PERSPECTIVES
in Genetic Counseling

newsletter of the National Society of Genetic Counselors, Inc.

Vol. 11, No. 4 Winter 1989

ELECTION RESULTS

Diane Baker, Nominating Chair, has announced the results of the 1989 elections. Congratulations to...

Joan Scott ..... President-Elect
Betsy Gettig ..... Treasurer
Barbara West ... Region I Representative
Stephanie Smith .Region III Representative
Bonnie Baty ..... Region V Representative

Serving on the 1990 Nominating Committee are: Debra Collins, Chair, Nancy Callanan, Caroline Lieber, Janice Cox Palumbos and Vickie Venne.

on the inside

THEME: OUTREACH

An Outreach Program for Management of Stillbirth

by Catherine A. Reiser, M.S., Susan J. Kirkpatrick, M.S., Richard M. Pauli, M.D., Ph.D., Clinical Genetics Center, University of Wisconsin-Madison, Madison, WI

Impediments to the adequate etiologic investigation of stillborns have included unfamiliarity with what constitutes an appropriate evaluation; the unavailability of detailed procedural protocols; and the problem of transporting all stillborns to a major referral center in terms of both distance and the often unexpected nature of stillbirth.

Approximately one in every 125 deliveries results in a baby born still, accounting for about one-half of all perinatal deaths. Using the World Health Organization's definition of stillbirth as "products of conception with a gestation of at least 20 weeks which show no evidence of life after extraction or expulsion,"[1] then there are more than 500 stillbirths each year in Wisconsin and about 25,000 nationally.

When a stillborn is well studied, congenital malformations or other genetically relevant data are found in about 25% of such infants. Comparison of three previous university-based studies [2,3,4] suggests that much of the variability in the frequency of demonstrating fetal causes of stillbirth is secondary to variability of thoroughness of the evaluation; that is, the more extensive the evaluation, the higher the proportion of infants with recognized, etiologically significant abnormalities. Yet in most locales, few, if any, stillborns are adequately assessed.

The Wisconsin Stillbirth Service Project (WiSSP) is a community based system for evaluation of stillborns and the subsequent counseling of their parents, in which primary responsibility for carrying out an evaluation remains with the hospital of birth. Implementation of a community-based stillbirth evaluation program require:

- development and dissemination of easily followed, algorithmic protocols for all steps

continued on p. 4

Establishment of a Genetics Outreach Service

by Susan M. Jones, M.S. and Carolyn Eckert, B.S., Div. Human Genetics, Children's Hospital, SUNY at Buffalo, Buffalo, NY

To increase the accessibility of services provided to traditionally underserved patients by the Western New York regional genetics program, an outreach effort was undertaken which included education of health care professionals regarding genetic services and the initiation of a system of satellite genetics clinics. This article describes the aims, implementation and outcome of the start-up activities necessary to establish this permanent program.

Two factors which may limit access of patients and their families to genetic diagnostic and counseling services are a lack of awareness by community health professionals leading to failure to refer and geographic distance between service providers and potential recipients. Since most genetics centers are located in major metropolitan areas, distant rural populations may be underserved. Furthermore, other

continued on p. 5

EdNotes — Visions, Viewpoints & Valued Opinions

The 217 respondents to this summer's *PGC* survey, compiled by Christine Barth, have cast a strong vote of support for *Perspectives* and have offered several thoughtful suggestions. As a result, the Editorial Board will be incorporating relatively few changes in Volume 12. Most noticeable will be the absence of "theme" issues and "Ed Notes." Theme issues were perceived by many as being too restrictive. It was thought that submissions which did not fit the theme but which were nevertheless excellent might not get priority consideration. Hopefully, the use of open issues will prevent that. And rather than allowing an entire column each issue for editorial notes, the editor will appropriate space on an as-needed basis.

Another idea that we'd like to implement in 1990 is a column in which a controversial issue would be debated by two especially interested or knowledgeable individuals. Among suggested topics: Should routine AMA require the services of a genetic counselor? ...When is peer support counseling appropriate? ...How should risk be reported in DS screening? ...Should CF carrier testing be routinely offered to all Caucasian couples? If you have a strong opinion about these or other issues and would like to be part of this feature, or if you know someone who might, contact one of the Editorial Board. We're all listed on p. 6.

In response to readers' interest in starting a professional journal — 125 offered to help with a journal in some capacity — Barbara Biesecker has asked me to chair an *ad hoc* committee to investigate its feasibility. Following its initial meeting in Baltimore, the committee has entered into discussions with several publishing houses.

One final note... Susan Jones from Buffalo has been appointed to fill the Professional Resources position, which has been vacated by Joan FitzGerald. If you know of any books, videos, software or courses that you would like to see reviewed (or would like to review, yourself) she'd be pleased to hear from you.

On behalf of *Perspectives in Genetic Counseling*, best wishes for 1990!

Ed Kloza

An Interview with Jeff Whitaker

New Frontiers in Genetic Counseling

Jeff Whitaker, a 1977 graduate of Bates College with a major in Biology, is President of Genetic Counseling Resource, Inc., located in Westborough, Massachusetts. In his twelve year career in the medical industry, Jeff has held sales and marketing positions, most recently at Integrated Genetics.

Traditionally, outreach in the genetic counseling community has been defined as travel to satellite clinics. With the innovative approach described here, outreach now expands that definition to include genetic counseling and consultation in private medical practices and in the corporate world.

WHAT PROMPTED YOU TO START GENETIC COUNSELING RESOURCE (GCR)?

I believe in the premise that the key to any discipline becoming a major force in medicine is technology, and as we have witnessed recently, genetic technologies appear to be boundless in their potential.

Over the past several years, I have had the opportunity to meet and speak with a significant cross-section of genetics professionals. The recurrent message was that genetics would resolve as a major force in medicine in the future, and it was hard to ignore the articles being written at the time in the major domestic magazines supporting these claims.

As I listened and read, I began to understand and appreciate the responsibilities genetic counselors had in the delivery of quality genetics services and the key role that these individuals played in the overall genetics health care picture. It also became increasingly apparent that genetic counselors, in general, were ready for new challenges and responsibilities. I recognized the need for the development and appropriate marketing of a unique, accessible and flexible genetic counseling concept, one that would be available in a convenient, outreach format that would assist the health care providers most dependent upon genetics: the obstetricians.

Ultimately, I believe this concept will be successful because of the caliber of genetic counselors in this country, the current trends in reproductive patterns, the newly emerging testing technologies and the continuous increase in public awareness of genetics and its diagnostic value.

WHAT SERVICES DOES GCR PROVIDE, AND TO WHOM?

The company provides three basic services at this time: genetic counseling; development and presentation of educational materials and programs for a variety of audiences; and clinical, technical and administrative support to our clients and their patients.

So far, we have provided services for solo and group practice obstetricians, medical centers, genetics centers and reference laboratories. Our outreach approach has such unique flexibility, benefits and appeal that we see no boundaries on whom we will be working with in the future.

WHAT ARE THE LOGISTICS INVOLVED IN PROVIDING THIS TYPE OF GENETIC COUNSELING SERVICE?

GCR is a privately held corporation with a staff of salaried employees. We do not effectively 'place' genetic counselors in jobs. We work with obstetricians, hospitals, medical centers, genetics centers and reference laboratories to provide genetic counseling and education services on a fee for service and/or contractual basis. In general, response to our services has been excellent, and we have enjoyed acceptance by a wide variety of health care providers in our target markets.

