ALLIANCE of Genetic Support Groups
A Coalition of Consumers and Professionals

ALLIANCE OF GENETIC SUPPORT GROUPS 1997 ANNUAL REPORT

The Alliance of Genetic Support Groups was founded in 1986 as a national coalition of support groups, organizations, consumers and professionals seeking to enhance optimum healthcare and quality of life for individuals with genetic conditions. As a key strategy, the Alliance fosters partnerships among consumers, professionals and the public sectors to promote education and information services as well as to give a voice to the common concerns of individuals living with genetic conditions and their families.

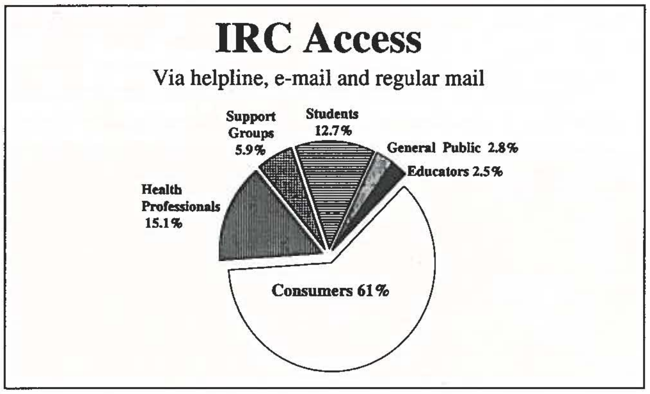
For the past 11 years, the Alliance has promoted the interests of children, adults and families living with genetic conditions. During 1997, many service innovations stimulated growth while building directly upon Alliance founding objectives. While mission priorities never shifted, energies were focused on strengthening service outreach and locating revenues to support new programs.

One of the year's highlights was a gathering of consumers and professionals at the White House on July 14, 1998 to witness President Clinton's declaration of support for federal genetic nondiscrimination protections. Over the year the Alliance increased participation in public policy discussions, bringing policy issues to the attention of members and developing a stronger national consumer voice.

Alliance staff and volunteers exhibited member brochures and promoted the shared mission of Alliance member organizations at the 1996 meetings of the National Society of Genetic Counselors and American Society of Human Genetics in San Francisco. Left to Right: Joan Weiss, Founding Director; Susanne Emmerich, National Incontinentia Pigmenti Foundation; Nachama Wilker, Partnership Program Director; Mary Davidson, Alliance Executive Director.

In October 1996 Mary Davidson, MSW, a veteran social worker, Peace Corps volunteer and parent of an adult child with a genetic condition took the helm as Executive Director. The organization's highest priority was realized in September 1997: all resource, referral and information services were consolidated into an Information Resource Center (IRC), staffed by a full-time genetic counselor. In addition, the Alliance dedicated special funds to set up new phone and voice mail systems, create a more sophisticated resource database and upgrade computer systems.

Information Resource Center (IRC)



Over 180,000 people visited the Alliance website: www.geneticalliance.org.

Member groups sought the full spectrum of technical assistance. The **Alert** monthly newsletter provided policy updates and spotlights on new programs, current public policy issues and upcoming meetings. The Alliance exhibited at four professional meetings and sent resource materials to twenty-five national and regional conferences.

HuGEM I and II

The Human Genome Education Model Project brings consumers and professionals together to enhance understanding of the challenges facing individuals living with genetic conditions. Co-directed by Founding Director Joan Weiss and Principal Investigator Virginia Lapham, HuGEM I was both a model of the partnership spirit that informs the Alliance and evidence of the power of consumer involvement in education. The first phase of the multi-year project produced a consumer survey. The results were published in a special genomics edition of Science Magazine (10/96), lending weight to growing concerns about genetic discrimination in health insurance and employment. HuGEM I also underscored the need to educate allied health professionals, based on survey results which showed the level of allied health professional genetics literacy to be below that of the consumers they serve.

HuGEM II, built upon the success of HuGEM I, is a national educational initiative to put genetic and related ethical, legal and social issues on the agendas of seven allied health professional associations: National Association of Social Workers; Council of Social Work Education; American Psychological Association, American Dietetic Association; American Speech-Language-Hearing Association; American Occupational Therapy Association; and the American Physical Therapy Association. HuGEM II is funded by a grant to Georgetown University from the ELSI Research Program of the National Human Genome Research Institute; Alliance activities are supported by a sub-contract from Georgetown.

