



4301 Connecticut Avenue, NW, #404 • Washington, DC 20008-2304
(202) 966-5557 • FAX: (202) 966-8553 • (800) 336-GENE – helpline only
e-mail: info@geneticalliance.org • <http://www.geneticalliance.org>

ANNUAL REPORT: October 1, 1997 to September 30, 1998

Executive Director's Report

The Alliance experienced major growth this past year as exemplified by these program and mission objective parameters:

- Program activities and services to members and the public increased significantly through addition of HuGEM II and Partnership Programs, enhancement of Information Resource Center, increased focus on member/public outreach services and greater participation in public policy discussions.
- A process of clarifying and prioritizing Alliance mission objectives was initiated.
- Alliance Guiding Principles were developed.
- Board activities and products increased, resulting in Alliance Guiding Principles, new By-laws, new membership application, fee structure and policies, improved board communication, development of board committees and projected agenda for next year.
- Membership services, benefits and needs received thoughtful attention of board and staff, with a survey of member satisfaction and suggestions and enhanced focus on assuring that programs and activities demonstrate and reflect Alliance goals.
- Through active recruitment of new organizational members, Organization memberships increased from 210 to 270.
- Program achievements reflect founding mission, partnership legacy, consumer perspectives, membership surveys and new enhanced Alliance program capacity:
 - Improved involvement of consumer members in design and implementation of Alliance programs and services - see reports by HuGEM and Partnership
 - 1998 Biennial Membership Conference: Forging Genetic Partnerships: Researchers, Policy Makers and Consumers
 - New Alliance website
 - Alliance Support Group Brochure Archives
 - New Alliance brochure
 - 1997 Annual Report spotlighted achievements
 - Enlarged resource data base of support organizations and related resources
 - Revision of Directory of National Genetic Support Organizations
 - Consumer Guidelines of Fundamental Elements of quality service delivery
 - Upgraded Alert newsletter

- Increased dissemination of Alliance materials
- Began regional analysis of Alliance services and programs
- Developed ethnocultural diversity scholarships for biennial meeting and will bring more than 15 consumers with these NHGRI and Alliance funds
- Continued to act as a voice for genetics consumers and support groups and began developing common agenda of member groups through survey and networking to establish common perspectives on research ethics and healthcare delivery, for example.
- Enhanced coalition efforts with Alliance partners: ASHG, NSGC, MCH, CDC, NORD, NHGRI ELSI, BIO, National Coalition for Health Professional Education in Genetics, Coalition for Public Awareness in Genetics, ACLU and others
- Greater involvement in discussions about clinical research ethics, informed consent, definition of genetic information, genetic nondiscrimination protections, genetics and public health, genetic testing issues and policies, importance of consumers role in public policy discussions
- Developed new Alliance grant proposal, 'Public Education through Newsmedia: PEN Project' and continued to revise and resubmit 'GeneInfoNet' and 'Genetics Informed Consent Project'.

This exciting growth in program outreach to members, consumers, support groups, professionals and the public was successful because:

- Staff increased from one full-time, six part-time staff, interns and volunteers to eight full-time, five part-time, graduate genetic counseling interns and volunteers. From 124 hours per week to 408: a multiple of nearly four in terms of overall staff hours.
- FY 98 year-end revenues increased from a total of \$299,722 in FY 97 to total FY 98 revenues of \$ 639,804.
- Beginning FY 99 revenues will increase about 71% in comparison with \$447,692 in FY 98 secured grants and projected revenues on October 1, 1997 to \$764,500 on October 1, 1998 for FY 99. Total income over FY 98 increased about 43% over beginning income to \$639,804 September 1998.

Office was moved to 4301 Connecticut Avenue and work space expanded from approximately 1000 square feet at \$27 per square foot to 2400 square feet at \$21 per square foot.

Computer network and new phone/voicemail were installed, a new time-saving central printer purchased, discount furnitures located and computer/telephone desk stations increased from six to 13 to accommodate new staff.

- Expanded administrative staff developed necessary personnel, accounting, grant management, administrative and fiscal policies and procedures to support and sustain program expansion.
- Alliance funders and supporters demonstrated increased commitment to the Alliance, our programs, services and shared mission of promoting consumer issues and perspectives.

Report on Alliance Programs:

