nsgc

PERSPECTIVES IN GENETIC COUNSELING

newsletter of the National Society of Genetic Counselors, Inc.

Vol 14, No. 4 Winter 1992/93

LOOKING AHEAD

LOOK FOR AN NSGC MAILING next month, filled with opportunities to express your voice. It will include:

- *Call for Nominations* — your opportunity to have a voice in NSGC's future leadership
- *Call for Abstracts* — your opportunity to share your work with colleagues
- *Strategic Planning Questionnaire* — your opportunity to define our future.

LOOK IN YOUR "TO DO" STACK for your 1993 dues invoice and honor the Friday, January 29 deadline.

LOOK FOR THE POSTCARD included with this newsletter. Be sure to return it.

LOOK FOR A DESIGN CHANGE in *PGC* Vol. 15...taking us into the '90s.

in this issue...

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.

RISK MANAGEMENT CONSIDERATIONS FOR GENETIC COUNSELORS

by Chantelle Wolpert, M.B.A., PA-C
University Hospital of Buffalo, Buffalo, NY

Genetic counselors are not immune from litigation. Ms. Wolpert, an assistant risk manager with a background as a physician's assistant, discusses a case and means for counselors to reduce their risk.

Ms. Smith was referred to the prenatal clinic because she had documented sickle cell trait. During the primary counseling session, it was learned that the baby's father had never been tested for sickle cell trait, and it was suggested that he be tested. At the return visit, the results of his hemoglobin electrophoresis had not yet been received, so the counselor called the laboratory to obtain the results. A verbal report by the technician was negative, and the parents were told that their baby might be born with sickle cell trait, but could not be born with sickle cell anemia. Two weeks after birth, the infant was diagnosed with sickle cell by routine newborn screening.

An investigation revealed that the written report of the father's hemoglobin electrophoresis filed in his medical record showed he was positive for sickle cell trait. Ms. Smith sued the clinic.

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As the above scenario illustrates, becoming a defendant in a medical malpractice lawsuit is a potential reality for genetic counselors. For this reason, genetic counselors, like

continued on p. 4

TRIAL BY JURY: A COUNSELOR'S STORY

by Gail Goldberg, R.N., M.S. , Mountain States Genetic Services, Denver, CO
with Karen Copeland, M.S.

On occasion, even the best risk management techniques cannot prevent a genetic counselor's involvement in a lawsuit. Here, Gail Goldberg describes her bout in the legal system and the impact of this experience on her professionally.

I was recently involved in a year-long lawsuit, which only concluded this past September. The lawsuit centered around the disposal of the cremated ashes of a 25 week gestation fetus following the ultrasound diagnosis of severe anomalies and subsequent termination.

Prior to this case, I had been informed by the hospital pathology department that fetal remains were separated from other hospital remains and scattered in the vicinity of a local landmark outside the city. While the family was given the opportunity to make their own arrangements, they elected for hospital disposal of the fetus and signed the appropriate releases. Hospital policy had subsequently changed; all tissue remains, including fetal, were disposed of in a

continued on p. 5

From the President

A Joint Partnership Between Leaders and Membership

NSGC has a tradition of strong leadership. The leaders of yesterday had the goal of establishing a Society. The leaders of today have the task of determining the future goals of your Society…where you wish to go and what message you wish to impart.

Leadership was the topic of our recent national Presidential election. My feelings regarding my role as your president are reflected in the my feelings toward leadership in this nation. Leadership unifies; it does not pit one group against another. Leaders must have a vision, but they also must have a mandate from their membership.

Leaders know the importance of keeping in touch with the people they represent. NSGC is a member driven Society, not governed by the Executive Director (staff) or the Board alone. The postcards in *Perspectives* asking your opinion or obtaining your vote demonstrate the desire of the leadership to obtain membership input. Similarly, the newsletter is used as a forum to keep members informed about all issues.

NSGC is a member driven Society, not governed by the Executive Director (staff) or the Board alone.

One example of this interaction was the decision to forfeit our meeting in New Orleans. The membership was polled regarding its opinion, but it was the *Board* who ultimately assumed responsibility for the decision. We will be meeting in Atlanta in 1993. This was also an example of NSGC taking a leadership position in the genetics community. By remaining consistent with our reproductive freedom statement and the majority view of the membership, NSGC can be proud not only of the decision, but of the process, as well.

Leadership in this organization cannot be Board restricted. Earlier this year I placed a "call for action" in *Perspectives.* This will be the year of the volunteer for NSGC. To ensure that your needs continue to be met, you must be involved. In my private life as a local politician, I am sorely disappointed at the complacency of the electorate. Citizens often complain, but don't participate. As NSGC members, you are both empowered and obligated to let your leadership know what you want and what you think about the many issues before us.

The work of NSGC is quite diverse, and there is a place for all interests. If you want to be active, donate a few hours or days to the Society. Some activities take a few hours, some a few days in the course of a year…others take more! Some committees have projects that recur year after year and some are completely new and different. If you want to know how much time it takes, we will let you know. Pick up the phone…call me, any member of the Board or the Executive Office to help find your match.

Betsy Gettig, M.S.
President, 1992/1993

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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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RESTRUCTURING OF ABMG

NSGC TO MOVE TOWARD HEALING; VISION

The American Board of Medical Genetics (ABMG) will restructure, and the American Board of Genetic Counseling (ABGC) will incorporate without delay. *(See insert, this page, for text of the letter sent by Anne Spence to all ABMG diplomates on December 15, immediately following the tally of the vote.)*

The concerns and interests of the genetic counseling community will be well served by both certifying organizations. As a member of the restructuring committee, I know the dedication and throughtfulness of all involved on the ABGC restructuring committee during the arduous process of preparation for the reality of this outcome. I have elected to resign my ABGC Board appointment, not as a protest, but to avoid any possibility of a conflict of interest as your Chief Elected Officer. The relationship between the NSGC and the ABGC will be one of mutual respect and cooperation.

It is now time to move forward and in a sense to heal. The discussion and sometimes arguments regarding restructuring did not, in fact, divide our society. Rather it provided an open forum for mutual opinion sharing...and venting, too!

One lingering concern has been the ability to successfully retain the status that ABMG certification has brought to the genetics community. It was Eleanor Roosevelt who said, *"You must do the thing you think you cannot do."*

Counselors get the job done. As we further define our profession and formulate our own concepts of not only *who* we are but *where we are going*, we will be well served by both NSGC and ABGC. Realistically, the certification exam should change very little, and accreditation of training programs is a task long overdue. Who better to accredit the training programs than those within the field?

No one can predict the future impact of restructuring; however it is certain that the profession of genetic counseling will survive and, now more than ever, on terms defined and created by genetic counselors themselves.

Now is the time to embrace both our vision:

The National Society of Genetic Counselors will be the leading voice, authority and advocate for the genetic counseling profession.

...And our mission:

The National Society of Genetic Counselors will promote the genetic counseling profession as a recognized and integral part of health care delivery, education and public policy.

In the next several months, your Board will explore the creation of a strategic plan, one that will help us move toward our vision and our mission. We are ready to reach toward the future.

Betsy Gettig, M.S.
President

December 15, 1992

Dear Diplomate:

The Accounting firm of Harab, Kamerow, and Associates has relayed to me the results of the vote on the Bylaws. There were 1195 ballots cast, 977 in favor and 200 against. There were 18 ballots cast which were not properly submitted and could not be counted. Therefore, the proposed changes WILL be incorporated into the Bylaws of the American Board of Medical Genetics.

Since the changes were approved we will move immediately to separate the certification of genetic counselors from the functions of the ABMG. The Restructuring Committee, serving as founding members, will incorporate the American Board of Genetic Counseling (ABGC) and invite certified counselors to join. The ABMG will then enter into a legal contract with the newly founded Board and split the assets of the existing Board as described in the written material distributed to you at the time of the meetings. The examinations scheduled for June 1993 will proceed as scheduled and those sitting and passing the Genetic Counseling examination will receive their certificates from the ABGC.

