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

FDA and Needed Drugs: A November conference on Capitol Hill sponsored by George Washington University spotlighted the Federal Food and Drug Administration. Long considered a bottleneck for treatments for many genetic disorders, the FDA is an agency that is a familiar target for consumer and Congressional anger. The speakers concurred that the agency, created in 1937 to protect the public, may not be well-suited to meet present medical demands. The point was made that consumers are better informed about their disorders and needed treatments and are both eager and able to participate in the decision-making process. For people who have genetic conditions, the slow pace of FDA approval often means that drugs which have been approved for other uses but are effective for genetic disorders are considered “experimental” by HMOs and insurance companies. Consequently, they either balk or refuse to pay. Pressure tactics can be counter-productive, yet changes are necessary if needed drugs are to be brought to market in a timely manner. It was suggested that FDA employees be moved around within the Agency at intervals so that their power is diluted. Such a change could result in a loss of expertise, but it could also diffuse the very real problem of bureaucratic roadblocks within this important agency.

HuGEM Video Series: The Human Genome Education Model Project (HuGEM) is a collaborative project of Georgetown University Child Development Center and the Alliance of Genetic Support Groups. This video series contains overviews of the ethical, social and legal issues raised by genetic research as well as in-depth discussions of issues raised during the HuGEM Forum held in May, 1995. Tapes can be effectively used individually or together as a comprehensive tool for education. $15 each (includes postage and handling; $50 for series of five tapes).

TITLES AVAILABLE
- The Human Genome Education Model Project: An Overview (18 min.) Narrator: Dr. Francis Collins
- The Human Genome Project: Opportunities and Challenges (30 min.) Narrator: Dr. Francis Collins
- Privacy and Discrimination (45 min.) Narrator: Dr. Karen Rothenberg. A panel of four people with a genetic disorder in the family reveal their experiences and concerns about actual and potential discrimination in insurance and the workplace when privacy and confidentiality are not maintained.
- Genetic Testing Across the Lifespan (30 min.) Narrator: Dr. Neil Holtzman. Individuals describe the impact of genetic testing on themselves and other family members.
- Working Together (25 min.) Narrator: Dr. Robert Murray. Individuals describe barriers to effective care-giving and present ways that consumers and professionals can work together to improve services.

Contact the Alliance Office for an order form: 1/800/336-GENE.