PERSPECTIVES
IN GENETIC COUNSELING

A NEWSLETTER OF THE NATIONAL SOCIETY OF GENETIC COUNSELORS
Volume 1, Number 2. June 1979.

"ASILOMAR EAST" MEETING

The Asilomar East Meeting was held in Williamsburg, Virginia on April 23-25, 1979. Sponsored by the Health Services Administration in order to evaluate certain aspects of the training and roles of genetic counselors, this meeting was planned by the directors and representatives of the genetic counseling programs at Irvine, Berkeley, Wisconsin, and Sarah Lawrence. Approximately fifty individuals convened to work on four panels to develop position papers on the following topics: (1) Curriculum and training of genetic counselors; (2) Sources of support and reimbursement for the genetic counselor; (3) Continuing education; (4) Evaluation procedures. The participants reflected all geographic regions of the United States and many professional groups (MD's, genetic counselors, PhD's, representatives of federal and state agencies, and third party payor representatives).

The position papers and the panel's recommendations are being prepared as a formal report which should be published in the near future. In that many of the recommendations and conclusions emerging from this meeting are highly relevant to the interests of genetic counselors, a report of the meeting and all recommendations will be published in the September issue of the **Perspectives.**

NEWS FROM THE DISTRICTS

District I: An informal meeting of eight genetic counselors in the New England area was held on April 19, 1979 at the home of Stacey Kacoyanis. We spent the first half of the evening introducing ourselves and detailing our job descriptions.

The remainder of the meeting was devoted to suggestions and ideas about the potential of our little group and the Society as a whole. We also discussed issues of importance to various individuals present. The following will summarize that which was mentioned:

1. There is no set "job description" for a person with a Master's degree in genetic counseling; it follows that there is no standard job title. The titles used in this area range from the very appropriate "Genetic Associate" to the very inappropriate "Senior Laboratory Research Technician".
2. The Society could serve as a central source for job opportunity information. We in New England plan to send a letter to local professionals in the field of genetics. The letter will ask that job information be sent to either the district representative or another person not yet named.
3. Continuing education may become a requirement for genetic associates. The Society is in a position to sponsor meaningful educational programs geared to meet the needs of the genetic associate. (cont. on p.3)

PARENT GROUPS: A MECHANISM TO FACILITATE PARENTAL ADJUSTMENT, AND A USEFUL ADDITION TO THE GENETIC COUNSELING TEAM

Carolyn Bay, M.S., Dept. of Pediatrics, UC, LaJolla

For the past 22 months I have been actively involved with a parent support group, which helps members adjust to what is a tremendously difficult task: having a child with a multiply handicapping condition. This group works. Why does it work when so many other groups fail? I think there are three reasons: 1) A few individuals (including myself) really want it to work, 2) It is linked with the University genetics clinic and the local chapter of the March of Dimes, and 3) the services provided are really needed. Most groups have only #3, and unfortunately, that is not enough.

What does the group provide? The parents named it themselves: REACH OUT. Reach is an acronym for: Reassurance, Encouragement, Adjustment, Concern, and Hope. These parents wanted to reach out to others experiencing similar feelings. Additionally, parents have the opportunity to feel that they are helping others, have a sense of belonging, and have someone with whom to share their feelings. These are very important intangibles that most parents really need.

The group holds moderately well-attended monthly meetings, which usually involve a guest speaker. During one of our recent meetings, the Chairman of the Department of Plastic Surgery discussed the pivotal role he felt parents played in the success of major craniofacial reconstructive surgery. The group has very well attended pot-luck dinners about every 3 months, 2 parties per year for the children, and a quarterly newsletter. The REACH OUT newsletter is printed and posted by the local March of Dimes chapter, and contains articles contributed by the parents, regular columns, briefs about books, and pertinent news. It is sent out to all the families on the mailing list (which exceeds our membership lists), to pediatricians and service agencies in our community. We also trained some of the parents to provide "crisis intervention" for "new" couples. All of our services are provided free of charge, and everyone involved volunteers their time. However, we are looking into local funding to stabilize the services provided, and allow the president to work on this project full time.

I personally use the group and the meetings as an opportunity to follow up the families from our clinic and to provide long term genetic counseling. By attending meetings, it is much easier for me to learn the needs of each couple and give them any advice I have to offer. With the trust that time builds, the parents find it much easier to ask questions. Parents also reassure each other, particularly with regard to amniocentesis, and I am there to make sure that the information one mother gives to another is correct. (cont. on p.2)

Parent Groups, continued

What have I learned during the last 22 months? Lots of things; some of the most important are listed below. 1) Parents need an excuse to get together, but once they are there, they really enjoy themselves. 2) Parents of children with various kinds of disorders bond to each other because of the multiplicity of the handicaps, and despite the differences of the disorders. 3) Fathers will come to meetings. 4) Parents of foster children often feel as bonded to their children as natural parents, and should be dealt with accordingly. 5) Parents whose children have died have different long term needs and often as a part of adjustment must leave the group.

