nsgc

PERSPECTIVES IN GENETIC COUNSELING

newsletter of the National Society of Genetic Counselors, Inc.

Vol 13, No. 4 Winter 1991/92

MEMBER BENEFITS GROW IN '92

Two new member benefits are being offered beginning in 1992: the long awaited first issue of the *Journal of Genetic Counseling* and Connecting Links, an access service to help you network with members.

The information necessary to enter your data into Connecting Links has been included with your 1992 Membership Invoice, which was mailed to you on December 2. Please respond by the January 31 deadline to ensure a steady and uninterrupted flow of communications from our office to yours.

on the inside...

The NSGC gratefully acknowledges Integrated Genetics' support of this issue of *Perspectives*

Committed to providing highest quality DNA-based, cytogenetic and prenatal biochemistry testing, service and education.

TAKING A STAND AS LEADER IN THE GENETICS COMMUNITY

by Edward M. Kloza, M.S., NSGC President

Decision makers are risk takers, people willing to accept the possibility of an undesirable outcome for the promise of a specific benefit.

Much of genetic counseling focuses on decision making: *Should I have this test? Should I have this baby? Should I change my life style?* To some degree or another we expect, even demand, that our patients be informed before they make decisions. To determine whether the counseling process has proceeded to the point where information has been communicated effectively, we only need to listen. Listen to what patients say (or don't say) when relating a family history; listen to *their* interpretation of *our* interpretation of risk; listen for clues in their language that may expose apprehension, confusion or anger.

How we inform ourselves prior to decision making isn't much different than how we inform our patients — one-on-one counseling sessions are similar to phone calls or corridor discussions with colleagues; group counseling is similar to plenary sessions, workshops and open mike sessions at our educational meetings; informative patient booklets and pamphlets are mirrored by articles in *Perspectives in Genetic Counseling,* the *Journal of Genetic Coun-*

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NEW ORLEANS ISSUE ADDRESSED

TOUGH DECISION

by Michael M. Kaback, M.D.
President, ASHG

At ASHG's annual membership meeting, held during the 8th International Congress of Human Genetics in Washington, the Board of Directors announced that, after an extensive analysis of possible alternatives and legal implications, it had voted to honor its contracts for the 1993 meeting in New Orleans. The following information was incorporated into that decision:

- While recognizing its responsibility as the major professional society of human/medical geneticists in North America, ASHG is not a single issue organization. Research, education and service are all parts of our aggregate

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CUT TO THE CHASE

by Betsy Gettig, M.S.
President Elect, NSGC

Quite simply, choices are the only issue to consider.

As our membership is asked to express individual opinions to the Board whether or not our organization should hold its 1993 Annual Education Conference in New Orleans, we have many points to consider. The activities of the Louisiana legislators, our public Reproductive Freedom statement, the lack of financial obligation and our tradition of meeting along with ASHG all factor into our choices.

From the tradition of the Civil Rights movement of the '50s and '60s, boycott has been a major non-violent approach to social and legis-

• continued on p. 7, col. 1 •

From the Desk of the President

FACING THE RISKS AND REALITIES OF LEADERSHIP

Past NSGC presidents have challenged us to come to the edge, to take risks. We accepted the challenge to become more visionary. We were encouraged to be more self-directed and listen to our own inner voice. We were cautioned against prolonged dependence and have since defined our unique relationship with other professionals who acknowledge our expertise.

The history of this society is a compendium of risks taken, successes achieved. We cannot be afraid to take risks if we are to grow. The NSGC reserves the right to establish its own direction and recognizes that risks need to be taken along the way. We now have new opportunities to take risks. We are compelled to voice our opinion regarding the location for our 1993 meeting site.

This year will bring new guiding principles, and our membership will vote on companion resolutions. We are also compelled to take our proper role in the public mind as a unique resource for information about genetic counseling and its role in health care. Now is the time to establish the NSGC as the national authority regarding the integration of counseling with technology.

As we assume that leadership role, I believe it would be valuable to establish guidelines for the provision of genetic counseling services that address the issue of quality of care. To that end, I have appointed an ad hoc Quality Assurance Committee to consider related issues, and to be chaired by Karen Greeendale. I have also appointed an ad hoc committee to develop a "Bill of Rights" document for consumers. The document will outline appropriate expectations in a genetic counseling session and will be distributed to genetics programs, institutions, consumer groups and the media, empowering consumers to receive the full benefit of their interchange and reaffirming our role as patient advocates. Lastly, I've created a Communications Committee to coordinate all NSGC publications, with the exception of *PGC* and the *Journal.* This committee will identify the need for other NSGC publications and work with the media.

'The history of this society is a compendium of risks taken, successes achieved.'

My term will be dedicated to helping the NSGC find its voice - not only in response, but also in inquiry. Not only to endorse, but also to initiate. I know that I can count on this Board and on the membership to make that vision a reality as the NSGC continues to mature. To be part of this effort is an honor.

Edward M. Kloza
President, 1991-1992

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Send case reports, resources, materials and books for review to appropriate editors; address changes, subscription inquiries and advertisements to Executive Director; all other correspondence to Editor-in-Chief.
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MEET YOUR 1991/1992 BOARD OF DIRECTORS

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Ask a Colleague

You are scheduled to see a couple for a routine pre-amniocentesis session. Upon meeting them, you notice that the father of the pregnancy has Treacher Collins syndrome. What do you do next?

This is a variant of the many situations we face in which we must impart unexpected news.

When faced with this type of session, I follow my usual approach to counseling. I want to assess the genetic risks, determine the patient's knowledge about the condition, prepare him for the information, impart the information in a benevolent, non-directive manner and discuss available options.

I can accomplish the assessment by beginning with routine questions: "Do you have any health problems? Have you had any surgery, been hospitalized or do you take medication on a regular basis?" If the patient does not tell me of any problem, I wait until the family history and then ask questions that reflect knowledge of the problems particular to that condition.

I try to determine his perspective when I ask: "Is there anyone in the family who has anything unusual about his or her appearance? Is anything different about the size, shape or placement of their eyes, nose, mouth or ears? Does anyone not resemble other members of the family?" The routine questions about the family health history can be so specific that at some point the patient must answer, "Yes, me."

Create an anticipatory anxiety

A few specific questions will usually suffice to make the individual begin to wonder about the purpose of the inquiry. In asking questions that relate to the physical and medical problems of the condition, I purposefully create an anticipatory anxiety which can have a protective effect when delivering unexpected information.

This anxiety cannot necessarily lessen the long term impact, but it may cushion the initial shock, as this uneasiness may raise the question in the mind of the patient, "Is there something wrong?" He is preparing himself for unexpected news.

Before this uneasiness becomes unmanageable, I say, "You may be wondering why I am asking these questions. The reason is that I have the impression that what we are discussing is part of a condition called the Treacher Collins syndrome. Have you ever heard that term?" "No." "Would you like me to tell you about it?" "Yes."

Begin with information

In describing the condition, I comment that this disorder is highly variable such that some individuals escape diagnosis. I am sensitive to the patient who has considered himself normal and use language as neutral as possible, emphasizing the positive aspects but being realistic about the implications of the diagnosis. I also discuss prenatal options such as ultrasound, emphasizing its limitations.

I prefer to leave the putative diagnosis open pending evaluation by a medical geneticist and radiographic studies. By doing this, I allow the patient opportunity to integrate information before the diagnosis is finalized. A follow-up appointment allows for confirmation and further discussion of the diagnosis as well as time for questions about the implications for the current pregnancy.

Continue with support

Despite the counseling plan, the patient may still be overwhelmed by the information. At this point, I articulate how difficult it may be to hear this information, and I again emphasize the importance and implications of the diagnosis. By recognizing and verbalizing that the patient is upset and the information is burdensome, one can salvage the relationship which may be jeopardized by the new information. Realistically, it is possible that the patient will not return for follow-up.

Lastly, and as always, the referring physician should be apprised of the diagnosis for facilitation of further evaluation and potential fetal testing *and* to help the patient adjust to the information.

Elsa Reich, M.S.
New York University Medical Center, New York City, NY

NSGC...What's In It For Me?"

