

ALLIANCE OF GENETIC SUPPORT GROUPS

ANNUAL PROGRESS REPORT

TO: Board of Directors
FROM: Joan O. Weiss, Executive Director *JOW*
DATE: October, 1993

QUARTERLY REPORT: October 1, 1992 through September 30, 1993

Membership as of September 30, 1993

Individual Members: 210
Organizational Members: 203

Membership as of September 30, 1992

Individual Members: 220
Organizational Members: 172

Incoming Telephone Calls for One-Year Reporting Period:

Total: Approximately 6,004*

SUBJECT OF CALLS:

Inquiries re: specific disorders and/or genetic counseling: 21%
Administrative 9%
Conferences: 8%
Calls for miscellaneous information: 10%
Inquiries re: support groups: 12%
Information re: Alliance and membership: 7%
Requests for technical assistance: 7%
Social Issues and Ethics: 4%
Calls from Board Members: 5%
Inquiries about insurance, discrimination and policy: 5%
Directory of National Genetic Voluntary Organizations: 3%
Calls related to regional genetics networks or CORN: 3%
Media: 2%
Calls from students: 2%
Grants, Funding, and Accounting: 3%

*Please note:

This averages to 500 calls per month. The subject matter and number of calls has some variability depending on work in progress at the Alliance and publicity received.

Funding Activities

Grant Applications:

Approved:

Department of Health and Human Services, Genetic Services Branch: 3-yr continued funding grant approved.
National Institutes of Health, National Center for Human Genome Research, Ethical Legal and Social Implications Program: Application for education project with Georgetown University for 1/2 the amount requested.
Sero Laboratories: Alliance/NORD conference \$500 approved.
Integrated Genetics, subsidiary of Genzyme Corporation: Funding of November, 1993 media workshop and pamphlets: Approved \$10,997
RGK Foundation: Application for funding of Health Care Resource Project: received \$5,900
Jacob & Hilda Blaustein Foundation, Inc. for Alliance/NORD conference: approved \$2,500
The Lester & Eleanor Levy Family Fund for Alliance/NORD conference: approved \$400
Maternal and Child Health, Genetic Services Branch for Alliance/NORD conference approved for \$10,700 for consumer support.
Sandoz Pharmaceuticals: Printing of 7,000 programs for Alliance/NORD conference approved and completed.
National Society of Genetic Counselors: \$2,000 for *Directory of National Genetic Voluntary Organizations*.
March of Dimes: Application for \$29,000 for revision of *Health Insurance Resource Guide* and annual meeting: approved but **not** funded.

Pending:

Biotechnology Industry Organization: Application for funding of Alliance Library Project, pending.
National Institutes of Health, Human Genome Mapping Project, Ethical Legal and Social Implications Program: Discussion re: Alliance role in Genome Project ongoing.
National Institutes of Health: Pilot project in conjunction with CORN for genetics data base: pending.

Denied:

Mars Foundation: Request for funds for November meeting denied
Enzon, Inc: Request for funds for November meeting denied

Robert Wood Johnson Foundation: Application to fund *Health Care Resource Guide*: denied.

Executive Office:

Paid Staff

Director: Joan Weiss 4/5 time
Assistant Director: Martha Volner 1/2 time
Consumer Representative: Mary Ann Wilson 2 days per week
Bookkeeper: Gerry Siegler 2 days per month
Secretary: Mieko Kosobayashi 2 1/2 days per week
Volunteer: Donna Foster 1 day per week

Current staff is working overtime on an unpaid basis. The scope of our activities is such that we are severely understaffed. We are having to rely more and more on volunteer help to keep up with workload.

Alliance Representation/Exhibits

October 5-6	NIH Workshop on IRBs	Rockville, MD
October 13-14	University of Vt.	Burlington, VT
October 28	Mayor's Committee on Newborn	Washington, DC
November 8-11, 1992	American Society of Human Genetics & Nat'l Society of Genetic Counselors	San Francisco, CA
November 20-22, 1992	Alliance Membership Meeting	Phoenix, AZ
December 2, 1992	Consortium on Rare Diseases	Washington, DC
December 4, 1992	Office of Technology Assessment Biomedical Ethics in Public Policy	Washington, DC
December 6-9, 1992	Genome Analysis - DOE Workshop	Cold Spg Harbor, NY
Jan. 13, 93	CCD Annual Meeting	Rockville, MD
Feb. 5	NIH-NF Meeting	
Feb. 10	NIH - Panel for Oncology Social Workers	
Feb. 12-13	AAAS Presentation	Boston, MA
Feb 24	NORD Banquet	Washington, DC
March 5	CORN Meeting	Alexandria, VA
March 13	MARGHN Meeting	Crystal City, VA
March 25, 26	Genetics Orgs.	San Francisco, CA
March 27, 28	ASHG Board Meeting + COMGO	LaJolla, CA
April 2	AAAS - Ira Magaziner briefing	Washington, DC
April 7	a.m. Maternal & Child Health p.m. White House	Rockville, MD Washington, DC
April 22	Georgetown U. Pediatricians Meeting	Washington, DC
April 22-23	Family-Professional Collab. Project Advisory Committee	Burlington, VT
April 26-29	American Academy of Neurology	New York, NY
April 30	Families USA-Health Reform	Washington, DC
May 4	COMGO	Washington, DC
May 7	Media Committee Meeting	Boston, MA
May 10	ELSI, NIH	Bethesda, MD
May 11	Ira Magaziner Briefing	Washington, DC
May 12	Consumer Panel Georgetown U.	Washington, DC
May 15	TAG	Long Island, NY
May 20	Senate Hearing, Dr. Francis Collins	Washington, DC
May 21 & 22	Family Support Institute	Albany, NY
May 25	Hillary Clinton - Health Reform	Washington, DC
May 28	Industrial Biotechnology Assn	Washington, DC
May 30-June 1, 93	ACCH - Exhibit & Rep	Chicago, IL
June 5	Mid Atlantic Spina Bifida Conference	McLean, VA
June 11	Sickle Cell Conference CORN/MCH	Washington, DC

