"Shoot for the moon; the worst that can happen is that you end up somewhere in the stars."

Bill Demby

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

UPDATE on ALLIANCE ACTIVITIES

HuGEM: The Alliance and Georgetown University Child Development Center are holding an invitational conference on June 10 at Georgetown for national organizations of health professionals to address the need for education on the Human Genome Project and its ethical, legal and social implications. Nine professional disciplines were identified in our Human Genome Educational Model (HuGEM) survey as having a minimum of education in genetics while providing clinical services for persons with genetic disorders. The faculty includes Dr. Francis Collins, Director of the National Center for Human Genome Research, leaders of allied health professional organizations, and consumers of genetic services. This conference represents an important step towards effective interdisciplinary education.

ELSI WORKING GROUP: Joan Weiss serves as a liaison representing the Alliance to the NIH-DOE Joint Working Group on Ethical, Legal and Social Implications, commonly referred to as ELSI. At the May meeting, the agenda focused on the Task Force on Genetic Testing which recently published “Interim Principles for Genetic Testing.” (See the April Alert.) On April 29, Joan testified at a public hearing in Baltimore about the need for an overriding principle on the importance of privacy and confidentiality in genetic testing. The ELSI Working Group has issued a statement on the use of genetic information by employers. If you would like a copy, contact the Alliance office.

PRIM&R: Since its founding in 1974, PRIM&R, which stands for Public Responsibility in Medicine & Research, has been a strong advocate for ethical human and animal research that will improve individual quality of life and benefit society as a whole. The organization is committed to the consistent application of ethical precepts in both medicine and research. Recently, several Alliance organizational representatives took part in a Round Table Discussion moderated by Dr. Phillip Reilly and Joan Weiss. The subject was “What consumers of genetic services expect from the genetics research establishment and the research establishment's response. Given the many ethical dilemmas raised by advances in biotechnology, PRIM&R’s conference drew participants from all over the country, and the panel generated a healthy discussion.

PARTNERSHIP: The planning and initial implementation for the Partnership for Genetics Education Training Project are well underway. The project’s goal is to integrate consumers into the genetics education of primary care providers in medical schools and managed care settings. The first meeting of the Steering Committee will be held in Washington on June 7 and 8. The meeting will focus on refining the plans of the project and developing educational materials. The pilot phase is anticipated to begin in September in three regions: MARHGN, GLaRGG, and PacNoRGG. This phase, as we currently view it, will include a consumer orientation in each region and the choice of one or more medical schools or managed care settings in that region to conduct our training. We are looking for 20 to 25 consumers in each of the pilot regions to participate. If you or your organization is interested in getting involved at your regional or state level, contact Nachama Wilker or Donna Foster at the Alliance office.

The Alliance ALERT is a publication of the Alliance of Genetic Support Groups

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e-mail: alliance@capaccess.org • 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