"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.

HOT OFF THE PRESS!

- *Informed Consent: Participation in Genetic Research Studies.* This booklet from the Alliance explains the nature of genetic research along with its benefits and risks. It suggests questions that prospective participants might want to ask before they consent. Written in easily understood language, this long awaited brochure is available for $1 a copy, including postage and handling. Call the office for discounted rate for multiple copies.

- Also available from the Alliance are copies of the proceedings from our highly informative conference entitled *Empty Pocket Syndrome: How To Get Funds.* The proceedings contain practical fundraising strategies, a guide to writing grants, and countless fundraising ideas shared by our members. Limited availability. Cost: $10 from the Alliance.

- *The Student with A Genetic Disorder: Educational Implications for Special Education Teachers, Physical Therapists, Occupational Therapists, and Speech Pathologists* by Diane Plumridge, Robin Bennet, Nuhad Dinno, and Cynthia Branson. Judging by the number of calls received by the Alliance, this book fills a need in many school systems for information about children who have genetic disorders and chromosomal abnormalities. Comprehensive but understandable, this book covers the basic principles of genetics and inheritance, special education laws, resources, more commonly occurring disorders, and a host of other pertinent subjects. The special education department of every school system should keep this book on hand as a resource. Includes a checklist to help the child with special needs, a discussion of appropriate referrals for genetic counseling, a list of national support groups for the 44 syndromes commonly found in school settings, and a glossary. Cost: $73.75. Available through Charles C. Thomas Publisher, 2600 South First Street, Springfield, IL 62794-9265; TEL: 217/789-8980.

GREAT NEWS: The Alliance Media Committee is in the process of putting together a media kit for use by our members. We would like to include example of press releases which have been successfully used by groups. Please share copies of the original press release and the article that was actually published. We also welcome examples of press coverage about your group that illustrate good, responsible reporting and samples of stories that do not measure up. All samples will help us to develop strategies for successful interactions with the media. Please send your clippings and samples to the Alliance office, 35 Wisconsin Circle, Suite 440, Chevy Chase, MD 20815; Attn.: Martha Volner.

OFF-LABEL USES OF DRUGS: The National Organization for Rare Disorders (NORD) has asked for concrete examples that will demonstrate to Congress that patients are having trouble getting reimbursement under public or private coverage plans for recognized “off-label” therapies. Many rare disorders are treated with drugs that are marketed for prevalent diseases and do not have “FDA approved” labeling for uncommon