"I am an idealist. I don't know where I'm going but I'm on my way."

Carl Sandburg

This ALERT functions as a vehicle of communication between the Alliance and its constituency. It is our goal to provide timely and useful material in a readable, easy access format. Feel free to send in your announcements, share your ideas or ask for help.

RE-CONTACT ADVISED: A virtual explosion of technology in the field of genetics is producing new information of value to families with genetic disorders. New techniques involve the identification of genes or gene markers that are potentially useful for the identification of at-risk family members and for prenatal diagnosis. Families who have had genetic counseling in the past and who were told that no testing was available should periodically re-contact their genetic center for the latest information. Genetic centers are understaffed and over-worked and often cannot re-contact former patients while servicing the increasing number of patients being referred because of new testing. It is in the best interest of families that they take responsibility for keeping themselves up-to-date with regard to genetic testing that is relevant to them. Your Department of Health should have a state listing of genetic centers, or call the Alliance for a referral to the center nearest you.

NEEDS ASSESSMENT: In response to many inquiries regarding the "how-to's" of setting up a support group, the Alliance has developed a simple Needs Assessment designed to help identify who needs what. The answers can be used to help leadership determine the kind of group best suited to the individuals involved. It is a good idea for groups to assess the needs of their membership periodically. Groups have a life of their own, and program directions must be re-examined to ensure that they reflect the needs, interests and expectations of the members. For a copy of the Needs Assessment, contact Alliance Coordinator Joan Weiss: 1/800/336-GENE.

GUIDELINES SOUGHT: Members of the Alliance have requested information on policies developed by groups on research participation. A new group was approached by two different research teams needing subjects. The group created a Research Advisory Committee of parents and affected adults who set about writing a policy statement for their Foundation. It became quickly apparent that there was a difference of opinion between what the group and the researchers perceived as important. Any group with established guidelines for research participation is asked to share their materials with the Alliance. Please send copies to Joan Weiss at the Alliance office: 1001 22nd Street NW, Suite 800, Washington, DC 20037.

PARTICIPATE IN REGULATION DEVELOPMENT: The American Foundation for the Blind (AFB) reminds professionals and consumers that it is our responsibility to provide comments to the various federal agencies which are charged with writing the regulations that will determine how the Americans with Disabilities Act (ADA) works. The ADA's impact will be governed in large measure by these regulations. The AFB Information Network, a service that provides periodic "alerts" on legislative and regulatory issues, keeps its members apprised of agencies that call for comments with all relevant dates, addresses and contacts. Membership in the Information Network is free by contacting the American Foundation for the Blind, Government Relations Department, 1615 M Street, NW, Suite 250, Washington, DC 20036; telephone: 202/457-1487.

HAVE YOU HEARD? The Alliance welcomes nominations for its "Art of Listening" Award. This award will be presented to the service provider who best demonstrates that "Hearing is a gift; Listening is an art." The next award will be presented at the Alliance membership meeting in September 1991. Let us hear from you.

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