nsgc PERSPECTIVES
IN GENETIC COUNSELING

THE NEWSLETTER OF THE NATIONAL SOCIETY OF GENETIC COUNSELORS, INC.
Volume 2, Number 4. December 1980

AMNIOCENTESIS COUNSELING AT THE PRENATAL DIAGNOSIS LABORATORY OF NEW YORK CITY: THE FIRST YEAR'S EXPERIENCE,

Hodie L. Tannenbaum, M.S.

In June 1980, the Prenatal Diagnosis Laboratory (PDL) completed its first year of operation; more than 1,000 specimens were processed and over 300 patients were seen by PDL employed counselors for pre-amniocentesis genetic counseling.

The PDL was planned as a "megacenter" for the prenatal detection of chromosome abnormalities and neural tube defects. The intent of the Program is to educate women in New York City about the existence of prenatal screening, and to make these tests available to all women in the City who are at an increased risk of carrying a fetus with one of these condidtions.

The project was initially undertaken in 1975 by a Task Force of the New York Scientists' Committee for Public Information. In 1976 the New York City Department of Health joined the sponsorship of the program by providing space for the laboratory site.In early 1977 the New York State Department of Health awarded a grant for the Program and entered into a contract with the Medical and Health Research Association of New York City, Inc., a not-for-profit corporation, for the administration of the project.

The Program is comprised of public and professional education, counseling, amniocentesis and associated procedures, laboratory tests, post-amniocentesis services, record-keping, and quality, cost and utilization control. The public and professional education services, the record-keeping and the laboratory are centralized, The counseling, amniocentesis, and associated procedures are decentralized.

Financial barriers to all components of the Program have been eliminated. The PDL is funded by the New York State Department of Health and there is no direct billing of patients for PDL services. The Program requires the participating hospitals to establish a sliding-fee scale for the amniocentesis, ultrasound and related services so that no woman will be denied the service because of her inability to pay.

The Program was designed to provide individual counseling to patients who may be eligible for prenatal diagnosis at the hospital where the patient is receiving her obstetrical care. The counseling is required to meet the standards established by an Advisory Committee of experienced genetic counselors. The Committee drafted a set of guidelines designed tomeet the highest standards for pre-amniocentesis counseling. Such counseling strives to give the women accurate and up-to-date information on the benefits and risks of the procedures and on the options available to them. The counseling must present the most recent information relative to the prospects for and management of individuals afflicted with conditions detectable by the Program. Counseling must be given in a manner that enables the patients to understand the conditions and procedures under discussion while encouraging them to discuss their anxieties and feelings. The couselors are required to demonstrate clinical knowledge sufficient for complete and accurate recording of histories and pedigrees.

The first year of operation of the Program has been very encouraging. To date, nineteen hospitals in all five boroughs of the City of New York have entered into contracts with the PDL; an additional eight hospitals have requested participation and have been placed on a waiting list. The contracts stipulate that the hospitals provide pre-amniocentesis counseling to all patients whose amniotic fluid samples are forwarded to the PDL, and post-amniocentesis counseling, without delay, when there is an abnormal or equivocal result. Post-amniocentesis counseling must be provided by a genetic service which the Hospital itself maintains, or one with which it enters into written agreement. The PDL is a New York State approved medical genetic center. Although all participating hospitals are offered the services of the PDL for pre-amniocentesis counseling, eight are currently availing themselves of the service. The remaining eleven, either have sufficient coverage of atheir own and/or are restricted by various legal constraints involving liability coverage. On occasion, when a hospital employed counselor has been ill or on vacation, patients have been referred directly to the PDL for this service.

The couseling staff included three master's level trained individuals: (1) a Coordinator of Counseling, Educational, and Record Services; and (2) two Genetic Counselors. Amniocentesis counseling clinics are

(continued on page 2)

Publication of **Perspective in Genetic Counseling** is supported in part by a grant from the March of Dimes-Birth Defects Foundation.

scheduled twice a month at each of eight hospitals; all patients are seen by appointment. The referring physicians are required to provide the PDL counselor with information regarding their patients and to sign and authorization for their patients to use our services. A pre-amniocentesis counseling session generally takes one hour. The majority of patient-couples were given information at the same time, but each was seen individually for intake. In addition to their own counseling PDL couselors monitor the counseling services provided to all patients whose amniotic fluid specimens are sent to the PDL, and maintain records and follow-up data.

