"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

ALLIANCE UPDATE:
We are gearing up for 1998 State and Federal Legislative Agendas and look forward to reconnecting with you! New phone and e-mail technology will help expand our reach without sacrificing the human touch: For general requests, call 202-966-5557; for helpline assistance, call 1-800-336-GENE. Helpline callers will talk to a live human being; other calls will be greeted by voice or voice mail. If you haven’t received an answer to an e-mail request this past month, try again. Our email was down for more than three weeks, but now we have a fast and efficient connection through a direct internet line. If all else fails, come visit us, face-to-face, at 4301 Connecticut Ave. NW, Suite 404, Washington D.C. 20008. A very special thanks to everyone who made a special year-end donation to the Alliance.

New Consumer Scholarship Fund: To support more active consumer involvement in policy making, Alliance staff has decided to establish a special scholarship fund. This was inspired by a generous holiday contribution from Dr. Linda Randolph, in the names of 21 genetic counselors from ALFIGEN/The Genetics Institute, and matched by the generosity of Alliance staff. Special thanks to the founders of this new program and to future contributors!

STATE LEGISLATIVE UPDATE: State legislation has focused more on protection of health insurance than protections in the workplace. At least 31 states introduced proposals to protect health insurance in 1997 and 11 passed antidiscrimination legislation: Alabama, Arizona, Connecticut, Florida, Hawaii, Illinois, Indiana, Nevada, North Carolina, Tennessee, and Texas. Arizona, Illinois, North Carolina, and Texas enacted workplace antidiscrimination legislation. State laws differ tremendously in how they define genetic information, third party access and legal recourse. Many states that have not passed legislation are looking to Congress to pass Federal legislation that would provide protection for all Americans. Continuing progress on the state level is an important factor in strengthening national commitment to Federal protections. For further information on state legislative progress, contact Barbara Fuller, J.D., at the National Human Genome Research Institute, NIH, at 301-402-0955.

FEDERAL LEGISLATIVE UPDATE: Vice-President Gore Endorses Genetic Legislation: At the Third Annual James Watson Lecture on January 20, organized by The Genome Action Coalition, Vice-President Gore received the James Watson Award and called for legislation to prevent genetic discrimination in the workplace. Gore discussed the tremendous promise as well as the potential for misuse of genomic research. "We want legislation that will prevent employers from requesting or requiring genetic information for hiring or for setting salaries; that will stop employers from using this genetic information to discriminate or segregate the workplace; and that will ensure that genetic information is not disclosed without the explicit permission of the individual." Senate Staff Briefing on Genetic Discrimination in Employment: On January 23, Executive Director, Mary Davidson, spoke passionately about consumer reports of genetic discrimination in employment and health care. Other panel members included Mary Jo Ellis Kahn, of the NAPBC Working Group on Hereditary Susceptibility; Francis Collins, M.D., Ph.D., Director of the National Human Genome Research Institute; Marvin Krislov, Acting Solicitor, U.S. Dept. of Labor; Karen Rothenberg, J.D., Director, Law and Health Care Program University of Maryland School of Law; and Lewis Maltby, Director of the ACLU National Task Force on Civil Liberties in the Workplace. Sponsored by Senator Daschle and Representatives Lowey, Lazio, Slaughter, Stearns, and Kennedy, this informative and well-attended briefing introduced staffers to the scientific, legal, regulatory and human aspects of genetic discrimination. For copies, call 202-966-5557, ext. 207. Please remember: we need real life case histories to put a human face on this problem for legislators, the public and the media.
Alliance Board Member to Testify: Jannine Cody, M.S., a member of the Alliance Board of Directors and president of the Chromosome 18 Registry and Research Society, will testify on January 29 before the House Appropriations Committee for Labor, Health, and Human Service. Jannine will attest to this committee, which determines House budget recommendations for the National Institutes of Health, the need for increased funding for clinical research on chromosome abnormalities. Jannine's statement will be available through the Alliance.

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.


Surviving with Survivors presented by Cancer Care Inc., and the National Brain Tumor Foundation is a free teleconference for caregivers and friends of brain tumor patients * February 18, 1998 12:00-1:00 PM ET; Contact the Cancer Care Counseling Line at 800-813-HOPE or Cancer Care's National Office at 212-302-2400.

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 at 301-530-7127.

The 15th Annual Clinical Care Symposium for NF * February 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 * April 6, 1998; Baltimore, MD. A short training course for occupational therapists taught by HuGEM faculty and consumers from support groups. Contact Joan Weiss, HuGEM Co-Director, at the Alliance on Mondays or Wednesdays at 202-966-5557 ext. 205.

Genetics in the 90s Conference * April 3, 1998; Children's Hospital Education Center, Columbus Ohio. Contact Eleanor Garrison, Professional Conference Coordinator at 614-722-4939


Thirteenth Annual TAG Patient/Parent Conference * April 25, 1998; Courtyard Marriot, Laguardia Airport, NY. Contact TAG at 1-800-522-7222.

Alliance of Genetic Support Groups 1998 Membership Meeting * Partnerships in Policy, Genetic Services and Education * September 11 to 13, 1998; Key Bridge Marriot Hotel, Washington D.C. Contact Mary Ann Wilson at the Alliance at 1-800-336-4363. Mark your calendars now!

Alliance Executive Committee: Joan Burns, M.S., President; Jayne Mackta, Past President; Leslie A. Platt, Esq., Treasurer; Peggy Mann Rinehart, Vice-President for Consumers; Ann C.M. Smith, M.A., Vice-President for Professionals. Alliance Board of Directors: Jannine Cody, Ph.D.; Brad Margus, M.B.A.; Theresa Hadley, M.S.W.; Betsy Trombino; Debra Collins, M.S.; Susanne B. Emmerich; Nelson Freed. Medical Advisor: Reed Erwin Pyeritz, M.D., Ph.D. Alliance Executive Director: Mary E. Davidson, M.S.W.