WHAT IMPACT DO YOU SEE GCR MAKING ON THE FIELD OF GENETIC COUNSELING?

My vision for GCR is both short and long ranged. I would like to see it...

- Develop an alternate career opportunity and work environment for genetic counseling professionals
- Establish standards for office-based genetic counseling services
- Develop useful genetic educational materials and programs for a variety of audiences
- Improve the availability and accessibility of genetic counseling services
- Enhance the perception of the genetic counseling discipline on medical, social and professional planes
- Establish a national presence over time,

continued on p. 3

Case Report

Case Nos. 18 & 19

Genetic Counseling in an Outreach Setting

by Ann M. Garrity, M.S., Children's National Medical Center, Washington, D.C.

Genetics outreach programs, which often serve inner city and rural residents, were established to increase accessibility to genetics services by these underserved populations.

In the inner city, counseling cases are dominated by issues relating to drug and alcohol abuse during pregnancy. Many pediatric referrals are for developmental delay or dysmorphic features which result from such substance abuse. Many referrals to the rural outreach clinics often result from consanguineous relationships. In either clinic setting, genetics services may be considered extraneous and esoteric to an uneducated family whose children lack basic medical care. Financial issues are also a concern for many families who, despite having full-time employment, may be un- or underinsured.

Counseling a family where they live is helpful because providers can better understand the family's daily routines, living conditions, aspirations and needs. For example, the management of a child with a specific genetic condition is complicated when the family has no heat, telephone or running water. Attending outreach clinics makes one more aware of the day to day struggles faced by many of the families we serve.

Our outreach clinics, which are supported by grants from the District of Columbia and the State of Maryland, were established to provide accessible genetics services to anyone, regardless of their ability to pay. Clinics are held at various sites throughout Maryland and the District and are attended by a clinical geneticist, a genetic counselor and a Community Health Nurse (CHN) who serves as the local coordinator. CHNs are a vital link between the patient, the local pediatrician and the genetics team. They make the patients aware of our services and explain the genetic counseling process. The CHN will often do a home visit both before and after the genetics visit to reinforce information, provide support, help parents apply for financial aid and schedule follow-up appointments. In many cases, the family is already known to the CHN before referral and important information about the family and social situation can be shared with the genetics team. The following two examples from Maryland illustrate how genetics patients are served through an outreach program based on cooperation between the genetics staff and local health care professionals.

CASE No. 18: A couple was seen in the Charles County Genetics Outreach Clinic with their 20 day old son, J.O., who had probable Zellweger syndrome. The child had been evaluated soon after birth by a geneticist and was noted to have respiratory distress, hypotonia and dysmorphic features. Biochemical studies showed an increase in very long-chain fatty acids and deficient red blood cell plasmalogen content, all consistent with the diagnosis. When J.O.'s parents were seen, he had developed a seizure disorder and was fed by nasogastric tube. In the initial counseling session, which was also attended by the CHN, we reviewed the diagnosis, management, etiology and recurrence risks for Zellweger syndrome. The couple was told that prenatal diagnosis in future pregnancies would be possible if a skin biopsy to evaluate the specific biochemical defect could be obtained from J.O. We also discussed the benefits of an autopsy after J.O.'s death. The CHN began to make weekly visits to this family and put them in touch with the County Hospice Program. The next month, a skin biopsy performed on J.O. confirmed the diagnosis of Zellweger syndrome and made it possible to offer J.O.'s parents prenatal diagnosis in future pregnancies. By this time, increased seizure activity and difficulty with feeding and managing secretions made J.O.'s home management problematic. The CHN continued to visit the family and the Hospice Program helped the family prepare for J.O.'s death. Arrangements for an autopsy and protocols for the geneticist on call, funeral director and parents were worked out with the help of the hospice worker and the CHN. J.O. was last seen by the genetics team three months later and died at home three weeks after that visit. The CHN, who was called immediately by the parents, obtained consent from the parents for an autopsy and assisted with final arrangements. Throughout J.O.'s life, the CHN acted as the primary means of assessing the family's status and needs. Having genetics services available in their community facilitated the family's visits for counseling and management and the local CHN provided important feedback to us about the family's needs.

CASE No. 19: The W family lives in rural St. Mary's County and has been followed by the genetics team for many years. Mrs. W had six children: two sons are alive and healthy, two sons had died from complications of osteogenesis imperfecta (OI), type II, and two daughters have an unknown syndrome consisting of mental retardation, hypotonia, ectodermal dysplasia and mild bone fragility.

The parents are Mennonite and are consanguineous. The family does not have a car (they travel by horse and

continued to p. 11

VV&V

New Frontiers from p. 2

based on market demand and demographics.

Routinely, each member of our team, currently comprised of three ABMG-certified genetic counselors and two administrators, has input into projects and decisions regarding company direction and policy, which ensures that everyone remains committed to this philosophy in practice.

WHAT DO YOU SEE AS THE ROLE OF COMPANIES LIKE GCR IN THE FUTURE?

There will always be an important need for genetic counseling in the traditional medical center and university settings, but I am convinced that as key technologies change, social adjustments continue and the genetics profession matures, these traditional venues will develop cooperative service efforts with endeavors like GCR. This collaborative effort will produce major benefits and help cope with what is certain to become an overwhelming future demand for genetic counseling in this country.

Over time, GCR plans to establish effective cooperative working relationships with genetics centers nationwide to help genetics services become more readily available.

viewed as important in the assessment of stillborns,
- on site educational programs at each of the 85 birthing hospitals within the targeted area and
- establishment of a network of "stillbirth contacts" in each of the collaborating facilities.

Targeted hospitals included all those with at least 100 births per year and, therefore, likely to experience at least one stillbirth per year. This would include about 94% of all stillbirths within the targeted region.

Laying the Groundwork

The educational programs, consisting of either inservice seminars or videotape programs, included discussion of parental needs following a stillbirth, the need for stillborn evaluation, rationale for various portions of the recommended protocol and clarification of respective commitments and responsibilities. Obstetricians, family practitioners, pathologists and obstetrical nursing staff were all encouraged to attend.

Local hospital responsibilities included informing the parents of the need for and availability of stillbirth evaluation, coordination and implementation of the evaluation using the provided protocols, forwarding all evaluations to WiSSP, and coordinating parental follow-up and counseling. The university-based WiSSP staff is responsible for project organization, educational outreach, review of all materials and generation of diagnoses, summarizing diagnostic information for the referring physician and direct counseling of referred families.

Other outreach and service activities initiated by WiSSP staff have included a day-long conference to help hospital contacts educate their own staff regarding stillbirth evaluation and the needs of families, the production of a videotape, *Life and Death Before Birth: Evaluation of the Stillborn* (See p. 9), provision of written grief resources in parent bereavement packets available to all participating hospitals and compilation of an annotated bibliography of over 100 written and video grief resources available for loan through the WiSSP lending library.

We were initially concerned about the level of collaboration we could expect, but were impressed by the overall goodwill of private practitioners toward the program and this type of outreach activity. Of 85 initially targeted hospitals, 81 requested and were provided with on-site educational programs. Approximately 1,100 physicians, nurses and other health professionals participated in these programs. Seventy-five hospitals elected to become collaborating members.

