

ALLIANCE OF GENETIC SUPPORT GROUPS

ANNUAL REPORT

1992

REPORT FROM JOAN WEISS, MSW EXECUTIVE DIRECTOR

Fiscal Year 1992 was a landmark year in the life of the Alliance of Genetic Support Groups.

In October, we held the first international meeting of support group networks, attended by representatives of 15 countries. The structure and character of the support group movement appears to depend on the population and wealth, cultural attitudes, and form of government of its home country.

During the year, Alliance staff was hard at work on two major publications, the *Health Insurance Resource Guide* and the *Directory of National Genetic Voluntary Organizations*. Both went through the compilation and editing phases and were, by year's end, at the printing and distribution phase.

In 1992 the Alliance brought to fruition its project to create a support group for families with children who have chromosomal deletions. After spending a year compiling a list from people who had called, we arranged a conference call and launched the group. (The list of 40 families has more than tripled to 135!) Still in the "gestation phase" is another group for families with children who have been born with extra chromosomal material. That group will be initiated during the next year.

The Alliance's toll free number was printed in a number of publications which have nation-wide distribution. The number of resource directories in which the 800 number is listed also increased substantially during the year. This resulted, during the course of the year, in a doubling of the number of incoming calls the Alliance receives.

The year 1992 saw the Alliance move from the law offices of Roberts and Holland to its own new headquarters in Chevy Chase, Maryland. This large developmental leap is in keeping with the Alliance's rising national visibility and its acknowledged position in the genetics community. Increasingly, the Alliance is playing a leadership role in projects involving the National Society of Genetic Counselors, the American Society of Human Genetics, the National Institutes of Health, and the Department of Health and Human Services. More and more often, Alliance expertise is called upon by other organizations such as the National Organization for Rare Disorders, Congressional Committees, the American Association for the Advancement of Science, the March of Dimes, and the Institute of Medicine, to name a few.

Indeed, it is increasingly clear that current staffing levels are not adequate to meet these demands. A major goal for the coming year is to create additional funding sources, so that the Alliance can continue to meet the needs of the consumer and professional genetics community.

Joan O. Weiss, MSW
Executive Director
November, 1992

The Alliance also maintains a network with other national organizations whose programs have similar goals, such as the National Society of Genetic Counselors, the American Society of Human Genetics, the Association for the Care of Children's Health, the March of Dimes Birth Defects Foundation, the National Information Center for Children and Youth with Handicaps (NICHY), the National Organization for Rare Disorders (NORD), and the National Health Council. In addition, the Alliance is asked frequently now to send a representative to conferences pertaining to the ethical, social and legal implications of the Human Genome Program, as well as educational genetics programs, involving such diversified subjects as how to keep a genetics support group in existence, women's issues in reproductive screening and testing, and population screening for carriers of the gene for cystic fibrosis. We are also asked to review grants and manuscripts, for independent individuals, organizations, and for the government. The media has increasingly sought to involve the Alliance putting together articles and television broadcasts. Recently, we were asked to help a media advocacy group in California defend the privacy rights of a well known television anchorwoman who has a genetic disorder and her right to have children with the same disorder, if this is her desire.

In summary, the original goals of the Alliance, which was formed in 1986, are being steadily carried out: to help formalize genetic support groups, to help them become a unified force with identified common purposes, to link them to the medical and scientific communities, and to help them educate professionals and the public about genetic disorders. In our common forum, these groups learn from one another and share experiences. The Alliance continues to work to improve the availability and appropriateness of genetic services by identifying gaps in services and by developing model programs or recommendations to fill these gaps.

Joan O. Weiss, MSW, Project Coordinator

Coordinator's Report

In 1991 the activities of the Alliance of Genetic Support Groups were diversified and exciting. Our membership as of the first of the year 1992 is 164 genetic voluntary organizations and 239 individual members, increasing daily as a result of the current membership drive and growing visibility of the Alliance. The Alliance exhibits were held at the following conferences: the National Society of Genetic Counselors; the Association for the Care of Children's Health, the International Gathering of Networks of Support Groups, and the International Human Genetics Conference.

The Alliance co-sponsored a meeting with the Mid Atlantic Regional Human Genetics Network (MARHGN) September 1991 which was well attended both by consumers and professionals and very well received: *The Human Genome Project: A Public Forum*. It was held in Alexandria, Virginia and funded by the National Center for Human Genome Research, the National Institutes of Health; the March of Dimes Birth Defects Foundation; and the Genetic Diseases Services Branch, Maternal and Child Health Bureau. This public forum explained the meaning and explored the ethical implications of this vast scientific undertaking which seeks to unlock the mysteries of the entire array of human genes.

