent project of the Education Committee has involved exploring alternative methods for providing continuing education to the membership. Because not every NSGC member can attend annual conferences, there is a need to provide education in other ways. One alternative method, written modules, may be used to self-teach about new areas in genetics and review for the ABGC exam. These modules will include a written text, references and a self test. The first module, *Nonmendelian Patterns of Inheritance,* is currently under development.

Evaluations, returned by 57% of participants of the Short Course on Cancer Genetics, were favorable. There appeared to be increasing satisfaction with the conference in proportion to the number of previous conferences one had attended. Over 90% rated the course very good or excellent. With respect to timing, 82.5% preferred that short courses be offered prior to the AEC; and 85.4% responded that two days was an appropriate course length.

A short course about molecular genetics, which would be available on a regional level, is also being created. The course is being developed to be taught by a regionally identified faculty.

A survey will be conducted this Fall to assess the membership's educational needs, including evaluation of:

- present educational programs
- present meeting format
- appropriateness of continuing to meet with ASHG and
- other educational opportunities.

NATIONAL ASSOCIATION OF BIOLOGY TEACHERS

Many of our members have teaching credentials or working relationships with local biology teachers. NSGC would like to foster a relationship with organizations whose members are instrumental in the public knowledge of genetics. The NSGC exhibited at the National Association of Biology Teachers

1995 ANNUAL EDUCATION CONFERENCE MEMBERSHIP POLL RESULTS

332 (27%) of the members responded to the poll in *PGC* 16:1. The results were discussed with the AEC Subcommittee and the theme for 1995 will be "Adult Onset Conditions." Some of the other topics below will become workshop. We hope to develop the conference with a short course-like format and welcome your involvement.

Wendy Uhlmann, MS and Carol Strom, MS
1995 Annual Education Conference Co-Chairs

TOPIC	1	2	3	4	TOTAL
Adult-Onset Conditions	60	45	4	1	110
Psychotherapeutic Techniques	31	17	2	0	50
DNA Technology	23	18	1	2	44
Research Techniques for GCs	22	9	2	1	34
Assisted Repro Technologies	14	11	0	1	26
PN Diagnosis Update	11	10	0	1	22
Teratogens	10	8	0	0	18
Clinical Supervision	8	4	0	0	12
Other	5	8	3	0	16
TOTAL	184	130	12	6	332

Key: 1 = Enthusiastically Support
2 = Support
3 = Do Not Support
4 = No Indication

…INVOLVEMENT

1993 annual meeting in Boston. This year, we have applied to sponsor an NSGC member to speak at their annual conference. Susan Guckenberger has submitted an abstract on our behalf.

COMPUTER WORKSHOP AT AEC

The Education Committee will sponsor a workshop in Montreal. Debra Collins, well known for her computer literacy, will give members hands-on experience with various computer databases and networks. Join us on the information superhighway. Learn how to enhance your work, access genetic information and communicate with your colleagues.

WANTED: COUNSELING CASES FOR GENETIC EDUCATION

The Education Committee is developing a genetic counseling casebook. We are seeking cases involving diagnostic or counseling challenges, medical-legal issues or ethical dilemmas. If you have a case which would be useful in health professional or genetic counseling education, write a one-page description. Include:

- background history
- summary of medical and genetic information
- relevant issues
- tests and results
- actions taken and
- counseling summary.

Please do not compromise patient confidentiality. Send cases to Ellen Matloff or Ellen Limber. ■

Maureen Smith, MS, Chair
Education Committee

Infogen: A Database of Genetic Resources

Efforts began two years ago to develop a database of genetic resources which would be widely accessible and could serve the needs of both genetic professionals and lay people seeking genetic information. NSGC is one of about 15 collaborators. This database has been named "Infogen."

CURRENT STATUS

The Infogen project is in the data-gathering stage and is still evolving. Technical development has been managed by Dan Jacobson of the Applied Bioinformatics Department at Johns Hopkins University School of Medicine. To make Infogen as widely accessible as possible, it is now available via Internet.

TO ACCESS INFOGEN

A World Wide Web (WWW) or Gopher client will allow you to travel via the Internet and connect to the Gopher server at the Welch Laboratory at Johns Hopkins. Infogen may be accessed in several ways:

- Computers with WWW or Gopher link to Internet: Tell the Gopher to connect to the following address:
  gopher.gdb.org
  A Gopher menu will appear.
- Computers with Internet access, but no WWW or Gopher client: Telnet to the following address:
  mouse.gdb.org
  Login: elsi
  Password: (none - hit return)
  A Gopher menu will appear.
- Computers with a modem, but no Internet link: Set your modem as follows: VT100 terminal, 8 bytes, no parity, 1 stop.
  Phone: 14106142665
  Login: elsi
  Password: (none - hit return)
  A Gopher menu will appear.

