ALLIANCE OF GENETIC SUPPORT GROUPS
ANNUAL PROGRESS REPORT

To: Board of Directors
From: Joan O. Weiss, Executive Director JOW
Date: November, 1994

Increasingly, the Alliance is becoming a well recognized and well established national organization, a major component of the genetics community, successfully fulfilling our original mission to establish a partnership between consumers and professionals. Ironically, requests for our services are exceeding staff and financial resources as they now exist. Let us examine some of the activities of the Alliance during this past full year, with an eye to the future of the Alliance.

Telephone

In the first quarter of this year (Oct.-Dec., 1993), we had 2205 calls, the greatest number of calls this year. We believe this was due to calls about our Nov. conference and also the Alliance having been written up in Women's Day and Family Circle. The media brings in many calls to our 800 number and reflects a need on the part of the public for general information about genetics as well as about specific disorders. 26% of the calls related to the conference and 16% to specific disorders. In the second quarter there were 1700 calls, with 16% about specific disorders and 13% about support groups. In the third quarter we had 2100 calls, reflecting activities around the HuGEM survey (16%) and 15% about specific disorders. In this last quarter (see enclosed) there were 1800 calls, with 22% on specific disorders, the highest in this category of any quarter. We attribute this to the media attention in US News & World Report (see enclosed). Incoming calls total 7,805 this year (averaging150 per month), reflecting an increase of 1800 calls over last year.

Membership

Organizational members have increased this year from 215 to 229; individuals from 226 to 267.

Funding Activities

We are discouraged in our efforts to obtain funding outside of the government, as we have been encouraged to do. Perhaps it is just a sign of the state of economics in this country. Commercial agencies and foundations in the private sector are reluctant to give funds because of the ongoing health care reform uncertainty. Individuals give to the specific genetic voluntary organization which represents their interest or family disorder. Foundations fund specific geographic areas, special activities and programs, replicable projects on local levels, or popular causes such as AIDS, and the homeless. Many do not fund operating expenses, which is what the Alliance needs most of all. Funding sources are receiving an overwhelming number of applications for limited funds. Perhaps when genetic diagnoses really impact on the general public and when biotech companies have something to market on a large scale and are more secure themselves, the situation will change.

There is general agreement that the Alliance has merit. Often the interest is there, but financial support is not forthcoming. With the exception of the National Society of Genetic Counselors, the professional genetic organizations appear disinterested in helping us, claiming that their money is needed for research.

Alliance Activities

During the first quarter of this year (Oct. - Dec.), we were busy with our "Health Care in Flux" conference, co-sponsored with NORD. This included much activity in planning the media workshop and developing media guidelines, in addition to having our Board meeting and holding the November conference with NORD. As you remember, this was an extremely well-received conference. Our exhibits included the one at the November conference and the American Academy of Pediatricians.

In the second quarter (Jan. - March), there was much activity around health care reform, particularly in working with the Consortium for Citizens with Disabilities (CCD) and keeping up with the progress and prospects of health care reform legislation. Martha was our representative both with CCD and with the Ethical, Legal and Social Implications Branch of the National Center for Human Genome Research at NIH. Mary Ann and Board member Gerry McGrath manned the Alliance exhibits at the March of Dimes and the American College of Medical Genetics meetings in Florida.

The third quarter (Apr. - June) and this past quarter (July - Sept.) activities included concentrated efforts to raise funds both for the Directory and for the next Alliance national conference, HuGEM telephone interviews by Joan, Martha, and Mary Ann, and planning the next membership conference with Robin, which is to be entitled "THE ABCs (XYs) of GENETIC COMMUNICATIONS. At the request of the Board Planning Committee, because of the shortage of staff and funding, that conference has been postponed and will be discussed at our Board meeting. Alliance was represented at national meetings including PRIM&R (Public Responsibility in Medicine and Research) in Boston and coalition meetings in D.C. to hear talks about health care reform by Hillary Clinton and Senator Edward Kennedy. We were pleased to help with a first national conference for primary care physicians to learn about genetics, sponsored by Harvard, MIT, and the Cambridge Hospital (where the conference was to take place in early October). We donated 100 Directories, Alliance brochures, and Informed Consent guidelines, to be included in each physician's packet.

Publications

In February we published a new updated Alliance brochure. We are due for another one soon to show our new organizational members. The Directory and the Informed Consent guidelines remain our two bestsellers, particularly our Directory. Robin has sent the office the Media Workshop Proceedings, which we hope, with Board approval, will be printed soon to go out with our Media kit.

Perhaps at that point we can charge $10 rather than the $5 we have been charging.

We need now to zero in on our efforts to fund and publish the Directory. Since we are short of staff, I suggest that we obtain another volunteer or a student to help Mary Ann with this project.

Staff

The more activities we are called on to do, the more we feel the need to increase our small staff, which is further depleted by Martha's absence. Our volunteers have been our salvation! In the first quarter of this year, we only had one volunteer, Donna Foster, but in the second quarter we added Fred Bergmann and Connie Bernton. Each volunteer works one day a week. In this last quarter, with Martha on sick leave, we were fortunate to have several summer genetic counseling interns from the National Center for Human Genome Research, NIH, who helped Mary Ann with a Directory survey, answered the phone, and helped pack up for the Montreal genetics exhibits.

Future Planning

As your Executive Director, I feel proud of the Alliance and of what it has been able to accomplish in a relatively short period of time. With Jayne as our inspiring leader, both staff and Board have accomplished miracles, considering our limited resources. I feel responsible for the day-to-day activities of the Alliance and confident that we have a dedicated and competent staff. Even more, I feel responsible for ensuring that the Alliance has a future.

Our focus now must be a narrow one. We need funding to continue on after the federal government, which has been good to us since our conception, can no longer help us. We need more staff. We need more office space. Our two main activities, the 800 number and the Directory, have to be funded. We are recognized for providing quality services to our genetic organizations, to genetic counselors and other professionals, and to the public at large. Everyone assumes that we will continue to offer these services and that funding will be there somehow for the Alliance. But this is no longer necessarily true.

I realize that our present staff and Board are not expert fundraisers. Our expertise lies elsewhere. But we need people who have the know-how to open up the doors of funding resources. We need individuals to help us who are recognized leaders either in the genetics field or in fundraising for other organizations. It is time, as Jayne suggests in her letter to you, that we create an Advisory Council to supplement the Board of Directors. It is also time to hear from each of you as to where you would like us to go from here and what you think we should be doing in the future. I look forward to seeing you in November.