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.

Jayne Mackta, Editor

ELSI STATEMENT: The Alliance, represented by Executive Director Joan Weiss, is now a liaison member of the NIH-DOE Joint Working Group on the Ethical, Legal and Social Implications (ELSI) Working Committee. Enclosed with this ALERT is an ELSI statement on The Bell Curve, a highly publicized book by Herrnstein and Murray (1994). The ELSI Working Group is troubled by the authors' claims about the genetic determinism of behavioral traits and concerned that the legitimate successes of the Human Genome Project in identifying genes associated with human diseases be misused in this way. Please share this information with your members and colleagues.

ELSI NIH BROCHURE FOR LAY AUDIENCE: The Human Genome Project: From Maps to Medicine is a new color brochure from the NIH National Center for Human Genome Research (NCHGR) about the genome project and its expected impact on medical genetics. A four-page foldout illustration depicts the flow of discovery from gene isolation to treatment for inherited illnesses. For free copies, contact the NCHGR Office of Communications: 301/402-0911 or e-mail: SharonD@od.nchgr.nih.gov.

ADAPTIVE PRODUCTS: Robert Van Etten, a Rehabilitation Engineer, has redesigned a quality desk chair called the ErgoChair for Little People to provide the lumbar and leg support needed by a person of short stature. He has also researched manufacturers and accumulated literature on numerous products geared towards meeting the needs of a person of short stature. For information, contact Robert at Adaptive Living, 2 Charles Street, Rochester, NY 14608; TEL: 716/235-0922.

RECOMMENDED: Mapping Fate: A Memoir of Family, Risk, and Genetic Research by Alice Wexler, Times Books, Random House, $23. This book is the story of a scientific breakthrough, but even more, it is the story of one family's effort to live with fear, denial and yet, ultimately, with love and dignity. Alice Wexler, a writer and historian, chronicles the story of her mother, who died of Huntington's Disease in 1978. Although a commentary on death, the book is more of a commentary on living with an ever-present dilemma of choosing to know or not know how one will die. The book is a tribute to the author's sister, Nancy, who serves as the glue and catalyst in bringing together HD organizations, families and researchers, to the HD Collaborative Research Group, and to her father, Milton, whose creative workshops got the HD research rolling in the early 70s. Their combined efforts eventually led to locating the gene and the possibility of presymptomatic testing.

TRIALS BEGIN: Gene therapy trials for patients with the Fanconi Anemia Group C gene began in May.

The Alliance ALERT is a publication of the Alliance of Genetic Support Groups
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Alliance is funded in part by project #MCJ-241009-03 from the Maternal and Child Health Bureau (Title V Social Security Act), Health Resources and Services Administration, Department of Health and Human Services