AND THEN…

Once you have reached the gopher menu, choose the fifth item: GENOME PROJECT. Infogen is located within this file with several other items including *Human Genome News.* Another is a directory of contact people from the organizations involved in the Infogen project. Another, the University of Nebraska Medical Center, links you to the UNMC Gopher server, through which you can access the Great Plains Genetic Services Network bulletin board, developed by Brad Schaefer, MD and Beth Conover, MS.

FUTURE OF INFOGEN

The plan is to first incorporate existing genetic resources including databases, bibliographies and directories. Another is to eventually categorize and include other genetic resources (pamphlets, books, audiovisual materials).

If you have developed a database or other information that you would be interested in making accessible via Infogen, contact Dan Jacobson at Internet: danj@mail.gdb.org Phone: 410-955-1704 or Jannell Sloan, 304-842-4955. ■

Jannell W. Sloan, MS
Co-Chair, Patient Database Subcommittee

MEMBERS ON THE SUPERHIGHWAY

Your "Let's Get It Right" information update card, included in this issue, requests your E-mail address. We would like to add this field to the master database and directory. When you enter your information, please type or be sure to print clearly, using case-sensitive letters and numbers exactly as they need to be accessed. ■

Resolution, Position Statement Drive Social Issues Activities

Significant progress has been made toward enhancing communications between our Social Issues Committee and the Social Issues Committees of ASHG and ACMG and toward the adoption of both a new resolution and several position statements.

Position statements and resolutions serve to better define us as genetic counselors and assist our Society in fulfilling our mission. They are also helpful when we are contacted by the media and other organizations and asked to comment on policy issues.

RESOLUTION

In light of the current activities on Capitol Hill, a NATIONAL HEALTH CARE REFORM RESOLUTION was developed by the Legislative Subcommittee and approved by the Board to support our existing resolutions. As NSGC members, your responsibility is to carefully review the statement below and provide *written* response to Vivian Weinblatt by *July 15.*

Once the comments have been reviewed and appropriate changes have been made, a final draft of the resolution will appear in *Perspectives,* accompanied by a post card ballot.

Resolutions are adopted by a majority vote of the Full membership. They require a vote because they are not necessarily derived from the existing Code of Ethics or Position Statements which have already been approved by the Board.

POSITION STATEMENT

Several position statements regarding laboratory screening tests are under review by the Board and will be presented to the membership after the Fall Board meeting. Position statements do not require a membership vote.

MEETING OF THE MINDS

A meeting among NSGC, ASHG and ACMG Social Issue Committee chairs is scheduled to occur during the genetic conferences in Montreal this October. We expect that this will foster dialogue and the potential for joint policy statements.

We look forward to receiving your comments on the Health Care Reform Resolution and will continue to update you on the progress of this resolution as well as other Social Issues Committee activities.

Lori Williamson-Kruse, MS
Member, Social Issues Committee

HEALTH CARE REFORM RESOLUTION

(Pending Membership Comment and Vote)

The NSGC supports any Health Care Reform measures which provide universal access to and guaranteed coverage for:

1. Safe and legal abortion
2. Genetic services regardless of race or ethnic background, religion, socioeconomic status, disability or sexual orientation
3. Prenatal care, family planning services, pediatric and long term care and psychological counseling
4. Health insurance without respect to health status including future genetic risks.

LEGISLATIVE UPDATE

ACTION ON… HEALTH CARE REFORM; ACCESS TO ABORTION; SUPREME COURT NOMINATION

Two House subcommittees have approved a modified version of President Clinton's Health Care Reform Bill; additions to the bill aide preventive health and include cancer screening. Retained are provisions for abortion coverage. Yet to be addressed are tough funding issues such as taxation; the bill will undoubtedly change format several more times. While the President wants health care legislation passed by this fall, the timetable for congressional consideration is lagging.

With elections this November, final votes may be postponed post-election. A powerful lobbying group, the March of Dimes, is tracking the legislation closely and would certainly welcome interested inquires. Contact your local Chapter to get involved or for assistance in contacting your Senator and/or Representative.

BRIEFLY

- The President signed into law legislation making it a Federal crime to block access to abortion clinics. Opposition groups vow to appeal. Early indications are that at least two states, Virginia and Texas, have filed appeals.
- The new Supreme Court nominee, Judge Stephen Breyer, remains ambiguous regarding his views on abortion rights. His past decisions have generally been supportive. ■

Lee Fallon, MS
Legislative Liaison

VISIONING THE FUTURE

Connecting Links and Speakers Bureau: Tapping Into A Society Resource

Analysis of the Membership Satisfaction Survey conducted in January 1993 in conjunction with the Strategic Plan revealed that Connecting Links and the Speakers Bureau ranked lowest as membership benefits in terms of perceived value. A one-year study has been conducted by the Executive Director from May 24, 1993 to assess their respective use.