Partnership for Genetic Services Pilot Program

The Partnership Program is a national educational initiative to enhance provider understanding of critical issues surrounding the quality of genetic services. The Partnership is a collaborative effort being piloted in the Pacific Northwest, Great Lakes and Mid-Atlantic regional genetics networks. Teams of trained consumers and professionals are working with managed care providers and second-year medical students to demonstrate the importance of comprehensive genetic services, provided with sensitivity and appropriate support.

Funded by The Robert Wood Johnson Foundation, the Alliance sponsored a meeting for managed care providers that explored connections between consumer and provider communities to enhance genetic services. This landmark meeting was attended by representatives from leading managed care organizations, consumer groups, the American Medical Association, the American Association of Health Plans, the National Coalition for Health Professional Education in Genetics and provider organizations.

Fueled by the dynamic exchange and energy of this meeting, the Partnership negotiated with several Mid-Atlantic managed care organizations that were interested in serving as program pilot sites, including Oxford Health Plans, Kaiser Permanente Mid-Atlantic, and NYLCare Health Plans.

Supported by funding from SmithKline Beecham, the Partnership is developing guidelines to define quality genetic services from a consumer perspective and prioritize the critical components of quality care. Staff collected close to 40 existing guidelines from both the professional and consumer communities. General principles extracted from these models were integrated into a draft document. During a meeting hosted by the Mid-Atlantic Regional Human Genetics Network, consumers took the first pass at identifying and ranking the components of quality care. The final document will be produced following further analysis by the Alliance Board, the Partnership Steering Committee and consumers nationwide.

Consumer Policy Network

The Consumer Policy Network was formed to inform policymakers and the public about consumer concerns about new ethical, legal and social issues raised by advances in genetic technology. The Network quickly proved to be a highly effective mechanism for responding to the increasing number of requests from consumers for on-going policy updates and requests for knowledgeable consumers to participate in national meetings and policy working groups.

Through the Network, the Alliance actively supported protections of genetic non-discrimination and made significant contributions to recommendations published by the Genetic Testing Task Force. Mailings and the monthly **Alert** newsletter kept members informed about federal and state legislative initiatives. Other activities included:

- Participation in the NIH Cystic Fibrosis Consensus Conference and follow up discussions
- Involvement on the Steering Committee of the National Coalition for Health Professional Education in Genetics
- Participation on the Enhancement of Rare Disease Research Committee of the Rare Diseases

NETWORK PARTNERS INCLUDED:

- The Breast Cancer Coalition
- The National Cancer Survivors Coalition
- The Office of Rare Diseases
- The Centers for Disease Control
- The Consortium for Citizens for Disabilities
- Research! America
- Families USA
- Family Voices

Members Survey

A membership survey laid the groundwork for a vigorous Membership Drive in 1998 and redeployed Alliance energy into program areas indicated as high priorities by members. Other outgrowths of survey results were the expansion of the Consumer Policy Network and creation of Brochure Archives of members' brochures. In addition, the monthly **Alliance Alert** increased the spotlight on public policy and genetics and Alliance educational programs and the policy network enlarged opportunities for member participation.

Future Challenges and Priorities

Reflecting firm commitment to confront concerns of national significance and fulfill founding mission objectives, the Alliance achieved exponential growth and progress during the past several months. A year of change and challenge on many levels, 1997 was devoted to external expansion and internal reorganization. Future challenges for the Alliance include: • Identifying new service and policy needs within the community of genetics consumers • Developing strategies to address emerging needs • Engaging the energies of a growing membership • Creating innovative programs to bridge service gaps • Strengthening the consumer voice in public policy discussions • Promoting understanding of the needs of people of all ages living with or at risk for genetic conditions and • Advocating for quality genetic services for all that need them.

Gala Highlights


Alliance Board members and staff celebrate together at the Tenth Anniversary Gala on October 12, 1996. L to R: Les Platt, Geraldine McGrath, Joan Burns (President), Mary Davidson (Executive Director), Joan Weiss (Founding Director), Jannine Cody, Jayne Makta, Patricia Farmer and Reed Pyritz.

