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

Bill Denby

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

ALLIANCE NEWS

Pausing for the Holidays: Stepping back from the minutiae of moving, Alliance staff wants to reach out to all of you, extending the warmest Holiday and New Year's wishes. None of us could do what we do without energizing circles of supportive staff, boards, families and friends. The Alliance support circle is made up of all of you. Your involvement will make it possible for all of us to meet the challenges facing consumers in public and provider education and genetics legislative and research policy in the coming year. Thank You and Happy Holidays from Mary, Joan, Nachama, Mary Ann, Donna, Mieko, Janet, Toni, Nancy, Eric, Arlen, Edie and Kara.

Alliance 1998 Membership Conference: The Key Bridge Marriott Hotel boasts a panoramic vista of Washington, DC from across the Potomac River and has been selected as the site for the Alliance’s three day national gathering from September 11 to 13, 1998. Program planners contemplate a three track theme - Genetic Partnerships in Policy, Research and Healthcare - with plenary meetings and break-out sessions to look at these critical consumer issues and to empower hands-on consumer involvement in local, regional and national policy circles. We want all of our members and supporters to attend - consumers and professionals and members of support groups, regional network consumer committees, professional associations and the broader genetics community. For info, contact Mary.

HuGEM Project Makes Good Progress: Five of the seven national professional organizational participants are beginning the process of integrating genetics within their organizations. They are setting up genetics advisory councils, publishing articles on genetics issues and ethics or arranging for HuGEM participation at their national conference. The needs assessment survey of genetics knowledge, skills, understanding, and resources of health professionals has been further refined and sent on to members of the HuGEM Advisory Committee and organizational representatives for final approval. A second Advisory Committee Meeting will be held on January 12 at Georgetown University.

Quality Guidelines Take Another Leap Forward: On December 5th, 33 consumers from around the Pacific Northwest met in Seattle to further the Partnership for Genetics Services Pilot Program's identification of critical issues of quality genetics services from a consumer perspective. Discussions at the meeting also focused on ranking the ten most critical elements of the guidelines and establishing a set of overarching principles. A more detailed report of the guideline ranking will be available in future issues of the Alert. If you would like a copy of the Executive Summary of either the meeting in Seattle or the consumer meeting in Washington, DC on September 19, contact Nachama Wilker in the office: nlwAllianc@aol.com

Office Furniture Needed: January 1 is the target date for moving the Alliance to our new home at 4301 Connecticut Ave. NW, Suite 404, Washington D.C., 20008. The Alliance toll-free 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. Call Janet Wegner at the Alliance office if you can donate used office furniture.

HEALTHCARE

Robert Wood Johnson Foundation Celebrates 25 years: Partnership Program Director, Nachama Wilker, represented the Alliance at a conference to celebrate the Foundation's role in making grants to improve health and health care for all Americans. Attended by RWJ grantees, the conference presented a forecast of the future of health and health care in 2005. Opportunities were presented to partner with our providers in expanding the definition of health to include psycho-social support and the power of consumer information in our daily lives. Challenges were identified from continued movement into care systems unprepared to handle the special needs of our populations. On behalf of Alliance, we would like to congratulate the Foundation on 25 years of grant making to make a difference and extend our appreciation of their support of the Partnership Program.
Health Professionals Call for End to For-Profit Health Care: In a recent issue of the *Journal of American Medical Association*, 2,288 Massachusetts doctors, nurses, and other health care professionals' names supported a statement from the Ad Hoc Committee to Defend Health Care: "Canons of commerce are displacing dictates of healing, trampling our profession's most sacred values." These professionals advocate for an end to for-profit health care and claim that that they are being "prodded by threats and bribes to abdicate allegiance to patients, and to shun the sickest, who may be unprofitable."

Americans, Health, and Media: The National Health Council surveyed attitudes toward health information in the media and found that 75 percent polled said they are interested in news about health and medicine, but often are confused by what they hear and read. 42 percent said they turn to doctors more for information as a result, but 82 percent said they never question the doctor's advice because of media coverage. Interest in health news seems to correlate with education, and only 2 percent polled said they used the internet.

Help for SSI Denials: Due to the 1996 Welfare Reform Act, as many as a quarter of a million children with disabilities could potentially lose their Supplemental Security Income (SSI). Appeals for the continuation of benefits can be filed within 10 days of receiving a termination notice. The Epilepsy Foundation of America has a list of phone numbers for free legal services. Call 1-800-EFA-1000.

Patient Bill of Rights: The Presidential Advisory Commission on Consumer Protection and Quality in the Health Care Industry, made up of 34 representatives of insurance companies, consumers, health care providers and employers, has recommended standards aimed at guaranteeing insured patients easier access, effective appeals procedures and information disclosure. Proposals call for more patient choices, confidentiality assurances and requirements of full disclosure to patients about all treatment options.