CONNECTING LINKS

Connecting Links provides member indicated areas of interest and/or expertise in approximately 20 general and specialty areas. The specific categories are identified on the bottom pages of your membership directory. Careful study of the survey results revealed that of those responding, 23% valued the service of extreme or high value and 25% responded with no opinion or had never used or heard of the service. The service is used predominantly by the members.

SPEAKERS BUREAU

The Speakers Bureau, used predominantly by the media, revealed a 14% rating in the extreme or high value categories and 40% in no opinion or never used or heard of the service.

RECOMMENDATIONS

Responsible strategic planning demands that we consider all members' perceptions and not delete services based on responses that appear to be either not useful or are simply underutilized. Based on this study of these services, recommendations are to:

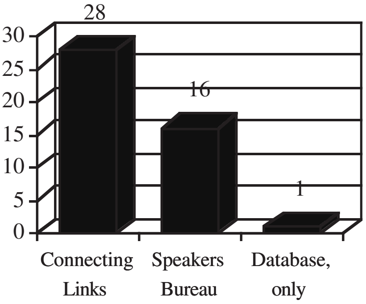
- continue monitoring their use
- pursue a marketing approach for the Speakers Bureau and
- conduct an awareness campaign for Connecting Links. ■

Bea Leopold, MA
Executive Director

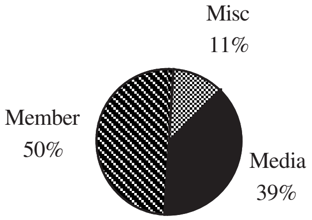
ACTUAL USE OF CONNECTING LINKS AND SPEAKERS BUREAU USE

	MEMBERS	MEDIA	OTHER
Connecting Links	19	5	3
Speakers Bureau	3	11	2
Other	0	1	0

PROPORTIONAL USE OF CONNECTING LINKS & SPEAKERS BUREAU BY OFFICE



PROPORTIONAL USE OF CONNECTING LINKS & SPEAKERS BUREAU BY REQUEST



Miscellaneous Category Use Includes Audiologist, College Biology Professor, Conference Planner, Researcher

13th Annual Education Conference

"TWENTY FIVE YEARS OF GENETIC COUNSELING: EXPANDING ROLES, EXTENDING HORIZONS"

OCTOBER 15 - 18, 1994

■ **REGISTRATION:**
Plan Ahead: The deadline for conference registration without penalty is *August 15.* Confirming your reservation early at LeMeridien will ensure your stay at our meeting hotel, the closest to the Convention Centre, and will help NSGC offset speaker expenses. Our block of rooms will only be held through *September 15.*

■ **WELCOME RECEPTION:**
The opening reception, scheduled for 7:00 pm on Saturday, October 15, will highlight our poster session with authors present to discuss their work and an interactive timeline. Help celebrate our 25th anniversary by adding your contributions of major events in our profession as it has evolved over the past 25 years.

■ **ANCILLARY MEETINGS:**
FINAL REMINDER: All meetings or receptions *must* be scheduled through the Executive Office. Request an Ancillary Meeting Reservation Form by phone or FAX by *July 15.*

■ **DIFFICULT DILEMMAS:**
This popular workshop is designed to allow counselors to share interesting cases and exchange feedback. To contribute your case, call Amy Arnoff, 415-923-3046 or Lavanya Misra, 212-523-4474.

■ **CANADIAN CUSTOMS:**
Information about entering Canada from other countries will follow in your registration confirmation letter.

Student Page

Smith-Lemli-Opitz Syndrome: Issues for Genetic Counseling

Michele Murray is a recent genetic counseling graduate who is working with researchers involved in the recently defined defect in cholesterol biosynthesis that causes Smith-Lemli-Opitz Syndrome (SLO). The researchers are studying the impact of a dietary intervention and the potential for carrier detection, while Michele's master's project involved studying the significance of this finding on genetic counseling. The following article reflects her thoughts as she learned about the implications of this research.

The cause of SLO has been described as an enzymatic defect in the conversion of the cholesterol precursor, 7-dehydrocholesterol (7-DHC), into cholesterol, which results in both an accumulation of 7-DHC and a decrease in the synthesis of cholesterol. The researchers I worked with are assessing the clinical correlation between the biochemical values and clinical findings as well as the effects of experimental dietary intervention. Because SLO is a rare disorder, collaborations are essential to conduct a large-scale study. It is premature to assess the effects of the treatment on a large scale.

COUNSELING CHANGES

Because the biochemical basis of SLO is better understood, changes in the genetic counseling process are necessary as our work moves from research to clinical service. In general, the availability of diagnostic and prenatal testing should be included in genetic counseling sessions. Participation in the clinical correlation protocol and information about the experimental diet may be of interest to families who already have a child with SLO.

One mother said that the "best thing a genetic counselor could do for a family" would be to provide them with as much information about SLO as possible, such as educational pamphlets or family networks. One such resource is Barbara Hook with the SLO (RSH) Advocacy and Exchange, 222 Valley Green Drive, Aston PA 19014; 610-494-5287.

