

# PERSPECTIVES

## IN GENETIC COUNSELING

A NEWSLETTER OF THE NATIONAL SOCIETY OF GENETIC COUNSELORS

Volume 1, Number 4. December 1979.

### GENETIC EDUCATION AT THE HIGH SCHOOL LEVEL: SOME IMPLICATIONS FOR COUNSELORS

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The genetic counseling literature has long cited poor public understanding of human genetics (and human biology in general) as one of the major obstacles to effective counseling. Lack of awareness of the importance of genetics to personal and family health also results in a great deal of retrospective, rather than prospective, counseling.

Over the last four years, the Center for Education in Human and Medical Genetics at the Biological Sciences Curriculum Study has been analyzing the status of genetics education for a variety of target populations. While the data and recommendations for each group are of general interest, the results of our research on high school and college students have important implications for practicing counselors, since these groups will constitute a large proportion of the individuals who will be in need of genetic services during the coming years. The data from our survey were originally published in the May 1978 issue of *The American Biology Teacher* and were corroborated by data from a similar survey conducted in Montreal by Charles Scriver and his colleagues. The Montreal data were published in the same issue of *ABT*. A recent paper in the *Journal of Heredity* (70:161, 1979) by Thomas R. Mertens, et al., details the responses of 542 secondary biology teachers to questions concerning educational needs in genetics and provides further insight into the knowledge level of high school students.

In the Center's study, survey responses were received from 724 high school students and 189 college students who had recently completed a course in general biology at each level. Items were grouped into three major subtests for analysis: facts, personal attitudes, and societal attitudes. Student responses on the fact subtest indicated the following deficiencies:

- A. **Genetic Diseases.** Students generally know very little about specific disorders although they are aware that genetic disorders can occur in the children of healthy parents.
- B. **Genotype/Environment Interaction.** Approximately 25 percent of the students were unaware that the environment, both physical and psychological, in which they live interacts with each individual's unique genetic constitution to determine, in large part, that individual's general state of well-being.
- C. **Medical Genetics.** Most students were unaware of common practices in genetic counseling and screening, including prenatal diagnosis. This, of course, deprives these prospective parents of access to an important form of preventive health care. (cont. on p.2)

### REPORT OF 1979 BUSINESS MEETING OF THE NSGC

The annual business meeting of the National Society of Genetic Counselors was held at the Hotel Leamington in Minneapolis on October 3, 1979. The meeting was opened by Audrey Heimler, president, who welcomed all present and introduced the current officers and committee chairpersons.

Lorraine Suslak, vice president, reported that she had reviewed the regional boundaries used by DHEW and those established by the NSGC for the purpose of realigning the NSGC district boundaries to agree with those used by DHEW. The purpose of such a change would be to facilitate coordination with pre-existing regional genetics programs and applications for funding. The funding question might become significant for regional education programs and meetings. A complete list of these changes will be published in the next issue of *Perspectives*. Nine states and Canada will be affected by this reorganization. Lorraine also reported that she submitted an application for one time funding to the National Foundational-March of Dimes; this application is now under consideration.

Niecee Singer, treasurer, presented the financial report. To date, most funds have been derived from the original interest fee. Income as of 9/30/79: \$2127.68; disbursements: \$1355.02; balance on hand as of 9/30/79: \$772.68.

Education Committee co-chairs Roberta Spiro and Judith Dichter reported that they are beginning to receive the needs assessment questionnaires which were sent out earlier this fall. To enhance regional participation in planning educational programs, there will be one individual from each of the six districts appointed to represent that region's needs and to effect plans. The Education Committee is considering a project to develop guidelines for individuals planning educational programs. Also announced was the fact that Tabitha Powledge of the Hastings Center Institute of Society, Ethics, and the Life Sciences has agreed to speak at the NSGC meeting during the 1980 Birth Defects meeting.

Elsa Reich, substituting for Membership chairperson Evelyn Lilienthal, reported that there are 233 individuals who paid the original interest fee on the mailing list. Those interested in membership in the NSGC should request applications from Evelyn Lilienthal, 34 Duncan Drive, Greenwich, CN 06830. Change of address notices should also be sent to the Membership chairperson.

Phylliss Klass, chairperson of the Professional Issues Committee reported that her committee will be addressing topics relating to the improvement of the art and science of genetic counseling and that of the professional identity of the non-MD counselor in relation to the medical genetics team. This committee plans to (cont. on p. 3)

- D. **Basic Genetics, Chance, Randomness, and Probability.** Despite the amount of time devoted to these topics in modern texts (usually with non-human examples) students do not appear to be learning the basic tenets of the discipline.
- E. **DNA Structure and Function, Protein Synthesis.** Again, the level of understanding demonstrated by students is disappointing, especially given the heavy treatment of these topics in most high school texts. One may reasonably ask, however, whether it is at all important that the average high school student understand these processes and whether they should be priority items for high school students, most of whom will have only one exposure to genetics in their formal education.
- F. **Personal and Societal Attitudes.** The tremendous inconsistencies in attitudes as measured by the survey seem to confirm the notion that students have little opportunity in the high school or college curriculum to reflect upon the personal and societal implications of advances in human and medical genetics (or of advances in any other scientific discipline, for that matter). Paul Hurd, Emeritus Professor of Education at Stanford, concluded in his historical and philosophical analysis of genetics education, that "the overwhelming choice of the textbook authors is not to consider human genetics in any context where social, economic, political, moral, ethical, or value issues may be aroused. The question of genetic health as a personal or societal attribute is also avoided."

