"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 a readable, easy access format. Feel free to send in your announcements, share your ideas, or ask for help.

Jayne Mackta, Editor

Partnership Opens Dialogue With Managed Care Organizations: The Partnership for Genetic Services Pilot Program initiated the development of strategic relationships on July 8 in Washington, D.C. Sponsored by the Robert Wood Johnson Foundation, the meeting brought together representatives of NYL Health Care, Prudential Health Care, Patuxent Medical Group of Blue Cross and Blue Shield, George Washington Medical Center, and the American Association of Health Plans with genetic providers, counselors, and consumers. Presentations focused on the importance of genetic services, provided several models of current services, and outlined the resources of the consumer and clinical communities in providing quality services. The meeting offered one of the first opportunities for these communities to come together to develop a better understanding of each other. Topics discussed included the need for consumers to understand their policy benefits and to lobby their employers for desired benefits in their plans, the need for guidelines for genetics services from a consumer perspective, and the need for providers and managed care organizations to be educated in the field of genetics. For more information about the meeting, contact Nachama Wilker at the Alliance.

HuGEM II Starts Up July 1: Once again, the Alliance and Georgetown University are co-sponsors of the Human Genome Education Model Project (HuGEM II). The ELSI (Ethical, Legal, and Social Implications) branch of the National Human Genome Research Institute is supporting this collaborative consumer/professional educational program for another three years. Joan Weiss and Virginia Lapham continue as co-directors. Building on the experiences and products of the first HuGEM project, HuGEM II will educate allied health professionals about human genetics and associated ethical, psychological and legal implications of the Human Genome Project. The seven collaborating health professional organizations are the American Dietetic Association, American Occupational Therapy Association, American Physical Therapy Association, American Psychological Association, American Speech-Language-Hearing Association, Council on Social Work Education, and National Association of Social Workers.

FIGHTING EMPLOYMENT DISCRIMINATION: Demonstrating increased awareness of the risk of genetic discrimination, Senator Tom Daschle (D-SD) has introduced The Genetic Justice Act, S. 1045, which prohibits genetic discrimination by employers. The bill protects applicants during the hiring process and in the terms and conditions of on-going employment. An employer can request genetic information only if an offer of employment has been made, in the case of an applicant, and, for applicant/employees, only if the requested information is job-related and consistent with job necessity. Voluntary, knowing and written consent must precede information disclosure. According to the bill, individuals who experience violations of the Genetic Justice Act may take action against their employer in state or Federal court and seek an award for legal or equitable relief.

E-Mail Update: There are now several ways to be in touch with the Alliance through the Internet. In addition to using alliance@capaccess.org, you can send us mail at GeneGroups@aol.com. Mail concerning the Partnership Program should be sent to GenePartnr@aol.com.

See Page Two for a special letter from Alliance President Joan Burns and Dr. Francis Collins, Director of the National Human Genome Research Institute, NIH

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

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Dear Friends,

Your letters, faxes and e-mails to President Clinton over the past weeks helped bolster White House commitment to legislation prohibiting genetic discrimination in health insurance. On July 14th we joined representatives of genetic support groups, professional organizations, genetic research and biotechnology in the East Room of the White House to support President Clinton’s announcement of legislative action to restrict such discrimination on the basis of genetic information. The audience included many consumer organizations and gave high visibility to the need for protection of those affected by genetic disorders. The following genetic conditions were represented: Ataxia Telangiectasia, Breast Cancer, Cystic Fibrosis, Gaucher Disease, Hemochromatosis, Hemophilia, Huntington Disease, Klinefelter Syndrome, Multiple Sclerosis, Neurofibromatosis, Tourette Syndrome and Tuberous Sclerosis among others.

Robust public policies that prevent genetic discrimination serve us all--families with hereditary disorders, health researchers, and indeed any one with DNA. For the targets of genetic discrimination today are those who carry gene alterations that, for better or worse, appear at the top of our list of scientific discoveries. Genetic tests for inherited disorders often quickly follow the isolation of disease genes, well before treatments can be developed. But in time, we will all find ourselves in a similar situation. There are no perfect genetic specimens. We each carry from a few to a few dozen DNA changes in the complex and diverse encryptions of our genetic code that place us at risk for disease.

That is why President Clinton urged Congress to pass legislation prohibiting health insurance companies from using genetic risk for a disease, in the absence of a genetic diagnosis, to deny, cancel, terminate or change the conditions of health care policies. He supports a modified version of H.R.306, the Genetic Information Nondiscrimination in Health Insurance Act of 1997 drafted by U.S. Representative Louise Slaughter (NY). The President described the tragic consequences of consumer concerns that genetic information, generated by research participation, might jeopardize health care coverage.

We have all reveled in the excitement of tracking down disease genes, knowing that one day those discoveries would help find a way to treat or prevent human illness. But until now, that excitement was always tempered by the unfortunate reality that those same discoveries could put people at risk of losing access to medical care by virtue of losing access to affordable insurance. The President’s support of federal legislation prohibiting genetic discrimination in health insurance promises to end that.