Other matters need to be dealt with now that we are moving to retain our recognition from the ABMS. The board will work with the AMA, the American College of Medical Genetics, the American Council of Graduate Medical Education (ACGME) and other relevant organizations to complete this process as efficiently as possible. Program Directors and Diplomates will be kept fully apprised of the developments.

Thank you for your involvement in this process. The field of medical genetics is facing many new challenges in the coming year. We will need your continued support, interest, effort, and cooperation as we face these issues. No matter how you personally voted and feel is the "correct" answer, we must all work to make this new arrangement succeed. It is time for medical genetics to come of age and the process will not be painless. However, as we have interacted this past year in difficult times, we can continue to interact, respect each and every opinion, and move together as a true "community" in the future.

Sincerely,
M. Anne Spence, Ph.D.
President

Risk Management Considerations...

continued from p. 1

all health care professionals, need to take a proactive approach to prevent medical malpractice and its accompanying lawsuits. This may be accomplished by incorporating risk management fundamentals into clinical practice.

Risk Management Defined

Risk management is based on the belief that malpractice can be controlled. The practice focuses on preventing lawsuits and financial loss. This can be achieved by identifying risks, often termed Exposures, and implementing measures called Risk Control Techniques. Risk control techniques prevent the identified exposures from occurring or reduce the severity of an exposure if it does occur.

Risk Assessment: An Art

The most difficult and challenging component of risk management is risk assessment. It is an art, but one genetic counselors may grasp easily since they consistently use risk assessment analysis as part of counseling. An exposure is any activity that has the potential for causing harm or loss. In the context of risk management, risk assessment is the practice of identifying any exposure that could cause a lawsuit or financial loss.

Initially, the exposures must be identified. The case described in the beginning of this article is based on a real malpractice lawsuit. In that case, there are two exposures: obtaining the father's hemoglobin electrophoresis result over the telephone and the lack of obtaining written follow-up to confirm the verbal result.

One way to identify exposures is to review mistakes or problems that arise in genetic counseling practice. For instance, one genetic counselor recounted a case of a karyotype being misfiled. This misfiling resulted in the counselor informing parents that their baby was going to be a boy. A short time later, everyone was surprised when the patient gave birth to a girl.

Obviously, the exposure in this case was the misfiled karyotype. However, there is always the potential for results to be misfiled, so procedures for reducing these errors must be established.

In another instance, a counselor was conducting a psychosocial follow-up for families who had a child with Down Syndrome. The counselor mailed a carefully crafted letter along with a questionnaire to all families in their files who had a child with Down Syndrome. Unfortunately, one family who had delivered a normal child received the thoughtful letter and questionnaire.

Both of these examples highlight the fact that genetic counselors are faced with exposures dealing with communication. Therefore, careful attention must be given to the accuracy of *all* communication.

Identification of risk exposures is an ongoing process, particularly in the fast-growing field of medical genetics. Therefore, it is important to always identify new exposures and ways to minimize them.

Risk Control Techniques

Once the exposures are identified, risk control techniques can be considered. There are three risk control techniques: *exposure avoidance, loss prevention* and *loss reduction.*

- Exposure avoidance means foregoing risk activity. For example, obstetricians would decrease their

Practical Considerations for Risk Reduction

Following are risk management considerations which may improve efforts to prevent medical malpractice as well as the quality of genetic services.

- **Document** all genetic counseling services provided and all communication with patients, even phone calls, in the medical record in a careful, thorough, consistent and timely manner.
- **Do Not Assume** that because an MD or PhD co-signs a consultation note that liability is removed from the genetic counselor. Instead, liability is then incurred by both parties. The legal doctrine of *respondeat superior* provides that if an employee acting within the duty and scope of employment commits negligence, supervisors are also liable for that employee's actions.
- **Check** with the hospital risk manager or legal counsel to ascertain what type of professional malpractice insurance coverage exists, if any. Generally, if a genetic counselor is an employee of a hospital or other health care facility, coverage is provided in the hospital's malpractice insurance policy. For genetic counselors not covered by their employer and those in private practice, medical malpractice insurance coverage becomes more complicated. Many malpractice insurance companies do not offer malpractice insurance for genetic counselors or may require them to be licensed psychologists. Consult an attorney for any questions regarding malpractice insurance coverage.
- **Understand** the reporting requirements of the insurance policy. Many policies are claims-made policies, which means a health care provider must file a claim even if there is the *potential* of a lawsuit.
- **Consult** the hospital risk manager or legal counsel immediately about *any* situation that involves a questionable legal matter or potential law suit.
- **Implement** quality assurance protocols in your practice. Quality assurance, a related activity, broadly focuses on improving patient care by monitoring clinical performance to determine compliance with standards.

...FOR GCs

risk by referring a patient who has genetic concerns to a genetic counselor, rather than seeing those patients personally.

- LOSS PREVENTION is any activity that reduces the likelihood of an adverse occurrence. Examples of loss prevention techniques include: strictly limiting instances when test results would be relayed verbally, designating one professional to follow-up on all results, using a tracking system to ensure all test results have been seen and noted prior to being filed in a patient's medical records and sending a follow-up letter to the patient's referring physician which clearly delineates particular follow-up responsibilities.
- LOSS REDUCTION minimizes the severity of a loss. An example is to always counsel patients that, despite sophisticated testing and a "good" test result, a positive outcome cannot be guaranteed.

PRACTICE PRUDENTLY

Genetic counselors should provide care using their best clinical judgment and should not provide care solely for the purpose of avoiding a lawsuit. However, as members of the health care team, genetic counselors have a responsibility to employ techniques to prevent medical malpractice and its accompanying lawsuits. While this does not guarantee that medical malpractice or a lawsuit will not occur, it may reduce the likelihood of such an occurrence.

RECOMMENDED READINGS

1 Rhodes, A M. "Minimizing the Liability Risks of Genetic Counseling," *Maternal Child Nursing,* 14(5):313.

2 McDonald, M G et al. (1991) *Health Care Law: A Practicial Guide.* New York. N.Y.: Matthew Bender.

3 Buri, C E and Hecht, F. "Tort Liability in Genetic Counseling and Genetic Diagnosis," *American Journal of Human Genetics,* 42(3):353-355.

4 Capron, A. "Tort Liability in Genetic Counseling," *Columbia Law Review.* 1979:618-684.

A COUNSELOR'S STORY, *from 1*

county landfill. When the couple discovered the ashes had been placed in a landfill, they sued the hospital and several members of the medical team, including their genetic counselor (me). The suit alleged negligence, misrepresentation, deceptive trade practices, breech of contract, outrageous conduct and intentional infliction of emotional distress.

"...there was nothing out of the ordinary, no 'tip-off,' that this was a litigious family."

After 11 grueling months in negotiation limbo, the case finally went to trial. The trial lasted five days. Although I was technically dropped from the suit on day three when the plaintiffs decided they could not prove outrageous conduct, I was asked to remain as a representative of the hospital. After less than three hours of deliberation, the jury found for the defendants on all charges, and no damages were awarded.

CAUGHT BY SURPRISE

This experience was difficult for me for many reasons, besides the obvious ones involving lawsuits. At our initial counseling session, when discussing the ultrasound findings, prognosis and options, there was nothing out of the ordinary, no "tip-off," that this was a litigious family. We develop a sixth sense about some patients or families and hope nothing unusual happens in their particular cases. I had no such feeling in this situation and was amazed to learn of the suit.

The couple had been offered counseling and coordination of their needs by the medical staff. Numerous special arrangements were made in the course of their care, including delivery by a midwife (requiring special permission), handling of the fetus after delivery, arranging for baptism after the couple reversed their decision and obtaining mementos. All those involved felt they had gone the extra mile to accommodate this couple.

