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.

NEW GROUPS: A voluntary group is forming to network families with Scapuloperoneal Muscular Dystrophy (SPD) or SPD Syndrome. Contact Michael Curivan, 201 Birchwood Road, Manchester, NH 03104; TEL: 603/644-4734.

A group is forming to provide mutual support to people affected directly or indirectly by Shwachman's and Shwachman-Diamond Syndrome, a very rare digestive and respiratory disorder characterized by insufficient digestive enzymes and abnormally low leukocyte counts. Onset is usually during infancy or early childhood. Because nutrients are not properly digested, short stature and other problems with bone growth develop. The group will offer a patient registry, a phone network, a newsletter and information on research. Contact Joan Mowery, 44 Meadowlark Road, Vernon, CT 06066; TEL: 203/870-5454.

Have You Been Denied Benefits? People with non-life threatening rare disorders are often charged with inflated rates or denied life insurance policies. A law firm is investigating to determine whether class action legal procedures may be warranted for denial of benefits to people with non-life threatening disorders. If you know of people who have been denied life insurance or charged inflated rates even though their disorder will not shorten their life, send a brief description of the problem to: Susan Charlton, Esq., Anderson, Kill, Olick & Oshinsky, Suite 7500, 2000 Pennsylvania Ave., Washington, DC 20006. (NORD-On-Line).

Just Published: Assessing Genetic Risks — Implications for Health and Social Policy explores the social impact of the new genetic frontier, balancing the advantages of genetic knowledge against the many troubling questions that arise when we achieve a glimpse of our future. Lori B. Andrews, Jane E. Fullarton, Neil A. Holtzman, and Arno G. Motulsky, Editors; Committee on Assessing Genetic Risks, Institute of Medicine. 353 pages; $44.95. Available through National Academy Press, 2101 Constitution Ave., NW, Washington, DC 20418.

Resource Saved: The Allegheny Health, Education and Research Foundation has picked up publication of Genetics in Practice, formerly funded by the March of Dimes Birth Defects Foundation. For eleven years, this publication has emphasized the necessity of human geneticists having an important role in educating all health professionals and the lay public about recent scientific and clinical advances. Dr. Reed Pyeritz, Director of the Center for Medical Genetics, will edit the newsletter with Dr. Kenneth Garver. For information, Genetics in Practice, Allegheny General Hospital, 320 East North Ave., Pittsburgh, PA 15212-4772; TEL: 412/359-6388.

APPROVAL: The Food and Drug Administration has approved the recombinantly produced enzyme, Cerezyme, a second generation drug to treat Gaucher disease.