PUBLIC POLICY
Daschle Bill: In November, the Alliance responded to Senator Daschle's request for comments from the consumer perspective on The Genetic Justice Act, S.1045, which prohibits using genetic information in employment decisions. For copies of the letter, drafted by Alliance Policy Consultant Volunteer Barbara Miller, esq., contact Mary Davidson.

New Legislation on Medical Privacy: On November 4, Senator Patrick Leahy (D-VT) introduced the "Medical Information Privacy and Security Act," and referred the bill to the Senate Committee on Labor and Human Resources. The bill states that genetic information should be treated the same as all other medical information. Other key points include: individual right of access to personal health information, the authority to challenge record accuracy and completeness, and the right to limit use and disclosure of personally identifiable information. The person entrusted with health information would be required not to disclose or use the records without the authorization of that individual. Also, an Office of Health Information Privacy within the Justice Department has been proposed to enforce the Act.

Extension of National Bioethics Advisory Commission (NBAC): NBAC was granted an extension until the end of 1999 through an executive order issued by President Clinton, in recognition of the terrible wrongs committed in the Tuskegee Institute syphilis research studies. The NBAC's mission is to ensure that human subjects do not unknowingly participate in research studies when a cure for their condition is available. The two sub-committees, the Human Subjects Subcommittee and the Genetics Subcommittee, handle the major work of the commission.

RESEARCH POLICY
Human Genome Diversity Project Approved by NRC: The National Research Council recommended modifications to a NIH and National Science Foundation proposal to study genetic variation across the entire human population. The study has been delayed for six years due to controversy over protection of research subjects and the focus of study. Samples will be totally anonymous, and disease genes will not be included.

Appropriations Bill Calls for Health Research Priority: In recent years there have been frequent complaints to Congress about unfair setting of health research priorities. Consequently, Speaker of the House Newt Gingrich will appoint a panel to examine the process and policies used by the National Institutes of Health to set national research priorities. The recent Labor-HHS-Education appropriations bill requires the Secretary of Health and Human Services to contract the Institute of Medicine to study the funding allocation process for NIH biomedical research.

SCIENCE UPDATE
Strong Genetic Links to Allergies: Scientists at Washington University School of Medicine have identified a genetic mutation that appears to make certain people more susceptible to allergies. A senior author stated that "with this mutation, you are 10 times more likely to be allergic." This genetic finding is a step towards identifying individuals at high risk, beginning intervention strategies and developing medications to treat allergies.

BE SURE TO RENEW YOUR MEMBERSHIP IN THE ALLIANCE OF GENETIC SUPPORT GROUPS. WE WELCOME CONSUMER, PUBLIC, PROFESSIONAL AND COMMERCIAL MEMBERS.
Call the Alliance Office for a Membership Form: 301-652-5553/1-800-336-GENE.
Progress in Gene Therapy: Researchers at Tufts University report that they have grown blood vessels in 9 people using gene therapy to inject them with a synthetic replica of the gene prompting human blood vessel growth. With FDA approval, the next step is attempting this procedure in a blood deficient heart.

Aging Process Correlated to Single Gene: Researchers in Tokyo, Japan believe they have identified a gene named klotho that when mutated in mice, that causes an aging process similar to that in humans. Other scientists, however, report skepticism that a single gene controls aging. The research was published in the journal Nature.

RESOURCES FOR CONSUMERS

• DateAble, A Singles Group with Heart: DateAble is a non-profit organization that provides person-to-person introductions for members, most of whom have a disability or health condition affecting mobility, vision, hearing or speech. Activities include social events, social support groups, newsletters, and community linkages. DateAble: 35 Wisconsin Circle, Suite 205, Chevy Chase, MD 20815; 301-657-DATE; fax: 301-657-4327; website: http://www.dateable.org; e-mail: Robert@dateable.org.


• American Self-Help Clearinghouse publications, call 973-625-9565.
  • Listing of Self-Help Clearinghouses in US & Canada - free
  • The Self-Help Sourcebook - $12.00
  • How to Cope with Distress & Manage Crisis in Your Group - $3.00
  • A Guide for the Self-Help Group Phone Contact Person - $3.00

• Youth Disability Sports Program provides young people with physical disabilities sports opportunities widely available to able-bodied youngsters. For more info, call the U.S. Disabled Athletes Fund at 770-850-8199.

• Antiepileptic Drug Pregnancy Registry, North America's first registry for pregnant women who are taking any antiepileptic drugs. All information is confidential. Call 1-888-233-2334.

Family Voices: What's Happening in the States, 51 state coordinators give updates on the status of state health programs for children with special needs. Each state also has a Family Voices contact person and telephone number. Included is a glossary technical terms and state contact information. Contact Family Voices at 505-867-2368, PO Box 769, Algodones, NM 87001.

OCCUPATIONAL OPPORTUNITIES TO GET INVOLVED

Seeking Professional Journalists with Disabilities: The President's Committee on Employment of People with Disabilities is in forming a national association to address the concerns of professional journalists with disabilities. Contact John Donnelly, 1331 F St., NW, Washington D.C. 20004-1107.