"About three years ago, I went through the somewhat long and arduous task of trying to justify a salary increase to the powers-that-be. As many genetic counselors know, this can be a frustrating experience. It meant compiling data related to job descriptions and salary ranges from "bench mark" institutions and collecting other information such as the percentage of counselors who hold faculty appointments. The task was made more manageable thanks to the information made readily available from the NSGC. A complete profile of genetic counselors' varied responsibilities, salaries, and other pertinent data was found from the Professional Issues survey. This data could be referenced with respect to geographic location and years experience in the field. The NSGC pamphlet eloquently described the profession in clear, concise terms in a professional format. Armed with overwhelming evidence, and backed by a national organization, I was able to present a formidable argument that led to both a substantial pay raise and a faculty appointment."

Ronald G. Cadle, M.S.
University of Kentucky, Lexington, KY

VIEW...

Time and technology appear to be shifting the consensus regarding population screening for cystic fibrosis. The following articles are written by two genetic counselors who have been offering CF carrier testing to patients who do not have a family history of CF. This movement is also taking place on other fronts: The Human Genome Project is funding CF education and counseling studies (see Letters, p. 13, Genome Update, p. 7), and the Northern California Kaiser Permanente is conducting a study to screen 5000 Caucasian women using blood drawn for routine prenatal purposes. Patient education is accomplished at prenatal classes utilizing a video tape. Those with positive results will receive counseling at which time partners are offered testing. Carrier couples will be offered prenatal diagnosis. Psychological impact and attitudes will be measured by formal testing.

With the evolution of this movement, I call to our readers' attention Barbara Bernhardt's Letter to the Editor, NEJM, 324:61-62. She wrote: "...simply stating that screening should be accessible to all will not make it so. There is a need for lobbying efforts to improve third-party coverage of genetic services, particularly those relating to genetic screening and counseling."

Seth Marcus, M.S.
ViewPoints/PointCounterPoint

CF CARRIER TESTING: AN OBLIGATION TO DISCLOSE

by Lisa Stevens, MS.,
St. Lukes Roosevelt Hospital,
New York

In 1990, The American Society of Human Genetics determined that general population screening for cystic fibrosis should *not* be offered until a detection rate of 95% is attained. Current advances are such that the testing is now thought to be 85%-90% sensitive for certain populations.

There are realistic concerns and justifications for not offering general population screening. However, there are other issues that need to be addressed. What about the ethical and moral obligations to our patients? How different is 75%, 85% or 95%? In all cases, there is still an element of uncertainty. The field of genetics is inherently fraught with ambiguity, risk assessment, less than perfect testing methods and anxiety.

ROLE IS TO INFORM

I feel an obligation to disclose the availability of carrier testing to my patients. My role is to inform them of the options in a nondirective, precise and supportive manner giving them the choice to make a decision about the information. Withholding this knowledge may represent a paternalistic approach that is difficult to reconcile.

The availability of limited CF screening has been discussed with some of my patients who have a negative family history since Spring 1990. Initially, both members of the couple had to be solely of Northern European descent. Since August 1991, with the identification and data available on W1282X, I have included the Ashkenazi Jewish population. Due to inconclusive detection capabilities, other Caucasian groups, blacks and Hispanics, are not offered screening unless they specifically mention it. Therefore, due to the diversity of backgrounds and referral indications, this was and is not routinely offered to the majority of patients counseled.

'Withholding this knowledge may represent a paternalistic approach that is difficult to reconcile.'

In most cases, the referral was to discuss CVS or amniocentesis. An appropriate time to mention CF appeared to be at the conclusion of the family history. The benefits and limitations were addressed, as were the possible ramifications of negative, discordant and positive results. The discussion took about fifteen minutes, and couples had the opportunity to ask questions and discuss their feelings. It was emphasized that their risk was not increased over other individuals of their background.

PATIENTS' REASONS TO ACCEPT OR DECLINE

For those who chose to be tested, risk perception seemed to be a major factor, as was their general anxiety level. Some also knew of an affected person who had severe manifestations.

One reason for declining the screening was the perception of a 1/2500 risk as minimal. Others seemed not to be concerned because they knew individuals who have had a mild course, did not know anyone who was affected, or because mental retardation is not a component of CF. Possible lack of insurance coverage and inconclusive results were the other reasons for declining the test.

The discussion did not appear to elevate anxiety levels. On the contrary, many people seemed to be appreciative. For most, their expectations in coming for genetic counseling included hearing about possible testing options. To date, negative feedback has not been received from either the patients or referring physicians.

CF general population screening is still a new and controversial frontier, one that is difficult for patients and practitioners. Nevertheless, the key issue regarding screening for CF remains whether or not to withhold information. To do so appears to be unjustified, harmful and possibly an invasion of the inherent right to know.

...POINT

CF CARRIER TESTING: NEW OPPORTUNITIES

by Debbie Costakos, M.S.
Genetics & IVF Institute, Fairfax, VA

Cystic Fibrosis screening should be offered routinely to Caucasian pregnant or soon-to-be pregnant women who have no family history of the disease. The benefits — better detection, patient choice, increased information to the patient — are substantial. The objections to screening are not specific to CF, but, because of the nature of our health care system, are inherent in any new or widespread medical procedure.

I currently offer cystic fibrosis screening to all Caucasian pregnant women regardless of family history. The availability of testing and its limitations are discussed with the patient during prenatal counseling. We offer direct testing of fetal specimens to those women undergoing amniocentesis or CVS for other indications.

Results are reported in a modified risk format incorporating the ethnic background of the patient. As part of a pilot study, we track the patients' decisions whether to have testing, the results of this testing and the patients' subsequent actions.

WHO ACCEPTS TESTING?

Those families choosing testing were provided with valuable information about their carrier status through the initial testing of their fetus. Current screening methods permit 85% and 95% carrier detection rate for non-Jewish Caucasians and Jewish ancestry, respectively. Forty four percent of our patients undergoing CVS and 21% of those undergoing amniocentesis have elected to test the fetus for CF. Forty-eight fetuses of 1598 tested (3%) were identified as at least carriers of one copy of a CF gene. No pregnancy has been terminated. Risks that these carrier fetus are affected with CF have ranged from as high as 1/5 to as low as zero. The latter risk occurs when both unaffected parents are each found to carry one copy of a mutation and the fetus inherits only one of the mutations.

The cost of CF screening has only occasionally been reimbursed by insurance. However, withholding information about available testing because of its cost is by nature paternalistic and directive. Worse, by not informing patients of available testing, only those who are educated in genetics and can afford testing have a choice. This adds yet another division in the provision of health care to the well recognized and problematic division between those who can pay for medical care and those who cannot. Under the view that general screening should not be offered, only the educated, private-paying patient will currently be tested for carrier status of CF.

OPPORTUNITY TO DEVELOP COUNSELING MODELS

Time in a counseling session is limited, and the demands made of genetic counselors continue to escalate. As the Human Genome Project increases the amount of genetic information about available and appropriate tests, the opportunities and responsibilities of genetic counselors to disseminate that information will increase.

Screening for CF should be approached as an opportunity to explore innovative methods of disseminating information to patients. Counseling models to accommodate the impending flood of new tests should be developed now.

" 'Ignorance is bliss' has never been a tenet of genetic counseling; nor should it be."

A common dissent to current screening of pregnant patients has been that it unnecessarily increases patient anxiety. Knowledge *can* cause more anxiety, and not every test interpretation will be unambiguous. However, counselors are trained to recognize and teach patients how to handle anxiety. "Ignorance is bliss" has never been a tenet of genetic counseling; nor should it be. We have always prided ourselves in providing nondirective and informed counseling, and CF screening should be no exception.

As with any test, the risks, benefits and costs need to be discussed and the psychological impact on each patient appropriately addressed. Only then can a patient make an informed decision. CF screening is only one of many tests soon to be developed, and the exponential growth rate in the field of molecular genetics will force genetic counselors to find new ways to efficiently and effectively disseminate information to the general population. Admittedly widespread screening will impose increased demands on genetic counselors and the health care system, but the benefits to the pregnant or soon to be pregnant patient of

NOW AVAILABLE FROM NIH

NIH has recently published two documents related to CF

- *NIH Collaboration Launches Research on Education and Counseling Related to Genetic Tests*
- *NIH Clinical Studies of Testing, Education and Counseling for CF Mutations* — Backgrounder 11/91

To obtain a copy, contact NCHGR Communications Office. For address, see *PGC* 13:3,7.