ISSUES AROUND DIETARY INTERVENTION

The decision to treat a child with SLO appears to be difficult. The families voice concerns about the pain, the effectiveness, determining how the child would do without treatment and the decision to stop if changes are not readily apparent.

On the cusp between research and clinical service, several questions need to be addressed surrounding information shared in the counseling session. How will knowing what effects the experimental treatment has alter how families are counseled regarding prognosis? In light of a potentially effective treatment, how will couples who are at increased risk rethink their family planning?

Another professional concern is recontacting families. What would be the benefit of recontacting a family who has discontinued family planning or has a child who is now an adolescent or adult and may or may not benefit from the treatment?

WONDERFUL PREPARATION

These issues are not dissimilar from those generated from advances in diagnosis and treatment of other genetic conditions. As a student, studying issues particular to the area of moving from research to clinical service and working with SLO families has been enlightening and an excellent preparation for the discoveries that will occur during my career as a genetic counselor. ■

Tint GS, Irons M, Elias, E, et al. Defective Cholesterol Biosynthesis Associated with the Smith-Lemli-Opitz Syndrome. *NEJM* 1994;330;107-113.

American Journal of Medical Genetics, May 1994;326-376 contains several articles devoted to SLO.

Michele S. Murray, MS,
Brandeis University

MASTER LEVEL PROJECTS

The following are five of six theses projects submitted from the University of Cincinnati GC Training Program. We noticed the nature of some topics seem more directed to basic science than genetic counseling, and we are keenly interested to learn about topics chosen by students in other programs.

- Diane Barker, *The Protective Role of Melanin Against Photocarcinogenesis.* 513-751-8792.
- Mary Kay Dabney, *The Effect of Medication of Behavior, Family and Issues of Adolescents with ADHD.* 513-221-5080.
- Shelly Hammer, *Perceptions and Practices of Social Workers Regarding Prenatal Alcohol Exposure.* 513-559-0461.
- Julie Jackson, *Influence of Phenotype on Adult Neuropsychological Outcome in Early-treated Classical PKU.* 513-662-6309.
- Denise Jones, *Knowledge of Pregnancy Related Risk Factors and Perceived Need for Education among College Undergraduates.* 513-559-1925.

Rich Dineen, MS and Bonnie Hatten, MS

OUR CODE OF ETHICS: SOCIETY AND YOU

Section IV of the NSGC Code of Ethics states that genetic counselors have the responsibility to take part in promoting the well-being of society. The establishment of the Social Issues Committee at the time of NSGC's inception demonstrates that this responsibility is well recognized by our professional organization.

However, each guideline in Section IV suggests ways in which the individual genetic counselor can fulfill his or her responsibility to society.

STAY KNOWLEDGEABLE

The easiest guideline to follow is the first one - "Strive to keep abreast of societal developments that may endanger the physical or psychological health of individuals." Although similar to guideline 1 in Section I, "seek out and acquire all relevant information required for any given situation," the implication in Section IV is much broader.

Rapid progress in genetics, with its attendant media attention, piques the public's curiosity, but it is often misinterpreted. Genetic counselors have a responsibility to stay informed, not only about genetic information necessary to share with patients, but about societal understanding and responses to that genetic information.

NEED TO DO MORE

Just acquiring knowledge does not fulfill the genetic counselor's role in relation to society. It is also important to take action. There are many ways that this can be achieved:

- as participants in activities which promote socially responsible change
- as resources for reliable information to policymakers
- as informers to the public
- as active participants to prevent discrimination and
- as concerned citizens.

It has become increasingly apparent that a change is necessary in our health care delivery system. Genetic counselors, with their knowledge and training, can contribute a great deal to resolving this societal problem and assist in developing more adequate health care for the entire population. Furthermore, we are in the position to be advocates for the special needs of patients with genetic concerns.

EDUCATE PUBLIC AND POLICY MAKERS

Genetic counselors are trained to be good communicators. This skill can be used to keep the general public informed about the impact of new scientific and technical developments. The proliferation of knowledge from the Human Genome Project is just one example.

There is a great need to be available to the media and policy makers as a source of reliable information and opinions as to the possible impact of this information on society. We have the responsibility to make this information understandable to society.

Discrimination on the basis of race, gender, sexual orientation, age, religion, genetic status and socioeconomic status has certainly not been eliminated. Genetic counselors should be sensitive to any kind of discrimination and when becoming aware, should help to eliminate it. All kinds of discrimination are harmful to our society.

No one counselor can take part in all of these activities. But we can each choose to act where we believe we can be most effective. ■

Rose Grobstein, BA
Paoli PA
and Judith Benkendorf, MS
Georgetown University,
Washington DC

This concludes the four-part series on the Code of Ethics. Members are invited to bring specific issues of concern to any member of the Ethics Subcommittee, currently chaired by Vivian Wang.