How can you start a group like this? Find five or more parents who feel the need for such a group and have leadership qualities and confidence. Get them together and give them encouragement. Provide them with access to other parents' names (i.e. the clinic population) and the name of a helpful service agency, like the March of Dimes. Always help them when they need it, but let them run the group themselves.

THE "SPECIALTY" ORGANIZATIONS

In addition to the local parent groups, there are national and regional groups committed to helping parents of children with similar birth defects or genetic disorders. We have seen in Ms. Bay's description of REACH OUT that the local parent group can offer vital "grass roots" support to parents who otherwise might feel alone in a difficult situation.

The national "specialty" groups, which in some cases offer less in the personal contact area, do provide important support to such parents. Keeping parents supplied with current information regarding research or treatment of a particular disorder can be another means of sustaining hope in an otherwise bleak or at least troublesome situation.

Offered here are the names and addresses of some of these organizations. Granted, it is a partial list, but hopefully those of you who know of other similar groups will provide that information to be printed here at a later date. In this way we can develop a resource list that will inevitably enhance the quality of services provided to families in the genetics or specialty service.

It would be interesting to learn what other types of resources are used in different geographic regions. Or, how important does the genetic counselor regard his/her role in providing such information to families? What are the differences between the ways in which parent involvement is structured and implemented in a rural as opposed to an urban community? Your responses to these or other related questions are welcomed.

The American Brittle Bone Society
712 Dartmouth Avenue
Cinnaminson, NJ 08077

Cleft Lip and Palate Group of the Childbirth
Education Association
814 Fayette Street
Conshohocken, PA 19428
215-828-0131

Closer Look
P.O. Box 1492
Washington, D.C. 20013

Committee to Combat Huntington's Disease
250 West 57th Street
New York, NY 10019
212-757-0443

Cystic Fibrosis Foundation
3379 Peachtree Road N.E.
Atlanta, GA 30326
404-262-1100

Down's Syndrome Congress
P.O. Box 400
Milton, WA 98354

Little People of America, Inc.
National Headquarters: Box 126
Owatonna, MN 55060
507-451-3842

Mucopolysaccharidosis Society, Inc.
c/o Mary E. Majure
552 Central Avenue
Bethpage, NY 11714
516-433-4410

Muscular Dystrophy Association
810 7th Avenue
New York, NY 10017
212-986-9487

National Association for Retarded Citizens
2709 E Avenue East
Arlington, TX 76010
817-261-4961

National Foundation for Sudden Infant Death, Inc.
1501 Broadway
New York, NY 10036
212-563-4630

The National Neurofibromatosis Foundation, Inc.
340 East 80th Street, #21-H
New York, NY 10021
212-744-4601

National Tuberous Sclerosis Association
P.O. Box 159
Laguna Beach, CA 92652
714-494-8900

Osteogenesis Imperfecta Foundation, Inc.
102 Harold Drive
Hot Springs, AZ 71901
501-525-1272

Retinitis Pigmentosa Foundation
Rolling Parks Bldg.
8331 Mindale Circle
Baltimore, MD 21207
301-655-1011

Spina Bifida Association of America
343 S. Dearborn, Suite 319
Chicago, IL 60604
312-663-1562

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301-655-1011

Spina Bifida Association of America
343 S. Dearborn, Suite 319
Chicago, IL 60604
312-663-1562

ASHG to Meet in Minneapolis

The annual meeting of the American Society of Human Genetics will take place October 3-6 in Minneapolis, Minnesota at the Leamington Hotel. Current members should have received registration materials prior to this time. If you are not already a member of the ASHG, information regarding registration and accomodations can be obtained by writing to:

Dr. Carl J. Witkop, Jr., Chairman
ASHG Local Arrangements Committee
Human and Oral Genetics-Dentistry
Health Sciences Unit A 16-262
University of Minnesota
Minneapolis, Minnesota 55455

Applications for membership are supplied with registration materials. A late fee will be applied to those registrations received after August 15, 1979.

At the May 29 meeting of the board of directors of the National Society of Genetic Counselors, it was decided that membership in the ASHG should be urged for all NSGC members. While there are areas in which the goals and functions of the two societies overlap, membership in the NSGC should not supersede that of ASHG participation. Dual participation will be facilitated by holding the annual business meetings of the NSGC concurrent with the ASHG annual meeting during such times that do not conflict with any of the ASHG sessions or activities.