TOUGH DECISIONS

Kaback, from p. 1

mission. A formal statement of the ASHG supporting a woman's right of choice about pregnancy termination for genetic indication was adopted in 1990 by a near unanimous vote of ASHG members and has been promulgated widely. We continue to stand by that position.

- The ASHG, like other large societies, must commit by contract to meeting locations 4-5 years in advance. The Board researched the options of breaking the New Orleans contracts, but could not without significant financial exposures. Moreover, a satisfactory alternative site for the 1993 meeting was not available, particularly where we could be certain that restrictive abortion legislation would not be enacted by 1993.
- Rather than reacting by boycotting the city, the Board felt it would be appropriate to take a positive stand in New Orleans and create a strong program dealing with genetic issues in women's reproductive choices. Such program activities are to be directed both to public and professional audiences.

An open and protracted discussion followed at the membership meeting in Washington. A motion from the floor to poll the membership by mail concerning the Board's decision failed.

Not unlike the frequent clinical situation in genetic counseling, we were faced with having to make a decision from a series of difficult choices. No one is entirely satisfied. Yet we must not let this issue divide us, not undermine our continued efforts to bring important issues related to human genetics to the attention of both professional and lay audiences.

ASHG values its partnership with NSGC. The participation of your membership in our annual meetings has added to the diversity and quality of those conventions. Your continued support and participation are very much desired by the Board and by the membership of ASHG.

Taking A Stand as Leaders

Kloza, from p. 1

seling, regional newsletters and presidential memos.

The NSGC Board does not make decisions in a vacuum. Each Board member has the responsibility to acquaint him or herself with the facts surrounding the issues and, especially in the case of Regional Representatives, to know what their constituents want. When issues which are tied strongly to personal values arise, the NSGC membership is asked to express individual viewpoints directly. We've done that with our pro-choice policy, our Code of Ethics and will do so with our Resolutions and the Society's Vision Statement later this year.

'...the process we use for decision making is as important as the ultimate decision.'

Currently, the Board is asking for guidance regarding the location of the 1993 conference site. Membership input is not generally requested regarding meeting location. But in this case, it is not simply a question of geography. The issue addresses the degree to which your personal and professional investment in the freedom of choice issue should be reflected by NSGC action. The challenge is to recognize the opportunity that this gives us to strengthen our society.

The process we use for decision making is as important as the ultimate decision. Just as counselors are asked to respect the decision of patients who choose a course of action which might be contrary to the counselor's preferred decision, so must our debate be respectful and tolerant. We have the freedom among our colleagues to be directive, persuasive and passionate in our discussion. However, we must not obscure the fact that our maturity as an organization demands as much recognition of differing goals and values among our colleagues as we acknowledge among our patients.

Indeed, these are interesting and challenging times.

ONE MEMBER'S VIEW

THE CASE FOR NEW ORLEANS AS MEETING SITE

by Lynn Weintraub, M.S., New Orleans, LA

Our professional society has taken a public stance on the issue of a woman's right to make her own reproductive decisions. There is a serious conflict with this belief and the recent law passed by the Louisiana state legislature. However, the decision to relocate our meeting based on our initial reactions to this legislation would be unfortunate.

A federal injunction has been granted suspending the new law. This case, or one similar to it, may come before the U.S. Supreme Court and Roe v. Wade may be overturned. A significant number of states would then pass similar laws. To predict where this process will be in two years is ludicrous.

I believe that the relocation of our meeting would have a negligible political impact. However, the economic consequences for the city of New Orleans would be significant. As a resident of the city of New Orleans, it is clear to me that the city and the state are very distinct entities. Support for the recent anti-abortion law has come primarily from constituents and legislators outside the boundaries of Orleans Parish. The intent to punish the regressive activities of these individuals is appropriate, but relocation of our conference would be a misdirected and meaningless action.

I suggest that the NSGC take a positive and productive position on the issue. We have nearly two years to formulate an action plan that could be implemented in New Orleans. It could be more powerful than any boycott and would not injure innocent parties.

CUT TO THE CHASE

Gettig, from P. 1

lative change. The intent of a decision to *not* hold the meeting in New Orleans is not to harm local business people, but rather to send a message to the electorate of Louisiana that their reproductive law is unacceptable. Their voting power is *their* choice.

The NSGC has always been an organization separate from ASHG. Although many NSGC members are ASHG members as well, and the goals of the organizations are similar, our approach has been different and our identity unique.

Due to our size, we have the luxury of committing to a meeting site as little as one year in advance. At this time, our organization has no financial liability if we choose not to go to New Orleans. Boycotting Louisiana would surely be an act of self-determination on our part.

Another major issue is, quite simply, reproductive freedom. Our association adopted a Reproductive Freedom Policy Statement in 1987. Many of our members have jobs that rely on the availability of prenatal diagnosis and the option of safe and legal abortion services.

Do we as an organization wish to meet in a state that has willingly and knowingly chosen to limit access to abortion and reproductive services? Do we choose a state where patient counseling or referrals cannot *by law* present balanced information about options regarding prenatal care?

I suggest that those states which have limited access to reproductive choices (including, sadly, my own, Pennsylvania, as well Utah, Louisiana and Missouri) *not* be knowingly selected as NSGC meeting locations.

The issues revolve around choices concerning self-determination, finances and our need to support our organization's reproductive choice policy. Will we make a huge political or economic impact? Probably not, but I will sleep better knowing that I personally enacted my right for choice.

HUMAN GENOME PROJECT UPDATE

This column will regularly provide an update of information about the Human Genome Project. All opinions, ideas and information for the column are welcome. — Joanne Inserra, Norwalk Hospital, Norwalk, CT

CF PILOT PROJECTS FUNDED

Seven research teams will begin a 3-year study to define the best methods for educating and counseling individuals being tested for the gene that causes CF. These studies will supply health professionals with information to increase a person's understanding of genetic testing, protect confidentiality of results and reduce test-related stigmatization and discrimination. According to Eric Juengst, "one of the underlying goals of these studies is to help determine whether testing services for the CF gene should remain focused on members of families already known to be at risk, or whether it is feasible to offer the test more widely in an ethically acceptable manner."

HG INITIATIVE: IMPACT ON GENETIC COUNSELING

The HGP will be the focus of the NSGC's 1992 Annual Education Conference in San Francisco. Plenary sessions will address the impact of the Human Genome Project on genetic counselors and ethical, legal and societal issues that will accompany the new advances will be explored. Workshop topics will deal with other areas of the profession. Curbside consultations, contributed papers and posters as well as open forums will complete the program.

Comments, questions and suggestions can be directed to co-chairs Ann Happ (518-445-5120) or Lynn Hauck (602-795-5675).

FRAMEWORK MAP

HGP scientists have begun a unified effort to develop a framework map of the human genome. This interim map will establish an ordered set of special, high quality "index" markers on each human chromosome to help scientists pinpoint genes or other genetic regions more quickly. The project is expected to take up to three years to complete. Although about 2000 markers have already been assigned to human chromosomes, only a small fraction are of high enough quality or sufficiently informative to be used as index markers.

WHAT'S AHEAD?...

- December 8-11: *Human Genetics and Genome Analysis: A Practical Workshop for the Nonscientist,* Cold Spring Harbor, NY (J. Witkowski, 516-549-0507).
- March 13-15: *Second Invitational Conference of Genetics, Religion and Ethics,* Houston, TX (R. Nelson, 713-797-0600).
- March 19: *NCHGR Lecture Series: Social Implications - Genetics & Popular Culture,* Bethesda, MD (C. Dahl, 301-402-0838).
- June 15-19: *Genomic Information: Ethical Implications,* Seattle, WA (B. Brownfield, 206-543-5447).

Research Network

The Behavioral Genetics and Neuroimaging Research Center of the Johns Hopkins University Hospital and the Kennedy Institute is currently seeking families to participate in a clinical research project being funded by the NIH. Participating families must have a female child between 6 and 16 years of age who has been diagnosed with Fragile X.

All families will receive free, comprehensive cognitive, social and behavioral evaluations as well as financial compensation. Limited funds are available to cover travel expenses. Free cytogenetic and DNA testing may also be available.