MEETING MANAGER

Meeting Manager

July 5 - 6	Region III Education Conference, Litchfield-by-the-Sea, Pawleys Island SC. Theme: *Unusual case presentations and teenage counseling issues.* Contact: Shane Palmer, 919-946-6481.
Oct 6 - 8	Ninth National Perinatal Bereavement Conference, Denver CO. Contact: Lutheran Medical Center's Women's and Family Services, 303-629-4412 or 303-425-2229.

RESOURCES

BOOK

Medical Genetics: A Self-Instruction Guide and Workbook Based on Mendelian Inheritance in Man
Author: Victor McKusick, MD
Publisher: The Johns Hopkins University Press, 1993
Price: $30.00; 125 pp.
Reviewer: Janice Berliner, MS, Institute for Basic Research, Staten Island NY

After having compiled the most comprehensive volume of clinical genetic information to date, Dr. McKusick took this daunting task one step further to create the on-line version of Mendelian Inheritance in Man (OMIM). Since it is continuously updated, OMIM is somewhat more useful than the text. However, it may seem complicated to use. The *Self-Instruction Guide* leads the reader to a fuller understanding of the powers of the program and how to access the necessary information most directly.

Searching capabilities of this program allow a differential diagnosis to be made from two or three key characteristics, as long as they are specific. Information about the number of listings is available within seconds, and the user is allowed to revise the search if more than a certain number of entries are located.

The *Self-Instruction Guide* gives a few examples of how to perform this type of search, and provides a large variety of sample questions with answers to help learn the program. However, I often found it difficult to revise the search, because some of the questions were too general. It takes creativity to target the desired information.

The program gives many options for different types of searches, and each is presented in a fairly clear multi-step direction. One can search for a clinical synopsis, particular disorder, the MIM number, references for that syndrome, allelic variants and map location.

The sample questions help the reader gain expertise regarding the most direct way to search for information. Sometimes it is necessary to read the entire entry. However, because so many sample questions are provided, one can usually focus on the best way to ask the question.

Dr. McKusick provides a list of references for basic, medical and molecular genetics. Overall, the study guide is vast in scope, specific and reasonably clear in instruction. It provides multiple opportunities for understanding the complexities of the field of medical genetics and the ways in which specific information can be obtained. It is very useful reference for students and the genetic community at large.

NEWSLETTER

The Wisconsin Stillbirth Service Program has recently initiated *WiSSPers,* a newsletter for health providers who work with families of stillborn infants. Articles include topics related to stillbirth, summaries of current literature, guest articles, reviews of parent literature, personal stories and reader comments.

The 12-page quarterly is available for an $8 annual subscription fee. Checks may be made payable to Statewide Genetics Service Network, c/o Catherine Reiser, MS, Univ Wisconsin Clinical Genetics Ctr, 1500 Highland Ave, Madison WI 53705-2280.

SUPPORT GROUPS

As awareness about cancer genetics increases, counselors may find themselves identifing family histories positive for a variety of cancers. The following are three national support organizations available for individuals and families who have cancer. Many local groups also exist. No groups are currently available to support hereditary cancers specifically, although the Alliance of Genetic Support Groups has material to help people who are interested in developing such a group.

- American Cancer Society
  1599 Clifton Road NE
  Atlanta GA 30329-2345
  800-ACS-2345

  Several state chapters with literature, support groups and rehab service information.
- Cancer Information Service
  National Cancer Institute
  NIH Building 31, Room 10A24
  9000 Rockville Pike
  Bethesda MD 20892
  800-422-6237 or 301-496-5583

  Regional information specialists available to answer questions about statistics, diagnosis, treatments, screening, current clinical trials
- Y-ME
  National Organization for Breast Cancer Info and Support
  18220 Harwood Ave
  Homewood IL 60430-2104
  800-221-2141

  Hotline, counseling, educational programs, support meetings for patients, families and friends.

Third Trimester Amnio

Counselors who have practiced only a few years sometimes have concerns that veterans take in stride. The following is such a situation requesting input.

A 39 year old, G1, Hispanic female was referred for a perinatal evaluation after an abnormal ultrasound exam. The patient, who began prenatal care at 10 weeks, had reportedly declined amniocentesis. At 25.5 weeks gestation, an ultrasound revealed a unilateral choroid plexus cyst and polyhydramnios. Given the ultrasound findings, the patient was offered amnio, accepted and subsequent chromosome analysis revealed trisomy 18.

During follow-up counseling, the possibility of early induction was discussed, but it was explained that this would require approval from the hospital bioethics committee. The patient asked to have an induction, including a do not resuscitate order.

The attending perinatologist spoke with a hospital lawyer prior to the bioethics committee meeting and was told that early induction for trisomy 18 was unlikely to be approved, since it was not considered a lethal defect. Since the physician concluded he would not receive approval, he canceled the meeting and told the patient that induction was not an option.