The PDL staff has prepared a genetic counseling protocol which is distributed to all physicians, midwives, clinic supervisors, and other health professional who may be referring patients for pre-amniocentesis counseling. In this way, staff in the participating hospitals can familiarize itself with the information imparted and the topics covered during a counseling session. Of ta total of one thousand amniotic fluid specimens received, PDL counselors have seen 289 patients for pre-amniocentesis counseling. We have counseled 69 families who have not had amniocentesis because either their indication did not meet our criteria, the pregnancy was spontaneously aborted prior to the scheduled amniocentesis date, or the patient elected not to have an amniocentesis. We have received follow-up data from 180 of a total of 468 patients whose estimated date of confinement was prior to June 1980. These data include follow-up information from 9 patients who had therapeutic abortions, 11 with sponataneous abortions, and 2 stillbirths. The remaining data is from normal livebirths.

During this year a workshop for amniocentesis genetic couselors in the New York metropolitan area was held at the PDL. The workshop was co-sponsored by PDL staff and the Genetic Counseling Advisory Committee. The Director of the PDL served as medical genetic consultant to the workshop. The program was comprised of two sessions. The first consisted of presentations dealing with counseling situations that have become controversial: prenatal diagnosis based on equivocal results, prenatal diagnosis of XYY, or a history of infertility or fetal loss. These presentations were followed by group discussion. The second session dealt with presentations regarding new approaches to genetic couseling; group counseling and the use of audiovisual aids were presented and discussed.

A pilot study is now being conducted to determine the effectiveness of pre-amniocentesis couseling. An anonymous questionnaire is being distributed before and after couseling to a sample population of patients seen by the PDL and hospital employed counselors.

My colleagues, Gloria Harris and Beth Siegal, have found that the services of the genetic couselor are universally welcomed and appreciated in the hospitals. The counselors are called upon to assist with a wide variety of problems and questions. Due to its unusually large case load volume, the PDL has virtually become a clearing center for clinical and cytogenetic problems, not only in the New York City àrea but world-wide.

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Call for Abstracts

Abstracts are requested for the Genetic Counseling Session and other sessions of the American Society of Human Genetics 1981 meeting in Dallas, Texas. Guidelines will appear in the January, 1981 issue of the **American Journal of Human Genetics.** Our profession has an important contribution to make to the field of genetic counseling. Please review your work and submit appropriate abstracts.

Nominating Committee

Julie Shapiro, M.S., of Johns Hopkins Hospital in Baltimore, has been elected by committe members to serve as chairperson of the 1980-1981 Nominating Committee. Other committee members include: Diane Baker, Audrey Heimler, Evelyn Lilienthal, and Lucille Poskanzer.

Education Committee

I have apponted and the Board of Directors has approved Carolyn Bay, M.S. to serve as co-chairperson of the Education Committee. As former Region VI Representative, Carolyn organized two highly successful Region VI continuing education meetings. In addition, she is serving as a Co-Chair of the NSGC, Inc national education meeting which is described elsewhere in this issue. Carolyn will bring creativity, experience, and energy to her new position.

Beverly Rollnick, M.S,, Ph.D.
President, NSGC, Inc.

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Oakdale, Iowa 52319

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1981 NATIONAL CONTINUING EDUCATION CONFERENCE "STRATEGIES OF GENETIC COUNSELING: AN UPDATE"

A ten person committee has finished the preliminary planning of the 1981 National Society of Genetic Counselors Continuing Education Program entitled "Strategies of Genetic Counseling: An Update". In an effort to reduce costs of those attending, the program has been scheduled to immediately follow the 1981 Birth Defects Conference. The conference will be held at the Town and Country Hotel in San Diego, California on Thursday evening, June 18 and all day Friday, June 19, 1981. Funding to support this meeting has been requested from the March of Dimes - Birth Defects Foundation.

The theme of the conference is "Strategies of Genetic Counseling". The intent is to discuss strategies now employed and to identify new and innovative counseling methods. The conference will provide a feeling for the circumstances in which these strategies are most effective and describe the usefulness of such strategies in improving the quality of services provided to families affected by birth defects and genetic diseases. The results of the Continuing Education Needs Assessment Questionnaire were utilized in order to provide a program which will meet the educational needs of our membership.

INVITED SPEAKERS

The first invited speaker, a counselor, will discuss and expand upon our current approaches to the counseling aspects of genetic counseling. This speaker will provide insight regarding the needs of persons coming for genetic counseling and ways in which various counseling techniques can be successfully applied to genetic counseling.

The job of the second invited speaker will be to give the participants a feeling for the strategies now in use throughout the United States and Canada in order to provide necessary background reference information and serve as a stepping stone from which we can look for the most effective methods of providing service.