The patient participated in a television interview in which she showed all the mementos I had given her as her only memories of her child while telling what a despicable person I was for allowing her child to be deposited in a landfill. No mention was made that I was the one responsible for those mementos. The patient became verbally abusive and threatening on a few occasions. I experienced a tremen-dous sense of betrayal.

INSIGHTS

During the deposition and trial, negative information regarding the patient was presented. A previous miscarriage, history of substance abuse in the recent and a previous pregnancy, attempted miscarriage in the recent pregnancy, mental instability and marital discord all became a matter of public record. It was emotionally stressful for the plaintiffs as well as myself.

Clearly the trial was not providing a catharsis or sense of closure for the family over the loss of their baby. Why was the family doing this?

When the stress became too much for my husband and me to deal with on our own, I sought the help of a therapist. With her assistance, I tried to make sense of what had happened and place it in perspective in my professional and personal life.

The explanation that made the most sense to me was to understand the patient's response as a case of projection. We determined that she was extremely angry with herself because of her guilt, both real and imagined, and her inability to emotionally handle her decisions. This woman appeared to have projected her feelings of rage onto me, and, in turn, I seemed to have became the focus of her self-hate and anger. My therapy sessions

continued on next page

A COUNSELOR'S STORY, *from previous page*

proved to be invaluable in that they allowed me to better cope with this horrific experience.

SUPPORTIVE DOCUMENTS; RESOURCES TURN INTO QUESTIONABLE SOURCES OF ANGST

Interestingly, the plaintiff's attorney entered into evidence the NSGC Code of Ethics, claiming my behavior was unethical since I had not obtained all of the pertinent information. In simple terms, he implied that all this would have been avoided if I had made a 15 second telephone call to the morgue to determine what would happen to the fetus. That I acted at the time with available information and no evidence that the information had changed did not seem relevant to him.

> ***"We all have occasion to wonder about our professional competence... This usually occurs in the private arena of our mind...Mine occurred on the nightly news."***

In addition, the NSGC Executive Office was contacted for a list of genetic counselors in the area to identify an expert witness to testify against me. Either the plaintiffs did not find one or decided not to pursue this line, since no other counselors were called to testify. The thought that my professional organization was being used to solicit my colleagues to testify against me was a bit chilling.

In general, I experienced tremendous support from my colleagues and friends. Since I had been advised not to discuss the case with anyone but my husband (he had immunity) because they could be called as witnesses, I was limited to sharing feelings and thoughts, but no details.

TAKING IT PERSONALLY

During the process of deposition, examination, cross-examination and recross-examination, it was hard to stay focused and keep a sense of self and balance. I would doubt myself and loose sight of the truth as I knew it. I would wonder if the nasty things the plaintiffs and their attorney said about me were true. Frequently, I felt my words or actions were misrepresented or distorted. Most importantly, my professional abilities and judgments were being questioned.

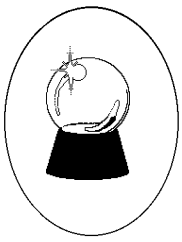
We all have occasion to wonder about our pro-fessional competence after an interaction which may not have been the best or most appropriate with a particular patient. This usually occurs in the private arena of our mind or with chosen colleagues. Mine occurred on the nightly news.

While all this was happening, I questioned whether I would be able to return to counseling. I had a tremendous fear and vulnerability about the potential risk that every case represents. I considered changing jobs, but in our current society, you can be sued in any situation. Luckily, within days of the verdict, I counseled another couple after they had an ultrasound revealing fetal anomalies. While I went a bit overboard presenting information, it forced me to face my fears and begin the professional healing process.

FINALLY OVER

The trial concluded this past September. I was cleared of all charges, but there was tremendous cost to all parties involved. I hope that this sharing of my experience with the genetic counseling community will empower others to protect themselves. Furthermore, it has helped me immeasurably to open myself to the support of my colleagues.

VISIONING THE FUTURE



THE NSGC WILL BE THE LEADING VOICE, AUTHORITY AND ADVOCATE FOR THE GENETIC COUNSELING PROFESSION

TOWARD A DIVERSE PROFESSION: MINORITY OUTREACH PROJECT

A special project was recently successfully completed with the collaboration of the Executive Office and genetic counseling training program directors. The project funded a mailing of NSGC's college-level packet, "Is a Career in Genetic Counseling in Your Future," to 1000 advisors across the nation who have access to minority and underserved students. The packet included:

- *NSGC: a voice, a resource and an educational environment for the genetic counseling profession*
- a fact sheet
- a list of training programs
- a bibliography & list of resources
- a list of area contacts, by state
- two articles featuring counselors
- the '92 Professional Issues Survey

A cover letter introduced the purpose of the project and included a tear-off for recipients interested in additional information.

Thanks to Program Directors/ Coordinators Diane Baker, Carl Huether, Lorna Phelps, Judith Tsipis and Jon Weil for contributing labels. And a *special thanks* to Jon Weil for spearheading the project.

TOWARD INCREASED PROFESSIONAL RECOGNITION: NEGOTIATING BENEFITS

Have you successfully negotiated

...a salary increase? ... a faculty position? ... a promotion? ...a conference budget (other than NSGC/ASHG)? ...a budget for books or the certification exam fee? ... a flexible working schedule?

If you answered YES to any of the above, please send a brief summary of how you achieved your goal to: Wendy Uhlmann, M.S., Chair, Professional Issues Committee by January 31.

The Committee would like to share the information with members and organize a workshop.

GeneBytes

Genetic Software Packages: A Review of SMS Genetics Systems

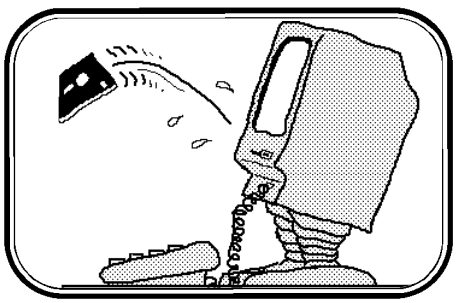
Many genetic departments and cytogenetic laboratories have developed (sometimes piecemeal) in-house computer programs to manage patient and laboratory data.

To Buy or Not To Buy

For departments just beginning to utilize computers, a decision must be made whether to develop a program or purchase a commercially developed software system. The advantage of developing a program is that it can conform exactly to your specific needs; the disadvantage is time and money. Purchasing and modifying a software package can be faster and less expensive. Unfortunately, there are relatively few packages from which to choose. We will review some available products in upcoming columns.

SMS Offers Option

Shire Management Service (SMS) in Birmingham, England has developed a product called the Genetics Computer System (GCS) that is used extensively in genetic units in the United Kingdom, as well as some cities in North America. The software is comprehensive and includes modules for cytogenetics laboratory, DNA laboratory and clinical genetic patient management. GCS is an integrated database, so information is available to all modules. CGS runs on the PICK operating system, so is designed as a multi-user system to accommodate single users, small groups or over several hundred users.



Laboratory Module

The cytogenetics module includes: specimen accessing, label generation, specimen tracking, result reporting, statistical reporting and result coding for later retrieval for clinical or research use. The modules are specialized for blood chromosomes, amniotic fluid, CVS, tissue and cancer studies, reflecting the different handling in the laboratory. The DNA module also allows for phasing of results and integrating results on a pedigree drawing program.

Clinical Genetics Module

The clinical genetics module includes patient intake, counseling and procedure scheduling, appointment notification letters and labels, appointment and procedure outcomes, chart note writing, pregnancy outcome and abnormal prenatal diagnosis result follow-up, coding of diagnoses and statistical reporting for workload analysis or other reporting. A staff schedule function integrates patient appointments with other scheduled events such as department meetings.

