"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.

DISCRIMINATION: We have received several media requests for the names of individuals or families who have been discriminated against for employment or insurance because of their carrier status or potential for a genetic disorder. If you have been discriminated against, and you would be willing to have your name publicly disclosed, please contact the Alliance at 800/336-GENE.

IT'S THE LAW: Social Security Disability (SSDI) recipients are often reluctant to accept employment because it will mean an end to their Medicare coverage. Effective April 1, 1990 (under P.L. 101-239) people who return to work will be able to pay for extension of the twelve-month trial work period. Under this law, Medicaid is required to pay the Medicare premium for SSDI recipients who earn less than $11,960 per year, although in some states, people who earn 150% to 200% of the poverty level may have to pay part of their premium on a sliding scale.

PUBLIC FORUMS ON THE HUMAN GENOME PROJECT PLANNED: The National Institutes of Health and the Department of Energy are spearheading the U.S. role in a world-wide effort to develop detailed maps of each of the 23 different human chromosomes and eventually to determine the order, or sequence, of the 3 billion chemical subunits of human DNA, the substance that makes up our genes. The scientific knowledge gained from this 15-year initiative called the Human Genome Project will one day help scientists understand the molecular events that underlie some of the thousands of genetic diseases that afflict human beings. Understanding the molecular details of human heredity promises to give researchers astounding new opportunities to learn where on each chromosome the genes are located, what they look like, and how they work both in health and disease.

To help ensure that the fruits of the human genome project are used for human good, approximately 3 percent of the project's annual budget has been set aside to study the ethical, legal and social implications of the availability of human genetic information. Policy options will be developed to address issues that may arise as project discoveries make it increasingly possible for us to know the secrets locked away in our genes. The Alliance is working with the National Center for Human Genome Research at NIH to conduct a public forum where consumers and professionals can learn more about the project and raise issues that concern them. Planned for late January 1991, the first public forum will be held in San Francisco and will be an opportunity for the public to help shape policy. We urge all groups with members or chapters on the west coast to plan to have representation at the public forum. We will be soliciting testimony from consumers in the Bay area who wish to raise particular issues with the Human Genome Ethics Committee and to give voice to concerns they wish aired in public.

Watch The Alert for more information.