The annual business meeting of the NSGC is scheduled for October 3, 5:30-7:00 P.M. The location for this meeting will be announced. Also under consideration is a special workshop devoted to issues in genetic counseling. To this end, the co-chairs of the education committee will approach the program committee regarding the feasibility of including this activity on the program.

News of the Districts, continued

We plan to have another meeting this summer. We also hope to be able to coordinate a meeting which would enable the members from New York to meet with those from New England. Kathie Cote, Prenatal Diagnosis Laboratory, MGH, Boston. MGH, Boston.

District II: In response to questionnaires sent to all known interested parties in District II, 23 responses were received. A membership roll is being compiled and will be sent to regional members so that a network for communication can be established. Of members actually in the district and responding, 17 were in favor of a regional meeting with 3 against. A work-shop will be planned for the fall to avoid interfering with summer vacation plans. Delaware seems to be the best location geographically, as our members are spread from northern New Jersey to Virginia. Linda Nicholson, our newsletter representative, is investigating possibilities for holding the meeting at the A.I. DuPont Institute in Wilmington. Virginia Corson, Prenatal Diagnosis Center, Johns Hopkins Hospital, Baltimore.

District VI: The first annual Genetic Counselors Conference for District VI has held on May 19 and 20 in Berkeley, California. Forty six participants attended, mostly from California, Washington and Oregon. Many of the participants had their way paid to the conference either by their department or by their local chapter of the March of Dimes. The March of Dimes provided financial help for this conference.

The purpose of the conference was to build a network of communication within our District, and also to generate enthusiasm for the National Society of Genetic Counselors. I think we were definietly successful on both counts. Collaborative research projects (like a prospective teratogen registry) were discussed, and I hope these will be initiated shortly.

One of the most important feelings I had from the conference was the tremendous openess of everyone participating, and the surprising need to share our work; both the tensions and the rewards. I think there is a bond that truly links us all. I was floored at how quickly people began to get to know each other: our Saturday night excursion to Chinatown in San Francisco was a rousing good time.

During the meeting of the members of District VI, it was decided that this conference should be at the very least an annual event, with the goals of the next conference including communication and continuing education. A needs assessment will be sent out to District VI participants in order to help decide what areas to discuss. Participants stressed the need for true regional representation for the Society, so that everyone across the country could feel that they had some "say" in the workings.

Additionally, a questionnaire was filled out by most participants regarding information about educational background, attitudes toward genetic counselors, salaries, duration of employment and job descriptions. I will tabulate this information and provide it in later District VI reports. A written summary of the conference will be made available to all District VI members and to anyone requesting the information outside District VI. Anyone wishing a copy of this summary may write to me for a copy. A summary of some of the topics of discussion will appear in the next issue of **Perspectives.**
Carolyn Bay, UC, LaJolla.

NEW DISTRICT REPORTERS

In the first issue of the newsletter, there were still two districts without reporters. These positions have now been filled, and it is with pleasure that their names are included here.

District II Linda Taylor Nicholson
A.I. DuPont Institute
P.O. Box 269
Wilmington, Delaware 19899

District V Joseph McInerney
Biological Sciences Curriculum Study
Group
P.O. Box 930
Boulder, Colorado 80306

POSITIONS AVAILABLE

Position for a genetic counselor. Requires one year in a masters program in genetic counseling or a relevant masters degree. Activities include general genetic counseling, amniocentesis counseling and public health concerns. Address enquiries to:

Meridee Gregory, M.D.
Director of Maternal Child Health
P.O. Box 1370
Riverside, California 92502
Phone: 714-787-6671

Position for individual interested in biomedical research, with a bachelor's degree and experience working with children and/or families as **Diabetes Research Coordinator/Clinical Counselor.**

Duties: Counseling newly diagnosed diabetic children and their families, and coordinating and assisting with research studies of diabetes (current research includes studies on the genetics of diabetes and longitudinal study of psychosocial aspects in families of newly diagnosed juvenile diabetics). Contact:

Lester Baker, M.D.
Children's Hospital of Philadelphia
34th and Civic Center Boulevard
Philadelphia, Pennsylvania 19104

Position for an R.N. with a B.S. and extensive experience with genetic counseling and intrauterine diagnosis in an established program of intrauterine diagnosis. Must be able to participate in pregnancy termination.

Duties: Coordinator of a regional prenatal diagnosis program in genetic counseling, outreach educational activities for physicians, nurses and public health personnel. Letters of application, curriculum vitae and three letters of recommendation to:

George P. Henry, M.D.
Department of OB/GYN B-198
University of Colorado Medical Center
4200 East Ninth Avenue
Denver, Colorado 80262

Position for a genetic associate to coordinate a genetics clinic in a pediatric hospital. Write to:

Haynes B. Robinson, Jr., M.D.
Pathology Department
Children's Hospital Medical Center of Akron
281 Locust Street
Akron, Ohio 44308

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