QUESTIONS

- *How is it determined that a condition is lethal and should trisomy 18 be considered lethal?*
- *How far do we carry the role of patient advocate?*
- *How do you counsel third trimester amnio cases when induction may not be an option?* ■

Fiona Fields, MS
University of Illinois at Chicago

GENEBYTES

DRIVING THE SUPERHIGHWAY WITHOUT A LICENSE

Counselors, start your computers. The Superhighway is here! Internet, the international computer network, is changing the face of communication. Genetic counselors should learn about this valuable communication tool, which may have as large an impact on genetic counseling as the Human Genome Project.

Internet is not a centralized, single supercomputer. Rather, it is an international network of a vast number of computers which communicate via modem. Electronic mail (E-mail) and manuscripts can be rapidly transferred across Internet. Infogen, a database of genetic resources, can be easily accessed. (See p. 7.)

In addition, discussion groups (similar to a news group or bulletin board) regularly address diverse topics such as aging, health care reform, medical informatics and fitness. A virtual plethora of topics exist. Multiple discussions about specific interest areas under the same umbrella can occur simultaneously.

Participation requires a computer, a modem and Internet access.

POSSIBILITY OF GENETIC COUNSELING DISCUSSION GROUP

In keeping with the NSGC's Strategic Plan's goal of improving communication, the NSGC Board is considering building a byway into this communication superhighway. NSGC members could benefit greatly by accessing a discussion group.

For genetic counselors topics would be related to the management and practice of genetic counseling, including clinical situations, conferences and grant opportunities. This moderated group is not meant to be a forum for lay persons to pose medical questions, but rather a place where genetic counselors can quickly discuss professional issues. A moderated group does not *censor* specific entries, but assures that the communications are appropriate to the user group. Imagine a prenatal discussion thread where counselors share experiences with different labs or advice is sought about the implications of unusual triple screen results or ultrasound findings. Other threads could deal with counseling dilemmas, teratogen questions or supervisory challenges.

Multi-institutional research project personnel could exchange data and discussion. It could also be a resource to request volunteers for particular NSGC projects or identify resources outside our Connecting Links. A genetic counseling bulletin board on Internet would augment *Perspectives.* Access could be extended to ISONG, ASHG and ACMG members to increase professional participation.

ARE YOU INTERESTED IN GOING FOR A RIDE?

All of these ideas about the benefits of Internet are the product of excited brains practicing the art of "What If." Before NSGC puts the pedal to the metal, we need to know how many members have access to Internet and have interest in a discussion group. Please include your Internet E-mail address, if you have one, on the "Let's Get it Right" card enclosed in this issue of *Perspectives.* Help build the future of your profession. ■

Vickie Venne, MS, Robert Resta, MS
and Karen Wcislo, MS

BULLETIN BOARD

ABGC UPDATE

A consensus development conference on accreditation and training issues was held January 20-23 in Chicago. Eighteen genetic counseling training program directors invited by the ABGC Board of Directors attended this working meeting to provide input into the development of academic and clinical training criteria for genetic counseling students. Several invited speakers addressed issues related to accreditation in related health professions, practice-based competencies and supervision.

Participants developed a set of competencies from discussions about the expectations for entry-level genetic counselors and the evaluation of case studies of typical counseling scenarios. Areas explored were expectations, standards for clinical training sites and supervision and documentation of this experience through the certification exam logbook.

The meeting provided a valuable opportunity for Board members and program directors to explore the implications of and options for program accreditation. Information from the conference is being used by ABGC to develop accreditation guidelines for masters-level training programs. ■

CALL FOR ABSTRACTS

The 20th National Primary Care Nurse Practitioner Symposium is accepting abstracts of research, innovative clinical practice, models and roles and other professional papers relating to primary health care nursing. This symposium, sponsored by the University of Colorado Health Sciences Center School of Nursing, will be held in Keystone CO, July 20-23, 1995. Deadline for abstracts is September 15. For more information, contact Ellen Lernberg, 303-270-7436. ■

INSURANCE WHOAS BECOME EXEC'S WOES

After several false starts, we have finally connected with a carrier who will provide insurance at a reasonable rate for our Full members… with the exception of genetic counselors practicing in the New York City area. It appears that the company perceives that their risk is too great to underwrite at this time. If you are practicing in the NYC area, re-try the American Counseling Association. The pursuit of comprehensive service for the entire Full membership will continue.

Liability and other types of insurance can be offered by NSGC only if we have a positive response. If you now need or anticipate a need for liability insurance, and are a Full member, request an application from the Executive Office. ■

PATIENT INTERVIEWS NEEDED FOR GENOME GRANT

The Alliance of Genetic Support Groups is a co-investigator in a NIH grant to develop a Human Genome Education Model for genetic service consumers and non-genetic health professionals. To develop this model, the Alliance is seeking 300 members of support groups who would be willing to spend about 30 minutes in a telephone interview. They wish to obtain information from as diverse a population as possible. Survey participants must be a least 18 years old, have a positive family history or increased risk of a genetic disorder.