Results

From its initiation in 1983 to November 1989, evaluations of 767 babies stillborn in all areas of the targeted region were completed. Specific causes of stillbirth were demonstrated in about 38% of cases; in 22% of these, a specific *fetal* cause was found. This yield is comparable to published, solely university-based evaluations[2,3,4] and indicates that a community-based program can be successful in generating diagnostic information crucial in counseling parents of stillbirths. The need for continuing expert involvement is evident from the diversity and complexity of the different fetal causes which were found, including:
- 11 infants with 11 different Mendelian disorders,
- 32 with 10 different chromosomal abnormalities,
- 18 with 9 different single birth defects, and
- 18 with primary disruptions (within the first 500 evaluated).

Pros and Cons

Such an outreach program has tradeoffs: significant time commitment for staff travel and inservice education; bureaucratic impediments which are roughly proportional to the size of the institution; periodic and recurrent confusion about what happens in small hospitals where stillbirth is an infrequent event; variability of quality of evaluations; issues surrounding cost and reimbursement; and concerns about adequacy of local counseling and difficulty in assuring adequate follow-up. However, advantages of a community-based system include increased professional awareness of the needs of families following the birth of a stillborn child and of what is involved in the appropriate evaluation of the stillborn; increased number of stillborns evaluated, diagnoses generated and families counseled; and increased visibility of clinical genetic services.

This community-based system where local hospitals distributed over a large geographic region play a primary role in the generation of genetic services to a targeted population may serve as a model for provision of similar services by other centers and to other targeted groups.

1 *World Health Organization International Classification of Diseases,* 9th edition, Geneva, 1977.

2 MacLeod P, Dill F, Hardwick DF. Chromosome syndrome and perinatal death: the genteic counseling value of making a diagnosis in a malformed abortus, stillborn, and deceased newborn. *Birth Defects Original Article Series 15;* (5A) 105-11, 1979.

3 Poland BJ and Lowry RB. The use o spontaneous abortuses and stillbirths in genetic counseling. *Am J Obstet Gynecol* 118: 332-26, 1974.

4 Mueller RF, Sybert VP, Johnson J et al. Evaluation of a rpotocol for psot mortem examination of stillbirths. *N Engl J Med* 309: 586-91, 1983.

Professional Code of Ethics Update

The last issue of *Perspectives* featured the report of the *ad hoc* Committee on Ethical Codes and Principles. It concluded with the recommendation that a Professional Code of Ethics be established for the NSGC. This was enthusiastically supported by the Board and our committee is now gearing up to meet this challenge during the next 12 months. We are fortunate to have acquired an energetic and knowledgeable bioethics consultant, Kevin FitzGerald, who is a double Ph.D. candidate in Bioethics and Genetics at Georgetown. He has agreed to work with us for the duration of the project.

Because we believe that *you* are the NSGC, and that our Code of Ethics represents *your* ideals and practice, we encourage you to engage with the committee in ongoing dialogue. To enhance this process we will be publishing updates on our progress and providing other relevant information in future issues of *Perspectives.* Additionally, we are planning a workshop at the 1990 NSGC Educational Conference which will present the proposed Code of Ethics to the membership and provide an open forum for discussion.

Our Committee is excited about creating a document which will serve the NSGC in its second decade, and see our profession into the 21st century. We look forward to sharing our work with you and welcome your input along the way.

Judith Benkendorf, M.S., Nancy Callanan, M.S., Rose Grobstein, B.A., Seymour Kessler, Ph.D., and Susan Schmerler, M.S.

socioeconomic factors may hinder patient access to genetic counseling. Individuals institutionalized in developmental disability facilities, for example, often do not receive genetic evaluation unless a specific relationship has been developed between the institution and the local genetics group.

AIMS

A grant was provided by the New York State Office of Mental Retardation and Developmental Disabilities to the Division of Human Genetics (DHG) of Children's Hospital of Buffalo towards support of a coordinator to formulate and carry out a program designed to initiate such activities for developmentally disabled patients and their families. It was anticipated that this project would serve also to increase referrals of patients with other genetic concerns and thus enable the regional genetics program to meet the State's requirement for provision of outreach service. The project, which was implemented in three phases over a six-month period, consisted of:

- education of local health care professionals regarding genetic services
- establishment of satellite clinics and
- development of a data base for collection of demographic, statistical and medical information.

The DHG provides genetic consultation for 1.6 million individuals in eight Western New York counties. Seventy-four percent of the population resides in Erie and Niagara counties, both of which include major urban areas (Buffalo and Niagara Falls); the remaining six counties are rural in character. The catchment area includes towns 45 minutes to the north, an hour drive to the east and a two hour drive southward. Because the travel time faced by patients is greatest to the south and east, these areas were targeted for the establishment of rural clinics.

Case analysis suggests that some families seen for genetic consultation through outreach efforts formerly would not have been recognized as being appropirate candidates for referral.

IMPLEMENTATION

The outreach activity was initiated by informing local health care professionals about the purposes and availability of genetic services. These contacts included discussions with physicians, public health nurses, hospital administrators, county health commissioners and directors of developmental disability facilities. A total of 21 lectures/presentations were given by a medical geneticist and/or genetic counselor; these discussions outlined appropriate indications for referral, mechanisms of evaluating patients and assessing genetic risks, and benefits to the patient/family of genetic diagnosis and counseling. A pamphlet on genetic services was developed for distribution to local health practitioners.

Data analysis demonstrated that the proband census during the control period was 422, while the number of probands seen during the project period was 680, an increase of 61%.

At the conclusion of this educational activity, seven satellite clinics were inaugurated. Two general clinics are presently established in small cities which represent the largest population center in their respective rural counties. One of these cities is also the site of a state school for children who are visually impaired and developmentally disabled; the medical director of this institute was highly motivated to obtain genetic service for these children. Thus, a trip to one rural area enables the genetics staff to provide consultation at two sites. Efforts to initiate a clinic in another rural area were not successful; local physicians felt that the service needs of their patients were being met through referral to Children's Hospital.

In addition, two urban outreach clinics are currently established and are held on a bi-monthly basis to serve minority (Black and Hispanic) patients, many of whom are financially disadvantaged; these services are provided at long-established community health centers. Lastly, genetics clinics are held on a bi-monthly basis at two local developmental disability facilities. Patient intake for these clinics is arranged either by the local institution or thorough the DHG.

OUTCOME

In January 1988, a data base was developed and implemented using the Apple IIe microcomputer. This was used to compare genetic services rendered both for a six-month control period before the initiation of the project and the six-month period of the outreach effort itself.

Data analysis demonstrated that the proband census during the control period was 422, while the number of probands seen during the project period was 680, an increase of 61%. In the county in which two outreach clinics were established, the number of patients evaluated rose by 425%. In two counties in which no clinics were established, the number of probands fell slightly, although the number of patients seen was too small to permit meaningful analysis. It is presumed that the efforts of the DHG staff were at least partially responsible for the overall increase in patient referrals, although a cause-and-effect relationship cannot be proven.

Case analysis suggests that some families seen for genetic consultation through outreach efforts formerly would not have been recognized as being appropriate candidates for referral. In some cases, practitioners sent more patients for genetic services. In other instances, patients evaluated through the newly-established developmental disability clinics were diagnosed as having genetic conditions, e.g., unbalanced chromosome complements, that prompted evaluation and identification of increased reproductive risk in other health relatives.

Establishment of an outreach genetic service is a multifaceted effort that includes significant preparatory work and statistical documentation of service in addition to the provision of genetic information. We believe that efforts to educate health providers about the benefits of genetic evaluation/consultation and to render services in locations geographically convenient to patients has the potential to increase utilization of genetic counseling by previously underserved clients.

