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

Bill Demby

This Alert is a vehicle of communication between the Alliance and its constituency. It is our goal to provide timely and useful material in readable, easy access format. Feel free to send in your announcements, share your ideas, or ask for help.

Jayne Mackta, Editor

Senate Labor and Human Resources Committee Hearing on Medical Records Privacy Proposal: Consumers, providers, insurers and employers endorsed personal medical information privacy rights at a Senate hearing on October 28, 1997 but disagreed about how to achieve that goal. The AMA and consumer groups delivered strong testimony in favor of express patient consent; commercial groups expressed concern that disclosure authorization requirements might add to administrative costs. Most speakers asked that the Clinton administration limit the ability of law enforcement officials to see and use an individual's personal medical files. A.G. Breitenstein, director of JRI Health Law Institute in Boston, expressed grave concern that the administration's proposed system would result in "wide access to most every commercial and governmental entity". Congress is required by the Health Insurance Portability and Accountability Act to pass privacy protections by August 1999. The Alliance is looking for real life examples of unauthorized access to medical files to represent more fully this critical genetic issue.

Alliance Meeting with ASHG on October 28, 1997: Mary Davidson, Joan Burns and representatives of Alliance member organizations met with the American Society of Human Genetics' Board of Directors to dialogue about critical issues and concerns shared by consumers and researchers. The need to improve communication, coordination and collaboration between clinical researchers and research participants was quickly identified by all in attendance. A working group will be created to develop "Points to Consider" for clinical researchers and consumer participants to enhance communication and achievement of shared research goals. Alliance member representatives included: Brad Margus, AT Children's Project; Vicky Whittemore, National Tuberous Sclerosis Association; Sharon and Patrick Terry, PXE, International Inc; and Paul Mendelsohn, Neurofibromatosis, Inc.

The Alliance is Moving and Expanding: January 1 is the target date for moving to our new office location at 4301 Connecticut Avenue, Suite 404, Washington D.C., 20008. We will double current office space, giving us ample room to operate new program activities and comfortably house 7 full-time, 4 part-time staff, volunteers and interns. From December 1 Janet Wegner will join staff as full-time Office Administrator and will orchestrate the installation of new office systems. The Alliance toll free helpline number (1-800-336-4363) will move with us. We will alert you next month to changes in e-mail addresses and telephone and fax numbers. A new multi-line telephone system will link callers directly to administrative and program staff while helpline calls will be answered by a live, warm human voice. The office move will be a challenge but we expect to bounce back --after a short adjustment period-- more energetic, invigorated, empowered and better staffed than ever. When you're in DC, please come visit and see for yourselves!

Personal Note from the Executive Director: As we pack to move to larger office space, with increased staff and new programmatic challenges, I find myself tripping over memories and images from this past year: the Gala tribute to Founding Director Joan Weiss, Francis Collins strumming genetic civil rights songs; the Science Magazine article on Genetic Discrimination; San Francisco, Baltimore and the genetics conferences; the July 8th meeting with Mid-Atlantic managed care organizations; discoveries of the second TS and PXE genes; July 14th at the White House and the flood of helpline calls after our phone number appeared in a USA Today Weekend edition. But even more than these memorable events, I am playing back all the small, everyday conversations -- mostly by phone -- with Alliance members, calling with ideas, suggestions and to say "hello", and with helpline callers, thankful to find a warm human voice to listen to their request and questions. A year ago a board member told me that the Alliance was all about connecting people and groups and resources and molding together their unique strengths. This poetic image has empowered me through many challenges this past year and been confirmed several times over. From my perspective as the parent of an affected 23 year old son and as Alliance executive director, this has been a most meaningful, stimulating, and productive year. Like you, I look forward to what 1998 has in store for the Alliance of Genetic Support Groups. Happy Holidays! Mary Davidson, medallianc@aol.com.

The Alliance ALERT is a publication of the Alliance of Genetic Support Groups
35 Wisconsin Circle, Suite 440, Chevy Chase, MD 20815 * 1-800-336-GENE * 301-652-5553 * email: alliance@capaccess.org
website address: http://medhelp.org/www/agsg.htm * The Alert is funded by Project #2 MCJ-241009-06-0 from the Genetics Services Division of the Maternal and Child Health Bureau, Health Resources and Services Administration, Dept of Health and Human Services and the Community Partnership Program of SmithKline Beecham, Inc.