ALLIANCE OF GENETIC SUPPORT GROUPS

1995-6 PROGRESS REPORT

The tenth anniversary year of the Alliance of Genetic Support Groups has seen a consolidation of past accomplishments and a move in creative new directions for the consumer genetics movement.

National Consumer Voice: The Alliance is solidly in place as the national voice for common concerns of genetics consumers before groups such as Council of Medical Genetics Organizations (COMGO), the National Society of Genetic Counselors, the American Society of Human Genetics, the Genome Action Coalition, the Human Genome Project, and the American Academy of Science. This important representation means that the consumer point of view is more frequently heard in formulating genetics policy. There are a number of additional ways in which the Alliance represents consumer interests. The Alliance is asked to serve on government and private sector committees, panels, and advisory groups, on Ethical, Legal and Social Issues task forces. Further, the Alliance is asked to testify before Congress and to exhibit and present at many national conferences and symposia. The year 1995 saw the Alliance in the Senate, the House of Representatives, ELSI, AAAS, NIH, the NASW, ASHG, NSGC, among others. The major dilemma for the Alliance is not in finding avenues to make the consumer voice heard, but in selecting among the many requests for our participation.

Staff: Executive Director Joan Weiss works full-time. Health Policy Director, Martha Volner, Consumer Staff Representative, Mary Ann Wilson, and Administrative Assistant, Mieko Kosobayashi each work half time. Bookkeeper Geri Siegler works 2 days per month, and staff support Donna Foster works 12 hours per week, primarily staffing our new project, *Partnership for Genetics Education.* Since the start of 1996, Nachama Wilker has been working on a consultant basis to formulate and implement the new *Partnership for Genetic Education: Consumers and Professionals in Medical Schools and Managed Care Settings.* Student intern, Margaret Chen, has been helping with general office tasks and with keeping up with the volume of correspondence, e-mail and telephone calls. She worked as a volunteer during 1995 and is being paid a nominal sum for the spring semester of 1996.

Directory: A major undertaking for the Alliance staff, a revised edition of *The Directory of National Genetic Voluntary Organizations* , the Alliance's best seller, was completed in 1995. Three thousand copies were printed for the Alliance's use, of which 1,152 remained in stock as of March 30, 1996. The *Directory* has been a tremendous success with genetic counselors, social workers, early childhood educators, librarians and physicians. Large blocks of distribution have included the organizational members of the Alliance, people who attended both Human Genome Education Model (HuGEM) Project conferences, the Washington State Department of Health, the March of Dimes chapters, public libraries in Allegheny and Westmoreland Counties, Pennsylvania through the University of Pittsburgh and the Genetics Education Center at the Kansas University Medical Center. Discount rates were established for full members of the National Society of Genetic Counselors, the International Society of Nurses in Genetics, March of Dimes affiliates, individual members of the Alliance and those purchasing the Directory in bulk. At the 1995 genetics meetings in Minneapolis, genetic professionals from foreign countries were interested in the *Directory* as a model that could be used in their countries. In addition to the hard copy, the Alliance has placed its database on all office computers. This has enabled us to update the information on an ongoing basis and has served to streamline delivery of our help-line services.

On-Line Services: The first cyberspace achievement of the Alliance has been installation of an e-mail system (alliance@capaccess.org). in December, 1995. This provides an additional dimension of communication with both consumers and professionals. In addition, all groups listed in the *Directory* were asked to supply their e-mail numbers for inclusion in the *Directory.* After a slow start, the e-mail is now in lively use, generating 5-10 messages daily. As the e-mail address is more widely disseminated, we expect the volume to grow.

Web Site: During the final months of 1995, the Alliance of Genetic Support Groups achieved a long-time goal of establishing a home page (http://medhlp.netusa.net/www/agsg.htm) on the world wide web, under the sponsorship of a non-profit organization, MedHelp International. In April, 1996, the data base for the *Directory* was placed on the web site. This achievement means that Alliance and the *Directory's* support group information is available to a much expanded pool of consumers and professionals. Indeed, during the month of March (the first month in which the data base was on the web site)1,255 browsers visited at the home page and/or the data base. This number was achieved prior to placement of the information with various "search engines" in April. In April, MCHNet and the Alliance web site exchanged "hot buttons" meaning that with one click, a web browser can enter each of the sites from the other. Staff is currently working with the On-Line Mendelian Inheritance in Man (OMIM) to establish a link with this data base.

Policy: 1995 has been a year of fighting an uphill battle for the rights and services of people with genetic disorders, along with all people who have medical problems. With the consolidation of American medical care delivery into Health Maintenance Organizations and Managed Care, specialized services have become more difficult to obtain as medical "gatekeepers" attempt to hold down costs. Additionally, at the Federal legislative level, efforts continue to be made to balance the budget by reducing Medicaid/Medicare expenditures and by relegating the programs to the State level via capped block *grants* to the states. The Alliance has worked with the Consortium of Citizens with Disabilities to fight maneuvers which would effectively cut services to our members. At the writing of this report, it appears that a much scaled down health care reform measure, the Kennedy-Kassebaum Bill, has a decent chance of making it through the 104th Congress. We are further informed that an anti genetic discrimination clause may find its way into the legislation via a "technical amendment". This would represent a monumental victory for the genetics community. The other good news on the policy front is that efforts to reduce expenditures for medical research were thwarted. This means that monies for the Human Genome Project and other genetic research endeavors have not been cut. It is important to note that Federal legislators have become aware of our problems -- largely through the strength of the consumer movement -- and are seeking solutions to them. The Alliance has been active on all of these legislative fronts, advocating for the consumer position and helping to formulate policy which will benefit people who have genetic conditions.