Advantages & Disadvantages

One of us (KW) has been using the system onsite for over a year and can realistically discuss the advantages and disadvantages. The advantages have been:

- improved access to information for both the lab and clinical staff
- immediate access to patient information when chart is not readily available
- improved lab management ability with decreased turn-around time
- facilitation of state reporting requirements
- ability to search previous patient information by diagnosis for research or improved clinical management purposes
- ability to easily analyze workload in both lab and clinic, including phone consulations
- decreased clerical support needs with automation of many time-consuming functions (e.g., appointment letters, schedules for procedures and clinic, follow-up letters, AFP lists)
- ease of data access and report generation, and
- modifications can be made by SMS to customize the system to individual needs.

The disadvantages are:

- the PICK operating system is not well known to many PC/IBM users, so knowledgeable support staff may not be available in-house
- the training, procedural changes and implementation has been more difficult than anticipated
- efficient use of the system requires good typing skills
- with 75+ users at 4 locations, there has been mixed reception
- the wordprocessor is not as good as WordPerfect, and
- with such a large implementation, a full-time system administrator is necessary to triage problems and keep up with changes.

Up for a Try?

SMS has recently developed an excellent demonstration diskette that can be used on any IBM compatible machine. To obtain the demo disk, contact their U.S. distributor, Bob Nordgren, Active Data Processing, 510-460-8488. The cost for the system depends on the number of users, the modules purchased and amount of customization desired.

by Karen Wcislo, M.S. and Robert Resta, M.S.

Reporter's Notes: We would like to review pedigree drawing programs in a future column. If you are familiar with any, please call us so we can get a demonstration disk [KW: 408-972-3306 or RR 206-386-2101].

Celebrate Ourselves

First Jane Engelberg Memorial Fellowship Awarded in San Francisco

Katherine Schneider, M.P.H., the first recipient of the Jane Engelberg Memorial Fellowship, will receive $25,000 to write a book, *Counseling about Cancer: Strategies for Genetic Counselors.* The award was announced at the NSGC's annual business meeting in San Francisco.

Kathy envisions this resource as a tool to assist counselors and eventually other health professionals who identify cancer when taking pedigrees. Rather than creating another didactic tome which lists and explains the over 200 Mendelian disorders with cancer as part of their phenotype, this reference will provide practical strategies for counselors when faced with a patient with a family or personal history of cancer.

Kathy graduated from Yale University School of Public Health in 1985. She worked at Yale and then in Boston before taking maternity leave in 1990. In July 1991, she joined Dr. Frederick Li, Chair of the Division of Cancer Control and Epidemiology. She has been involved with the high risk breast cancer clinic and helped create the protocol for the p53 predictive testing program.

In the new and explosive area of cancer genetics. Kathy and her colleagues have identified many ideas, but have limited time and resources. As the first recipient of this Fellowship, Kathy's contribution to her department increases both her professionalism and value as a member of the genetics team.

1993 SPF Award to Focus on Cross-Cultural Counseling

Diana Punales-Morejon, M.S. and **Vivian Wang, M.S.,** received this year's NSGC Special Projects Fund Award. They will develop a training handbook about cross-cultural genetic counseling. According to the authors, America is quickly becoming a multicultural society. This trend creates the need to incorporate multiculturalism into genetic counseling training programs.

Diana and Vivian will use the award to develop a self-contained, easily updated handbook to be made available to genetic counseling training programs. The handbook will include material about basic cross-cultural counseling theory as well as case vignettes, role playing and role analysis. Audiovisual slides and references will also accompany the handbook. These tools will help sensitize students to the experience of culturally distinct populations.

According to the creators, this handbook will be easy to incorporate into existing program curricula as either an independent entity or as a supplement to existing material. Anticipated completion of the handbook is January 1994.

Ethics on the Road

The members of the Ethics Subcommittee, **Judith Benkendorf, M.S., Nancy Callanan, M.S., Rose Grobstein, B.A., Susan Schmerler, M.S.** and **Kevin FitzGerald, S.J.,** had an abstract regarding the development of the NSGC Code of Ethics accepted for poster presentation at the Inaugural Congress of the International Association of Bioethics, which was held in Amsterdam, The Netherlands, October 5-7. The abstract was entitled "The Development and Implementation of a Professional Code of Ethics: The National Society of Genetic Counselors' Experience." Judith represented the committee at the Congress.

Member Addresses Science Reporters

Maureen Smith, M.S., addressed a group of science reporters at the 1992 Science Reporter's Conference, sponsored by the AMA last October. Maureen's topic was "Genetic Counseling: Assessing and Understanding Family Risk."

ABGC Board Annoounced

Diane Baker, M.S., Debra Collins, M.S., Beth Fine, M.S., Edward Kloza, M.S., Joan A. Scott, M.S., Ann C.M. Smith, M.A. and **Ann P. Walker, M.A.** have been named as founding members of the newly incorporated American Board of Genetic Counseling. Certified counselors are being invited to join.

NSGC Goes to the Movies

Filming a movie about a boy with adrenoleukodystrophy in Pittsburgh, Pennsylvania presented some interesting dilemmas. First, the film, ***Lorenzo's Oil,*** takes place in an East Coast city *and* in Africa. Second, the star, **Susan Sarandon,** was pregnant at the time of the shooting and several crew members were breast feeding.

Enter **Betsy Gettig,** brought on to the project to deal with issues of teratogenicity and potential health hazards if the casting crew took the shoot on location to the Comoros Islands in East Africa, a location known to be infested with chloroquine resistant malaria.

Betsy, true to her character and commitment to the Society, requested that, in lieu of a consultant's fee, the NSGC be listed in the credits. According to our sources who previewed the film at its recent opening in Washington, Betsy's request met with success.

From all of us, Thanks, Betsy!

NEW LIFE FOR MEMBERSHIP COMMITTEE

A new life has been given to the Membership Committee, which, along with Education, Finance, Professional Issues and Social Issues, comprise the NSGC's five standing committees.

The assumption of many of the initially assigned responsibilities of this committee by the Executive Office and the need to find a home for some new NSGC activities has prompted the Board of Directors to vote in favor of restructuring and expanding this committee.

The potential for continued growth in the profession is evidenced by the graduation of more than 100 genetic counselors annually.

There are many new and exciting activities open to shape the profession's future. In addition to soliciting new members, the duties of the committee have been expanded to address the following:

- ENHANCING internal communication through the work of the regional representatives
- INCREASING participation of inactive members
- MARKETING the career to attract top students into the field
- EXPANDING job opportunities
- ENHANCING student participation and networking in the NSGC
- PRODUCING AND REVIEWING publications
- PROMOTING communication among the genetic counseling graduate training programs
- INCREASING the career's visibility by adding it to aptitude tests and the Peterson's guide

Existing activities include:

- REVIEWING AND REVISING the college/career change level and high school level career packets
- TARGETING mailings of career packets to resources for minority population outreach
- EXPANDING distribution of career packets in members' home states
- DEVELOPING display materials for job fairs
- CREATING student and member mentor programs
- EXPLORING ways of becoming more visible to the media

MENTORING: A VOLUNTEER OPPORTUNITY HIGHLIGHTED

The success of the proposed mentor program depends on member involvement. Mentor opportunities include:

- HIGH SCHOOL STUDENTS — to spark interest in the field;
- COLLEGE STUDENTS — to identify appropriate and qualified individuals for the profession;
- GRADUATE STUDENTS — to smooth the transition into the work world;
- MINORITY STUDENTS — to address the special needs of this constituency in a work or academic setting; and
- STUDENT-TO-STUDENT — to interface among the training progams.

As chair of the Membership Committee, I would like to thank those who have already volunteered and welcome anyone who is interested in these activities or has additional ideas.

Bonnie LeRoy, M.S.
Chair, Membership Committee

MENTORS - BUILDING BRIDGES

Are you a new genetic counselor, brimming with enthusiasm and ready to set the world on fire? Or are you a few years down the road, resonant with the wisdom that comes from experience? In either case, you may benefit from a mentor relationship.

