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.

Alliance Speaks Out: Representatives from the Alliance were well received at a recent White House meeting with key members of the Health Reform Task Force. We voiced concerns shared by individuals with genetic conditions and their families and were encouraged to continue raising relevant issues in communications that will be directed to the leaders of specific study teams within the Task Force.

ADA Information: The Disability Rights Education and Defense Fund has established a toll-free information line to provide technical assistance on the ADA to businesses, state and local government entities, and people with disabilities and their advocates. The voice and TSS number, available from Noon to 7:30 PM EST, is 1/800-466-4ADA.

NF Video: “Is There A Place for Me?” (15 min., open captioning for the hearing impaired) is a new educational video narrated by Nancy Stafford, national spokesperson for Neurofibromatosis, Inc. It features members of NF, Inc.-Mid-Atlantic Chapter who share personal stories and physicians who provide medical expertise about NF-1 and NF-2. $20 from NF, Inc., Mid-Atlantic Chapter, 8855 Annapolis Road, Suite 110, Lanham, Maryland 20706-2924.

Call for Publications Listings: The Consumer Issues Sub-Committee of the Great Lakes Regional Genetics Group (GLaRGG) is collecting lists of officially sanctioned publications available from member organizations. The objective is to compile a catalogue of source materials. Listings should include publication dates, information on obtaining individual publications, cost, if any, and format, i.e., pamphlet, poster, fact sheet, video). Please delete outdated or unavailable materials from listing. Send your listings by June 15 to Joy Johns, Rte. 1, Box 207, Otwell, IN 47564.

How Much Are You Spending? As the national examination of health care continues, we need specific examples of current annual “out-of-pocket” costs to families who have members with genetic disorders. Please help us collect this important data. What to send: a brief description of the disorder; the annual cost of care (details need only be in terms of whether they are for treatment, equipment, medicines); other pertinent information such as hardships imposed upon other family members. If you keep records on an entire group, your sharing such information would be really useful and will strengthen our position when dealing with policy-makers. Send your information to the Alliance, 35 Wisconsin Circle, Suite 440, Chevy Chase, MD 20815, Attention: Martha Volner.

We would particularly like examples from:
1. Individuals who are not receiving needed specialized treatment(s) because of insurance plans which restrict such access;
2. Individuals who have had multiple hospitalizations, where one would have been sufficient, in order to meet insurance guidelines;
3. Individuals facing denial of needed medical treatment in their health insurance plan.