Alliance of Genetic Support Groups

A Coalition of Voluntary Organizations and Professionals

1991 ANNUAL REPORT

The Alliance of Genetic Support Groups has witnessed another year of growth and development. With significant funding from the Genetic Services Branch of the Maternal and Child Health Bureau, we have fostered consumer-professional collaboration and served as a forum for sharing information about genetic disorders. Strengthened by our networking with other national organizations, the Alliance is a recognized resource serving families, professionals, and genetic support groups.

Our product is information. Whether we connect a new family to a support group, refer them to a genetics center, or bring together isolated families who share common needs, we are striving to insure that people affected by genetic disorders do not fall between the cracks. Ever mindful of gaps in services, we work with consumers and professionals to identify and meet needs. We provide information to the public through brochures, our monthly Alert, and our traveling exhibit of member brochures. We respond to media requests which recently have focused on discrimination issues and health insurance deficiencies. Through our educational programs,we offer our members opportunities to learn and share.

None of our achievements would be possible without the hard work of our dedicated staff who deserve recognition for outstanding commitment and service. For many, we are the starting point of a long search for answers — some of which may not exist. People who call often do not know what they need. They don't even know the right questions to ask. It is comforting to know that every call to the Alliance is handled with concern, compassion and competence.

We invite you to join us in the challenging year ahead. As the information unlocked by the Human Genome Project expands, our work increases. Now more than ever, consumers and professionals must share their resources and work in partnership to meet the needs of the growing number of people who are discovering that they and their families are affected by genetic disorders. We must be there for them as we are here for each other.

Jayne Mackta
President

Coordinator's Report

In 1991 the activities of the Alliance of Genetic Support Groups were diversified and exciting. Our membership, which numbered 164 genetic voluntary organizations and 239 individuals at the close of the year, is increasing rapidly as we gain visability.

> *It is not possible to convey the excitement of this conference: the technical knowledge shared by experts at the forefront of scientific discovery and application, and the intellectual and spiritual stimulation of discussing ethical and practical issues with concerned leaders of the many allied genetic organizations. I feel honored ...*
>
> Sheila Chadwick,
> Human Growth Foundation

The Alliance co-sponsored a meeting with the Mid-Atlantic Regional Human Genetics Network (MARHGN) in September 1991 entitled *The Human Genome Project: A Public Forum*. Well attended by consumers and professionals and very well received, this stimulating program was 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. Parrticipants learned about the vast scientific undertaking which seeks to unlock the mysteries of the entire array of human genes and explored its ethical implications.

In October 1991, the Alliance hosted the first International Gathering of Networks of Support Groups, a Satellite Meeting of the 8th International Congress of Human Genetics, at Georgetown University in Washington, DC. Sixteen countries were represented, and a newsletter documenting this historic meeting was written by the Alliance and distributed to the participants. It is hoped that an International Alliance of Genetic Support Networks will be established.

The Alliance *Alert* is sent out monthly to Alliance members and interested individuals and organizations. Requests continue to come to the office for our *Peer Support Training Resource Guide*. New publications include a *Health Insurance Resource Guide* and an updated, revised version of 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. Another thrust of our work is the integration of consumers into the ten Regional Genetic Networks. We are grateful to the regional coordinators and consumer committee chairpersons for their cooperation, and a report on this subject will be distributed in the spring.

A future task will be the linkage of adoptive families with children with genetic disorders to appropriate genetic support groups. An Alliance subcommittee has taken a leadership role in this activity.

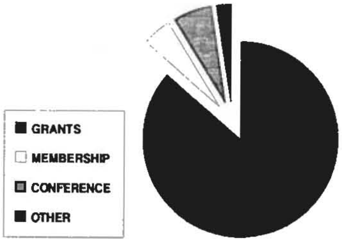
Our success depends in large part upon strong linkage with national organizations with similar goals. Constant communication supports our function as a forum for the exchange of information and ideas. The Alliance was asked frequently to represent the consumer viewpoint or to identify consumers who could speak to issues of concern. We participated in conferences pertaining to the ethical, social and legal implications of the Human Genome Program as well as educational programs as diverse as keeping a genetic support group going, women's issues in reproductive screening and testing, peer support training, and population screening for carriers of the gene for cystic fibrosis. We reviewed grants and manuscriptst. And as a consequence of our growing involvement with the media, a committee is developing a position paper on genetic disorders and the media. The organization has also developed a position paper in support of responsible animal research.

In summary, the original goals of the Alliance, formed in 1986, are being realized: 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, 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.

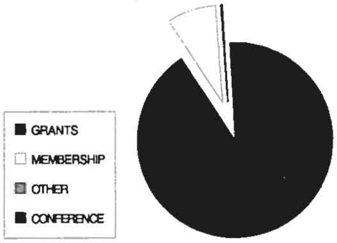
Joan O. Weiss, MSW

Financial Information

REVENUES - YEAR ENDED SEPTEMBER 30, 1990



REVENUES - YEAR ENDED SEPTEMBER 30, 1991



	Year Ended September 30 1991	1990
REVENUE COLLECTED		
Grants	$ 98,653	$ 94,810
Peer support training conference	-0-	7,222
Memberships	8,759	4,925
Resource guide	110	1,580
Other	18	926
TOTAL REVENUE COLLECTED	107,540	109,463
EXPENSES PAID		
Salaries and wages	44,332	31,464
Contract personnel	-0-	3,641
Office operations	16,055	11,860
Meetings	13,721	17,044
Exhibits	4,442	3,293
Board activities	3,842	4,379
Publications	7,466	1,121
Peer support training conference	409	36,847
Health insurance resource guide	1,908	-0-
Other	646	-0-
TOTAL EXPENSES PAID	92,821	109,649
EXCESS REVENUE COLLECTED OVER EXPENSES (EXPENSES PAID OVER REVENUE COLLECTED)	14,719	(186)
Fund balance, beginning of year	30,226	30,412
FUND BALANCE, END OF YEAR	$ 44,945	$ 30,226

BOARD OF DIRECTORS

Jayne Mackta, *President*
Betsy Anderson, *Vice President for Consumers*
Joan Burns, *Vice President for Professionals*
Joseph P. Smith, *Treasurer*
Charles F. Evans, *Secretary*

Ruby Bishop
Robin Blatt
Jessica Davis
Joan Edwards
Iliana Hernandez
Lee Kitchens
Steven Laver
Geraldine McGrath
Donna Gore Olsen
Luther Robinson
Barbara Smith
Betsy Trombino
Ann Walker

STAFF

Joan O.Weiss
Coordinator

Martha Volner
Health Policy

MaryAnn Wilson
Consumer Representative

Mieko Kosobayashi
Secretary

Geraldine Siegler
Bookkeeper

PROJECT OFFICER

Edward Duffy
Genetics Branch
Maternal & Child Health

CONSULTANTS

R.C. Baumiller
Beverly Raff

Alliance of Genetic Support Groups
A Coalition of Voluntary Organizations and Professionals
35 Wisconsin Circle, Suite 440
Chevy Chase, MD 20815
1/800/336-GENE

The Alliance is funded in part by project #MCJ-11108-03 from the Maternal and Child Health Program, Title V Social Security Act, Health Resources and Services Administration, Department of Health and Human Services