The data accumulated by the BSCS do not inspire optimism concerning the development of an informed citizenry capable of enlightened decisions in matters of genetics where personal and community health or public policy are concerned. Nor do the data indicate that the counselors' task in terms of education is likely to become much easier in the near future. Fortunately, however, these and other data also point to possible solutions for the problems, and the Center, with the help of literally hundreds of scientists, educators, philosophers, and others, has begun to address those solutions. In 1978, the Center published a series of **Guidelines for Educational Priorities in Human and Medical Genetics** that have been distributed to approximately 50,000 people in the United States and abroad. The Guidelines contain broad recommendations for the development of educational programs for a wide variety of target populations.

Interest in materials and programs is quite high. We continue to receive requests and suggestions from a variety of sources, including most of the major genetic counseling facilities in the United States. At this writing, over 70 people from across the United States and Canada have made arrangements to meet at the BSCS headquarters in Boulder in early November to discuss the coordination of program development and implementation on a national level. Among those individuals will be over a dozen genetic associates and representatives from 12 of the 21 HSA-funded genetic services programs. In addition, the Center has recently received a grant from the March of Dimes Birth Defects Foundation to develop materials for elementary schools and a grant from the Health Services Administration to develop materials for

junior high schools, in cooperation with the State of Colorado and the University of Colorado Medical Center. Plans are now pending for materials development for the high school and for community service personnel, such as family planning counselors. In addition, the Center is now seeking funding for a series of short films on genetic counseling for commercial television designed to reach young adults in their reproductive years who are no longer in formal educational settings.

The development of these programs will be accomplished with input from the same broad range of individuals whose ideas contributed so much to our initial work in this area. A large number of genetic associates from across the country have already been involved with the work of the Center. The National Society of Genetic Counselors has an excellent working relationship with the Center largely through the efforts of Roberta Spiro, the Society's Education Chairperson.

The interests of the Society are also, of course, represented by my own presence on the Center's staff, a situation which is indicative of the broad spectrum of professional opportunities available to genetic associates. It is important at this early stage of the Society's development that we as a group remain flexible enough in terms of mission, membership, and services to accommodate the professional needs and interests of those of us who have chosen to work outside the clinical setting.

As we at the Center begin to develop our materials and programs, we will welcome, and indeed require, input from all segments of the genetics community. Please feel free to send comments, suggestions, and requests for information to me at the following address: Center for Education in Human and Medical Genetics, Biological Sciences Curriculum Study, P.O. Box 930, Boulder, Colorado 80306.

#### AMERICAN BOARD OF MEDICAL GENETICS IS ESTABLISHED

The American Board of Medical Genetics was established by the American Society of Human Genetics as an independent body whose functions will be to formulate accreditation procedures and administer the first examinations. Ann Smith and Audrey Heimler were elected to serve on this board. The first meeting of the ABMG is scheduled for January 1980.

Suggestions or comments concerning the accreditation process should be directed to either Ann or Audrey at the addresses given below.

Ann C. M. Smith  
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Audrey Heimler  
Division of Human Genetics  
Long Island Jewish Hillside Medical Center  
Hyde Park, New York 11042



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undertake a project whose purpose will be to establish a set of uniform symbols and notations to be used in family pedigrees.

The report from the By-Laws Committee was presented by Hodie Tannenbaum, chairperson. A brief summary of this committee's activities was reported, and copies of the by-laws were distributed. The by-laws were ratified by the Board of Directors and were filed in the State of New York on September 28, 1979. Several revisions were required before this final version was approved, with a significant portion of discussion being devoted to the development of appropriate membership criteria. The final membership criteria as set forth in Article I of the by-laws are intended to be equitable to all those considering membership in the NSGC while simultaneously establishing standards that reflect the professional purpose of the Society.

Deborah Eunpu, Editor of **Perspectives in Genetic Counseling** made a brief presentation outlining long range plans to expand the format of the newsletter and urging members to submit articles, letters, book-reviews and announcements.

Reports from the regional representatives indicated that all districts have met or are planning to do so in the near future. Ann Smith, representative from District V, reported the tabulated results from her questionnaire which she distributed in September. Ninety four questionnaires completed were for a 51% return. Many responders included comments in addition to responses to the four questions. Three of the questions had been obviated by the fact that the by-laws were ratified prior to this meeting. These questions dealt with membership, ratification of the by-laws and elections. Responses to the fourth question indicated that 60 of 94 (63.8%) agreed that the membership should be polled as to the appropriateness of the Society's title. Ann's concluding remarks suggested that with the by-laws already ratified, the Society should turn its efforts toward developing a strong membership, and that the by-laws can, if needed, be amended as we continue to work together.