- **Overall Program Challenges:**

- Integrating support groups, consumers and professionals' participation, resources and experiences in Alliance programs.
 - Assuring fulfillment of Alliance mission objectives in Alliance program services and grant commitments.
 - Understanding the needs of our member organizations, both individually and collectively, and the Alliance's mission in relation to these needs.
 - Keeping up with grant timeline commitments which became difficult due to moving and expanding the office and hiring and orienting new staff.
 - Balancing staff needs and operational expense requirements between programs funded at distinctly different levels with respect to fringe benefits, staff development and travel and office operations.
 - Generating organizational procedures and systems to support, sustain and manage growth.
- **Information Resource Center:**
 - **Major services to member groups, professionals and public:** helpline, *Alert*, *Directory*, technical assistance to support groups, website, resource database, exhibit and publications
 - Staffed by genetic counselor who supervises genetic counseling graduate students, student interns and volunteers
 - Consumer Advisory Committee organization begun August 1998
 - Helpline database designed which will allow statistical analysis of helpline users
 - New website launched July 1998
 - *Alert* newsletter published monthly with larger format and new focus, in response to membership survey suggestions, on public policy and research ethics.
 - New brochure printed August 1998
 - Support Group and Directory Resource Database completed August 1998
 - Directory revision September 1998
 - PEN Project submission to MCH May 1998
 - **FY 99 plans include:**
 - Enlist experienced and skilled consumer to staff helpline alongside genetics counselor to provide consumer and personal perspective and technical assistance to support groups.
 - Complete evaluation follow-up of helpline services to determine impact of service
 - When IRC infrastructure revisions are complete, expand advertisement of toll-free number
 - **Public Policy Network**
 - **Consumer and support group involvement:** responded to support group requests that the Alliance provide emphasis on public policy issues. Responded to requests from coalition partners for consumers to speak on specific topics: genetics privacy, gene patenting, genetic testing and medical records privacy.
 - **FY 99 plans include:**

- Identify consumers with expertise in particular policy areas, send them to targeted policy meetings and discussions to develop their skills, encourage them to become involved in the public policy in their home state.
- Continue commitments to ASHG, ORD and research ethics
- Develop staff understanding of genetics public policies
- **Partnership Program**
 - **Consumer participation: 124 consumers and 19 professionals participated in Partnership Program focus groups, development and policy meetings**
 - **Achievements in FY 98**
 - Developed Fundamental Elements of Consumer Guidelines for Quality Genetics Services and consumer guidelines
 - Oriented 15 consumer educators for medical schools and established 13 faculty sponsors in Great Lakes region
 - Delivered final report of completed pilot site activities with NYLCare Health Plan's corporate office
 - Developed proposals for pilot site agreements to integrate resources of consumer community with Kaiser Permanente Mid-Atlantic and Kaiser Permanente Northwest
 - Received grant awards from MCH and NIH to full fund program
 - Hired program staff and evaluation consultant
 - Strengthened program links to member support groups
 - **FY 99 plans include:**
 - Finalize pilot site agreements
 - Recruit consumer and professional volunteers for each pilot site and full integrate into program activities
 - Orient 15 consumer educators and increase faculty sponsors
- **Human Genome Education Model II Project**
 - **Consumer have been selected for participation based on relevant experience with healthcare professionals. These new individuals have been added to the Alliance consumer database resource.**
 - Survey of allied health professional knowledge about genetics is nearly complete.
 - HuGEM website was launched and efforts now focus on developing fact sheets for specific genetic disorders and public policy issues.
 - HuGem will be a major participant in the membership conference.
 - **FY 99 plans include:**
 - Steering committee meeting September 14, 1998
 - Targeted workshops at seven collaborating organizations' national and regional conferences integrating consumers and the consumer perspective.
- **Membership Services and Membership Biennial Meeting**
 - Consumers, board and staff have collaborated in the design and development of the membership conference and successfully engaged Alliance coalition partners to participate in the conference as speakers and attendees
 - Major Achievements

- Designed new membership application, set new graduated fee scale, defined membership benefits
- Completed membership survey and analysis of results
- Increased organizational membership by 23% and began review of membership recruitment materials
- Staff and board collaborated on development of policies and procedures for membership application and renewal process
- Successfully planned and organized biennial membership meeting on Sept. 11th
- FY 99 Plans
 - Develop Mentoring Committee to bring the skills and experience of more mature organizations to smaller and new groups
 - Engage organizations and their members in policy discussions
 - Continue dialogue with member organizations to reconfirm the role they would like Alliance to assume in public policy discussions

The Alliance grew in organizational maturity and weathered a major growth challenge expanding programs, staff and revenues because:

- Board and staff are committed to Alliance founding mission objectives
- Board and staff are motivated to improve organizational cohesion, communication and coherency.
- New staff were selected on basis on identification with Alliance mission and programs and rapidly integrated into program activities and services.
- Staff and board are investing in board development and organizational restructuring, to meet changes required by organizational and staff size expansion and growth in program complexity and commitments.
- Board and staff demonstrated successful collaboration on significant projects: Guidelines, by-laws, membership meeting, membership fees/application/policies.
- Founding director facilitated transition to current executive director through mentoring, support, advice and counsel.
- The Alliance demonstrated appreciation of staff efforts and dedication. Despite restricted and uneven funding between program grants, we fulfilled long-standing commitments to provide full and part-time staff with health insurance, life insurance, pre-tax savings plan and expanded vacation, holiday and personal leave time.
- Board and staff have begun a challenging and necessary dialogue about Alliance mission priorities within the context of our larger organization, the needs of our member groups and new support groups, the illiteracy of the general public about genetics, current specific public policy discussions, genetics research and technology issues and the need for consumer voices and perspectives on a national, regional and local level.