"I am an idealist. I don't know where I'm going but I'm on my way."
Carl Sandburg

**INFORMED CONSENT:** The Alliance, with the support and cooperation of the American Society of Human Genetic's Social Issues Committee, is developing Guidelines to Informed Consent in Genetic Research Studies. These Guidelines will be made available to consumer groups for distribution to their members to help them become better informed participants in genetic research studies. Stay alert for future information.

A draft of the Guidelines was included in a packet of background materials distributed to participants in a recent NIH Workshop on Genetic Family Studies. Also distributed was an excellent, clearly written paper entitled “The Search for A Disease Gene: An Overview of The Methodology” by Elinor Langfelder of the Ethical, Legal, and Social Implications Program (ELSI), National Center for Human Genome Research. Call the Alliance office if you want a copy of the paper or if you want more information about the Informed Consent project.

**MICE MAKE VALUABLE CONTRIBUTION:** A new genetic map comprising easy-to-use markers on each mouse chromosome will greatly reduce the time required to identify and isolate genes implicated in diseases such as cancer, diabetes, high blood pressure, and other inherited disorders in mice. Because mice and humans share more than 90 per cent of their genetic makeup, the map will also help researchers find disease genes in human DNA. As reported in *Genetics*, the map consists of 317 markers evenly spaced along the mouse's 20 pairs of chromosomes.

- Dr. Edward Ginns of NIMH reported in the *Gauchers Disease Newsletter* that a strain of mice has been created that are born with a defective form of glucocerebrosidase, the enzyme affected by Gaucher Disease. Using a technique called targeted disruption or gene knockout, researchers have created mice that can serve as models in which novel enzyme replacement, cellular transplantation, and gene transfer therapies can be evaluated.

**PHYSICIANS' GUIDE TO RARE DISORDERS:** The National Organization for Rare Disorders (NORD), in cooperation with Dowden Publishing Company, has provided a new resource that will be of great value to physicians as well as patients diagnosed with rare or "orphans" diseases. This 1,224-page reference book includes a key chapter to help physicians communicate more effectively, "Rare Diseases: What Patients Need." Order from Dowden Publishing Co., 110 Summit Avenue, Montvale, NJ 07645-9895. Cost $69.50.

**ALLIANCE MEMBERSHIP DRIVE BEGINNING:** Your organizational and individual dues provide a critical financial and power base for the Alliance. To make membership as accessible as possible, we try to keep dues extremely low. Please join or renew now. Individual dues: $20; organizational: $50 which entitles three people to receive Alliance mailings.

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