Held at the Washington Park Hyatt Hotel, the Alliance's Tenth Anniversary Gala was attended by 240 friends and supporters, who gathered to pay tribute to Founding Director Joan Weiss and celebrate our flourishing coalition's achievements. Chaired by Geraldine McGrath and Beverly Raff, the event was hosted by Dr. Francis Collins, Director of the National Human Genome Research Institute and Judith Woodruff, CNN anchor and mother of a child with spina bifida. Representing all three members of the Alliance partnership among consumers, professionals and policymakers, Ms. Woodruff served as an Honorary Co-Chair of the Gala with Dr. Victor McKusick and United States Senator Nancy Landon Kassebaum. Thirty-one distinguished Americans comprised the Honorary Committee. Dr. Collins and Julie Kurnitz, an actress with Marfan Syndrome, delighted the guests with song and poetry in celebration of Joan, who was honored by family and colleagues throughout the evening.

During the Anniversary weekend, the Alliance staged a computer networking workshop and conducted its biennial Membership meeting. In the months that followed, Mary Davidson, the new Executive Director, established internal management procedures, submitted five grants to support new programs, revised personnel policies and implemented a more sophisticated accounting system. Staffing patterns changed from one full-time and five-part employees to four full-time and four part-time dedicated individuals with well defined areas of program responsibilities and, most importantly, strong identification with the Alliance mission. Ms. Davidson recruited community volunteers and college interns to supplement staff on the helpline and assist with administrative tasks until new revenues were located to fund additional staff positions.

Kaplun Awards

Frederick S. Kaplan, M.D., Chief of the Division of Metabolic Bone Diseases at the University of Pennsylvania Medical Center was presented with the Kaplun "Art of Listening" award for demonstrating skill in listening, with compassion and sensitivity, to the individuals and families who seek his care and counsel. He was nominated by the International Fibrodysplasia Ossifans Progressive Association.


Dr. Kaplan accepted the "Art of Listening award after a moving personal tribute by Sharon Kantanie, a teacher from Tennessee.

Kathleen Kennedy accepted the "Art of Reporting" award on behalf of ABC news along with Kathleen (Dee) Miller, Jayne Mackta (Past President) and Judy Woodruff, Gala host.

ABC News received the "Art of Reporting" Award for outstanding programming that portrayed the ethical and social implications of genetic testing as documented through the experiences of individuals living with genetic conditions. The Morris and Betty J. Kaplun Foundation provides funding to encourage professional excellence and compassion and positive collaborations with consumers.

FINANCIAL OVERVIEW – Fiscal Year 1997

From October 1, 1996 to September 30, 1997, 66% of expenses were program services and 34% were support services. The income statement below is excerpted from audited financial statements. A complete copy of the Alliance's audited financial statement is available upon request.

INCOME STATEMENT — OCTOBER 1996 - SEPTEMBER 1997	
Donations & Memorials	$11,163
Donated Services	500
Government Grants	180,829
Foundation Grants	40,248
Membership Dues	19,910
Publication Sales	2,784
Interest on Long-Term Savings	2,937
Gala Ticket Sales	40,420
Miscellaneous	7,606
Total Income	$306,397
Expense	
Salaries & Fringe Benefits	$123,613
Accounting	14,197
Printing, Copying & Design	15,237
Consultant Fees	11,414
Honoraria & Stipends	1,500
Rent	41,541
Equip. Purchase, Rent & Maint	21,905
Insurance	3,004
Depreciation	2,218
Telephone	10,495
Postage & Shipping	5,417
Office & Computer Supplies; Books	9,151
Registration Fees & Dues	1,200
Travel	21,527
Miscellaneous	974
Total Expense	$283,392
Net Income	$23,005

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EXECUTIVE COMMITTEE

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BOARD OF DIRECTORS

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FISCAL YEAR 1997 STAFF

Mary Davidson, MSW, LCSW, Executive Director
Joan O. Weiss, MSW, LCSW, Founding Director
Martha Volner, MSW, Director of Health Policy
Nachama Wilker, Partnership Program Director
Mary Ann Wilson, Consumer Staff Representative
Holly Landrum, MS, IRC Director
Mieko Kosobayashi, Membership Coordinator
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