BOOK BAG

The Family Genetic Sourcebook
By Benjamin Pierce, Ph.D.
Publisher: John Wiley Sons, 1990
Price: $14.95, paperback
Reviewed by: Ricki Lewis

Have you ever wanted an easy genetics reference book that you could simply pull off a shelf and read aloud to a patient...and have it be completely comprehensible? Benjamin Pierce's *The Family Genetic Sourcebook* accomplishes this often elusive goal, while at the same time presenting genetics as a normal part of everyone's life, rather than a morbid science to be considered only when someone falls dreadfully ill. Part genetics text and part McKusick's greatest hits, *The Family Genetic Sourcebook* is guaranteed to be dog eared in no time at all, by patients and clinicians alike.

The book is divided into two parts. The first section consists of six chapters that clearly explain the basic principles of heredity. Chapter One sets the theme of genetics as a broad discipline by introducing familiar problems with a genetic component: hypertension, diabetes, asthma and colon cancer. A short history of genetics follows, spanning agricultural origins of 10,000 years ago to recent advances on the molecular front...all in a dazzling few pages.

Chapters Two through Five present the basics of genetics and human development. I don't know how useful these chapters will be, because genetic counselors already know this material and patients may not have the patience to wade through them. Chapter Six, however, will be exceedingly useful to both readers, because it explains what genetic counseling is, and describes the tools of the trade used in prenatal diagnosis, newborn screening, carrier detection and even gene therapy.

The catalogue of traits in the second part of *The Family Genetic Sourcebook* will really grab attention. It emphasizes the familiar (i.e. multi-factorial) but more common single gene defects are represented as well. Although Pierce hasn't covered many of McKusick's more colorful and obscure examples — such as the inability to smell skunk, tune deafness and the Jumping Frenchmen of Maine — the listing teems with everyday problems, whose genetic components may be surprising. Patients will undoubtedly flip first to their particular condition (which won't be here if it's an orphan disease), but along the way they will find themselves caught up in discussions of alcoholism, mental illnesses, anorexia nervosa, bedwetting, psoriasis, sleepwalking, allergies, birthweight, breast cancer and even such hard-to-describe "traits" as intelligence and personality.

The author of this unique resource is an assistant professor at Baylor University in Waco, Texas.

Perspectives in Genetic Counseling is published quarterly by the National Society of Genetic Counselors, Inc. Editorial Staff:
Edward M. Kloza, *Editor-in-Chief* • R.R. 2, Box 109D, Sebago Lake, ME 04075; 207-892-3910; FAX#\ 207-883-1527
Vickie Venne, *Assistant Editor; Technology* • Nichols Institute, 26441 Via DeAnza, San Juan Capistrano, CA 92675; 800-642-4657
Karen Copeland, *Professional/Personal Issues* • Baylor College of Medicine, 6550 Fannin, #921, Houston, TX 77030; 713-798-4691
Trish Magyari, *Legislative Issues* • Georgetown University Child Development Center, CG52 Bles Bldg., 3800 Reservoir Road NW, Washington, DC, 20007; 202-687-8635
Seth Marcus, *Interviews* • Lutheran General Hospital, Perinatal Center #325, 1875 Dempster St., Park Ridge IL 60068; 312-696-7705
Sylvia Mann, *Resources* • Shriners Hospital, 1310 Punahou Street, Honolulu, HI 96826; 808-948-6872
Barbara Bernhardt, *Counseling Approaches* • U Maryland School of Medicine, Div Human Genetics, Bressler Bldg 11-037, 655 W. Baltimore St., Baltimore, MD 21201; 301-328-3815
Susan Jones, Professional Resources • 126 Grandview Ave, Buffalo, NY 14223; 716-878-7545
Bea Leopold, *Executive Director* • 233 Canterbury Drive, Wallingford, PA 19086; 215-872-7608; FAX# 215-872-1192

Send case reports, resources, materials and books for review to appropriate editors; address changes, subscription inquiries and advertisements to Executive Director; all manuscripts and correspondence to Editor.

Publication Date for Next Issue: March 15

Deadline: February 10

Letter to the Editor

To the Editor:

I read with interest the case report (CR #17) submitted by Karen Copeland, dealing with that perennial question, "What would you do if you were in my shoes?" I think it highlights a common problem which arises in genetic counseling: the lack of experience (both personal and normative) in decision making. In dealing with abnormal or ambiguous results, couples are often facing the first "adult" decision of their lives, and are unsure how to go about the process. Should they logically weigh the facts? Should they trust their gut feelings? How do they know when they've made the "right" decision? By explaining her own thought processes, Ms. Copeland helped her client by not only demystifying her own standing, but also by illustrating the elements of decision making, thus validating the couple's own decision. The client learned that another woman would approach the process in the same way that she had, by weighing medical information in light of her own situation and priorities.

There are other techniques which can be used to help couples facing a tough decision. A simple device is to talk about the decision-making process, including what to expect emotionally (that partners often disagree about what is important and why; there may still be uncertainty and self-doubt even after the decision is made). It is also possible to present hypothetical illustrations of how other people proceed in the same situation: ("I've known couples who choose A because of B, C, and D; and others who opt for X because...") which demonstrates the decision-making process without focusing on the person making the decision. This also helps the couple realize that other people have faced similar situations and have survived; as impossible as their task may seem, it is resolvable.

While I feel that most clients are able to separate discussion from persuasion, there may be some who are vulnerable to being swayed by an authoritative decision ("Well if she knows what's going on and she would make a different decision, then maybe I'm wrong..."). A client who identifies with the counselor's situation ("She's a single mother, too" or "She's a Catholic, too...") may feel subtle pressure to adopt her counselor's viewpoint as well. Finally, a client may feel awkward about seeking emotional support later if she knows that the counselor would have make a different decision.

Thanks to Ms. Copeland for sharing a case with which I know we all can identify.

Liz Stierman
Los Angeles, CA

9TH EDUCATION CONFERENCE BRINGS PRAISES AND GREAT IDEAS FOR 10TH

BY BETH FINE AND BETSY GETTIG, CO-CHAIRS, KAREN GREENDALE, PROGRAM CHAIR

Our 1989 annual education conference, *Strategies in Genetic Counseling: Reproductive Genetics and New Technologies,* was a resounding success: a record 453 members and non-members attended. Of those attending, 121 have turned in evaluation forms. The vast majority of participants rated the plenary speakers and workshops good, very good or excellent.

Those evaluating the program were asked to suggest topics which could be incorporated into future conferences. Some of special interest follow:

- licensure for genetic counselors
- professional and career advancement
- grant writing
- counseling pregnant teenagers
- counseling technique and theory
- topics of special interest to students
- primers or short courses on DNA testing or other areas undergoing rapid change
- counseling mentally retarded patients
- role of new technological advances in treatment of genetic disease
- helping to set up support groups

Participants were very impressed with the quality of the contributed papers this year and asked that we expand the time allotted for this activity. Many would like more time to meet new colleagues in small groups or at social events. Nearly unanimous, 120/121 stated that they enjoyed the tenth anniversary event.