In October 1991 the Alliance hosted the International Gathering of Networks of Support Groups, a Satellite Meeting of the 8th International Congress of Human Genetics, at Georgetown University in Washington, D.C.. Sixteen countries sent representatives, and as a result of the meeting an international newsletter was written by the Alliance and distributed to the participants in each of the countries represented. It is hoped that an International Alliance of Genetic Support Networks will be established in the future.

The Alliance *Alert* is sent out monthly to Alliance members and interested individuals and organizations. Requests continue to come to the office for the Alliance *Peer Support Resource Guide for Training Programs*. Additional publications by the Alliance will include the *Alliance Health Insurance Resource Guide and the Directory of National Voluntary Genetic Organizations and Related Resources*, both due to be published by late spring 1992. The *Directory* was previously published by the National Center for Education in Maternal and Child Health.

One of the main activities of the Alliance is to assist in the formation of new genetic support groups and the strengthening of existing ones. We now have literature to send to those interested in assessing the needs of members of a group, on starting a support group, and on such essential subjects as how to become tax exempt.

Another thrust of our work is the development of consumer involvement in the ten Regional Genetic Networks. We are grateful to the regional coordinators and consumer committee chairpersons for their cooperation towards this goal. The Alliance will be distributing a paper on the subject of consumer regional involvement to those who are interested.

A future task will be the linkage of adoptive families with children with genetic disorders to appropriate genetic support groups. An Alliance subcommittee has been formed for this purpose.

1992 Annual Report for the Alliance of Genetic Support Groups

President's Report

The Alliance of Genetic Support Groups has witnessed another year of continuing growth and development. National and regional consumer-professional collaboration on behalf of the Alliance has been reenforced with the increased involvement of national related organizations such as the National Association of Genetic Counselors, the American Society of Human Genetics, the National Center for Human Genome Research (Ethical, Legal and Social Implications Program), the March of Dimes Birth Defects Foundation, and the continuing support of the Maternal and Child Health Bureau's Genetic Services Branch, but also the Regional Genetics Networks. Genetic support groups have been initiated all over the country and developing at a steady rate.

Our office staff, consisting of Joan Weiss (Project Coordinator), Martha Volner (Health Policy Director), Mary Ann Wilson (Consumer Staff Representative), Mieko Kosobayashi (Secretary), and Gerry Siegler (Bookkeeper), continue to work to support and implement our many activities and reply to countless requests for service.

We continue to provide information to the public through our Alliance brochures, our monthly *Alerts*, and our Alliance exhibits of member brochures at national professional and consumer conferences. We also have been increasingly involved with media requests related to discrimination issues and health insurance deficiencies, as well as educational programs about genetics and genetic counseling.

While we still continue to receive membership, governmental and grant support, funding activities must increase in the coming year in order to meet the need for the development of new projects and programs and the increasing requests for Alliance services.

Join us in this year of challenge to work for the developing partnership of consumers and professionals interested in meeting the needs of those with genetic disorders and their families.

