ALLIANCE
of Genetic
Support Groups

A Coalition of Voluntary Organizations and Professionals

REPORT TO MEMBERS 1992

From The President

The Alliance of Genetic Support Groups has grown significantly since its inception in 1986. We now have 200 member organizations in addition to an increasing number of individual members representing both consumers and professionals. We receive close to 500 calls on our toll-free 800 number each month. While we appreciate the power of numbers, we recognize that each call, each contact has tremendous implications for individuals and families. "Is there anybody else...?" "Where can I find...?" "Is there any information...?" The questions never seem to change, we just get more of them.

Our daily telephone log supports the need for a centralized genetics clearinghouse staffed by an information specialist trained to provide callers with consumer-friendly information and resources. The combined pressures of information overload and technological advances have potential for dehumanizing that process. We hear from too many people who may have the energy to make just one call. If they reach voice mail or get referred elsewhere, they can easily fall between the cracks and become one more statistic. Our challenge is not to count calls; rather we must deliver real help in terms of accessible and usable information.

Any review of Alliance activities would be incomplete without special mention of our outstanding staff. The compassion and commitment of each person drive our coalition and set the tone of quality and caring that the public has come to expect from our organization. The other critical components, of course, are your on-going support and involvement.

Jayne Mackta

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President

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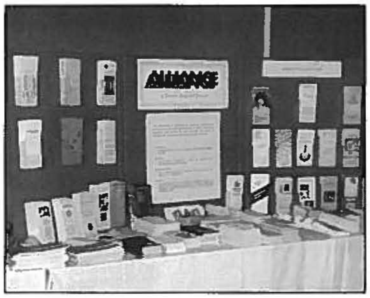
A Brief Overview

The Alliance is a link between consumers and professionals. We connect families with support groups if they exist. We bring families together if they don't. We support groups with programs to strengthen their organizations and network them with other groups with similar concerns and needs. We are a forum for sharing ideas and strategies.

The Alliance toll-free 800 number has become a virtual lifeline. The number appeared in many publications with national distribution as well as resource directories resulting in a doubling of the number of incoming calls received.



During 1992, we published three documents: the *Directory of National Voluntary Health Organizations*; a *Health Insurance Resource Guide*, and a pamphlet entitled *Integrating Consumers into the Regional Genetics Networks*. We are in the final stages of editing the proceedings from our highly successful membership meeting, "The Empty Pocket Syndrome; How To Get Money," held in Arizona during November.

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 of people who had called seeking help and a connection, we arranged a conference call and launched the group. The original 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 formalized during the next year.

The Alliance took another giant step by moving from the law offices of Roberts and Holland to its own 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.

Dear Mrs. Clinton:

My daughter was born with a rare genetic condition called Pallister-Killian syndrome.... I now work two part time jobs to help support our family. Neither job offers insurance benefits. We did not choose the family coverage from my husband's employer because it is costly, contains a pre-existing condition clause and requires a medical exam... It seems there is little help for middle class families like us who can afford to pay reasonable premiums, but have a family member who is "uninsurable." ...Our family would like to see a health care plan that would make medical care available to all families and allows for their choice of doctor. Children and adults with genetic conditions should have equal access to medical care and insurance coverage.

Marianne Haven

Having just returned from the TEXGENE Conference, I found your observations ("Integrating Consumers into the Regional Genetics Networks") on the potential for meaningful dialogue and emerging alliances between "prosumers" within a neutral setting to reflect our own experience at the Regional Network meeting. The opportunity to share educational materials and access to services with such a broad-based group of healthcare providers was invaluable. Case in point — we learned of two Late Onset families residing in the greater Houston area. We disseminated information on the extended diagnostic scope of our services. Reciprocal relationships thus began to emerge — an element presently lacking within the traditional service delivery model.

Debi Gutter
Executive Director
National Tay-Sachs & Allied Diseases Association

Increasingly, the Alliance is playing leadership roles in projects with 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. Our expertise is sought by other national organizations, and we work closely with groups such as ELSI, the American Association for the Advancement of Science, the March of Dimes, the Institute of Medicine, Family Voices, State Genetics Coordinators, and of course the Regional Genetics Networks.

We are proud of the "Guidelines to Informed Consent in Genetic Research Studies" that is in the final stages. A taskforce is working on media guidelines and a statement on treatment of genetic conditions by the media. We have already disseminated a position statement in support of responsible animal research.

As our networks expand and requests for participation grow, it becomes increasingly clear that current staffing levels are not adequate to meet the demands. A major goal for the coming year is to identify additional funding sources so that the Alliance can continue to meet the needs of consumers and professionals within the genetics community.

Joan O. Weiss, MSW
Executive Director

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Publications

Resource Guide on Peer Support Training (1990)
Integrating Consumers into the Regional Genetics Networks (1992)
Directory of National Genetic Voluntary Organizations (1992)
Health Insurance Resource Guide (1992)

Morris J. and Betty Kaplun "Art of Listening" Award Winners
John Carey, MD, nominated by S.O.F.T.
Elsa Reich, MS, nominated by the Treacher Collins Foundation
Raymond Duncan, MD, nominated by the Pallister-Killian Family Support Group