Next year's conference, *The Interface Between Public Health and Clinical Genetics,* will be chaired by Karen Greendale. It has been scheduled in Cincinnati on October 14 - 16. The Planning Committee is very interested in receiving suggestions. Please make your suggestions known to the following persons:

- *Plenary topics and speakers*
  Becky Butler, MSW, Program Chair, Arkansas Genetics Program, 512B, University of Arkansas Medical School, 4301 W. Markham, Little Rock, AR 72205-7199; 501-686-5994.
- *Workshop ideas and facilitators*
  Jane Halperin, MS, Dept. Neurology, Box 1137, Mt. Sinai Hospital, One Gustave Levy Place, New York, NY 10029; 212-241-8915; Diana Punales, MS, 212-420-4179; or Maureen Smith-Deichmann, MS, 312-908-7441.
- *Contributed papers/posters*
  Rhonda Schonberg, MS, 351 Bella Vista Way, San Francisco, CA 94127; 415-540-2546.
- *Logistics*
  Leah Hoechstetter, MS, Chair, Cincinnati Regional Genetics Center, 3300 Elland Ave, Pavilion 2-52, Cincinnati, OH 45229; 513-559-4760.

The Call for Abstracts will be mailed in late January or early February. Information about the application process for the SPECIAL PROJECT FUND is detailed at the bottom of this page.

Most importantly, be sure to plan to attend, for it won't be the same without you!

CONFERENCE STATISTICS & ACKNOWLEDGEMENTS

- For the first time ever, registration topped the 400 mark, with a resounding 453 participants, including: 307 Full and Associate members, 39 Student members and 107 non-members, speakers, workshop guests and exhibitors.
- Our 10 Year Anniversary Celebration, chaired by Luba Djurdjinovic and Deborah Eunpu, received accolades. A special thanks to the fine work of Diane Baker, script writer extraordinaire, and to Betsy Gettig, our ace producer, who painstakingly spliced together outtakes of classic films with genetic references. (Do you remember these references from *The Fly I & II, Paternity, The Big Chill, The Pope of Greenwich Village?* ...to name a few.)
- We visited with old and new friends in our exhibitor's suite, among them: Alliance of Genetic Support Groups, Collaborative Research, GeneScreen, Inc., Genetrix, Inc., Genica Pharmaceuticals Corporation, Integrated Genetics, March of Dimes Birth Defects Foundation, Nichols Institute Reference Laboratories, Perceptive Systems, POSSOM and Reproductive Toxicology Center. And we acknowledge with special appreciation: Genentech, for an unrestricted donation to the Conference Fund and a Breakfast Lecture, Integrated Genetics for conference notepads and Roche Biomedical Laboratories for their generous funding of the conference program book.

SUCCESS OF SPECIAL PROJECT FUND ANNOUNCED IN BALTIMORE

The NSGC is pleased to announce the success of its fund raising campaign to establish the SPECIAL PROJECTS FUND. This year-long effort, resulting in a starting base fund of more than $22,000, was made possible by members and their families, corporate friends, voluntary organizations in the genetics community and genetic counseling training programs.

Each year, beginning at the Tenth Annual Education Conference in 1990, interest from the SPECIAL PROJECTS FUND will be awarded to one or more genetic counseling professionals for innovative projects that focus on the future of the genetic counseling profession and/or the provision of genetic services. These projects will be reviewed on the basis of their merit and strength as well as their vision of the future of the profession.

All NSGC members will be eligible to submit proposals for consideration. Forms may be requested by contacting the NSGC Executive Office. The following information will be requested: Name of Project Manager(s), Title, Goals and Objectives, Method, Evaluation Process, Projected Timeline, Line Item Budget and Total Amount Requested. The Project Manager(s) will be expected to submit a report for publication by the National Society of Genetic Counselors.

All applications submitted to the SPECIAL PROJECTS FUND are to be sent to the Executive Office, postmarked no later than May 15 in the year of the funding request. The requests will be coded for anonymity and forwarded to the review committee chairperson. Notification of awards will be made by August 30. Awards will be announced at each Annual Education Conference beginning in 1990 at the annual business meeting and will be published in the Winter issue of *Perspectives in Genetic Counseling.*

The NSGC will continue to accept donations to the SPECIAL PROJECTS FUND. Please send your check, payable to NSGC, to: Luba Djurdjinovic, Genetic Counseling Program, 16 Leroy, Binghamton, NY 13905, Attention: SPECIAL PROJECTS FUND.

••• Conference Notes •••

APHA Call for Abstracts

The Genetics Committee of the American Public Health Association's Maternal and Child Health Section will be sponsoring/co-sponsoring a number of sessions on genetics-related topics at the APHA annual conference in New York City, October 1-4, 1990. Genetic counselors are invited to submit abstracts for the following proposed sessions:

- Genetics Issues in Public Health
- Psychosocial Issues in Genetics
- Genetic Screening Issues
- Birth Defects Surveillance
- Teratogen Issues (poster session)
- Genetics Issues in Nursing

Instructions for submitting abstracts to the MCH Section can be found in the *American Journal of Public Health* or in *Nation's Health* (December issue). Abstracts are due by February 12 and must be marked "Genetics Sessions."

For more information, contact Becky Butler, 501-686-7886.

Ethical and Legal Issues of Prenatal Diagnosis

The Divisions of Human Genetics and Maternal Fetal Medicine of the University of California, Irvine and Long Beach Memorial Medical Center will present a conference entitled *Prenatal Genetic Diagnosis and Fetal Therapy — New Technologies: Ethical and Legal Issues.* The Conference will take place April 19 - 20 at the Red Lion Hotel in Costa Mesa, California. While the conference is aimed primarily at physicians and nurses in obstetrics, it should be of interest to genetic counselors, as well. Further information and a prospectus can be obtained by calling Ruth Schweitzer, 213-595-9734.

The Eye and Genetics

Ophthalmic Genetics Update 1990, a course specifically designed for ophthalmologists, geneticists and genetic counselors, will cover major genetic diseases affecting the eye. Genetic implications of both isolated and multisystem ocular disorders will be reviewed, including cataracts, microphthalmia, retinitis pigmentosa and retinoblastoma. Psychosocial issues and the development of the visually handicapped child will be covered.

The conference will be held at Jules Stein Eye Institute UCLA Center for the Health Sciences this Spring. For further information, contact Michelle Fox at 213-206-6581.

Gastrointestinal Disorders

The 1990 Clinical Genetics Conference, sponsored by the March of Dimes Birth Defects Foundation and Wayne State University School of Medicine, will hold its meeting in Dearborn, Michigan, July 8-11. *Genetics of Gastrointestinal Disorders* will emphasize molecular and cell biological approaches to understanding normal and abnormal gastrointestinal development and function.

For more information, contact Carol Blagowidow, 914-997-4524.

Region II Conference Announced

Linda Nicholson, Region II Representative, has announced that *Counseling Issues in Clinical Genetics: Delivery of Counseling Services* will be the topic of the upcoming conference on March 25-26 at Trump Plaza in Atlantic City.

All interested genetic counselors are invited to attend. Contact Linda at 302-651-4234.

Canadians Combine Conferences

The 1990 Canadian Association of Genetic Counselors (CAGC) will again meet just prior to the Canadian College of Medical Genetics (CCMG) annual conference. The meeting will be held at the Old Orchard Inn, Wolfville, Nova Scotia, February 21 - 25.

•••••

Video Counseling

Elaine Strass is interested in knowing if any genetic counselors are videotaping counseling sessions or are interested in beginning this practice. Contact her at ASHG, 301-571-1825.