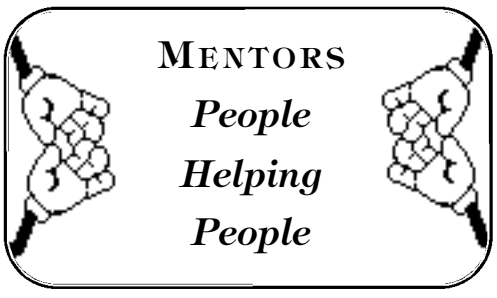
Mentor was Odysseus' trusted counselor and guardian in Greek mythology. In the business tradition, a mentor is an advisor and teacher one or two rungs up the career ladder who helps you develop by making sure you know the right skills and the right people.

For genetic counselors, a mentor can provide practical advice in areas never covered in graduate school. For instance, my mentor recently helped me through a conflict with a co-worker. She encouraged me to confront the situation constructively, helped me practice my strategy and gave me objective input about how it might come across.

There are many ways a mentor can help:

- *Who are all these people?* —making introductions at conferences and around town.
- *Beyond please and thank you* —getting the most from support staff, co-workers and superiors.
- *I don't get no respect!* — being valued as a non-MD in the medical world.
- *Love in the workplace* — turning down unwanted advances from colleagues; conducting an office romance without getting burned.
- *Office politics* — handling conflicts with co-workers...or your boss.
- *Money isn't everything, but* — negotiating a raise, conference funds and other benefits.

A mentor can be a bridge to the genetic counseling profession for the new counselor. For an experienced counselor, being a mentor brings a sense of satisfaction and accomplishment, reminds you how far you've come, exposes you to new ideas and may rekindle your own enthusiasm.



The NSGC Membership Committee is exploring formal mentor programs. Stay tuned for more details.

Liz Stierman, M.S.
California Birth Defects Prevention Program

Letters to the Editor

Semantics and State Legislators

To the Editor:

I feel it is necessary to respond to the recent article in the *Legislative Briefs* column (PGC 14:3, Fall 92) written by Bonnie Jeanne Baty, summarizing the continuing problems in Utah with reproductive freedom. I was particularly concerned about the statement, "As states pass laws restricting reproductive freedom, there is grave danger to the professions of medical genetics and genetic counseling."

In my opinion, the NSGC should not publicly align itself with this volatile issue in this fashion since it is not unlikely that this type of statement could be twisted to mean that these professions will disappear unless reproductive freedom is maintained. Personally, I feel that the uneducated public (our former and future patients) may be confused by these messages and misconstrue "pro-choice" to "pro-abortion."

To stimulate interest and involvement from the membership in this way as well as by issuing public statements representing the NSGC as supportive of abortion, is to run the risk of damaging the reputation of the organization collectively and of its members individually. I personally have to represent the work of genetics to an unsympathetic State Legislature just to keep the clinic doors open. Our opponents would like nothing better than to read that our jobs depend on the issue of reproductive freedom.

Joan FitzGerald, M.S.
Shodair Children's Hospital

Response:

I appreciate Ms. FitzGerald's concerns about the perception of a strong "pro-choice" position as "pro-abortion." Since a pro-choice position implies an acceptance of abortion as one alternative to reproductive choice, then in that sense it is supporting the abortion alternative. However, I personally am an equally strong supporter of women's and families' rights to continue pregnancies, no matter how serious the abnormalities diagnosed. I think that reproductive decisions are best left to women and their medical care providers. The families I work with always take their ethical responsibilities seriously in making decisions such as whether or not to continue a pregnancy, continue extraordinary life support measures, or put a child through the pain of multiple medical procedures.

I am also employed in a conservative state and have chosen to publicly work to maintain reproductive choice. Danger to our profession can come in many guises. I personally am not concerned about our jobs, since families need care regardless of the reproductive options they choose. However, the Utah law posed two very specific types of danger to genetic counselors and medical geneticists. It put medical professionals at risk of prosecution for a felony for aiding women in obtaining an abortion. It also posed a moral dilemma for medical professionals who believe that prohibiting abortions for serious conditions is wrong. The vagueness of the "grave fetal abnormalities" exception has been problematic in practice, and has restricted some women from obtaining abortions for serious conditions.

Ms. FitzGerald has valid concerns about the politics of state government. I think her point is that actions carried out to help our patients can sometimes backfire. In Utah, it has been important in the last two years to take legislative action to protect our patients' interests. This activity has thus far not resulted in genetic services being targeted for funding cuts. The genetic community in each state has to make choices about the actions in the best interests of their state.

Bonnie Jeanne Baty, M.S.
University of Utah Medical Center

The Problem or the Solution?

To the Membership:

Only 6.5% of the respondents of the 1992 Professional Issues Survey identified themselves in categories other than Caucasian. Furthermore, the training directors conference at Asilomar this past June focused on issues of cross cultural training and concluded that there is an urgent and desperate need to train more members of ethnic minority groups as genetic counselors.

Historically, Howard University in Washington, DC has been the only minority training institution in the nation currently offering a genetic counseling track. It is also the only program in the greater Washington/Baltimore area. Howard University genetic counseling students face great barriers in achieving board eligibility in genetic counseling due to a critical shortage of genetic counseling training sites in their area.

Although there are over 60 hospitals in the Washington/Baltimore area and several programs offering medical genetic services, there are only *two* ABMG accredited training sites for genetic counselors.

Moreover, one of these sites requires a $1200 fee for a three month rotation. As many of the students are unable to meet this financial demand, their chances of achieving 12 months of clinical training at accredited sites is virtually impossible.

I am calling on my colleagues to offer the new generation what was given to you. Apply for accreditation to train genetic counselors and open opportunities for these students.

Ilana Mittman, M.S.
University of Maryland

All Right Now

To the Membership:

Just a quick note to say thanks for the wonderful thoughts, cards, calls and flowers. I had to go all the way to San Francisco to have a heart attack, but am out of the hospital, home and at the office a few hours each week now. It was a scary experience, but made a bit easier by all the get well wishes I received from my special genetic counselor friends.

Thank you so much.

Natalie Paul
March of Dimes

Letters to the Editor

Even the best laid plans...

By all standards, the 11th Annual Education Conference was a grand success. With full understanding that perfection is not a realistic or achievable goal, even the best laid plans can go awry. Such is the case of one plenary speaker. While the program committee has a policy of informing invited speakers about our profession and the anticipated audience, our information is not always considered when a speaker is preparing. As a follow-up to the conference, we would like to share with the registrants the following letter sent to Jurg Ott, Ph.D., on November 23. We trust you will consider it our way of clearing the record on behalf of our profession, our conference and ourselves.

L.H., A.B., A.F.

Dear Dr. Ott:

This letter serves a twofold purpose in regards to your presentation at the National Society of Genetic Counselors meeting in San Francisco.

First, we would like to thank you for your time and participation in our eleventh education conference. Your work in linkage analysis is well known and well respected by our membership. A few genetic counselors have had the pleasure of hearing you present in the past.

In addition, we wanted to provide you with some feedback about your presentation in the event you present to genetic counselors in the future. You may not be aware of the nature of our academic backgrounds, and we would like to acquaint you with our profession. The majority of genetic counselors have a Master's degree in Human Genetics with an emphasis in Genetic Counseling. In addition to intense clinical rotations, the genetic counseling curriculum includes graduate courses in molecular, clinical and population genetics as well as courses dealing with ethical and psychosocial issues. Graduates of accredited genetic counseling programs are regarded as eligible to sit for the American Board of Medical Genetics. The majority of our membership are board certified [or eligible] by ABMG.

The genetic counselors who had previously heard your lecture on lod scores and multifactorial inheritance expressed disappointment on the elementary nature of your talk at the NSGC meeting. We may have failed to adequately inform you of what we anticipated you would address in your talk as well as the typical background of genetic counselors. We hope this provides you with a better understanding of our knowledge base. With the "explosion" of the Human Genome Project, we acknowledge the necessity for genetic counselors and Ph.D./M.D. geneticists to collaborate. We look forward to working with you in the future.