For further information, call project coordinators, Kathleen Green or Megan Sanders collect at 410-550-9313 or write c/o The Kennedy Institute, Behavioral Genetics and Neuroimaging Center, Suite 507, 550 N. Broadway Ave, Baltimore, MD 21205.

Celebrate Ourselves

'Art of Listening' Award

The Alliance of Genetic Support Groups honored **Elsa Reich,** New York University School of Medicine, with the second "Art of Listening" award. This award was established by the Alliance two years ago with funding from the Kaplun Foundation to acknowledge medical professionals who demonstrate the capacity to listen and understand.

Authors in our Midst

Four members have written a chapter on genetic counseling in *Reproductive Risk and Prenatal Diagnosis,* edited by Mark Evans (1992: Appleton & Lange, Norwalk, CT). **Eric Krivchenia, Anne Greb, Kathryn Sargent** and **Wendy Uhlmann** co-authored the chapter on genetic counseling. The counselor-written contribution has been given second- chapter placement, an important statement about genetic counseling services in relation to prenatal diagnosis and testing.

Ricki Lewis has written *Life* (1992: Wm C. Brown, Dubuque, IA), a biology text that devotes eight chapters to genetics.

Amy Cronister Silverman along with Randi Hagerman co-edited *Fragile X Syndrome* (1991: Johns Hopkins Press, Baltimore) . Amy wrote the chapter on genetic counseling.

Gettig Wins Council Seat

Betsy Gettig was elected Councilwomen for the Borough of Forest Hills, a suburb of Pittsburgh. She will be sworn in on January 6 for a four-year term. She is preparing for this responsibility by taking a course in local government for newly-elected officials, co-sponsored by the Community College of Allegheny County and the University of Pittsburgh.

Betsy also serves as a Democratic committeewoman in her district.

Public Acknowledgement

The *Pittsburgh Press, Philadelphia Inquirer* and *The European,* and the production staffs of TV's "Nightline," "Good Morning America" and "20/20" have contacted **Betsy Gettig** as a result of the NSGC's testimony on genetic discrimination, submitted for inclusion into the Congressional Record. *(See p. 12)* Responses to the October membership alert were included in the submission and will be used in future documentation.

Send additional cases to Betsy Gettig, c/o Reproductive Genetics, West Penn Hospital, 4800 Friendship Ave, Pittsburgh, PA 15224.

Long Range Planning

Visioning NSGC's Future

NSGC members were invited to participate in focus groups during the recent International Congress of Human Genetics in Washington, DC, as part of a visioning process (see article *PGC* 13:3, 10) related to the Society's future. Under the guidance of the ad hoc Long Range Planning Committee, each of the five lunchtime sessions provided an opportunity for up to 14 counselors to share their dreams and visions for the profession, which were then ranked to achieve a sense of priorities within each group. Common themes included:

- recognition of genetic counselors as leaders, educators and authorities in the field
- identity as advocates for patients and the profession
- encouragement of diversity in the field of genetic counseling

Results from the focus groups will be used by the Committee to prepare a report for the Board of Directors. Members are encouraged to contact committee members with personal thoughts and visions for the NSGC.

An opportunity for discussion of the Committee's report will be available during the 1992 NSGC Annual Education Conference in San Francisco.

Virginia Corson, Chair,
Debra Collins, Andrea Fishbach, Denise Greene, Ann Happ,
Trish Magyari, Mimi Riesch-Donnelly and Bea Leopold (ex officio)

Monday's Visioning Focus Group featured NSGC's Council of Presidents. Seated, from left: Audrey Heimler, Diane Baker, Ann P. Walker, Ann C.M. Smith, Beth Fine. Standing second from left: Barbara Biesecker, Luba Djurdjinovic, Ed Kloza, Joan Scott, Ginny Corson, Deborah Eunpu, Debra Collins and Betsy Gettig. Bea Leopold standing, far left, faciliated the session. Ann Happ standing, far right, was recorder.

Membership Jumps the 1000 Hurdle!

Rarely is a moment captured as a pure moment. Rather, it is a process, relating to its past, present and future. So it was with the long anticipated Society goal of reaching a membership of 1000. That day, the mail included three completed applications: one each in Full, Associate and Student membership categories. We welcome our newest members as we redirect our sights to reaching 2000.

Helga V. Toriello, MS, PhD, originally joined the NSGC as a Full member in 1980, having completed a master's degree in human genetics at Rutgers University and nearing completion of her PhD in genetics from Michigan State University. She is currently Director, Genetic Services, Butterworth Hospital, and Assistant Professor, Pediatrics and Human Development at MSU. "I rejoined because I believe the NSGC is the best network, resource and information available for the application of the complex theories generated from Human Genome activities. I consider these NSGC benefits vital for both my teaching and patient care responsibilities."

Our newest Associate member, **Dianne M. Bartels, RN, MA,** holds a master's degree in psychosocial nursing. She is associate director at University of Minnesota's Biomedical Ethics Center, teachs ethics in the University's genetic counseling program and is editing a book on ethics in genetic counseling. "I suspect I will spend the rest of my career in genetics-related ethics. I joined NSGC because I wanted to go right to the source, to the professionals involved, to continue learning. Although I would have joined regardless, I consider the *Journal* a valuable privilege of membership."

Meghan R. Taylor, BS, expects to complete her master's degree in genetic counseling from the University of South Carolina in 1993. Her research-oriented undergraduate degree in biotechnology provided her with the recognition that she wanted to focus her career on direct contact with people. "What has pleasantly surprised me the most about my studies has been the broad ranged involvement of the profession. I have been particularly impressed with the attention given to ethical issues."

Fellowship Enhances Genetic Counseling Profession

A fellowship program for genetic counselors has been established in memory of NSGC member Jane Engelberg. The Jane Engelberg Memorial Fellowship (JEMF) will provide $25,000 each year to a genetic counselor (or counselors) for study, research, writing or exploration of new interests to enhance or develop skills, contribute to the body of knowledge in the field of genetic counseling or expand professional roles. All recipients will produce results of sufficiently broad interest and merit to warrant professional publication or presentation.

Jane Engelberg enjoys a view from the hills above Jerusalem.

The fellowship is funded by the Engelberg Foundation established in 1990 by Jane's husband, Alfred B. Engelberg. The Engelberg Foundation is a charitable trust which plans to support a wide range of activities in the fields of health care, science and education. An advisory board, selected from the NSGC leadership, is responsible for the receipt and review of fellowship applications, as well as selection of the awardee(s).

The JEMF is available to genetic counselors who are full members in good standing of the NSGC and certified in genetic counseling (or officially Board eligible) by the American Board of Medical Genetics. In future years, opportunities for students in master's degree genetic counseling training programs may also be available.

As this year marks the conclusion of the second decade in which master's level genetic counselors have been working in the field, our professional has begun to experience the need for the traditional sabbatical available to many of our academic colleagues. Now, NSGC members will have the opportunity for research, writing, future training or fulfilling otherwise unattainable professional dreams.

Fellowship applications and additional information may be requested in writing from Audrey Heimler, M.S., P.O. Box 351, Morris, CT 06763. Proposals for the first JEMF award will be due by April 1, 1992.

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JEMF Advisory Board

Audrey Heimler, M.S., Chairperson; Judith Benkendorf, M.S.; Barbara Bowles Biesecker, M.S.; Karen Greendale, M.A. and Edward Kloza, M.S.

JANE ENGELBERG

JANE ENGELBERG graduated from Sarah Lawrence College in 1973 with a master's degree in Human Genetics. During her fifteen year career in New York City at the National Genetics Foundation, Beth Israel Medical Center and Long Island Jewish Medical Center, she became particularly interested in genetic counseling for hemophilia and prenatal diagnosis. Because of her sensitivity to the special needs of Spanish speaking clients, Jane also became a bilingual genetic counselor.

Jane was committed to a high professional standard and viewed continuing education as a means of increasing employment opportunities for genetic counselors. Her insight, compassion and dedication were due in part to the fact that from 1969 until her death in 1988 she was continuously under treatment for advanced Hodgkin's disease and was given little promise of living even long enough to obtain her master's degree.