If you know of an individual who might be interested in participating in this project, call Joan Weiss or Mary Ann Wilson at 800-336-4363. ■

SURVEY SEEKS JOB SEARCH INFORMATION

The Professional Issues Committee is interested in your opinions and experiences related to job searches and landing that "perfect job." Enclosed in this issue is a Professional Issues Job Search Survey. Responses obtained from the survey will be used to compile a job search manual for genetic counselors. Please take a few moments to complete the survey, adding an extra page if you wish, and honor the *August 1* deadline. ■

Michele Jenkins, MS,
Albany Medical Center
and Julie Berger, MS
Hutzel Hospital, Detroit

New Training Program Accepts Applications

Beaver College, a co-educational, undergraduate and graduate college in suburban Philadelphia, has established a Master's Level Genetic Counseling Training Program and will be accepting applications for students to begin training in September 1995. A search is being conducted for a board certified genetic counselor to serve as Director. *(See Employment Opportunities, p. 16)*

Additional information may be obtained by calling Raymond Rose, PhD, Department of Biology, 215-572-2198. ■

■ EMPLOYMENT OPPORTUNITIES ■

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

LITTLE ROCK AR: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join 2 nurse counselors, 3 MFM MDs in university-based PNDx ctr: CVS, amnio, PUBS, high risk U/S, MSAFP/hCG & teratogen service; coordinate anomalies clinic; oppty for research & teaching; close interface w/ Peds Genetics.
CONTACT: Susan Walker, RNC, Arkansas Genetics Program, University of Arkansas for Medical Sciences, Slot 506, 4301 W. Markham, Little Rock AR 72205-7199; 800-358-7229. EOE/AA.

GRAND CAYMAN, CAYMAN ISLANDS: Immediate opening for Genetic Counselor with degree in GC or Public Health w/ Genetic Training & Skills. Minimum 2 yrs relevant experience required. Salary range: CI $26,952 - $35,952 P.A. (tax free) = US $35,085 - $42,800 P.A. + 15% contracted officers supplement.
RESPONSIBILITIES: Construct pedigrees; counsel families; conduct home visits; investigate home situations; organize carrier testing, overseas lab/med svc; coordinate record keeping & various genetic clinics; participate in public health programs & liaison w/ social services department.
CONTACT: Public Service Commission, Government Administration Building, Grand Cayman, Cayman Islands; 809-949-8277. EOE/AA.

STRATFORD CT: Immediate opening for BC/BE Genetic Counselor with commercial labortory; 2-4 yrs experience in clinical genetics setting and excellent communication skills required.
RESPONSIBILITIES: Case management for growing genetics division w/ DNA, cytogenetic & AFP lab; significant involvement in education of clients & staff.
CONTACT: Gabi Schneider, Dianon Systems, 200 Watson Blvd, Dept 9005, Stratford CT 06497; (No Phone Calls, Please). EOE/AA.

BOSTON MA: July 1 opening for BC Genetic Counselor. Minimum 3 yr experience in PNDx required.
RESPONSIBILITIES: Active role in setting up new Perinatal Dx unit at tertiary center: all aspects of PNDx: MSAFP scrng, amnio, maternal fetal anomalies, terat coun, genetic eval; work w/ team of geneticists, MFM OB & U/S professionals.
CONTACT: L.B. Holmes, MD, Massachusetts General Hospital, Genetics & Teratology, Warren 801, 32 Fruit St, Boston MA 02114-2696; 617-726-1742. EOE/AA.

DETROIT MI: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join large genetics ctr w/ variety of counseling oppty: peds, adult & PN; oppty for teaching & publishing available.
CONTACT: Paula Czarnecki, MS or Lester Weiss, MD, Henry Ford Hospital, Medical Genetics CFP-4, 2799 W Grand Blvd, Detroit MI 48202; 313-876-3188. EOE/AA.

OMAHA NE: July & October openings for two BC/BE Genetic Counselors.
RESPONSIBILITIES: Join progressive team of 5 GCs & 4 MDs in academic setting based in university-affiliated program in multidisciplinary institute; diverse clinical oppty for genrl genetics, PN, satellite & specialty (neurogenetic, cancer, Marfan, FAS) clinics; participate in special projects, teaching & research.
CONTACT: Beth Conover, MS or Kristal Hagemoser, MS, University of Nebraska Medical Center, Meyer Rehabilitation Institute, 600 S 42nd St, Omaha NE 68198-5440; 800-656-3937. EOE/AA.

BROOKLYN NY: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Rapidly growing tertiary care ctr w/ variety of PN, ped, inpt consults; oppty to participate in public & prof education. Special interests in deafness, cancer, sickle cell, SE Asian issues.
CONTACT: Karen David, MD or Fiona Wallace, MS, Brooklyn Hospital, Section of Genetics, 121 Dekalb Ave, Brooklyn NY 11201 718-250-8032. EOE/AA.