Best of luck in your ongoing work.

Sincerely,
Lynn Hauck, M.A.
Ann Boldt, M.S.
Conference Co-Chairpersons and
Andrea Fishbach, M.S.
Chairperson, Program Committee

Home and Office...A Joining of the Two

To the Membership:

Twenty years ago, when my son was in the third grade, he was given a vocabulary building worksheet inviting the students to illustrate a series of statements. One in particular asked for a drawing for "It hangs on the wall." He drew a spider.

Although I am not a "saver," I have kept that worksheet as a humerous and joyful memory of him at eight.

Last month, at the Annual Education Conference in San Francisco, I was privileged to be lavished and showered with gifts by you, the current and past Boards and Membership, on the occasion of my fifth year of service to the NSGC. These treasures will assuredly be ones I shall keep as joyful and permanent memories.

First, the plaque ...not just in recognition of my five years as your Executive Director, but worded in recognition of my "direction, vision and professionalism" on behalf of the NSGC. It hangs in my office — proudly.

And then the framed poem, *When I am an Old Woman,** a magnificent and touching poem about a woman who, when she is old, will wear purple (my current favorite and the color of my kitchen), eat only bread and a pickle for a week (I've been known to mix strange culinary combinations) and press alarm bells (no, not yet!). The poem concludes that, of course, for now our behaviors must remain exemplary, but, maybe, just maybe, a little practice wouldn't hurt... "So people who know me are not too shocked and surprised/When suddenly I am old and start to wear purple." The poem hangs in my kitchen — so special.

The magnificent Southwest landscape print reflects my private retreat, a place I go when I need to be meditative. How did you know? It hangs in my den — so pensive.

And as for the standing ovation, simply, it hangs forever in my heart.

It isn't often that we both love our work and feel truly appreciated for our efforts. I feel so very fortunate for that match.

With all my appreciation for your many kindnesses these past five years and with visions of continued mutual feelings for our future professional growth together.

Bea Leopold, M.A.
Executive Director

*From *Warning* by Jenny Joseph.
Available in most specialty book and card shops.

RESOURCES • RESOURCES • RESOURCES • RESOURCES...

• BOOKS •

Designs of Life: Exploring the New Frontiers of Human Fertility
author: Robert Lee Hotz
publisher: 1991 Pocket Books, New York, NY
price: $9.00 pbk 276 pp; $21.00 hb
reviewed by: Patricia Olney, M.S.

In the light of recent dramatic advances in embryo preimplantation genetic diagnosis and embryo biopsy, this book is recommended reading for both genetic counselors and their patients undergoing fertility treatments. It explores all aspects of assisted reproductive technology, including medical, legal, ethical, financial and emotional issues.

Designs is the result of hundreds of interviews with patients and practitioners conducted by the author, a science reporter for *The Atlanta Journal* and *The Atlanta Constitution.* During a two year period, he extensively researched the field of infertility and observed the daily routines of several prominent medical pioneers. Hotz provides the reader with insight into the reproductive revolution, beginning nearly 15 years ago with the first successful *in vitro* fertilization.

Over the course of his investigations, he discovered that the patients themselves are the driving force of this revolution. The men and women in the book are not fictitious, and some have allowed their real names to be used. Hotz follows the lives of several couples in their relentless pursuit of a successful pregnancy. He enters into the most intimate parts of their lives, sharing their failures as well as their few successes. He reveals their innermost fears of experimental procedures and painful new fertility drugs. He explores the legal and ethical issues facing couples who are dealing with the advancement of a new technology.

The 12 chapters have interesting titles: "Swimming Against the Current," "Selling the Stork," and "The Spring Thaw." In a chapter entitled "The Mouse Is a Tomato," Hotz provides the reader with some fascinating insights in to the field of genetics. Hotz touches upon the intricacies of mastering the genetic code, the baffling nature of genetic imprinting and the revolutionary genetic screening of embryos. Hotz ends this chapter with an interesting comment by Dr. Paul McDonough, the 1990 president of the American Fertility Society. "To cure an embryo by rearranging its genetic structure was," he said, "the 'holy grail' of reproductive medicine." In essence, reproductive medicine has helped many couples attain the unattainable.

One criticism of the book is the overabundance of facts and information. Although facts are needed to understand and appreciate the complexities of infertility, they tend to overwhelm this reader. On the other hand, one comes away from reading this book with a greater awareness of the impact of infertility on the lives of these couples. Hotz brings to this book his experience as an acclaimed journalism and shares his excitement of exploring a new frontier in medicine.

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Guide for the Special Needs Child
author: Toby Levin
publisher: Starlight Publishing Co.
price: $12.95, 182 pg
reviewer: Christine Sauer, MS

As a pediatric genetic counselor, I often assist families in ways not always seen in prenatal genetics. Rather than dealing with the probability of genetic disease, I help individuals and families attempt to cope with the actuality of an affected family member. While there is sometimes literature available for families regarding the medical facts related to a particular disorder, seldom does one find anything written about helping a family adjust to the realities of life with a special needs child. As is stated in the author's introduction, "New mothers can turn to baby books for information and guidance. But when a baby is born with a disability, where is a need for answers to different questions."

The back cover of this book claims that it is "A Parent's Resource Book to Common and Rare Birth Defects." While this is an admirable ambition, I am not sure that this book truly accomplishes that goal. The author does an excellent job of identifying issues important to special needs families. Topics range from telling others about your baby's disorder and identifying support groups to planning vacations and traveling. The manner in which the author uses personal stories to illustrate sometimes sensitive subjects is effective. Often families find it useful to share feelings of daily experiences, and these stories reinforce the fact that they are not alone. Also interesting is her comparison of the availability of resources in past years to those available today.

Unfortunately, while many topics were described wonderfully, not all topics were handled as well. The author attempts to do too much with this volume. Not only does she describe family resources, but she tries to discuss medical information. I found the section about birth defects to be more confusing than helpful. Also, she has an extensive resource list with addresses and phone numbers of organizations mentioned in the test. However, when I attempted to contact some of them, I found some had incorrect phone numbers or the agencies dealt with topics different from what was described by the author.

I do not feel that this book is totally without value. Indeed, counselors may find the sections about coping and available resources of benefit to their patients. However, *Guide* should not be used as an information source for the medical issues related to genetic disorders. Such information is better handled elsewhere.

...RESOURCES •

• SUPPORT GROUPS •

COCHAYNE SYNDROME

Cochayne Syndrome, an autosomal recessive condition, is characterized by senile-like changes beginning in infancy, retinal degeneration, impaired hearing and photosensitity. Families may write to: Teresa Wall, P.O. Box 552, Stanleytown, VA 24168; 703-629-2369.

CHROMOSOME DELETION OUTREACH

Several mothers of children diagnosed with rare chromosome abnormalities have formed a support group. Contact: Chromosome Deletion Outreach, c/o Cheryl Drum, 6100 Cairo Rd, Westerville, OH 43081.

CORRECTION: JEUNE SYNDROME

NEW ADDRESS: The Jeune Syndrome Support Group listed in *PGC* 14:3, Fall 92 has a new address. Please note this change:
Kelly Bowron, 3710 West Temperance Road, Lambertville, MI 48144; 313-854-8132.

VACTERL

A nationwide VATER's (Vacterl) Support Group has been formed.
VATER is the acronym for:
(V)ertebral anomalies,
(A)nal atresia,
(T)racheo (E)sophageal fistula,
(R)enal anomalies and
(R)adial dysplasia.
VACTERL as an acronym adds congenital
(C)ardiac disease and
(L)imb defects.

Symptoms occur in various combinations and can be manifestations of several recognized disorders. Contact: Nancy McCarley, 520 Greensboro Street, Startville, MS 39759; 601-323-1951.