The third invited speaker will discuss the social, ethical, and legal issues in genetic counseling. This last topic was elicited directly from the Needs Assessment Questionnaire.

PROGRAM

The program will include three invited speakers, a series of five con-current workshops, and a session for papers contributed by participants. A luncheon business meeting has been scheduled for the Friday session, and a media room containing periodicals and educational materials will be open throughout the conference.

WORKSHOPS

The concurrent workshops will be chaired by genetic counselors who have been identified as having experience relevant to the specific topics At the conclusion of the workshops, one half hour will be reserved for presentation of summaries by each chairperson.

Workshop #1:	Parent Groups
Workshop #2:	Group Counseling
Workshop #3:	Family Therapy
Workshop #4:	Death, Chronic illness, and crisis intervention
Workshop #5:	Professional roles of the genetic counselor.

CONTRIBUTED PAPERS

In the session devoted to papers contributed by participants, half of the papers selected will be on the topic of strategies of genetic counseling and the remainder will be on topics pertaining to any aspect of genetic counseling. All submitted abstracts will be printed in the conference program.

Abstract Deadline: April 15, 1981. All abstracts must be typed, single spaced, on a single 8½ x 11 inch piece of paper with the author's name(s) and address(es) at the tope of the page. Send Abstracts to:

Susan Reed, M.S., Genetic Counselor
Division of Medical Genetics
P.O. Box C-5371
Childrens Orthopedic Hospital
4800 Sand Point Way, N.E.
Seattle, Washington 98105

Respectfully submitted,

Susan Reed
Seattle, Washington
Program Co-Chair

Elizabeth Thomson
Iowa City, Iowa
Communications Co-Chair

Carolyn Bay
San Diego, California
Logistics, Co-Chair

In order to anticipate attendance at the 1981 Continuing Education Program for the National Society of Genetic Counselors, Inc., we ask that you complete and return the attached coupon. Persons returning the coupon will automatically be sent registration materials and will be given preference if more than the maximum of 150 registrations are received.

CLIP HERE

Preferrerd Mailing Address:

NAME

I will	( ) attend the conference.
will not	( )
may	( )
I will	( ) submit an abstract
will not	( )
may	( )

RETURN TO: Elizabeth Thomson, R.N., M.N.
Clinical Coordinator, RGCS.
Division of Medical Genetics
Department of Pediatrics
University Hospital
Iowa City, Iowa 52242

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CORRESPONDENCE

Dear Dr. Rimoin,

I am writing regarding the information which I received about the certification procedure for individuals who provide Medical Genetic Service. There are several points that I would like to make. The first is that I feel it is very unfair to expect a person to submit a non-refundable $200 deposit with an application when that person is not informed as to how much the examination will cost, when it will take place, and where it will take place. It is imperative to know this information before applying.

I feel that a $200 deposit plus several hundred dollars more for the examination plus at least several hundred dollars more for travel and lodging is far too much to expect someone who makes around $15,000 a year, as many Genetic Associates do, to pay for the "privilege" of taking an examination.

Also, I am concerned about if it really is necessary to require the certification at all. It seems to me that the place to ensure good quality of Medical Genetic Service is in the curriculum of any training program from an accredited university. Should an individual, after successfully completing a program which qualifies her/him to give Medical Genetic Service, then be required to pay out a large amount of money for further examinations and documentation? Is the point of this certification procedure, in fact, to make a "closed shop" or elitist group of our profession. If a person does not have this certification, will that person be barred from employment in the field even though she/he has adequate training? If so, I feel that the legality of the certification procedure is on very shaky grounds.

Why is the examination going to be so costly? Would you please provide me with an itemization of the costs. Thank you.-

Sincerely,
Rebecca Berry, M.S.
Genetic Associate

Reply

Doctor Rimoin has forwarded your thoughtful letter to us for response on behalf of the American Board of Medical Genetics. You have raised several important questions, and we will do our best to provide you with a response.

We can certainly understand your objections to submitting a non-refundable $200 deposit when it was not possible to project the cost of the exam, particualrly with regard to the fee and the expense of traveling to the examination site. It was necessary to announce the examination quite far in advance of the projected date for administering the exam. The development of a certification examination is a complex project, as those of us on the board have learned in recent months. In order to determine the fee per applicant it is necessary to know the number of people taking the exam so that the fee can be prorated. For this reason we had to request registration at an early date. In addition, the board required funds to develop the examination. An advance deposit was required for these reasons.