The President’s timely action comes during a revolution in genetics research, when scientists and research participants are forming new partnerships to understand and overcome inherited disease. To unravel the complexities of those diseases, the American public will more frequently and in ever larger numbers be called upon to participate in health research. The saddest irony about consumer reluctance to participate in research is that these are the very studies that could produce future benefits and that could advance genetic science beyond disease gene isolation to the prevention, treatment and cure of genetic diseases. Protection of research volunteers against genetic discrimination is critical if federally sponsored biomedical research is to continue in good faith.

The President’s announcement represents a critical step toward genetic discrimination protection for all of us. More legislation and much more consumer advocacy will be needed before federal anti-discrimination protections are broad enough to embrace all children, adults and families identified with genetic information and living with genetic diseases. The Alliance of Genetic Support Groups and the National Human Genome Research Institute are working together to make this happen. We are counting on your continued support and urge you to write to the President and your representatives in Congress expressing your views.

Joan Burns  
Francis Collins
**Killer Cholesterol Gene Discovered:** Scientists have discovered the gene responsible for Niemann-Pick type C disease (NPC), an incurable cholesterol disorder in children. The gene, called NPC1, is located on chromosome 18 in humans and has also been located in mice. In NPC, a protein which plays a role in the transport of cholesterol is defective, leading to clogging of certain cells and eventual death of nerve cells. Researchers also found that inserting a working copy of the NPC1 gene into the skin cells of patients helped to correct their metabolism.

**Mighty Mouse:** Geneticists in Japan have made mice whose cells contain whole, functional human chromosomes, along with their own mouse DNA, allowing the mice to make a range of human proteins potentially useful against cancer, autoimmune diseases and infections. The transferred chromosomes contain about 1000 genes each, more than 50 times the amount of genetic material ever transferred before from a human to a mouse.

**A First in Parkinson's Research:** Scientists at the National Human Genome Research Institute and elsewhere have identified a gene that plays a role in the development of Parkinson's disease in some families. The finding establishes for the first time that at least one form of this illness can be inherited. More than 600 family members in one Italian family on three continents have been found, with about ten percent known to have the kind of Parkinson's that runs in families and appears before age 60.

**A Great Loss:** Rita Beck Black, a social worker and genetic counselor with a long involvement with the Alliance, died on July 5. Rita surveyed the needs of our voluntary genetic organizations at the first Alliance meeting in 1986 and co-authored several journal articles with Joan Weiss on the importance of the partnership between professionals and genetic support groups and on the need for genetic support groups to be a part of the delivery of comprehensive genetic services. A well-respected professor of social work at the Columbia University School of Social Work, Rita was the loving mother of two young girls. Her wonderful work and her interest in our families and their support groups will be sorely missed.

**IDEA Passes:** The House (420-3) and Senate (98-1) overwhelmingly passed the reauthorization of the Individuals with Disabilities Education Act (IDEA), putting an end to a two-year debate.

**UPCOMING MEETINGS**

**ANNOUNCEMENTS:** Member groups wishing to submit a meeting or conference announcement to the ALERT are asked to provide the following information within the body of the text so that it is readable: date, location, and contact information, including name of organization, mailing address, and telephone number. If we have room, we will be happy to include an e-mail address and/or web site.

"Genetic Testing for Hereditary Breast Cancer: Should We Stop It?" • Aug 23; Hyatt Regency, San Diego CA . Sponsored by the Pacific Southwest Regional Genetics Network. Contact Pamela Cohen, Regional Coordinator, 2151 Berkeley Way, Annex 4, Berkeley, CA 94704; TEL: (510) 540-2852; email: pcohen@genetic.dhs.ca.gov.

**MPS Picnics and Camp Weekends in the Western States** • Aug. 30. Call Sallie Martinez 760-489-5700 or Dorothy Baker 619-945-7495 (h) or 760-721-3895 (w).

**Nat'L MPS Society Conference** • Sept. 13 - 14; Radisson Plaza & Suites Hotel, Keystone at the Crossing, Indianapolis, IN. Contact National MPS Society, 17 Kraemer St., Hicksville, NY 11801; TEL: 516-822-2041.

**International Fanconi Anemia Scientific Symposium** • Sept. 18 - 20; Columbia Inn Hotel and Conference Center, Baltimore, MD. Sponsored by the National Heart, Lung and Blood Institute (NIH), the Office of Rare Diseases Research (NIH) and the Fanconi Anemia Research Fund. Contact Linda DeSpain, FA Research Fund, 1902 Jefferson St., Suite 2, Eugene, OR 97405; TEL: 541-687-4658. http://www.rio.com/~fafund


**National Organization for Rare Disorders Annual Conference** • Sept. 25 - 28; Washington, DC. Contact NORD, 100 Rt. 37, P.O. Box 8923, New Fairfield, CT 06812-8923; TEL: 203-746-6518.