BUFFALO NY: Immediate opening for BC Genetic Counselor with demonstrated experience in cancer genetics & computer familiarity.
RESPONSIBILITIES: Join active clinical, research, cytogenetic & DNA dx expanding group: identify cancer families, describe cancer genes & phenotypes for diagnosing disease, organize registries & databases, counsel CA pts & families, conduct genetic studies.
CONTACT: Nicholas J. Petrelli, MD, Roswell Park Cancer Institute, Dept Surgical Oncology, Elm & Carlton Streets, Buffalo NY 14263; 716-845-8983. EOE/AA.

NEW YORK NY: Immediate opening for Genetic Counselor with strong research interests.
RESPONSIBILITIES: Conduct linkage studies in movement disorder group, particularly dystonia, essential tremor & DNA testing for dystonia: enroll families, obtain pedigrees, coordinate research evals, visit families, assist in evals & videotaping, obtain blood samples, manage database; oppty for education, leading supt groups & independent research.
CONTACT: Deborah deLeon, MS, Neurological Institute, Box 77, 710 W 168th St, New York NY 10032; 212-305-5779. EOE/AA.

GREATER NEW YORK CITY/ NORTHERN NJ AREAS: Immediate opening for Part time BC/BE Genetic Counselor. Exp required w/ emphasis on prenatal.
RESPONSIBILITIES: Challenging, flexible position for independent GC: consultation, education & technical assistance to MDs providing PNDx in metro NY/NJ

Continued on next page

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

nsgc

**233 Canterbury Drive
Wallingford, PA 19086-6617**

EMPLOYMENT OPPORTUNITIES *from previous page*

areas; pt counseling & liaison between MDs & genetics ctr; ample supt from genetics team.
CONTACT: Charlene Schulz, MS, GeneCare, 225 W 14th St #4F, New York NY 10011; 800-737-0502. EOE/AA.

CLEVELAND OH: July 1 opening for BC/BE Genetic Counselor; experience, esp in cancer genetics, preferred but not required. Send resume + 3 ltrs reference.
RESPONSIBILITIES: Broad range of counseling & educational activities: PNDx; birth defects & dysmorph; cancer genetics; PN scrng (AFP, HCG, UE); teratogen risk assessment; biochemical, cytogenetic & molecular disorders. Participate in prof & public educ expected; oppty for clinical research avail.
CONTACT: Suzanne B. Cassidy, MD, Center for Human Genetics, Case Western Reserve University, 11001 Cedar Ave, Suite 510, Cleveland OH 44106-9959; 216-844-6940. EOE/AA.

GLENSIDE (PHILADELPHIA AREA) PA: Sept 1, 1994 (part time); Sept 1, 1995 (full time) opening for BC Director, Genetic Counseling Training Program. Minimum masters in GC; experience in clinical genetics; evidence of administrative success; demonstrated commitment to program development & training of GCs; teaching experience & scholarly publications highly desirable; familiarity w/ Philadelphia area may be asset.
RESPONSIBILITIES: Coordinate final development & implementation of GC program to begin Sept 95: develop curriculum, manage clinical placements, advise students, manage budget; some teaching responsibilities.
CONTACT: GC Search, Dept Biology, Beaver College, Glenside PA 19038; 215-572-2199. EOE/AA.

CHARLOTTESVILLE VA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join team of 2 GCs & 3 MDs in predominant PN position: CVS, amnio, PUBS, AFP, abnorm U/S; teratogen service.
CONTACT: Fotini Vavelidis, MS, UVA Medical Center, Box 387, Dept OB/GYN, Charlottesville VA 22908; 804-924-2500. EOE/AA.

NORFOLK VA: Immediate opening for BC/BE Genetic Counselor with Faculty Appointment.
RESPONSIBILITIES: All aspects of pediatric & general GC: outreach clinics; participate in medical student, resident & nursing education, teratogen information service, development of new clinical programs.
CONTACT: Marie T. Greally, MD, Eastern Virginia Medical School, Dept Pediatrics, Div Genetics, PO Box 1980, Norfolk VA 23501-1980; 804-446-5723. EOE/AA.

PORTSMOUTH VA: October 1 opening for BC/BE Genetic Counselor, Dept OB/GYN, Div Fetal and Maternal Medicine, Naval Medical Center. Contract period for one year, with options to extend for total of five years.
RESPONSIBILITIES: Request complete job description and minimum requirements in Solicitation N62645-94-R-0016.
CONTACT: Jamie Kiser, Contract Specialist, or Gilbert W. Hovermale, Contracting Officer, Naval Medical Logistics Command, Acquisition Management Dept, ATTN: Code 05, Bldg 833, Ft. Detrick, Frederick, MD 21702-5015; 301-619-3020. EOE/AA.