ISONG Officers Elected

Congratulations to the new officers of the International Society of Nurses in Genetics, elected at their annual conference last November in Baltimore:
Elizabeth Thomson, RN, MS....President
Anne Matthews, RN, PhD..President-Elect
Cathy Bove, RN, MS.....Secretary
Shirley Jones, RN, MS.....Treasurer
Betty Youson, BN..... Member-at-Large
...and to the following committee chairs: ByLaws, Betsy Phoenix, RN, MS; Education, Carolyn Farrell, RN, MS and Lynette Wright, RN, MS; Membership, Maureen Clark, RN, MS; Nominating, Janet Williams, RN, PhD; and Program, Maureen Clark, RN, MS and Anne Matthews, RN, PhD.

PGC Indices Available

Indices for *Perspectives in Genetic Counseling*, Vol. I - X, are now available at no charge to NSGC members. Write to the Executive Office for your copy.

Certification Review Courses Offered

The American Board of Medical Genetics will offer Board Certification examinations for the fourth time in June, 1990. Several short, intensive courses in genetics will be offered by three institutions this Spring. Individuals who attend these sessions may find themselves better prepared to take the Boards. However, the course directors wish to make explicitly clear that attendance at such a session does *not* guarantee that the individual will pass the Board examination.

Information regarding the courses is listed below; endorsement is *not* intended.

Sponsor:	NIH	University of Iowa	Baylor
Location:	Bethesda, MD	Iowa City, IA	Houston, TX
Date:	May 17-19	May 24-26	May 11-13
Cost:	$350	$150	$250
# Registrants:	400	50	200
Prev. Offered:	Yes (2X)	Yes (1X)	No
Contact:	Medical Genetics FAES 1 Cloister Ct #230 Bethesda, MD 20814-1460 301-496-7976	Elizabeth Thomson Div. Medical Genetics University of Iowa Iowa City, IA 52242 319-356-2674	Tamara Greiner Continuing Education Baylor Col Medicine One Baylor Plaza Houston, TX 77030 713-798-6020

BOOK

Dying and Disabled Children: Dealing with Loss and Grief
Editors: Harold M. Dick, David Price Roye, Jr., Penelope R. Buschman, Austin H. Kutscher, Boris Rubinstein, Francis K. Forstenzer
Publisher: The Haworth Press, New York and London, 1988, 153 pp.
Price: $24.95
Reviewed by: Susan M. Jones, M.S., Division of Human Genetics, Children's Hospital of Buffalo

This small volume is comprised of 19 short chapters by 17 authors who have worked in some capacity with seriously ill or handicapped children and adolescents. The authors, who are varied in training and experience, include physicians, nurses, psychologists, a parent of a teenager who died of cancer, and a funeral director. The writing covers both medical and psychosocial aspects of illness and disability.

Collectively, the chapters represent an oddly assorted melange of material. There is little consistency in style; some chapters are exclusively psychosocial in nature, while others contain a mix of both issues. Furthermore, the vignettes do not draw upon a wide range of disease. The majority of the material on disability relates to orthopedic disorders, notably amputations, while the writing on terminal illness pertains primarily to cancer. Indeed, apart from brief references to two brothers with Duchenne muscular dystrophy and a child with neurofibromatosis, the book contains very little on genetic disease.

The absence of reference to genetic disorders does not seriously hamper some of the stronger writing that deals with concerns of illness, impending death and disability, as these matters are not unique to inherited diseases. For example, a number of authors refer to the issue of body image for amputees and cancer patients; however, this material is also appropriate for individuals with neurofibromatosis and cystic fibrosis. Other issues reviewed that are relevant to genetic patients include: the child's loss of a sense of role in school and community produced by prolonged hospitalization and confinement; the value of parent support groups in enabling relatives to cope with the emotional demands engendered by serious illness or death; lack of parental absorption of medical information when an adverse diagnosis is given; and direction of parental anger towards health care staff.

Particularly interesting was a chapter on the concept of "seeking significance," the process in which dying individuals review their lives to find affirmation that their existence has had meaning. Similar behavior is thought to occur in bereaved parents, who examine their child's life and accomplishments to confirm the value of the child's existence. The author describes this phenomenon and identifies ways in which health professionals can facilitate this process.

This book can be recommended for purchase. While some of the material may be useful for teaching purposes, instructors in genetics programs who use this volume may wish to remind their students that while there is little reference to genetic disease, the material is valid for any chronic, debilitating or lethal disorder.

AUDIO-VISUAL

Life and Death Before Birth: Evaluation of the Stillborn
Produced by: The Wisconsin Stillbirth Service Project
Script by: Richard Pauli, MD, PhD, Director, Catherine Reiser, MS, Associate Director, Susan Kirkpatrick, MS, Genetic Counselor
Cost: $25
Reviewed by: Judy Garza

This informative video reflects the Wisconsin Stillbirth Service Project's (WiSSP) dual commitment to help meet the needs of parents who have experienced a stillbirth and to help hospitals better evaluate the causes of stillbirths.

The video addresses the lack of emotional support historically provided to parents of stillborn babies and attributes it to the practice of frequently considering the stillborn baby a non-person because it has no apparent past and no future. The video encourages health professionals to fill in the gaps left by an unresponsive community. Suggestions are offered to legitimize the grief, such as encouraging the parents to touch and name the infant and to hold a burial or memorial service.

While the WiSSP studies indicated that most parents were given the opportunity to do these things, many parents (71 of 204) said that they wished they had done more and none said they wished they had done less.

In addition, this video also deals with the grieving process in other siblings. The production very effectively advocates for a thorough evaluation of the stillborn in order to provide grief support, accurate reproductive counseling, proper perinatal management in future pregnancies, to decrease litigation and to enlarge the general knowledge of the etiology of stillbirth.

The video and the protocol packet detail the steps involved in a thorough evaluation including clinical evaluation, photographs, X-rays and chromosome analysis. It stresses how this protocol can be adapted to different situations, including parents refusal for autopsy.

The effectiveness of the WiSSP (begun in 1983) is reviewed. Over 600 referrals from all parts of the state have been made and the compliance for all parts of the protocol has been good.

This excellent video was designed for professionals in Wisconsin as a means of educating referring hospitals about the need for evaluation of the stillborn baby and the means of doing this. It was not intended to be viewed by parents or other lay groups. However, it is a sensitive and detailed model for other areas interested in developing a similar arrangement with local health care professionals. The graphs in the video are not always legible, but the graphics are included in the written packet.

ORGANIZATION

Foundation for Ichthyosis and Related Skin Types (formerly National Ichthyosis Fdt)

The National Ichthyosis Foundation has a new name - Foundation for Ichthyosis and Related Skin Types (F.I.R.S.T.). The group's structure and goals will remain the same but the disorders served have been expanded.

Following is a partial list of these disorders in addition to various types of Ichthyosis: Collodion Baby, Harlequin Fetus, Sjorgren-Larsson Syndrome, Chondrodysplasia Punctata Syndrome, Chanarin-Dorfman Disease, Refsum Disease, Tay Syndrome, Multiple Sulfatase Deficiency, the variable Erythokeratodermas, Peeling Skin Syndrome, Palmoplantar Keratoderma, Epidermal Nevus Syndrome, Pityriasis Rubra Pilaris, and Darier Disease.

F.I.R.S.T. can be contacted at: P.O. Box 252, Belmany, CA 94002, (415)591-1653.

Classified • Classified • Classified

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

LITTLE ROCK, AR: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Pediatric and adult genetics with wide range of specialty clinics, case coordination and teaching responsibilities.
CONTACT: Becky Butler, Coordinator, Arkansas Genetics Program, University of Arkansas Medical School, 4301 W. Markham, Little Rock, AR 72205; 501-686-7886. EOE/AA.

