ALLIANCE of Genetic Support Groups
A Coalition of Voluntary Organizations and Professionals

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ANNUAL REPORT

ALLIANCE OF GENETIC SUPPORT GROUPS

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For ten years the Alliance of Genetic Support Groups has connected people to genetic resources, information and peer support, promoted coalitions of consumers with professionals and developed innovative solutions to genetics service problems. The tenth anniversary year of The Alliance has seen a consolidation of these past accomplishments and a move in creative new directions and projects.

Toll-free Help Line: The heart of the Alliance is our resource referral services. Established long before the Human Genome Project, the toll free information line helps families and individuals sort out the facts and implications of a genetic diagnosis and make critical connections to professional and community support networks. Increasingly this public service is addressing the informational, resource and referral needs for a more diverse group of students, the general public, teachers, allied health professionals and genetic counselors. The help line connected the Alliance to over 9,000 people looking for answers to a whole range of concerns about genetic services and related issues this past year alone. As word continues to spread through additional phone listings in the media, directories, clinics and hospitals, and other resource referral agencies, the Alliance is touching an ever-growing number of consumers and professionals. Calls over the past two years have increased over 150% and the Alliance telephone carrier reports that over 24% of attempted calls find a busy signal instead. Of the total calls, approximately 27% seek information about specific disorders and another 23% hope to find others with whom to share their experiences. General queries about genetics are the focus of another 12% and a growing number of calls, currently 5%, pose bioethical questions about genetic discrimination. The Alliance has consistently received positive feedback from users of this service. The Alliance plans to improve the capacity of the resource referral center to meet the growing public need for answers to questions about genetic issues, information and support services.

Directory: The major resource for answering and directing the concerns of callers is the *Directory of Voluntary Genetic Support Groups,* a critical directory and data base resource which lists over 900 voluntary support groups and other resource organizations. A revised edition of *The Directory of National Genetic Voluntary Organizations* was completed in 1995. 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. The *Directory* has been a tremendous success with genetic counselors, social workers, early childhood educators and physicians. Public libraries, medical clinics, March of Dimes chapters and Alliance project and conference participants have accounted for large numbers of requests. 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. Future plans include an revised publishing of the Directory to reflect the data base's growing inclusion of new support resources and the publics' broadening range of questions.

On-Line Services: The first cyberspace achievement of the Alliance was the 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 established a home page on the world wide web, under the sponsorship of a non-profit organization, MedHelp International. In April 1996, the data base for the *Directory of Voluntary Genetic Support Groups* was placed on the web site. This achievement results in the availability of the *Directory* 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. In April Alliance information was placed with various "search engines" and Maternal and Child Health Net and the Alliance web page exchanged hot links. Staff is currently working with the On-Line Mendelian Inheritance in Man (OMIM) to establish a link with this data base. Future web improvements include enhancement of the content and graphics and additional plans to place member organization brochures on the Alliance web page with download access for consumers, genetic counselors and physicians.

Exhibits: The Alliance exhibited the brochures of member organizations at a variety of familiar genetic gatherings, including the National Society of Genetic Counselors and the American Society of Human Genetics and the March of Dimes/ American College of Medical Genetics Joint Clinical Genetics Meetings. Unfortunately, plans to expand our exhibiting capacity to new venues were thwarted by budget restraints. The Alliance has developed a cost effective, which can now be sent upon request at minimal shipping costs to the Council of Regional Genetics (CORN), regional and local meetings. Projected plans for 1996/97 include scheduling to exhibit at new professional conferences for nurses, social workers and teachers.

Partnership for Genetic Services Pilot Program: The goal of this project is to acquaint medical students and primary care practitioners practicing in managed care organizations with the issues and challenges presented by new genetic discoveries and technology. As people with special health care needs are seen increasingly by primary care physicians, the Alliance hopes to train consumers in several of the regional genetics networks to work with medical schools and with managed care organizations to provide "hands-on" exposure to the physical and emotional realities of living with a genetic disorder and inform students and physicians about supportive resources in the consumer community. Partial funding and support have been obtained from Regional Genetics Networks and several commercial companies. The Alliance has also applied to the ELSI Branch of the Department of Energy and several corporations. The first steering committee meeting took place in Washington, DC last spring and the planning session was just concluded October 3rd and 4th. This innovative project has received enthusiastic support from both the professional and consumer communities.