July 9	MWV	CCD Health Reform Briefing	Washington, DC
July 16	JOW, MWV	The Hastings Center	Poughkeepsie, NY
Aug. 19	JOW	Nat'l Marfan Foundation	Portland, OR
Aug. 21	MAW	Von Hippel Lindau Conf.	Annapolis, MD
Aug. 17		Alliance Exhibit	Dallas, TX
Aug. 29, 30		MARHGN Steering	Alexandria, VA
Sept. 9	JOW	CF Studies Consortium	Washington, DC
Sept. 10,	MWV	CCD - Health Reform Briefing	Washington, DC
Sept. 13	MWV	CCD Health Reform Briefing	Washington, DC
Sept. 18-19	Siegler	NPND Legislative Conf.	Washington, DC
Sept. 26, 27	JOW, MWV	Genetic Database Meeting	Baltimore, MD

ACTIVITIES

Daily telephone intakes and referrals for genetic services
 Handling requests for information on specific disorders
 Continuing counsel to new and existing genetic support groups
 Distribution of *Directory of National Voluntary Genetic Organizations*, *Health Insurance Resource Guide*, *Empty Pocket Syndrome*, and *Informed Consent Guidelines*.
 Developing new funding sources and writing grant applications
 Working with White House and with other health organizations to insure that genetic treatments and services are included in health care reform
 Working with CORN to formulate a consumer-friendly genetics resource clearinghouse
 Completing media guidelines and working on workshop to be held in conjunction with November, 1993 annual conference.
 Completing *Informed Consent* brochure.
 Preparing for *Health Care in Flux Conference* for November, 1993 meeting to be held in partnership with the National Organization for Rare Disorder

Publications:

Alliance Brochure
 Starting a Self Help Group
 Chapter Development
 Needs Assessment for Support Groups
 Bibliography: Genetics for High School & College Students
 Incorporating and Obtaining Non-Profit Status
Incorporating Consumers into Regional Genetics Networks
Health Insurance Resource Guide
Directory of National Genetic Voluntary Organizations
 ALERT - monthly
Informed Consent: Participation in Genetic Research Studies
Proceedings: Empty Pocket Syndrome: How to Get Funding
Peer Support Guide
 Annual Report

PLANNING FOR FUTURE ALLIANCE PROJECTS

Planning for 1994 Alliance Conference on Working with the Media

Media Committee: Publication of media pamphlets for consumers and for the media

Health Insurance Resource Guide and *Directory of National Genetic Voluntary Organizations..* Starting process of updating and revision

NIH-ELSI funding. Working to find additional sources of funding for Alliance projects.

Exploring options for funding Alliance Library Project.

Anticipated Representation/Exhibits

Oct. 6	Nat'l Assn. of Rehab. Facilities Attendant Care Conference	Washington, DC
Oct. 12-13	Grad School of Social Work	Burlington, V
Oct. 24-30	March of Dimes/Geotown Course	Washington, DC
Oct. 30-Nov. 2	Am. Academy of Pediatrics Exhibit	Washington, DC
Nov. 12	CCD - Health Reform Meeting	Washington, DC
Nov. 18-21	Alliance Health Care in Flux Meeting	Alexandria, VA
Feb. 18-20, 1994	Am. Grp. Psychotherapy Assn.	Washington, DC
March 13-15, 1994	MOD & Am College of Med Genetic	Orlando, FL
April 15-17, 1994	CORN Steering Committee	Washington, DC

Future Directions of the Alliance

It is said that a healthy organization moves forward rather than remaining static. The Alliance is at a crossroads of its organizational development. Increasingly well known, respected, and sought after, demands upon its financial and staff resource exceed supply. Staff has examined each of the major activities with an eye toward eliminating those which are not essential to the Alliance mission. Our conclusion is that it would be seriously detrimental to the organization to eliminate the toll-free line, the exhibits, the conferences, the newsletter, the technical assistance, and the monitoring of health policy and insurance practices. (Fund raising efforts are arguably utilize time which would be better spent in carrying out the central activities.) We conclude that current activities enhance the Alliance and that the Alliance should move forward on two fronts. (1) To meet public demand the Alliance should create a consumer library/resource center which includes books, pamphlets, computer networks, and videotapes, along with office space and personnel. (2) To gain efficiency additional administrative help is required. To accomplish both, Board assistance in fund raising efforts is essential.