Research Opportunity

Families of VATER (VATERL) children are being sought for a study investigating the developmental and psychological aspects of this disorder. Investigator: Nancy McCarley, Department of Psychology, P.O. Drawer 6161, Mississippi State, MS 39762; 601-325-3202.

FROM SAN FRANCISCO TO ATLANTA... NSGC ANNUAL EDUCATION CONFERENCES ROLL ON THE TRACK OF EXCELLENCE

TITLE: **THE TECHNOLOGY PARADOX: FACING THE CHALLENGES**

DATES: **OCTOBER 2 - 4, 1993**

LOCATION: **ATLANTA, GEORGIA**
Atlanta is the center of the rapidly growing southeast, a major air traffic hub and the site of the 1996 Summer Olympics. The city is progressive and has freedom of choice laws, yet retains a true "old south" charm with its famous southern hospitality.

HOTEL: **SWISSOTEL, ATLANTA**
The Swissotel is located on Lenox Square in Atlanta's principal shopping, entertainment and dining district — Buckhead. The well designed meeting facilities are on site and perfectly sized for our group. This new (1991) elegant hotel prides itself on European flavor and service. Original art hangs in the lobby and function areas, as well as guest floors. It also has two restaurants, a health club and pool. Next door is Lenox Square, the Southeast's largest shopping mall with connections to MARTA (subway).

Room are an affordable $107 per room, one to four people, with a nominal $10 cot fee.

AIR CARRIER: **DELTA AIR LINES**
Delta Air Lines, NSGC's official carrier has extended conference travel dates from Sept 28 - Oct 10. Registrants may obtain the best available fares by calling Delta Air Lines directly at 1-800-241-6760 between 8:00 am - 11:00 pm EST. Refer to File #MO387. For every 50 registrants using this method, the NSGC will be entitled to a ticket to offset the cost of speakers and staff, a potential major savings to the NSGC.

COST: As of early December, a trip from four sample major cities in the U.S., Los Angeles, Boston, Seattle and Detroit, will cost an additional $100 above the cost of a round trip ticket if members choose to attend both the NSGC and ASHG meetings in New Orleans. This estimate is subject to reductions with bargain rates. Watch for them and don't forget to use the special NSGC File #MO387 to help make a difference. Additionally, we anticipate that the differential in hotel costs for three nights in Atlanta will negate the additional airfare differential.

NEW THIS YEAR!!!

SHORT COURSE: **FRIDAY, OCTOBER 1, 1993**
THE ABC'S OF CANCER GENETICS, a one-day short course, will be offered to provide genetic counselors in prenatal and pediatric settings with the skills to evaluate a family history for cancer risk and to provide appropriate counseling and referrals. *Location: Swissotel, Atlanta, GA*

PLEASE COMPLETE THE POSTCARD ENCLOSED IN THIS MAILING.

Bulletin Board

HGP Sponsors Workshop for High School Educators

Applications are being accepted for an educational workshop with a focus on law, ethics and social implications of the Human Genome Project, jointly sponsored by the Department of Energy (ELSI), the University of Kansas Medical Center and Science Pioneers, Inc. The program has been developed specifically for secondary teachers and will require a two-year educational commitment in late June by the teachers accepted into the program.

Counselors are invited to refer middle and secondary science teachers with an interest in developing their knowledge of the HGP to apply by February 1 to: Genetics Education - Application, University of Kansas Medical Center, 3901 Rainbow Blvd, 4023 Wescoe, Kansas City, KS 66160-7318.

Board Review Course Offered in Pittsburgh

On May 21-23, the University of Pittsburgh will conduct "Medical Genetics: 1993," a review for the examination of the American Board of Medical Genetics. Local and visiting faculty will use lectures, workshops and practice questions to review dysmorphology, quantitative genetics and cytogenetic, biochemical and molecular diagnostics, as they apply to clinical and counseling cases.

For information, contact Department of Conference Management, University of Pittsburgh Medical Center, Nese-Barkan Building, 5th floor, 3811 O'Hara St, Pittsburgh, PA 15213-2593; 412-647-8232; Fax# 412-647-8222.

Region II Offers Educational Conference Choices

Two meetings for counselors have been scheduled in Region II.

- MARHGN and Region II will hold joint conferences scheduled March 12-15. The theme of the MARHGN conference is, "Legal Issues in Genetics," and will include lectures, workshops and a moot court. The Region II component, "Adult Onset Disorders," will be held on March 12 and will focus specifically on colon and breast cancer. The meetings will be held in Crystal City, Virginia.
- GENES and the New York State Department of Health will hold a two-day symposium on March 17-18 in Saratoga Springs entitled "Ethical Issues in Medical Genetics: Ideas to Ponder for Physicians, Counselors, Support Group Representatives, Patients and Families." The format will follow plenary sessions, panels, group discussions and workshops.

For information, contact Ann Boldt, Region II Representative, 518-445-5120; Karen Greendale, (GENES, only) 518-474-1753; or Jill Fonda Allen, (MARHGN, only) 202-745-4166.

German Geneticist's Daughter Seeks American Experience

Fifteen-year-old Emanuelle Wolff, daughter of genetic counselor/psychotherapist and NSGC-member Gerhard Wolff, would like to become an exchange student for three months (September - November, 1993) in the U.S. Emanuelle is the oldest of four children, is bilingual in French and German, and enjoys music, reading and film.

Counselors interested in pursuing this arrangement may contact her directly c/o Sternwaldstr. 10, D-7800 Freiburg, Germany; tel: 011-49-761-78410 or Fax#011-49-761-2707041.

1992 Program Books Available for Armchair Registrants

Were you unable to attend the NSGC's Annual Education Conference in San Francisco?

A limited number of Program Books are available for members, students and interested professionals who were unable to attend the Conference, "The Human Genome Project: Impact, Implications & Issues (or When We've Solved the Mysteries, What Will We Do with the Clues?)." The book contains abstracts of the seven plenary sessions and nine workshops, as well as all presented papers, posters and selected abstracts.

To obtain a copy, send your check for $12.50, payable to the NSGC, to the Executive Office. Order today. These books will not be reprinted.

Call for Proposals

Jane Engelberg Memorial Fellowship

The Jane Engelberg Memorial Fellowship provides $25,000 each year to a genetic counselor (or counselors) for study, research 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. The Fellowship is funded by the Engelberg Foundation, established in 1990 by Jane's husband, Alfred B. Engelberg. An Advisory Board, selected from the NSGC membership, is responsible for the review of Fellowship applications and selection of the awardee(s). Proposals are due by April 1, 1993.

Special Projects Fund

The NSGC's Special Projects Fund provides funding support of up to $2000 to one or more genetic counselor for project(s) that focus on the future of the genetic counseling profession and/or the provision of genetic services. Projects will be reviewed on the basis of their merit and strength as well as on their vision of the future of the profession. Proposals are due by May 15, 1993.

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Applications and information for either grant may be requested in writing from the Executive Office. Both awards will be announced at the 1993 Annual Business Meeting in Atlanta.

• CLASSIFIED • CLASSIFIED • CLASSIFIED • CLASSIFIED • CLASSIFIED •

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.

LOS ANGELES, CA: Immediate opening for BC/BE Genetic Counselor. Exp; bilingual in Spanish/English preferred.
RESPONSIBILITIES: Join univ PNDx ctr serving large multicultural population: all aspects of repro genetics, teratogens, perinatal loss counseling; coordinate pt & health care provider outreach program; participate in developing research & education projects. Access to univ continuing education.
CONTACT: Valerie Rappaport, MD, Dept OB/GYN, UCLA Medical Center, 14445 Olive View Dr, Sylmar, CA 91342-1495; 818-364-3222. EOE/AA.