Since the time of your letter to the American Board of Medical Genetics, progress has been made for obtaining a grant. I am pleased to be able to tell you that funds have been obtained to underwrite the cost of the examination. This will mean a considerably lower fee for all applicants and hopefully special consideration for the genetic counselor.

The last issue you raised is with regard to the justification of requiring a certification examination. The clinical genetics field is unusual in that many of the professionals involved are not specifically trained in clinical genetics. This is certainly true among the genetic counselors who come from many related fields, e.g. social work, nursing, public health and psychology. While I would agree with you that graduation from a recognized graduate program in human genetics or genetic couseling should indicate that an individual is qualified, there is the additional problem of documenting the qualifications of an individual who has training on the job or aspirations in this field with or without training on the job. Certification, it would seem to us, is important to insure quality throughout the field. A precedent for certification exists in medical specialties and in the related health fields. The legality of certification has therefore been demonstrated.

It is essential to develop a valid examination. For this reason the services of the National Board of Medical Examiners has been engaged to consult with the American Board of Medical Genetics. This is an expensive procedure. Clinical genetics is a relatively small medical specialty. The number of people taking the exam is an important factor in determing the fee per person as described above. This is the most important factor in determinig that the cost per person taking the examination will be higher than if the examination was going to be given to a much larger group.

I hope that this information will be helpful to you. Please be assured that we are not unsympathetic to the concerns you have raised, We do feel, however, that the end result of setting appropriate standards for our field will outweigh the negative factors of submitting to a certification examination.

Audrey Heimler, M.S.
Genetic Counselor
Ann C.M. Smith, M.A.
Genetic Counselor
for the American Board of
Medical Genetics.

POSITIONS AVAILABLE

Program Coordinator

To administer a statewide genetic services program for the Pennsylvania Department of Health. The program seeks to insure that genetic services are available as needed to all citizens of Pennsylvania. Applicant must have a Master's Degree in Social Work, Public Health Nursing or related displine; training in and/or experience with human genetic services; and two years of administrative experience. Previous experience in program development, community and professional education and in group work is advantageous. Send resumes to Daniel Brant, M.S.W., Pennsylvania Department of Health, P.O. Box 90, Harrisburg, PA 17120. Interested person may call Mr. Brant at 717 - 787-6013. An equal opportunity employer.

Genetic Counselors

A new, full-service Medical Genetics Program will require a genetic counselor at the Clinical Instructor level. This person will have both primary patient contact and administrative responsibilities. The position requires a Master's degree from a recognized training program in genetic counseling. Send resume and three references to Kathleen W. Rao, Ph.D., Department of Peduatrics, 127 Irons Building, East Carolina University, Greenville, NC 27834. An equal opportunity/affirmative action employer.

Full time position open for a genetic associate in a rapidly expanding state-wide program. Duties are varied and include genetic counseling for pre-amniocentesis patients. Tay-Sachs counseling, as well as clinic coordination, teaching and research. Send resumes to Mrs. Petrina Babcock, Department of Pediatrics, Women and Infants Hospital, 50 Maude Street, Providence, RI 02908

Genetic associate sought for growing medical genetics program in new medical school. Applicants should be graduates of a recognized training program in genetic counseling or have Master's degree and considerable genetic counseling experience. Duties include coordinating genetic clinic, counseling and education activities. Competitive salary. Open immediately Send curriculum vitae to S. Robert Young, Ph.D., Department of OB/GYN, USC School of Medicine, 3321 Medical Park Road, Suite 302, Columbia, SC 29203.

The Division of Medical Genetics of the University of Oregon Health Sciences Center has immediate opening for two genetic associates. One will be based at the Health Sciences Center, Portland, and the other at the Regional Services Center, Eugene. The positions will have a primary emphasis on clinical and educational activities. Applicants must have a Master's degree and clinical experience. Send letters of application, curriculum vitae, and three references to Jonathan Zonana,M.D Crippled Children's Division, Regional Services Center, Clinical Services Building, University of Oregon, Eugene, OR 97403, 503 - 686-3575.

University of Utah Medical Center has two positions available for genetic couseling associates starting on or after January 1981 and June 1981. M.S. degree or equivalent experience required. Send curriculum vitae to Dr. John Carey, Department of Pediatrics, University of Utah Medical Center, Salt Lake City, Utah 84132. An Equal opportunity/affirmative action employer.

Deborah L. Eunpu, NSGC
Clinical Genetics Center
Children's Hospital of Philadelphia
34th and Civic Center Boulevard
Philadelphia, Pennsylvania 19104