LONG BEACH, CA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join team in well-established, comprehensive genetics program: pre & early amniocentesis, PUBS, fetal anomalies, teratogen, MSAFP, family history counseling. Opportunity for involvement in pediatric genetic program.
CONTACT: Constance Sandlin, MD or June Peters, MS, Memorial Genetics Center, 750 East 29th Street, Signal Hill, CA 90806; 213-595-3965 or 3424. EOE/AA.

LOS ANGELES, CA: Immediate opening for BC/BE Genetic Counselor. Fluency in Spanish preferred.
RESPONSIBILITIES: Active pediatric genetic counseling team; prenatal diagnosis includes amnio, CVS, diagnostic ultrasound.
CONTACT: Atsuko Fujimoto, MD, LAC/USC Medical Center, Genetics Division, Room 1G-24; 1129 N. State St, Los Angeles, CA 90033; 213-226-3816. EOE/AA.

SAN DIEGO, CA: Immediate opening for Genetic Counselor with Masters or Nursing Degree. BC/BE (if BE, expected to sit for next exam). Salary Range: $34,038 - $47,653 depending on qualifications and experience.
RESPONSIBILITIES: Pediatric and prenatal diagnosis and counseling; consult with patients and physicians; utilize various hospital subspecialty programs.
CONTACT: Carol Heylman, Human Resources Dept., Childrens Hospital and Health Center, 8001 Frost Street, San Diego, CA 92123; 800-634-4441 (outside CA); 619-576-5827 (inside CA). Call for required application forms. Please include a CV and two or more references. For additional information: J.T. Mascarello, 619-576-5809. EOE/AA.

AUGUSTA, GA: March 1 opening BC/BE genetic counselor.
RESPONSIBILITIES: Coordinate and participate in preconceptional and prenatal genetic counseling; opportunity to participate in clinical and research activities.
CONTACT: Paul G. McDonough, MD, Medical College of Georgia, Human Genetics Institute, CK159, Augusta, GA 30912-3360; 404-721-3832. EOE/AA.

CHICAGO, IL: Immediate opening for BC/BE Genetic Counselor. Experience preferred but not required.
RESPONSIBILITIES: Coordinate preimplantation genetics program; CVS; amnio; MASFP follow up counseling; some pediatrics & general genetics. Clinical research opportunities exist.
CONTACT: Yury Verlinsky, PhD, Illinois Masonic Medical Center, 836 W. Wellington, Division Genetics, Chicago, IL 60657; 312-883-7095. EOE/AA.

BALTIMORE, MD: March 1 opening for BC/BE Genetic Counselor. Minimum 1 year experience with skills and ability to work independently preferred. Salary Range: Low $30, negotiable with experience.
RESPONSIBILITIES: Function independently at community hospital in prenatal diagnosis program: assist perinatologist during prenatal procedures; coordinate birth defects reporting system; act as liaison with medical departments and community.
CONTACT: Jeanne S. Ten Broeck, RN, MS, Sinai Hospital of Baltimore, Belvedere at Greenspring, Baltimore, MD 21215; 301-578-5885. EOE/AA.

BOSTON, MA: Immediate opening for BC/BE Genetic Counselor with at least one year clinical experience.
RESPONSIBILITIES: Serve as a service and technical liaison between geneticists/genetic counselors and our laboratory, sales and marketing departments. Primary contact and educator of testing technologies as related to our DNA-based, cytogenetic and prenatal biochemistry laboratories. Education and research opportunities in addition to excellent benefits and competitive salary.
CONTACT: David Nikka, Director of Human Resources, Integrated Genetics, One Mountain Road, Framingham, MA 01701; 508-872-8400.

BOSTON, MA: Immediate opening for BC/BE Genetic Counselor with minimum 2 years experience.
RESPONSIBILITIES: Join 1 genetic counselor and 2 MD geneticists in large successful HMO practice. Broad range of counseling issues; strong prenatal diagnosis program; prof education.
CONTACT: Martha MacMillin, MS, Harvard Community Health Plan, 147 Milk Street, Genetics, Boston, MA 02109; 617-654-7330. EOE/AA.

KANSAS CITY, MO: Immediate opening for independent BC/BE Genetic Counselor. Experience preferred. Salary Range: Starting in low 30's, negotiable with experience.
RESPONSIBILITIES: Prenatal counseling and consultation with patients and physicians; assist perinatologists with prenatal diagnosis and specialized disease counseling; coordinate MSAFP program.
CONTACT: David Galle, Coordinator, St. Lukes Hospital of Kansas City, 4400 Wornall, Department Maternal Fetal Medicine, Outpatient Center, Kansas City, MO 64111; 816-932-2009. EOE/AA.

CHAPEL HILL, NC: Immediate opening for BC/BE Genetic Counselor. Faculty position available.
RESPONSIBILITIES: Join team of 3 genetic counselors and 3 perinatologists in active prenatal program: CVS, PUBS, early amnio; regional hi-volume MSAFP screening program; professional and community education.
CONTACT: Lauren Lingley, MS, University of North Carolina School of Medicine, Dept. OB/GYN, MacKider Bldg CB7570, Chapel Hill, NC 27599-7570; 919-966-2229. EOE/AA.

CHARLOTTE, NC: Immediate opening for 2 BC/BE Genetic Counselors with excellent organizational, oral & written communications skills.
RESPONSIBILITIES: General genetic counseling and evaluation at large teaching facility; prenatal diagnosis for neural tube defect screening program; satellite clinics.
CONTACT: Human Resources Dept, Charlotte Memorial Hospital and Medical Center, P.O. Box 32861, Charlotte, NC 28232; 1-800-426-4677 (outside NC); 1-800-772-6133 (inside NC). EOE/AA.

Classified • Classified • Classified

GREENVILLE, NC: Immediate opening for BC/BE Genetic Counselor. Faculty Position available.
RESPONSIBILITIES: Wide range of genetic counseling opportunities; pediatrics, prenatal and specialty genetic clinics; participate in satellite clinics.
CONTACT: Theodore Kushnick, MD, East Carolina University School of Medicine, Brody Building, Room 3N51, Greenville, NC 27858-4354; 919-551-2525. EOE/AA.

WINSTON-SALEM, NC: Immediate opening for BC/BE Genetic Counselor with MS in genetic counseling.
RESPONSIBILITIES: Join active, multi-disciplinary pediatric department with large MSAFP program; prenatal program includes CVS, PUBS, amnio with in & out patient referrals; professional and community education opportunities.
CONTACT: Jeannette Bensen, MS, Bowman Gray School of Medicine, 300 S. Hawthorne Road, Dept. Pediatrics, Winston-Salem, NC 27703; 919-748-2213. EOE/AA.

CAMDEN, NJ: Immediate opening for BC/BE genetic counselor; Experience preferred; faculty appointment available for experienced counselor.
RESPONSIBILITIES: Comprehensive center includes: prenatal diagnosis; pediatrics; AFP screening; teratology; FAS; research; professional and community education.
CONTACT: Alice Lazzarini, MS, University of Medicine and Dentistry New Jersey /SOM, 401 Haddon Ave, Camden, NJ 08103; 609-757-7812. EOE/AA.

STATEN ISLAND, NY: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Wide variety of responsibilities in full service, comprehensive diagnostic program.
CONTACT: Susan Sklower, MD, NY State Institute for Basic Research, 1050 Forest Hill Road, Staten Island, NY 10314; 718-494-5240. EOE/AA.