CANCER GENETICS NETWORK

Members with a special interest in cancer genetics are invited to participate in an informal network for the purpose of sharing resources and information. Send your name, address, telephone, FAX# and a short summary of your involvement or interest in the topic to: Maureen Smith-Deichmann, Reproductive Genetics, Northwestern Memorial, Prentice Women's Hospital, 333 E. Superior, Chicago, IL 60611; 312-908-7441; Fax# 312-908-6643. ***[NOTE: Connecting Links will help other interest groups network. Please be sure to complete the information for our database, included on your 1992 Membership Invoice Statement.]***

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RESOURCE DATABASE EXPLORED

A subcommittee of the NSGC Education Committee is exploring the feasibility of creating a database for patient and professional education materials.

We would greatly appreciate information and input from members who know of existing local, state or regional databases *or* have developed pamphlets and educational materials which may not already be a part of an existing database. If you are willing to share your creations, please send one copy of each pamphlet, the price (if applicable), the ordering address and a contact.

Finally, if you would be willing to help set up an NSGC database, contact: Barbara Pettersen, Genetics Dept., Kaiser Permanente Medical Center, 260 International Circle, San Jose, CA 95119; 408-972-3311; FAX# 408-972-3298.

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STUDY SWAP '93

Overwhelmed by the thought of even beginning the process of studying for the '93 Boards? Unable to afford the time and expense of taking one of the prep courses? Prefer to study alone?

Janice Berliner has begun compiling a detailed study guide for the exams and is interested in swapping notes and resources with others who have begun the process. She plans to offer the finished study guide to others who face the daunting task of preparing for the exam or to anyone interested in a comprehensive basic reference. Contact Janice at 34 Webster Dr, Berkeley Heights, NJ 07922; 800-631-5250 x 2300.

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MEETING MANAGER

Jan 16 - 17: "Cystic Fibrosis Workshop for Genetic Counselors." Human Genetics Program, Sarah Lawrence College, Bronxville, NY. Workshop is free; lunches will be served. Speakers: Francis Collins; Kathy Valverde, Joy Redman, Amy Lemke, Debra Collins, Charles Scriver, Michael Kaback, Mark Skolnick.

Feb 27 - Mar 1: "Women's Realities, Women's Visions." Assn for Women in Psychology, Sheraton Long Beach Hotel, Long Beach, CA. Partial list of topics: cultural differences, reproductive issues, violence, interdisciplinary cooperation, issues related to the workplace. For more information, contact June Peters, Long Beach Memorial Breast Center, 310-595-2907; messages: 310-987-0396.

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LOST BUT NOT FORGOTTEN

The following members were moved to inactive status in 1991. We would like to give them the opportunity to reactivate their memberships in 1992. If you can help us locate them, or know that they have left the field permanently, please contact the Executive Office or encourage the member to contact us directly. Thank you.

NAME	LAST KNOWN ADDRESS
Region I	
DiMAIO, Miriam	New Haven, CT
HASKIN-LEAHY, Leanne	Boston, MA
HASTINGS, Valerie	Bedford, MA
HAWLEY, Pamela	Boston, MA
SAWYER, Pamela	Acton, MA
STRYKER, Janice	Boston, MA
Region II	
COHEN, Janet	Monsey, NY
COHEN, Sharona	Rego Park, NY
FOX, Paula	Mt. Sinai, NY
HONG, Hee-Kyung	Pittsburgh, PA
McAFEE, Marybeth	Reading, PA
McNALLY, Gloria	Washington, DC
PUSSO, Sharon	Bethel Park, PA
SCHWARTZ, Sheryl	Little Neck, NY
SICKEL, Ruth	Bethesda, MD
SOFFER, Jill	Ossining, NY
WALLACE, Fiona	Hollis, NY
WRIGHT, Kathleen	Syracuse, NY
Region III	
ANGRIST, Misha	Durham, NC
GALE, Elizabeth	Richmond, KY
HENDRICKSON, Jill	Gainesville, FL
HILLIARD, Margaret	Mobile, AL
HOSTETLER, Doreen	Chapel Hill, NC
Region IV	
BARA, Cheryl	Iowa City, IA
BECKER, Joanne	Madison, WI
BLOOM, Beth-Ann	St. Paul, MN
CAFFARELLI, Melissa	Chicago, IL
CHILDS, Mishun	River Rouge, MI
KOLACKI, Paula	St. Louis, MO
LEININGER, Anna	Madison, WI
PRINZING, Susan	Lansing, MI
Region V	
PRESCOTT, Karen	Denver, CO
WANG, Vivian	Arvada, CO
Region VI	
BUSTILLO, AnaMaria	Seal Beach, CA
CRAWFORD, Elizabeth	Del Mar, CA
IZYKOWSKI, Barbara	Seal Beach, CA
PEPIN, Melanie	Seattle, WA
PETERSON, Ann	Sacramento, CA
CANADA	
GAZZOLA, Beth	Ontario
BIDDLE, Catherine	Alberta
DIRCKS, Anita	Vancouver

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LOST & FOUND

Found at the NSGC Annual Membership Business Meeting in Washington: One pair of Liz Claiborne granny-style glasses with a green strap. Please call the Executive Office if they are yours.

GC PROGRAM IN NEW ENGLAND

New England now boasts not only its first NSGC President but its first Genetic Counseling Training Program, as well. Brandeis University is now accepting applications for Fall 1992 admission.
Referrals can be made c/o Judith E. Tsipis, PhD, Director, Biology Department, Brandeis University, Waltham, MA 02254-9110; 617-736-3165.

COMMITTEE NEWS 'N NOTES

AEC SUBCOMMITTEE

POLL RESULTS REPORTED...

In the last issue of *PGC* (13:3), the Annual Education Conference (AEC) subcommittee conducted a membership poll to determine your opinion regarding boycott as political statement. The specific issue revolved around holding the 1993 AEC in New Orleans. The response was:

Total Response Rate: 34%

32% I would *not attend* an NSGC Annual Education Conference held in a location with strict anti-abortion laws or other laws/policies contrary to the Society's policies or my personal beliefs.

54% I would *prefer* that NSGC's Annual Education Conferences *not be held* in locations ..., *but would consider attending anyway.*

7% I *would attend* an NSGC Annual Education Conference, *even if held* in a location ...

7% I do not believe that boycott is an effective means of political statement.

Thanks to all who responded to the opinion poll and refer to the related articles beginning on page 1 in this issue of *PGC* for the opportunity to provide additional input.

'92 AEC Site, Dates Announced

The '92 Annual Education Conference, "The Explosion of the Human Genome Project" has been scheduled for November 6 - 8 at the Grand Hyatt, San Francisco. The information and registration brochure will be mailed in the Spring. Please forward names of non-member colleagues who may be interested in attending to the Executive Office.

'93 Conference Chairs Announced

Regardless of the location, plans are underway for the 1993 NSGC Annual Education Conference. Stephanie Smith (601-984-1900) and Ron Cadle (606-233-5558) have volunteered to co-chair the conference. Both have served as Region III Representatives to the NSGC Board of Directors in recent years.

Susie Ball, M.S.

NON-MASTER'S LEVEL COUNSELORS

FINAL NML DOCUMENT AVAILABLE

Last year, the ad hoc committee on Non-Master's Level Counselors sent a *draft* of a document discussing the pros and cons of utilizing "single disorder" or non-master level counselors, to all NSGC members for review. A final document has been prepared, incorporating comments from the open forum at the 1990 NSGC Annual Education Conference in Cincinnati.

Copies are available upon request from the Executive Office.

Joan Scott, M.S.

ETHICS SUBCOMMITTEE

CALL FOR MEMBERS

One member will rotate off the Ethics Subcommittee in 1992. Interested full, associate or student members of the Society are invited to inquire about committee activities by contacting: Rose Grobstein, 503 Weatherstone Drive, Paoli, PA 19301; 215-889-7418.

Judith Benkendorf, M.S.

GENE BYTES

COMPUTER-ASSISTED PATIENT TRACKING

by Karen Wcislo, MS and Robert Resta, MS

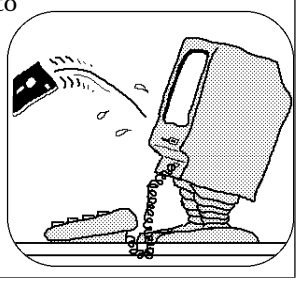
Computers can't make you counsel better, but they can help make you a better counselor. As your patient load increases (on a seemingly exponential curve), patient management and tracking becomes more difficult and time-consuming. Each of us has developed our own system for keeping track of what needs to be done for patients, but there is always the concern that something or someone might fall "through the cracks."