In addition to the foregoing reports, there were three special presentations: Ann Walker provided a brief summary of the Asilomar III Conference held in Williamsburg; Lorraine Friedman spoke about the ongoing work of the American Society of Human Genetics Council of Accreditation and Certification; and Barry Dichter, attorney for the NSGC, discussed the legal status of the Society.

#### NEWS FROM THE BOARD OF DIRECTORS

The officers, district representatives, and committee chairs convened for the first annual board meeting on October 4, 1979. Topics of discussion and important votes are summarized here.

- As proposed by Lorraine Suslak, the board voted to change the Society's district boundaries to agree with those used by the DHEW.
- The nominating committee, which will be representative of all six districts, will be appointed this winter as stipulated in the by-laws. This committee will be responsible for preparing a slate to run for the following positions in the

NSGC: president, vice-president, secretary and representatives for Districts II, IV and VI. Ballots will be mailed during the summer (1980), and results of the election will be announced at the annual meeting in September.

- The membership criteria as stated in Article I of the by-laws were amended in that applications from individuals who have only a baccalaureate degree and who otherwise satisfy criteria set forth in Article I will be considered for full membership during the next two years rather than the originally planned period of one year.
- Responding to the questionnaire circulated by Ann Smith of District V, the board voted to poll the membership regarding the Society's title. Additional information concerning the poll will be distributed in the next few months.

#### DISTRICT II MEETS

The first District II Regional Meeting was held November 10, 1979 at the A.I. duPont Institute in Wilmington, Delaware. Approximately 15 attended including some recent graduates who are currently job hunting as well as Audrey Heimler, President of the NSGC.

Corrine Boehm, from Johns Hopkins, gave a short presentation on the prenatal diagnosis of sickle cell anemia using linkage studies. Cindy Powell informed us that there is now a national organization for Neurofibromatosis and passed out their recent newsletter. (They can be reached by contacting the National Neurofibromatosis Foundation, 340 East 80th Street, #21H, New York, New York 10021, 212-744-4601.) The National Clearinghouse for Human Genetic Diseases was represented by Joci Spector. She explained their services and distributed catalogs (address: 1776 East Jefferson Street, Rockville, Maryland 20852).

Several people reported on the Birth Defects, ASHG and Asilomar meetings. Many were disappointed at the lack of papers and presentations that dealt specifically with genetic counseling. We discussed possible remedies for this. One option explored was the possibility of having a time before, after or during the Birth Defects or ASHG meetings for an education program that specifically addresses the non-clinical aspects of genetic counseling.

Ginny Corson, Regional Representative, reviewed the recently approved By-Laws. Audrey Heimler reported on the first meeting of the American Board of Medical Genetics. The guidelines for accreditation were discussed. Audrey was particularly concerned about the "grandfather clause" in the accreditation protocol for genetic counselors. Her concern was echoed by many of the members present. It was felt that the provisions, as stated, were too liberal. Also, they did not correspond with the guidelines stated for the other categories. A uniform "grandfather clause" for all categories is desirable.

Those present enjoyed the opportunity to meet on a more personal basis with our colleagues. We discussed plans for our region and decided to have another meeting in the spring with a workshop format.

—Linda Nicholson



## A NEW FILM RELEASE

"Amniocentesis: Prenatal Detection of Birth Defects" is the first film to clearly and simply describe the prenatal diagnosis of birth defects by amniocentesis. Its purpose is to educate the general public and is aimed at women and couples who, for various reasons, may not be aware of the procedure.

Animation is used to depict the withdrawal of the amniotic fluid. Emphasis is placed on the use of ultra-sound to visualize the fetus. The heart of the film is a series of interviews with women and couples who were "at risk" of having a child with a serious birth defect and decided to have an amniocentesis. Their reasons for using the procedure cover the full range of "at risk" situations.

Produced by Golden Door Productions for Children's Hospital Medical Center of Northern California, the film will be available in January, 1980. Requests for preview for possible purchase should be sent to Golden Door Productions at 10th and Parker, Berkeley, CA 94710.

13 minutes, color, 16mm film, price: \$240.00

(all video tape formats are also available)

## POSITIONS AVAILABLE

The Genetics Program of the Child Health Section, DSHS, State of Washington is seeking a person trained in human genetics and with at least one year's experience in Sickle Cell counseling or comparable program. The duties of the position are:

1. To work with people in the Black community, and in other minority communities, in the areas of education about genetic diseases
2. To counsel
3. To obtain diagnoses and services
4. To cooperate with regional genetics diagnosis and counseling clinics to obtain genetics services for minorities.

The State of Washington is an Equal Opportunity Employer and has an Affirmative Action program. Send inquiries to: Roberta Spiro, M.S., Health Services Administrator, GENETICS PROGRAM, 1704 NE 150th Street, Seattle, Washington 98155

Genetic Associate desired immediately for service and research position dealing with families with sickle cell anemia and with muscular dystrophy. Please contact Peter T. Rowley, M.D., Division of Genetics, Box 641, University of Rochester School of Medicine, Rochester, New York 14642 or telephone (716) 275-3461.

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