"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.

Volunteer: It's Good for You! Two Cornell University sociologists studied 313 women over 30 years and discovered that volunteers suffered almost 20% fewer major illnesses. The more involved women, they reported, tended to live longer. So men and women, volunteer today for a better tomorrow for everyone!

NEW: Individuals with anophthalmia or microphthalmia (unilateral or bilateral) are being sought for entry into a new registry. The goal is to catalog as many patients as possible to determine incidence, syndromes and other causes. All patients will be included on the mailing list for ICAN, a new parent support group (International Children's Anophthalmia Network). Contact Adele Schneider, M.D. or Jill Stopfer, M.S., Developmental Medicine and Genetics, Albert Einstein Medical Center, 5501 Old York Road, Levy 2 W, Philadelphia, PA 19141; TEL: 215/456-8722.

A support group for individuals and families dealing with Hermansky-Pudlak Syndrome (HPS) has been formed to network with members, correspond with health professionals, create a database and promote interest in the disorder. The group is interested in establishing ties with families and physicians in Puerto Rico where many affected families have been identified. Contact Donna Jean Appell, R.N., HPS Network, 39 Riveria Ct., Malverne, NY11565-1602; TEL: 516/599-2077 (GENESIS, Vol. V., No. 4, Winter 1994).

The Foundation for Nager and Miller Syndromes has a toll-free number: 800/507-FNMS.

PacNoRGG has a new address: Pacific Northwest Regional Genetics Group, CDRC, Clinical Services Building, 901 E. 18th Avenue, Eugene OR 97403-5254. TEL: 503/346-2610.

For your Information: Pseudoxanthoma Elasticum is a disorder of the connective tissue. An inherited skin disease with many systemic manifestations, it is characterized by abnormalities of elastic tissue which prominently involve the heart and blood vessels. In the US, 38 doctors report a total of 355 patients. Contact: Carolyn Freedman, President, National Association of Pseudoxanthoma Elasticum (NAPE), 1884 Cherry Street, Denver, CO 80220-1146; TEL: 303/321-6347.

Media Campaign Launched: The National Organization for Albinism and Hypopigmentation seeks volunteers to write letters protesting the negative portrayals of individuals with albinism in Hollywood films including The Firm and Lethal Weapon. There is a need for positive role models in the media for individuals of all ages with albinism. Contact NOAH at 1/800/473-2310 for more information.