“Shoot for the moon; the worst that can happen is that you end up somewhere in the stars.”

Bill Demby

Public/Private Cooperation to Promote Rare Disease Research: The Office of Rare Diseases has established a Special Emphasis Panel on the Coordination of Rare Diseases Research to produce a report to Congress on efforts to coordinate rare diseases research within existing research funds and resources. A public meeting has been called by the Office of Rare Diseases for representatives of voluntary health organizations, patient support groups, academic research centers, pharmaceutical and biotechnology companies and federal agencies on May 27 - 28 in Bethesda, Maryland. The Alliance and the National Organization of Rare Diseases are representing support groups and consumer interests on this panel and will be active participants in the meeting. Agenda items include:

- Identify existing approaches, barriers and novel methods of research planning, coordination and collaboration of research initiatives;
- To what extent does co-funding or sharing of research resources occur in both public and private sectors? What mechanisms could be utilized to foster more co-funded research projects?
- Identify strategies that will remove existing barriers to the coordination of research.
- What methods have been particularly effective in bridging the gap between basic and applied or clinical research?
- What innovative mechanisms could be utilized to stimulate the coordination of research on rare diseases?

Public commentary is scheduled for a portion of the May 27 meeting on a first-come, first-served basis. Anyone wishing to provide comment should contact Dr. Stephen Groft at 301-402-4336 immediately.

Dr. Groft wants to foster innovative collaborations between support groups interested in promoting and sponsoring research studies in their particular rare disease and researchers in academic and public research settings. He also wants to establish better connections to the support group system and asks that he be added to your mailing list: Dr. Stephen Groft, Director, Office of Rare Diseases, National Institutes of Health, 7550 Wisconsin Avenue, Room 618, Bethesda, MD 20892-9120.

TV Critics Wanted: In recent months, TV viewers have been seeing more about various genetic conditions on daytime and evening programs. "ER" has dealt with cystic fibrosis on at least two episodes. "Chicago Hope" has focused on neurofibromatosis and breast cancer testing. Other shows have dealt with diet and epilepsy, adrenoleukodystrophy (Remember the movie, Lorenzo's Oil?) and other genetic conditions. We encourage you to write to the producers of television shows dealing with genetic conditions and let them know how you feel the pertinent issues were addressed — both positively and negatively. You can get the producer's name and address from the local TV station that aired the program. Please send a copy of your letter and any response you receive to the Alliance. We will never have accurate and sensitive television programming unless you speak up.

Reviewers Wanted: The Alliance is seeking volunteers to help review the growing number of new books and videos sent to the office for review. Call Mary Davidson if you want to play a role in the dissemination of accurate, timely and useful information.