HuGEM: The third year of a joint Georgetown University/Alliance of Genetic Support Groups project included a 1995 Fall forum in Seattle, Washington, in conjunction with the Pacific Northwest Regional Genetics Group (PacNoRGG). Funded for three years by the Ethical, Legal and Social Issues Branch of the National Center for Human Genome Research, National Institutes of Health, the Human Genome Education Model (HuGEM) Project, developed for use nationwide by consumers and non genetics professionals, was completed in

August 1996. The results of 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 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. Funding is being sought for HuGEM II to educate interdisciplinary, professional organizations identified by the HuGEM survey as giving genetic services with only a minimum of training in genetics. A preliminary conference, sponsored by the Ethical, Legal and Social Issues Branch of the Department of Energy and of the National Institutes of Health, was held on June 10, 1996, which listed the enthusiastic support for such an educational program by at least six professional organizations.

Policy: The Alliance has been active on legislative fronts, advocating for the consumer position and helping to formulate policy which will benefit people who have genetic conditions. The Alliance worked with the Consortium of Citizens with Disabilities, the Genome Action Coalition and other like minded organizations to support legislative proposals addressing the need for genetic privacy protections, proposals to maintain or increase expenditures for medical research and the Kennedy Kassebaum Health bill. It is important to note that Federal legislators have become aware of genetic consumer issues largely through the strength of the consumer movement and are seeking solutions to them. Legislative draft proposals are now frequently sent to the Alliance for review and recommendations prior to final drafting. Plans for next year include establishment of a Public Policy Consumer Network to increase consumer participation in the legislative policy debates.

National Voice for Consumer Concerns: The Alliance is solidly in place as a national voice for the common concerns of genetic consumers before groups such as the National Society of Genetic Counselors, the American Society of Human Genetics, the Genome Action Coalition, the National Center for Human Genome Research, and the American Association for the Advancement of Science. This consumer perspective is gaining greater exposure and will result in greater impact on the formulation of genetics policy. The Alliance also sends representatives to serve on government and private sector committees, panels, and advisory groups and on Ethical, Legal and Social Issues task forces, such as the genetic testing task force. In addition, the Alliance is asked to testify before Congress and to exhibit and present at many national conferences and symposia. The Alliance has no difficulty finding open avenues to make the consumer voice heard; there is difficulty stretching the small staff to meet the many requests for our participation.

Gala: The Tenth Anniversary of the Alliance was celebrated at a gala fund-raiser on October 12, 1996, honoring Founding Director Joan O. Weiss and acknowledging the organization's accomplishments over the ten years. The bi-annual membership meeting, computer workshop and board meetings completed the weekend's schedule, providing learning opportunities for consumers and professionals in the areas of computer technology and peer support, as well as a time for networking and interchange of ideas.

Staff: Executive Director through September, Joan Weiss worked full-time. Health Policy Director, Martha Volner; Consumer Staff Representative, Mary Ann Wilson; and Administrative Assistant, Mieko Kosobayashi each work part time. Our bookkeeper Geri Siegler, retired as of September 1, worked 2 days per month, and staff support Donna Foster, worked 12 hours per week, primarily staffing our new project, *Partnership for Genetics Education: Consumers and Professionals in Medical Schools and Managed Care Settings.* Since the beginning of 1996, Nachama Wilker has been working on a consultant basis to formulate and implement the new *Partnership for Genetics Education:* project. Student intern, Margaret Chen, helped with general office tasks and with keeping up with the volume of correspondence, e-mail and telephone calls. When she left for a genetic counseling training program, she was replaced by several volunteers. Currently, Edie Lebson, a student at the University of Maryland, volunteers four hours per week.

New Executive Director: After having been intimately involved with the Alliance of Genetic Support Groups since its inception ten years ago and having served as its Executive Director for the past seven and a half years, I have decided to step down and give someone else a chance to take the helm. Needless to say, I leave this position with mixed emotions. However, I have absolutely no hesitation in turning over this most rewarding directorship to Mary Davidson who already has become a integral part of the Alliance family.

Joan O. Weiss, MSW
Founding Director

10/12/96