**1997 PKU Disney World Meeting** • Sept. 27; Kissimmee, FL. Contact Judy Kent, 139 Chesapeake Avenue, Tampa, FL 33606; TEL: 813-258-3829.
California's Newborn Screening Program: Past Accomplishments and Future Possibilities • Oct. 8 - 9; Hyatt Regency Hotel, Los Angeles, CA. Call the Department of Health Services, Newborn Screening Program: 510-540-2709.

Prader-Willi Syndrome Service Providers Conference • Oct. 16 - 18; Nashville, TN. Contact Prader-Willi Syndrome International Forum, 40 Holly Lane, Roslyn Heights, NY 11577; TEL: 1-800-358-0682 or 516-621-2445.

Healthy Mothers, Healthy Babies National Biennial Conference • Oct. 20-22; Baltimore, MD. Contact HMHB, 409 12th St. SW Washington, DC 20024-2188 or call the Conference Hotline: 202-863-2441.

Living and Learning with Fetal Alcohol Syndrome • Oct. 24 - 25; Ann Arbor, MI. Sponsored by Parents Supporting Parents (313-662-7291) and the Family Empowerment Network: 1-800-462-5254.

Sixth Annual Conference of the HHT Foundation International • Oct. 24-26; Downtown Atlanta Ramada, Atlanta, GA. For more info, write: HHT Foundation International, PO Box 8087, New Haven, CT 06530 or call 1-800-HHT-NETW; email: hhtinfo@hht.org.

Fundamentals of Phototherapy Workshop for Nurses and Technicians • Oct. 24 - 26; Scottsdale, AZ. Sponsored by National Psoriasis Foundation, 6600 SW 92nd Ave., Suite 300, Portland, OR 97223-7195. Contact Julie Honse, 1-800-723-9166, ext. 11.

ISONG Educational Conference — “Hand in Hand: Genetic Nursing Education and Practice Roles and Managed Health Care” • Oct. 27 - 28; Radisson Plaza Lord Baltimore Hotel, Baltimore, MD. Contact Dale Halsey Lea, Program Committee Chair, International Society of Nurses in Genetics, at 207-883-4131.

EB Awareness Week is Oct. 27-Nov. 2. Contact the DEBRA office at 212-513-4090 for materials.

Neurofibromatosis Symposium (in conjunction with the American Society of Human Genetics) • Oct. 28, 7-10 pm; Convention Center, Baltimore, MD. Contact The National Neurofibromatosis Foundation, 95 Pine Street; 16th floor, New York, NY 10005; email: NNFF@aol.com; Attn: Fran Morris.

THE Noonan Syndrome Support Groups Meeting • Nov. 1; Baltimore, MD. Contact TNSSG, PO Box 145, Upperco, MD 21155; TEL: 410-239-6926; email: wandar@bellatlantic.net.

Reviewing and Revising the Expedited Categories of Research • Nov. 6; Hyatt Regency, Bethesda, MD. Sponsored by Public Responsibility in Medicine and Research and Tufts University School of Medicine. Contact PRIM&R, 132 Boylston St., Boston, MA 02116; TEL: 617-423-4112.

Turner's Syndrome Society of the United States National Conference • Nov. 7 - 9; Hotel Sofitel, Minneapolis, MN. Contact the Society, 1313 5th St., SE, Suite 327, Minneapolis, MN 55414; TEL: 612-379-3607.

International Centennial PXE Conference • Nov. 7-9; Bethesda, MD. Contact PXE International, Inc. 23 Mountain Street, Sharon, MA 02067; TEL: 617-784-3817; email: pxe@tiac.net or http://www.med.harvard.edu/programs/PXE. Co-sponsored by the National Association of Pseudoxanthoma Elasticum.

International Down Syndrome Research Conference on Cognition and Behavior • Nov. 20-22; Amelia Island Plantation, just north of Jacksonville, FL. Contact the National Down Syndrome Society, 666 Broadway, 8th floor, New York, NY 10012; TEL: (800) 221-4602; e-mail: infot@ndss.org.

First National Symposium on Angelman Syndrome • Nov. 29; Brussels, Belgium; organized by The Angelman Foundation Belgium. For information, contact Dr. B. Dan, Avenue du Parc 147, 1190 Brussels, Belgium; FAX: +32 2 4773287.

Ethical Research in an Ethical Society, PRIM&R Annual IRB Conference • Dec. 8 - 9; The Sheraton Hotel, Boston, MA. Contact Public Responsibility in Medicine and Research, 132 Boylston St. Neurofibromatosis Symposium, Boston, MA 02116; TEL: 617-423-4112.

The Dana Alliance will maintain a year-round internet calendar of events open to the general public which relate to the brain and brain research: http://www.dana.org. To submit a listing, call Liz Quinn to request an information form: 301-657-9197.