"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.

Last Call for Volunteers: The Alliance and Georgetown University Child Development Center have issued a final call for HuGEM survey participants. Under a grant from NIH, they are developing a Human Genome Education Model for consumers of genetic services and multidisciplinary health professionals. In preparation, they are seeking members of various support groups willing to spend 25-30 minutes on the telephone responding to questions on ethical, legal and social issues related to the Human Genome Project. Survey participants must be at least 18 years old and have someone in the family with a genetic disorder that was diagnosed more than one year ago, or have a known risk of a genetic disorder in the family. To insure confidentiality, no identifying information will be used. The deadline to volunteer is June 1. Contact Joan Weiss if you are interested: 1-800/336-GENE.

Share Your Expertise: The Alliance is creating a Technical Resource Registry (TRR) which will be the basis of an organizational mentoring system to be implemented on the national and regional levels. The Alliance will use the registry as an aid in fulfilling the growing number of requests for technical assistance. We will be sending members resource forms to collect information about areas of expertise and willingness to assist other organizations seeking help in particular areas. Categories will include such activities as chapter development, fundraising, media relations, long-range planning, medical/scientific advisory boards, board development, leadership training, peer support training, and conference planning. There is a wealth of talent within the world of genetic support groups, and the TRR will be an effective way to parley the power and spread the wealth. Professionals will also have an opportunity to list their areas of special interest and to make known ways they want to work with groups.

Recommended: National Tay-Sachs and Allied Diseases Association has recently published "The Home-Care Book" on caring for a child with a terminal neurological disease. Interspersed with quotations from families who have lived this experience, this book addresses many practical care and emotional issues. Not limited to questions about caring for children with Tay-Sachs disease, this well-written book was several years in the making and contains much wisdom and good advice. Available from NTSAD, 2001 Beacon Street, Suite 204, Brookline, MA 02146; TEL: 617/4463. Cost $3.

Effective Communications: Save the date for the next Alliance Membership Meeting — May 20 - 21, 1995; The Rosslyn Westpark, Alexandria, Virginia. We will focus on all types of communication, verbal and written. Tentative topics: how to communicate with professionals/consumers; funders; lay leaders; the media; various publics and each other. Don't forget to renew your membership or to join the Alliance now. Organizational membership (with three contact people); $50; Individual membership: $20.