"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.

FOR SHAME: While new advances in genetic information and technology soar, funding for all genetic training programs in the Maternal and Child Health Bureau of the Department of Health and Human Services will be categorically eliminated as of June 30. There is already a shortage of trained specialists to make genetic diagnoses, conduct family studies, perform appropriate tests and interpret their results. There is already a shortage of trained specialists to educate health care professionals and the public about genetics. There is already a shortage of trained specialists to provide therapy and support. This withdrawal of funds is catastrophic for both the genetics professional and consumer communities. You might want to share your concern with your senators and congresspeople. Furthermore, you might write to:

The Honorable Donna Shalala
Secretary
Department of Health and Human Services
200 Independence Avenue, SW
Washington DC 20201

Dr. Audrey Nora
Director
Maternal and Child Health Bureau
Parklawn Building, Room 18-05
Rockville, MD 20857

New Fragile X Publication: *Fragile X — A Handbook for Families and Professionals* is designed for families, genetic counselors, caretakers, educators, and all those wishing to learn about fragile X syndrome. Authors are Brenda Finucane, M.S., Allyn McConkle-Rosell, M.S.W., and Amy Cronister, M.S. Cost: $1. Available from the National Fragile X Foundation, 1441 York Street, Suite 215, Denver, CO 80206.

WELCOME: Francis S. Collins, M.D., Ph.D., has been appointed director of the National Center for Human Genome Research. Dr. Collins will also head the Center's new intramural program of research at NIH which will focus on technologies for finding disease genes, developing DNA diagnostics and gene therapies. The division also plans a clinical program for human gene therapy. Dr. Collins is a co-discoverer of the genes for cystic fibrosis and neurofibromatosis type 1 and is a collaborator in the search for the gene for early-onset breast cancer.

MARCH WAS A BIG MONTH FOR DISCOVERIES: A team of scientists led by ALS Association-funded researchers announced the discovery of the gene, that when defective, causes most cases of the familial type of ALS, often called Lou Gehrig's disease. This breakthrough is the first real clue to finding answers to amyotrophic lateral sclerosis in the 130 years since the terminal, progressive neuromuscular disease was first identified. Also identified were the genes for neurofibromatosis type 2 and the Huntington's gene. In all three cases, researchers have yet to develop treatments or cures.

HAVE YOU HEARD? The Alliance welcomes nominations for the annual Morris J. and Betty Kaplun "Art of Listening" Award. This award is presented to the service provider who best demonstrates that "while