Computers offer some relief from the tedium of administrative detail. Database software such as DBase, RBase, FoxPro and Paradox (to name a few of the more popular DOS programs) can assist by:

- Identifying if and when a patient was previously seen, which professional(s) were involved, and the primary indications.
- Identifying a patient who has contacted your department but has not yet been seen ("but that intake sheet was here just a moment ago!")
- Listing patients who need return visits.
- Tracking referral records, charts, consultations and tests ordered.
- Identifying prenatal patients who have not made a decision by 16 weeks and need to be re-contacted.
- Generating appointment and result letters, as well as reminders of delivery dates to obtain pregnancy outcome.

Even for the novice, writing programs to perform these chores is less daunting than it sounds. Most database software come with "application generators", an option which automates program development for those with little knowledge of programming languages.

Getting bogged down in the mire of clerical detail can increase the risk of burn-out and job dissatisfaction. Allowing the computer to take care of routine administrative chores frees up the genetics counselor to concentrate on the genetic and psychological aspects of patient care, not "what have I forgotten?"



COOL TIPS

Clean your monitor screen with a used piece of fabric softener from your laundry.

WordPerfect for Windows is here, but don't buy it yet unless you do lots of graphics and layout work...first releases are always full of bugs.

Legislative Briefs

Congress Holds First Hearing on Privacy

A public hearing, "Domestic and International Data Protection Issues: Possible Uses and Misuses of Genetic Information" was held on October 17 by the Government Information, Justice and Agriculture subcommittee of the Committee on Government Operations. Chaired by Bob Wise, the hearing was in response to awareness generated by H.R.2045 (Human Genome Privacy Act), a bill introduced last summer by John Conyers. Both the hearings and the bill indicate a new interest in Congress for genetic issues, spurred by the high profile and large budget of the Human Genome Project (HGP).

In his opening remarks, Rep. Conyers posed three legal questions:

- how to protect the confidentiality of genetic information;
- how to protect people from discrimination in employment; and
- how to protect people from discrimination in access to health, disability and life insurance.

He cited that a recent OTA report indicated that 59% of employers *require* pre-employment health examinations, raising concerns that pre-symptomatic screening could be used against potential employees. He noted that although both ELSI committees made recommendations for inclusion, the regulations recently published by the EEOC did *not* explicitly state that the misuse of genetic information is a violation of the Americans with Disabilities Act. According to the EEOC, the ELSI recommendations "exceeded the scope of the ADA," a situation that Rep. Conyers vowed to change.

Testimony Covers Gamut of Issues

Dr. Bernadine Healy, Director of NIH, summarized NIH's commitment to exploring the ethical, legal and social issues associated with the HGP. Dr. David Galas spoke regarding the ELSI program in the Department of Energy, which will focus future funding on projects related to genetic privacy.

Dr. Nancy Wexler, representing the ELSI committee, gave testimony focused on insurability concerns, cases of persons being denied coverage solely on the basis of genetic risk. She told of persons opting to pay for genetic tests out -of-pocket to avoid possible insurance repercussions and called for legislation to address discrimination against persons at risk for genetic conditions.

Dr. Paul Billings, of the California Pacific Medical Center, who recognized the contributions of the NSGC in his oral testimony, reported on his collection of cases of genetic discrimination, especially related to the cancellation of insurance policies on the basis of genetic risk. Dr. Billings and others raised the possibility that issues related to genetic privacy required a Congressional commitment that would go beyond the current powers of the ELSI committees to make policy recommendations, and suggested that a Congressional Commission was needed to make timely policy recommendations.

Jeremy Rifkin, President, Foundation on Economic Trends, testified largely on the need for Federal legislation to protect genetic privacy.

Lastly, Dr. Phil Reilly, testified on behalf on ASHG, which views the Human Genome Privacy Act as an "important initial effort that with further study and revision should provide an important basis for the protection of privacy." He then innumerated a seven point plan to safeguard personal privacy, including to "characterize the violation of genetic data bank and wrongful collection, use or dissemination of genetic data as a criminal act and, also, create civil remedies for persons harmed by wrongful disclosure."

Trish Magyari, M.S.
Legislative Liaison

Arkansas Genetics Program in Jeopardy

The statewide, comprehensive genetic counseling program, the Arkansas Genetics Program (AGP), under the Departments of Pediatrics and Obstetrics/Gynecology, University of Arkansas for Medical Sciences, is being sued by a woman with cerebral palsy. Arkansas Right to Life is sponsoring the plaintiff because they believe the sole purpose of the AGP is to engage in prenatal screening for the purpose of aborting "disabled unborn children." Arkansas Right to Life alleges that prenatal diagnosis procedures such as CVS, amniocentesis and MSAFP should be prohibited because these procedures lead to abortion. Their acting medical consultant, a pathologist, believes all treatable abnormalities can be discovered through ultrasound. Dr. Harry P. Ward, UAMS Chancellor, has been consistently supportive of the AGP, stating at a press conference on August 13, "If abortions were made illegal, we would still need and have the Arkansas Genetics Program." Dr. Chris Cunniff, geneticist and Co-Director of AGP, also stressed that the AGP staff provides non-directive counseling when evaluating genetic and prenatal diagnosis patients. Dr. J. Gerald Quirk, maternal-fetal obstetrician and Co-Director of AGP, emphasized the benefit of prenatal diagnosis is the coordination of timing, method and location of delivery and preparing for proper treatment in the newborn period.

This lawsuit follows another by Ralph Forbes, who contends that UAMS and University Hospital (UH) are breaking state law by performing abortions for fetal anomalies. Arkansas Amendment 68 says that state funds may not be used to pay for abortions. UAMS and UH contend that since patient fees pay for the cost of the abortions, they are within the law, because the intent of the law was to prohibit the use of public or legislated funds to pay for abortions. In this case, the judge has issued a temporary injunction that an abortion can be performed *only* if the patient can pay at the time of admission. Those who are unable to pay in advance cannot receive abortion services.

Becky Butler, M.S.S.W.
Arkansas Genetics Program, Little Rock, AR

Letters to the Editor

Counselors Called On to Become Visible in HGP

To the Membership:

We recently reviewed grant proposals for the Ethical, Legal and Social Issues (ELSI) Program of the National Center for Human Genome Research. We were struck by the absence of applications from genetic counselors and their limited involvement in the reviewed proposals.

This is unfortunate, as potential projects are well suited to the skills and abilities unique to our profession. ELSI funds research projects about genetic counseling issues, the development and testing of educational materials and conferences regarding the ethical, legal and social aspects of the Human Genome Project.

Genetic counselors are uniquely qualified to develop and direct educational and research projects on these issues, either as Principal Investigators or collaborators. Our interdisciplinary training and practical clinical experience make us ideal candidates for these opportunities, particularly experienced counselors looking for new challenges, or those with faculty appointments looking for research funding.

NIH accepts applications during three funding cycles per year. Dr. Eric Juengst, Director of the ELSI Program is approachable and currently soliciting ideas for future applications. His office (301-402-0911) can supply the ELSI grant announcement and technical assistance in developing the application.

As a professional group, let's use our expertise and creative ideas to further the important goals of the ELSI program. We hope some of our gifted colleagues' names will be among the future applicants.

Trish Magyari, M.S.,
Macro International, Inc.,
Silver Spring, MD
and Ginny Corson, M.S.,
Johns Hopkins Hospital,
Baltimore, MD

Sex Selection: Culture and Access to Care

To the Editor:

Michael Begleiter provides an interesting counterpoint on the issue of sex selection in his Letter to the Editor, "Cultural Values vs. Morality: Not a Dilemma" (*PGC* 13:3). However, he displays a form of ethnocentricity and arrogance I find distressing.

The major issue in sex selection has not been the availability of abortion to those individuals who wish to terminate because of undesired sex of the fetus. The law in most of the land remains abortion on demand, whatever the reason. Would the author allow termination of pregnancy for social or financial reasons but deny it to those concerned with sex selection? ...47,XYY? ...HD?