SACRAMENTO, CA: Spring opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: All aspects of PN repro coun: amnio, early amnio, CVS, U/S, AFP, family history. On site cyto lab.
CONTACT: Douglas Hershey, MD, Medical Director, Prenatal Diagnosis of Northern California, 1315 Alhambra Ave, Suite 210, Sacramento, CA 95819; 916-736-6888. EOE/AA.

BRIDGEPORT, CT: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Diverse responsibilities in community-based, tertiary care ctr. PN coun: amnio, CVS, anomalies, referrals; monthly ped clinic; resident & prof educ; other projects.
CONTACT: Genetic Counseling, Bridgeport Hosp, Box 5000, 267 Grant St, Bridgeport, CT 06610. 203-384-3049. EOE/AA.

WEST PALM BEACH, FL: Immediate opening for BC/BE Genetic Counselor [Genetrix]
RESPONSIBILITIES: Function independently in rapidly expanding perinatal group at community hospital. PNDx: CVS, early & routine amnio, U/S, teratogens, MSAFP, pregnancy loss, PUBS. Assist in expansion of genetic svc; participate in satellite clinics.
CONTACT: Anne Graham, MD, The Perinatal Center, 1000 45th St, Suite 17, West Palm Beach, FL 33407; 407-863-9269. EOE/AA.

SPRINGFIELD, IL: Immediate opening for BC/BE Genetic Counselor. Faculty Position, Dept. Pediatrics.
RESPONSIBILITIES: Ped GC: coordinate clinics; consults at specialty clinics; teach med students & residents; professional & community education.
CONTACT: Catherine O'Malley, SIU School of Medicine, Box 19230, Springfield, IL 62794; 217-782-8133. EOE/AA.

DETROIT, MI: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join active team in large, diverse, rapidly expanding repro genetics ctr. Wide range ethnic, economic backgrounds. CVS, amnio, MSAFP, dx U/S, teratogens, novel fetal therapy. Oppty for research, publications.
CONTACT: Eric L. Krivchenia, MS or Mark Evans, MD, Dept Ob/Gyn, Div Repro Genetics, Hutzel Hospital, 4707 St. Antoine, Detroit, MI 48201; 313-745-7067. EOE/AA.

WINSTON-SALEM, NC: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Primary respon for MSAFP coord; option of rotating w/ 3 other GCs thru PNDx & genrl genetics, craniofacial clinic, Marfan clinic.
CONTACT: Peggy Berry, M.S., Bowman Gray School of Medicine, Medical Center Blvd, Winston-Salem, NC 27157; 919-748-2213. EOE/AA.

SYRACUSE, NY: Jan 93 opening for BC/BE Pediatric Genetic Associate. Experience preferred.
RESPONSIBILITIES: All aspects of coun/case mngmt for expanding Ped/Adult program in large, univ tertiary ctr; support svcs: cyto & molec dx labs; PN avail in OB dept; education & clinical research oppty available.
CONTACT: Laura Thomson, MS, Dept. Pediatrics, SUNY Health Science Center, 750 E. Adams St, Syracuse, NY 13210; 315-464-7610. EOE/AA.

CLEVELAND, OH: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Rapidly expanding, well supported univ affiliated ctr with broad range of GC & educational activities: PNDx; birth defects/dysmorphology; triple screen; teratogens assessment; biochemical, cytogentic, molecular dx; participate in genetic education at all levels; oppty for clinical research.
CONTACT: Dr. Lois Dickerman, Human Genetics, Case Western Reserve University Ctr, UCRCII, Suite 510, 11001 Cedar Ave, Cleveland, OH 44106; 216-844-3936. EOE/AA.

TOLEDO, OH: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Coordinate MSAFP program for professionals & pts: test, counsel, follow-up; data collection; potential for research. Program to expand to incl HCG & estriol screening.
CONTACT: Thaddeus Kurczynski, MD, PhD, Dept. Pediatrics, Medical College of Ohio, PO Box 10008, Toledo, OH 43699-0008; 419-381-4435. EOE/AA.

OKLAHOMA CITY, OK: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: All aspects of GC for Genetics, Endocrin & Metab section, Dept Pediatrics. PN & pediatric coun; satellite clinics.
CONTACT: Kelly McCampbell Gentry, RN, MS, Dept. Pediatrics 2B275, University of Oklahoma Health Sciences Ctr, 940 N.E. 13th, Oklahoma City, OK 73104; 405-271-6764. EOE/AA.

EUGENE, OR: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: GC & Program Coord Regional Svcs Ctr (southern OR): Genrl GC; specialty & outreach clinics; oppty for education, clinical research, community involvement.
CONTACT: Robert Nickel, MD, Oregon Health Sciences Univ, CDRC, Clinical Services Building, 901 E 18th, Eugene, OR 97403; 503-346-3575. EOE/AA.

NORRISTOWN, PA: Immediate opening for Parttime BC/BE Genetic Counselor.
RESPONSIBILITIES: Share coordination of MSAFP & Triple Test Programs for NE area US; provide clinical consults svcs for clients, client visits & presentations; continuing monitoring of testing program & pt follow-up.
CONTACT: Patti Mathis, MS, SmithKline Beecham Clinical Laboratories, 400 Egypt Road, Norristown, PA 19403; 800-523-5447 x4563. EOE/AA.

PHILADELPHIA, PA: Immediate opening for BC/BE Genetic Counselor; 3-5 yrs experience in PN preferred.
RESPONSIBILITIES: New position in growing PN center: MSAFP, amnio, CVS; large PN diabetic population; some admin related to marketing, education; research oppty.
CONTACT: Shelly Dougherty, Human Resources, Frankford Hospital Knights & Red Lion Rds, Philadelphia, PA 19114; 215-934-4349. EOE/AA.

PHILADELPHIA, PA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: PN coun for amnio, CVS, triple marker scrng, DNA testing.
CONTACT: Rose Giardine, MS, Dept Ob/Gyn, Univ Pennsylvania Medical Center, 3400 Spruce St, Phila, PA 19104; 215-662-3232. EOE/AA.

NATIONAL SOCIETY OF
GENETIC COUNSELORS, INC.
EXECUTIVE OFFICE
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HGP UPDATE & DEADLINES

HGP ADDRESSES WOMEN'S NEEDS

The National Institutes of Health have awarded the University of Chicago funding to support study of "The Human Genome Project and Women." The broad objectives of this project are to determine the impact of the Human Genome Project (HGP) on women, to examine whether this impact meets standards of fairness or gender justice and to identify ways of avoiding or reducing the possibility of unfairness or gender injustice in the formulation of institutional and social policies.

Specific aims include:

- Developing a common core of scientific, psychosocial, legal and ethical knowledge regarding the impact, or probable impact, of the HGP on women;
- Identifying criteria against which the possibility of gender justice may be measured and applying these criteria to three areas of research: cystic fibrosis, sickle cell disease and breast cancer;
- Determining an agenda for future research and public education concerning impact of HGP on women; and
- Recommending ways in which gender justice may be preserved or promoted by HGP research and its applications.

The principal investigator is Mary Mahowald, and co-investigators are James Bowman, Christine Kassel, Michelle LeBeau, Carole Ober and Amy Lemke.

NEW RESEARCH CENTER OPENS IN IOWA

A grant from the National Center for Human Genome Research to the University of Iowa College of Medicine makes them the ninth U.S. center funded for research on the Human Genome Project. Dr. Jeffrey Murray is the principal investigator in a four year cooperative effort with both scientific and social components. In addition to generating a series of gene maps, other team members will address ethical and legal issues such as confidentiality and access to health care insurance. The project also includes funds to allow high school science teachers to attend UI for lab and lecture opportunities.

GRANT DEADLINES

Deadlines for grant applications for the Human Genome Project are February 1, June 1 and October 1. The time between application deadlines and actual award announcements is about nine months.

Counselors are invited to request application information by contacting Eleanor Langfelder, National Center for Human Genome Research, c/o NIH, Building 38A Room 617, Bethesda, MD 20892.

JoAnn Inserra, M.S.