Consumer Health Action '98: The Alliance is a co-sponsor of the Families USA national grassroots meeting in Washington DC from January 22 to 24, 1998. This advocacy meeting will bring together community leaders from diverse constituencies to work together to protect all consumers. Help forge the consumer response to the health care revolution. Contact Families USA Conference, 1334 G Street, NW, Washington, DC 20005; Telephone: 202-628-3030.

Request for Parent Help in Preparing Survey Templates: The Burnham Institute seeks the help of experienced parents in preparing a questionnaire for parents of children with Carbohydrate-deficient Glycoprotein Syndrome (CDGS) to use during a study to test a new therapy. Parents will be asked to follow the"Health-Related Quality of Life" of their children, and consumer input is needed to design the instrument. If your support group or organization has conducted a survey regarding the effectiveness and improvement of therapy, please contact Hudson Freeze, Ph.D. at 619-646-3142, The Burnham Institute, 10901 N. Torrey Pines Rd., La Jolla, CA 92039; email: hudson@burnham-inst.org.

HuGem II Seeks Consumers: Consumers with personal experience working with social workers, psychologists, occupational and physical therapists, dieticians, and speech, language and hearing professionals are being enlisted to join the educational team for all HuGEM training sessions, conferences, and professional staff orientations. Contact Joan Weiss, Project Co-Chair, at the Alliance on Mondays and Wednesdays.

Learn Policymaking Skills: Opportunities to learn policymaking in important sites in Washington DC are available for parents and professionals through one-year Kennedy Foundation Fellowships. For more information, call 202-393-1250.
ASA Seeks Proposals: The Autism Society of America seeks proposals from individuals or firms experienced with autism and with disability and research funding issues to provide ASA representation within the legislative and regulatory branches of the federal government. Contact Joan S. Zaro at 301-657-0881, ext. 105.

Consumer & Professional Grant Reviewers Needed: The Corporation of National Service is seeking consumers and professionals with children with disabilities to assist in grant reviews. Contact Galen Ransom at 202-565-2786.

Alliance Welcomes Help Planning the 1998 Membership Meeting: Contact Jayne Mackta (908-629-4213), Board Committee Chair, or Mary Ann Wilson and Mary Davidson at the Alliance office.

Grant Opportunity for Courses in Research Ethics: The National Institutes of Health, Centers for Disease Control, Health Resources and Services Administration, and the Agency for Health Care Policy and Research invite applications for grants to develop, conduct, and evaluate short-term courses on ethical issues in research. Courses should improve the skills of biomedical, behavioral, social science and public health researchers in identifying and addressing the ethical, legal and social implications of their research, especially when human subjects are involved. Letter of Intent Receipt Dates: Feb 6 and May 22, 1998. Application Receipt Dates: March 6 and June 24, 1998. Contact Milton J. Hernandez, Ph.D. at 301-496-3775.

UPCOMING MEETINGS AND ANNOUNCEMENTS: Member groups wishing to submit a meeting or conference announcement to the Alert are asked to provide information in the following format: conference name, date, location, contact information, name of organization, mailing address, and telephone number and e-mail address.

First Non-Ketotic Hyperglycinemia Family Get-Together * Dec. 20; Clearwater, Fl. For more information contact Mary Lou Chandler at 407-578-1789 or Karen Carter at 813-799-4977.

Fifteen Years of Orphan Drug Experience sponsored by the Drug Information Association * Jan 12-13; Hyatt Bethesda Hotel, Bethesda, MD. Contact Carol Pratt at 215-628-2288.

Families USA Consumer Health Action '98 National Grassroots Meeting * Jan 22-24, 1998; Mayflower Hotel, Washington, DC. Contact Jeff Kirsch at 202-628-3030.


5th Joint Clinical Genetics Meeting sponsored by the American College of Medical Genetics/March of Dimes * February 27-March 1, 1998; Los Angeles, CA. Contact: ACMG. Tel: 301-530-7127.

The 15th Annual Clinical Care Symposium for NF * Feb 26, 1998; Century Plaza Hotel (Westwood Room), Los Angeles, CA. Contact Francine Morris at 212-344-NNFF (in conjunction with 5th Joint Clinical Genetics Meeting).


Southeastern Regional Genetics Group 16th Annual Meeting * March 20-21, 1998; Sheraton Colony Square Hotel, Atlanta, GA. Contact Mary Rose Lane, SERGG Coordinator, at 404-727-5844.


"Genetics and Occupational Therapy Practice and Ethical Considerations," inspired by the Alliance HuGEMII Project, a short training course in which a consumer from a genetic support group will participate along with HuGEM faculty. * April 6, 1998; Baltimore, MD. Contact Joan Weiss at the Alliance on Mondays or Wednesdays.

Help for People Living with Cancer, A Five Part Teleconference Seminar Series sponsored by Cancer Care, Inc.* Jan 28, Feb 25, March 25, April 29, June 24, 12noon - 1PM EST; Contact Carolyn Messner, A.C.S.W. at 1-800-813-HOPE or 212-302-2400.