PHILADELPHIA, PA: Immediate opening for BC/BE Genetic Counselor. Full or parttime negotiable.
RESPONSIBILITIES: Prenatal counseling with some travel to satellite facilities; opportunity for independent research; participation with multidisciplinary teams and projects, ie Cystic Fibrosis Center.
CONTACT: Ann McDonnell, RN, BS or Adele Schneider, MD, Hahnemann University, Broad and Vine Streets, MS#402, Philadelphia, PA 19102; 215-448-7050 beeper#1394. EOE/AA.

PROVIDENCE, RI: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Wide range of responsibilities: assist in coordination of MSAFP, birth defects, dysmorphology programs; teratogen, pre & post amnio counseling; professional & community education.
CONTACT: Krista M. Sauvageau, Employment Manager, Womens & Infants Hospital, 101 Dudley, 45 Willard Avenue Office, Providence, RI 02905-2499; 401-274-1100 x 8282. EOE/AA.

CHARLOTTESVILLE, VA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join team of four genetic counselors and three MDs. General responsibilities include: prenatal, pediatrics and specialty clinics; AFP; teratology.
CONTACT: Patricia Schnatterly, MS, University of Virginia Medical Center, Box 386, Dept. Genetics, Charlottesville, VA 22908; 804-924-2665. EOE/AA.

FAIRFAX, VA: Immediate opening for BC/BE genetic counselor, to join 3 medical geneticists, 2 PhD geneticists and 3 genetic counselors in newly-created position.
RESPONSIBILITIES: Coordinate outside referrals to DNA, cytogenetics and MSAFP labs; provide guidance for referring professionals, report results, participate in follow up; complete pedigree analysis for DNA tests, especially Fragile X. Counsel CVS, amnio patients in established outpatient setting.
CONTACT: Shirley L. Jones, RN, MS, Genetics & IVF Institute, 3020 Javier Road, Fairfax, VA 22031; 703-698-7355. EOE/AA.

NORFOLK, VA: Immediate opening for BC/BE genetic counselor.
RESPONSIBILITIES: Independent professional sought for full range of counseling in tertiary care, high-risk, perinatal setting: preconceptual, amnio, CVS, MSAFP, teratogen counseling, PUBS, consultation following ultrasound diagnosis of fetal abnormalities; bereavement counseling. Opportunities available for research and teaching.
CONTACT: Debra Lochner Doyle, MS, Eastern Virginia Medical School, Maternal-Fetal Medicine, 825 Fairfax Ave, Norfolk, VA 23507; 804-628-7300. EOE/AA.

CASE REPORT, FROM P. 3

buggy), electricity (except in one room for a child with asthma and another who has problems with temperature regulation), or a telephone. Through the local CHN, the family agreed for research (and potentially diagnostic) purposes to have skin biopsies performed on their daughters for collagen analysis, blood drawn for chromosome analysis and, even though it is against their religious beliefs, clinical photography. Because the studies were free-of-charge and transportation was provided, they also agreed to go to the National Institutes of Health to have MRIs and further biochemical studies performed on the two girls. At the genetics outreach clinic visit in the Spring, Mrs. W. was 7 1/2 months pregnant and a fetal sonogram revealed that this fetus also had OI. We arranged to see the family again one month after the baby, B.W., was born. Because B.W. had pneumonia the day of the scheduled appointment, we made a home visit and discussed B.W.'s condition and the possibility of obtaining a skin biopsy on her. B.W. died two weeks later and, due to the many contacts with the family and the rapport established, they had their pediatrician obtain the biopsy at the time of death. Only a week later, we were scheduled to be at the Outreach Genetics Clinic again and, despite their recent loss, the W family came with their two daughters to discuss general pediatric concerns.

Although the family had initially been skeptical about our role in providing help to their family, they eventually came to trust the genetics team and to cooperate in research efforts. We, in turn, learned to schedule their appointments so as not to interfere with planting and harvesting time. We learned that although our worlds are very different, our concerns are often the same.

IN SUMMARY

Outreach genetics clinics provide a necessary function for many communities by bringing otherwise inaccessible genetics services to families. The community health nurses, social workers, local pediatricians and other support services personnel are a vital link between these families and the medical genetics team.

Legislative Briefs

Medicaid Coverage for Pregnant Women and Children Expanded

As part of the 1989 Reconciliation Bill, Medicaid coverage for pregnant women and children under 6 will be expanded in 1990 to 133% of the federal poverty line, up from 100%. (See *Perspectives*, Spring 1989.) In addition, states will now have the option to serve all children under age eight below the poverty line and all infants up to 185% of the poverty line. These provisions, supported by the NSGC, will ensure that more women and children will have access to genetic services.

Pro Choice Momentum Grows

Frustrated by recent Supreme Court cases aimed at limiting reproductive freedom, Congress recently introduced the "Freedom of Choice Act of 1989." This landmark piece of legislation would place into law the principles of the 1973 Roe v. Wade decision.

According to the Nov 30 *NARAL Update*, "Codification of the principles of Roe will prevent states from enacting legislation to restrict women's right to make their own decision about abortion, without regard to any future action by the Supreme Court relative to Roe." As of November 30, this act had 21 State co-sponsors and 96 House co-sponsors.

Since Congress will not return to Washington until late January, now is an excellent time to make contact with your legislators on this and other genetics-related issues (funding, etc.) You can have an impact by thanking those who have already co-sponsored the bill (this is important...legislators need to know we support their actions) and encouraging those who haven't.

Write: Senator ____, U.S. Senate, Washington, DC 20510; or Rep. _____, U.S. House of Representatives, Washington, DC 20515. The U.S. Capitol Switchboard number is 202-224-3121.

Fact Sheet Revised

The NSGC "Prenatal Genetic Counseling Fact Sheet" has been revised to include statements regarding the need for increased services for persons with disabilities and the role genetic counselors play in accessing services for families who decide to continue affected pregnancies. Single copies sheet are available from the Executive Office.

Suggested uses of the Fact Sheet include educating state legislators, pro-choice groups and other health professionals regarding the NSGC.

Substance Use During Pregnancy

In direct response to pressure from the Coalition on Alcohol and Drug Dependent Women and Their Children, S.1444, a bill to bring punitive measures to pregnant substance abusers was blocked. Alternatively, the Coalition successfully lobbied for substantial increases in Federal funding for treatment, education and preventive services. However, punitive measures/mandatory reporting bills were passed in IL and DE. Genetic counselors working in these states should determine the impact on their work.

Alcohol Warning Labels

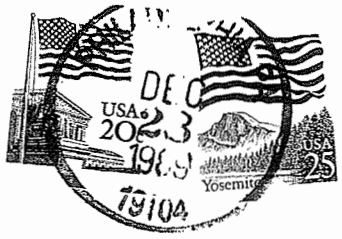
The Alcohol Health and Safety warning labels were required to be on all containers of beer, wine and liquor beginning November 18, 1989. The labels do warn against drinking during pregnancy but they do not specifically mention mental retardation or developmental disabilities as a possible outcome.

Consider writing a short piece for your community or Hospital newspaper on what FAS and the labels mean.

Trish Magyari

1979 NSGC 1989
10th Anniversary Year

Vol. 11, No. 4, Winter 1989
A publication of the
National Society of Genetic Counselors, Inc.
Executive Office
233 Canterbury Drive
Wallingford, PA 19086



Theme: Outreach