Rather, the debate in this country has centered around the issue of providing prenatal diagnosis, invasive procedures with limited availability, for sex determination alone. With the possible advent of a non-invasive and widely available early test for sex determination in the future, the debate will certainly escalate. However, I do not foresee the use of widespread preferential sex selection in this country as ever presenting a problem.

As to culturally based morals, Mr. Begleiter may be in possession of the book of "Universal Moral Codes," but I have not seen it. While many individuals in this country would not seek prenatal diagnosis or termination of pregnancy for sex selection, that does not make it a universal moral truth. We are not trained nor should we presume to be moral judges of our patients. To disregard or try to change cultural mores simply because someone is no longer in their country of birth or ancestry is insensitive.

As strongly as some may feel that sex selection is wrong, there are others who feel just as strongly that it should be allowed. What is "just plain wrong" is the imposition of my or anyone else's morals, no matter how prevalent, on an individual and denying them access to legal health care services.

Scott Polzin, M.S.
Lutheran General Hospital
Park Ridge, IL

Counseling Experience Shapes a Young Mind

To the Editor:

Part of my job involves providing services to drug dependent pregnant women at the D.C. General Hospital. One year ago, I met a woman who was 26 weeks pregnant and had recently become drug-free.

She recently informed me that her 12-year-old son had written an essay he wrote during his first week of 7th grade. In response to the question of what he wanted to be when he grew up, Elliott Ford wrote about becoming a genetic counselor.

This essay is particularly timely in these days of predicted personnel shortages. Lecturing to students and writing brochures are only part of the solution. We also have the ability to influence career choices through the families whose lives we touch.

Judith Benkendorf, M.S.
Georgetown University Medical Center, Washington, DC

Why I Want to be a Genetic Counselor

I want to be a genetic counselor because you can explain about things that could be passed down from your family members. I think more people should know more about genetics.

There are a number of diseases you can inherit from your family members. Some of these diseases are problems that can effect height and weight among other things.

Genetics is a part of biology that deals with heredity. Heredity is when you inherit certain characteristics from people in your family. By gathering this information I will be able to help people understand more about genetics. This is why I want to be a genetic counselor.

by Elliott Ford, Grade 7,
Hines Jr. High School

RESOURCES

• BOOK •

Mapping Our Genes
author: Lois Wingerson
publisher: Dutton, NY, 1990
price: $19.95, 338 pp
reviewer: Sylvia Mann, M.S.

I have read many books about genetic issues. *Mapping Our Genes* is one of the most entertaining.

Each chapter introduces a story and characters behind some facet of genetic research. Interest is immediately captured by the struggle of one family affected by Friedreich's ataxia. The family is followed on the long road to diagnosis and the slow, difficult work of tracing family members for genetic studies. Other chapters reveal similar behind-the-scenes tales about cystic fibrosis, Huntington's disease, diabetes, cancer and gene mapping. One of the best stories is about Janice Egeland's work with manic-depressive illness and the Amish population.

Throughout the stories, Wingerson poses ethical questions and conflicts. What is the future of genetic research and how will it affect our futures? Will our employment opportunities and insurance coverage be determined by our genetics?

The stories in this book are good examples about the progress and pitfalls of gene mapping. Information is clear and interesting. *Mapping* is a good introduction to people without a genetics background and is entertaining for those who already know their genetics.

• VIDEO •

Health Education for Non-Readers
distributor: Universal Health Associates, Inc., 1701 K Street, N.W., 600 Washington, D.C. 20006, 202-429-9506. (1990)
time, format, price: 17:10, 1/2 inch VHS;Beta and 3/4 inch available by special order only. $95.00
reviewer: Trish Magyari, MS

Have you ever wondered why so many brochures end up on the clinic floor? Why appointment letters go unheeded?

The field of genetics has many long words and complicated concepts, and some of our patients may not have the reading skills or educational background to comprehend them. *Health Education* sensitizes professionals to these realities and provides practical advice for meeting the needs of clients with little or no reading skills. As an added benefit, counselors' use of these techniques will improve the comprehension of all of our clients.

Health Education for Non-Readers is basically a slide presentation on videotape. However, what is sacrificed in format is made up in content. This thorough introduction presents information in a clear, concise manner and has many illustrative examples. Originally designed as part of the Health Literacy Project in Philadelphia, the video fills a previous gap in professional education. The video covers:

- the difficulties faced by persons with little or no reading skills in comprehending health education;
- how to identify passages at various reading levels;
- recommendations for improving the usefulness of written and oral instructions; and
- evaluation of the appropriateness of visual aids.

The bottom line…*keep it short, keep it simple and keep it in context.*

Weaknesses of the video are minor: omission of simple methods to calculate the reading level; use of incidence figures specific to Philadelphia; use of a few undefined jargon terms and some recommendations not followed by examples.

These minor flaws aside, the video is recommended for a number of audiences. Anyone communicating with patients should be familiar with these concepts. Genetic counseling training programs will find this a good investment for first year students. Genetic counselors who supervise students or residents may wish to require viewing prior to participating in a genetics clinic.

• NEWSLETTERS •

Alcohol Alert

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) publishes *Alcohol Alert,* a quarterly bulletin that provides information on alcohol research and treatment for health professionals. Each bulletin summarizes findings on a single topic in alcohol research. The latest bulletin, "Fetal Alcohol Syndrome," reviews research findings on the adverse effects of prenatal alcohol exposure and the incidence of fetal alcohol syndrome (FAS). It also explores two key questions in FAS research: "How much is too much?" and "When is the fetus at greatest risk?"

To request copies at no charge or add your name to the mailing list, write to: NIAAA, Attn: Alcohol Alert (SGC), Office of Scientific Affairs, Scientific Communications Branch, #16-C,14 Parklawn Bldg, 5600 Fishers Ln, Rockville, MD 20857.

• ORGANIZATION •

The National Tuberous Sclerosis Association (NTSA)

This multifaceted group offers several newsletters: *Perspectives* for the general membership, *Resources* for health professionals and *Grandparent's Voice* for grandparents. Also, support groups and contact persons are available as well as educational resources and research grants.

For more information, please contact: NTSA, 8000 Corporate Drive, #120, Landover, MD 20785; 301-459-9888; 1-800-225-NTSA.

• SUPPORT GROUP •

Coffin-Lowry Syndrome

The mother of a son with Coffin-Lowry syndrome has identified several other families who are interested in forming a database for exchange. Genetic counselors are invited to network interested families by referring them to: Mary Illa, 6790 N.E. Day Road West, Bainbridge Island, WA 98110.

• CLASSIFIED • CLASSIFIED • CLASSIFIED • CLASSIFIED • CLASSIFIED •

The classified listings printed in this issue represents 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.

LA JOLLA, CA: Immediate opening for BC/BE Genetic Associate.
RESPONSIBILITIES: Rapid growing academic center with wide range of clinical & laboratory services/GC oppty: general & reproductive genetics, amnio, CVS, teratology, MSAFP scrng.
CONTACT: Marilyn Quinnell, Personnel Manager, Univ California San Diego, 10280 N. Torrey Pines Rd, Ste 265, La Jolla, CA 92093; 619-597-2615. Refer to Job# 28329-L) EOE/AA.

OAKLAND, CA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join multidisciplinary team in hemoglobinopathy/coagulation disorders unit; occasional hemoglobin trait & PN referrals; community & professional education; research oppty avail.
CONTACT: Susan Pinheiro, MS, Hematology Dept, Children's Hospital of Oakland, 747 52nd Street, Oakland, CA 94609; 510-428-3167. EOE/AA.

OAKLAND, CA: Immediate opening for 2 BC/BE Genetic Counselors. (1 FT/1PT)
RESPONSIBILITIES: Join multidisc team in community hosp-affil MFM prog with expanding PN dx prog: routine & early amnio, CVS, U/S, terat, preg loss, maternal diabetes.
CONTACT: Dolores Madden, MS, Alta Bates Maternal Fetal Med, 5730 Telegraph Ave, Oakland, CA 94609; 510-540-1507. EOE/AA.