Exhibits: Our major exhibits for 1995 were at the Minneapolis meetings of the National Society of Genetic Counselors and the American Society of Human Genetics. Both exhibits were well attended. The exhibit went to Texas in March of 1996 for the March of Dimes/ American College of Medical Genetic Joint Clinical Genetics Meeting, staffed by Board member Jannine Cody who is a local resident. Unfortunately, plans to expand our exhibiting capacity have been thwarted by budget limitations. This means that we have had to be extremely selective and cautious in our choice of forums.

<u>HuGEM:</u> The third year of a joint Georgetown University/Alliance of Genetic Support Groups project included Spring and Fall forums in Washington, DC and Seattle, Washington. Funded for three years by the Ethical, Legal and Social Issues Branch of the Human Genome Project, National Institutes of Health, this model education program, developed for use nationwide by consumers and non genetics professionals, is near completion. A consumer survey and one for health professionals in University Affiliated Programs (UAP's) were tabulated during 1995. Preliminary results of note are that people who have genetic disorders are more aware than health providers of the Human Genome Project and approximately one-third of the consumers surveyed reported that their insurers had refused to pay for treatments of genetic disease. A set of videos generated by the two forums with a companion manual have been completed and are available for use by support groups, health care providers, teachers and others interested in education about ethical, legal and social issues in genetics. Currently, plans for an educational program for interdisciplinary, professional organizations that were identified by the HuGEM survey as giving genetic services with only a minimum of training in genetics are underway. (Funding will be sought outside of this grant application.)

<u>Toll-free Help Line:</u> Along with the *Directory of National Genetic Voluntary Organizations,* the 800 help line is at the heart of the Alliance operations. Through this line, we have been able to personally reach over 8,000 consumers during the past year. As word of the Alliance continues to spread through increased listings by other agencies and by a number of on-line /web site listings, the Alliance is touching an ever-growing number of consumers and professionals to help them find appropriate support and genetic services. Trends over the last several years held steady during the 1995-96 period of this report, with between 15 and 20 % of the callers seeking information about specific disorders or looking for diagnostics. Another 14% are looking for others with whom to share their experience. Feedback from people who have used this line lets us know that this service has helped many families to escape from their sense of isolation, while providing them with valuable, practical information about obtaining medical help for genetic problems.

<u>Additional Alliance Accomplishments</u>: During the last year, the Alliance Board drew up and approved apersonnel policy document which formalizes many of the policies which have been in place during the last ten years, formed a membership committee which met to explore ways to maintain and expand the number of groups who belong to the Alliance.

The Alliance was well represented at the CORN conference on primary care provider education in genetics. Consumer liasons and staff from the *Partnership for Genetics Education Project* brought a consumer perspective to the need for, and ideal components of, efforts to educate primary care providers. The conference was also used by the Alliance as an opportunity to discuss ways of joining efforts with on-going education projects with our Partnership project.

Following the conference, the liasons committee met for two days. The meeting allowed the consumer representatives to the Alliance share information about the activities of the consumer committees in the regions and explore avenues for further cooperation. (See attached minutes in Appendix.)

<u>Partnership for Genetic Education: Consumers and Professionals in Medical Schools and Managed Care Settings</u>: Newly conceived during the past year is the

Alliance regional training project. The goal of this project is to acquaint medical students, primary care practitioners and physicians practicing in managed care and health maintenance organizations with genetic diagnoses on a first hand basis. As health care is more and more practiced by primary care physicians, the Alliance hopes to train consumers in several of the CORN regions to work with medical schools and with HMOs to provide "hands-on" input into the physical and emotional realities of living with genetic diagnosis. Grant applications for funding for the Partnership for Genetics Education project were submitted to several of the Regional Genetics Networks, including MARHGN, Mountain States, Great Plains, PacNORGG, and TEXGENE. Funding was solicited from Integrated Genetics, Genetics IVF and LabCorp. To date, we have received $11,000 in cash support and $5,000 of in-kind travel support for members of the steering committee from GLARGG, GENES, PSRGN, SERGG, TEXGENE and GPGSN. MSRGN turned us down. There is a proposal pending with the National Institutes of Health/Ethical, Legal and Social Issues Branch. Letters of inquiry have been sent to Department of Energy/ELSI, the Robert Wood Johnson Foundation and SmithKline Beecham. Staff has been working to gather pertinent materials and to explore additional funding sources. The balance of the year will be spent in locating funding and in working out the details of the project.

Gala: For our Tenth Anniversary we plan to celebrate with a major fund raiser. This event will be preceded by a membership meeting and a computer workshop. The workshop will provide learning opportunities for consumers and professionals in the areas of computer technology and peer support, as well as time for networking and interchange of ideas. It will be capped by a banquet honoring the contributions of Joan Weiss, founder and executive director of the Alliance. In preparation for the October, 1996 Tenth gala, a funding request has been made to SmithKline Beecham Pharmaceutical Corporation. Carl B. Feldbaum, President of Biotechnology Industry Organization has agreed to chair the Corporate Sponsor Committee. He and his committee plan to approach Bristol-Myers Squibb Company, U.S. Health care, Inc., Hoffman-LaRoche, Inc., Merck & Company, Athena Diagnostics, Eli Lilly & Company, Avon Products Foundation, Inc.. and perhaps other corporations to underwrite the cost of the event. Advertisements for the Tenth Anniversary Souvenir Journal are to be sold to Alliance members, vendors, friends of Joan Weiss, and interested corporations and individuals. The ticket price has been set at $125 each for the event.