Jayne Mackta, President

MEMBER ORGANIZATIONS

Giving Voice to Common Concerns

MEMBER ORGANIZATIONS as of June 1991

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| AboutFace | Estate Planning for the Disabled | Int'l Rett Syndrome Assn. | Nat'l. Tuberous Sclerosis Assn. |
| ALS Assn. | FACES | IMPACC | Nat'l. Vitiligo Fd. |
| American Assn. of Kidney Patients | Familial Polyposis Registry | Jackson Co. Assn. for Sickle Cell Disease, MS | Neurofibromatosis, Inc. |
| American Narcolepsy Assn. | Families of Children Under Stress | Johns Hopkins Hospital, Medical Genetics | NJDHS, Office for Prevention |
| American Porphyria Fd. | Families of Spinal Muscular Atrophy | Juvenile Diabetes Foundation Int'l. | NY Hospital/Cornell Div. of Human Genetics |
| American Self-Help Clearinghouse | Family Support Network, UNC-Chapel Hill | Klinefelter Syndrome & Associates | Noonan Syn. Support Group |
| American Sickle Cell Anemia Assn. | Fanconi Anemia Research Fund | Lactic Acidosis Sup. Grp. | Organic Acidemia Assn. |
| Angelman Research Group | 5 p-Society | Let's Face It | Osteogenesis Imperfecta Fd. |
| Arkansas Genetics Program | Fd. for Ichthyosis & Related Skin Types | Little People of America | Oxalosis and Hyperoxaluria Fd. |
| Assn. for Children w/Russell-Silver Syndrome | Foundation for Nager and Miller Syndrome | Lowe's Syndrome Assn. | PKR Foundation |
| Assn. for Glycogen Storage Disease | Freeman-Sheldon Parent Support Group | Major Aspects of Growth in Children Foundation | PacNoRGG |
| Assn. for the Care of Children's Health | Genetic Interest Group, England | Malignant Hyperthermia Assn. of the US | Page's Disease Fd. |
| Assn. of Genetic Sup. of Australasia | Genetics Center, CHMC, Akron, OH | March of Dimes | Parent Assistance Comm. on Down Syndrome |
| Assn. for Neuro-Metabolic Disorders | Hallermann-Streiff Parent Association | Marion Co. Health Dept., Sickle Cell Program | Perceptive Systems, Inc. |
| Beckwith-Wiedemann Sup. Network | HBM Center for Human Genetics, Omaha | MARHGM | Pilot Parent Partnerships |
| Celiac Sprue Assn./USA | Healthy Mothers, Healthy Babies | Mt. Sinai Medical Center | Porcupine Health Unit |
| Charcot-Marie-Tooth Assn. | Hemifacial Microsomia/Goldenhar Family Support Network | NYC—Social Work Services | Prader-Willi Syndrome Assn. |
| Chesapeake Parent Support Grp. | Hemochromatosis Research Fd. | Nat'l. Assn. for Sickle Cell Disease, MD Chapter | RP Fd. Fighting Blindness |
| Chromosome 18 Registry and Research Society | Hereditary Disease Fd. | National Ataxia Fd. | Register of Inherited Metabolic Disorders |
| Cleft Palate Fd. | HHT Foundation | National Center for Education in Maternal and Child Health | Roswell Park Cancer Inst. |
| Clinical Genetics & Child Dev Ctr, Hanover, NH | Human Growth Fd. | Nat'l. Down Syndrome Congress | Santa Monica Hospital Med Center |
| Clinical Genetics Program, CHMC, Boston | Huntington's Disease Soc. of America, NY | Nat'l. Fd. for Ectodermal Dysplasias | Self-Help Clearinghouse of Gr. WA |
| Colorado Dept of Health, Family & Comm. Health | Maryland Chapter | Nat'l. Fd. for Jewish Genetic Diseases | Shriver Center for Mental Retardation |
| Cooley's Anemia Fd. | Northern CA Chapter | Nat'l. Fragile X Fd. | Sjogren's Syndrome Fd. |
| Cornelia de Lange Syndrome Fd. | Puget Sound Chapter | Nat'l. Gaucher Fd. | Smith-Lemli-Opitz Org. |
| Cystinosis Fd. | Rocky Mt. Chapter | Nat'l. Hemophilia Fd. | Soto's Syn. Support Assn. |
| D.E.B.R.A. | W. PA Chapter | Nat'l. Hydrocephalus Fd. | Southwest Communication Resources |
| DRADA | Indiana U Med Ctr., Clinical Services | Nat'l. MPS Society | Spina Bifida Assn. of America |
| Developmental Disabilities Prevention Program, NY | Immune Deficiency Fd. | Nat'l. Marfan Fd., NY Central Ohio Chapter | Sturge-Weber Fd. |
| Donald J. Allen Memorial Huntington's Disease Clinic | Inherited Metabolic Diseases Clinic | Nat'l. Neurofibromatosis Fd. | Support Group for Monosomy 9-P |
| Dysautonomia Fd. | Integrated Genetics | NOAH | S.O.F.T. 18, 13, & Related Disorders |
| Ehlers-Danlos National Fd. | International Joseph Diseases Fd. | NORD | TARSA |
| Eastern Area Sickle Cell Assn., Jacksonville, NC | | Nat'l. Parent Network on Disabilities | Tourette Syndrome Assn. |
| | | Nat'l. Scoliosis Fd. | Treacher Collins Fd. |
| | | Nat'l. Soc. of Genetic Counselors | Triad Sickle Cell Anemia Fd. |
| | | Nat'l. Tay-Sachs and Allied Diseases Assn. | Turner's Syn. Society of the US |
| | | | United Leukodystrophy Fd. |
| | | | U. of Michigan, Div. of Gen. |
| | | | U of NM Med Sch., Pediatrics |
| | | | Vivigen |
| | | | Von Hippel Lindau |
| | | | Williams Syndrome Assn. |
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