ORANGE, CA: Immediate opening for parttime BC/BE Genetic Counselor. BSN, related MS/MA or PH degrees with exp in OB also eligible.
RESPONSIBILITIES: Assist full-time MSAFP Coordinator in management of the Calif MSAFP Scrng Program in the Orange Co. area. Oppty for clinical education, GA student supervision & GC involvement.
CONTACT: Kathy Steinhaus, MS or Thea Wills-Olsen, MS, Dept Pediatrics, Div. Genetics, UCI Medical Ctr, Box 14091, Orange, CA 92613-4091. EOE/AA.

PANORAMA CITY, CA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join large team in comprehensive clinic & PN diag program: amnio, CVS, hi-level U/S, cytogenetics, teratogen coun; MSAFP, newborn hemoglobinopathy scrng, craniofacial svc.
CONTACT: Harold N. Bass, MD, Genetics Service, Kaiser Permanente Medical Center, 13652 Cantara St, Panorama City, CA 91402-5497; 818-375-2073; 818-564-3322. EOE/AA.

SAN JOSE, CA: Immediate opening BC/BE Genetic Counselor.
RESPONSIBILITIES: All aspects of counseling & case management for ped & general genetics; amnio; CVS; teratology; MSAFP; hemoglob scrng.
CONTACT: Karen Wcislo, MS, Genetics Dept, Kaiser Permanente Medical Center, 260 International Circle, San Jose, CA 95119; 408-972-3300. EOE/AA.

DENVER, CO: Immediate opening for Denver-based BC/BE Genetic Counselor. Minimum 3 years clinical exp required w/ emphasis on PN. *Possible upcoming openings in Dallas & Miami.*
RESPONSIBILITIES: Genetic consult support & technical assistance to physicians for pts with abnormal results; pt consults.
CONTACT: Brenda Jones, Human Resources, Genetrix, Inc., 6401 E. Thomas Rd, Scottsdale, AZ 85251; 800-333-GENE, x 108.

FARMINGTON, CT: Immediate opening for BC/BE Genetic Counselor or related masters degree professional with 2 years experience. Nursing candidates should have coursework in human genetics. Academic appointment available.
RESPONSIBILITIES: General/consult svc, Div. Human Genetics: Organize weekly clinic, assign medical staff on elective, intake & follow-up for families; integrate lab data; maintain stats & quarterly repts. Div. Ped Neuro: Serve as GC in neurogenetics clin, oppty for research. General GC: Provide independent GC for patients & families. Case mgmt, seminars, journal club, human genetics course for medical professionals.
CONTACT: Robert M. Greenstein, MD, Div. Human Genetics, MC6310, Univ Connecticut Health Center, Farmington, CT 06030; 203-679-1500. EOE/AA.

WASHINGTON, DC: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Participate in Human Genome Project: identify subjects; review med genetic records; interview families; coord participation in project; keep records. Some administrative functions.
CONTACT: Dr. Barbara A. Quinton, Div. Medical Genetics, Dept Pediatrics & Child Health, Howard University, 2139 Georgia Ave NW, Suite 3A, Washington, DC 20001; 202-865-3022. EOE/AA

TAMPA, FL: January 1 opening for BC/BE Genetic Counselor. Autonomous, independent personality pref.
RESPONSIBILITIES: Diverse & active ped/PN counseling oppty w/ emphasis on PN.

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NATIONAL SOCIETY OF GENETIC COUNSELORS, INC.
EXECUTIVE OFFICE
233 CANTERBURY DRIVE
WALLINGFORD, PA 19086

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CONTACT: Send 3 letters of rec w/ CV to Boris G. Kousseff, MD, Dept Pediatrics, Box 15G, Univ South Florida,1 2 9 0 1 Bruce Downs Blvd,Tampa, FL 33612-4799; 813-974 3310. EOE/AA

WEST PALM BEACH, FL: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: All aspects of PN coun, recurrent pregnancy loss, specialty clinics, paternity & pediatrics. Great oppty for practice in an established, growing, private Genetics Center.
CONTACT: Gene Manko, MD, Genetics Institute of Florida, 1401 Forum Way, Suite 210, West Palm Beach, FL 33401; 407-697-4200. EOE/AA.

WALTHAM (BOSTON), MA: Half-time Faculty Position starting June 1 for experienced BC/BE Genetic Counselor in newly established Master's Program in Genetic Counseling.
RESPONSIBILITIES: Tch & advis students, coord clin component of program, assist with the development & implementation of this new program.
CONTACT: Judith Tsipis, PhD, Biology Department, Brandeis University, Waltham, MA 02254; 617-736-3165. EOE/AA.

DETROIT, MI: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Peds & PN GC: amnio, CVS, diagnostic U/S; oppty for newborn scrng, outreach & education.
CONTACT: Lester Weiss, MD, Medical Genetics & Birth Defects Center, Henry Ford Hospital, CFP-4, 2799 West Grand Blvd , Detroit, MI 48202; 313-876-3188. EOE/AA.

DETROIT, MI: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Coordinate & provide GC in hospital-based comprehensive PN program: CVS, amnio, MSAFP, U/S, teratology. Oppty for professional & commun education.
CONTACT: Mary Helen Quigg, MD, Dept OB/GYN, Div Reproductive Genetics, Grace Hospital, 6071 W. Outer Dr, Detroit, MI 48235; 313-966-4278. EOE/AA.

DETROIT, MI: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join active team in large, diverse, rapidly expanding, reproductive genetics ctr: CVS, amnio, MSAFP, diagnostic U/S, teratogen coun, novel fetal therapy. Research, publication oppty.
CONTACT: Anne Greb, MS or Mark I. Evans, MD, Dept OB/GYN, Div Reproductive Genetics, Hutzel Hospital, 4707 St. Antoine Blvd, Detroit, MI 48201; 313-745-7067. EOE/AA.

CAMDEN, NJ: Immediate opening for BC/BE Genetic Counselor/ Administrative Assistant to Director.
RESPONSIBILITIES: Serve as service & technical liaison between physicians, geneticists, GCs & Repositories. Provide professional & community education of Repositories' services & activities.
CONTACT: Personnel Department, Coriell Institute for Medical Research, 401 Haddon Ave, Camden, NJ 08103. EOE/AA.

NEW BRUNSWICK, NJ: Immediate opening for parttime BC/BE Genetic Counselor. Experience preferred.
RESPONSIBILITIES: Pediatric & adult genrl GC in academic setting with tchg & research oppty; specialty clinics.
CONTACT: Ming-liang Lee, M.D., Robert Wood Johnson Medical School, Dept. Pediatrics, CN-19, New Brunswick, NJ 08903. EOE/AA.

NEW HYDE PARK, NY: Challenging position for BC/BE Genetic Counselor.
RESPONSIBILITIES: Diverse GC activities for PN & ped patients. Outreach respon.
CONTACT: Joyce E. Fox, MD, Schneider Children's Hospital, New Hyde Park, NY 11042; 718-470-3010. Long Island Campus for the Albert Einstein College of Medicine. EOE/AA.

STATEN ISLAND, NY: Immediate opening BC/BE Genetic Counselor.
RESPONSIBILITIES: Diverse PN/pediatric counseling: amnio, AFP, teratogen, malformations, etc; dysmorphology, fragile X, cytogenetic in developmental disability clinic & NICU outreach; education, newsletter, & advisory council participation.
CONTACT: Susan Sklower Brooks, MD, Comprehensive Genetic Disease Program, New York State Institute for Basic Research, 1050 Forest Hill Road, Staten Island, NY 10314; 718-494-5240. EOE/AA.

TOLEDO, OH: July 1 opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Coordinate MSAFP program for professionals & patients: testing, counseling, follow-up; follow-up data collection. Potential for research. Expansion plans include HCG & estriol scrng.
CONTACT: Thaddeus Kurczynski, MD, PhD, Dept Pediatrics, PO Box 10008, Medical College of Ohio, Toledo, OH 43699-0008; 419-381-4435. EOE/AA.

PROVIDENCE, RI: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join growing PN diagnostic service: established multiple marker scrng; CVS; amnio, PUBS, level II U/S; teratogen & dysmorphology counseling; follow-up & support groups; clinical research.
CONTACT: Krista Sauvageau, Employment Manager, Women & Infants Hospital, 101 Dudley St, Providence, RI