"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.

HEALTHCARE

“Evaluating Managed Care Plans for Children with Special Needs—a Purchaser’s Tool”: A product of the Children with Special Health Care Needs Continuing Education Institute at Children’s Hospital, Columbus, Ohio, this evaluation tool will assist purchasers in selecting and evaluating the capacity of health plans to serve children, particularly those with chronic conditions. The Purchaser’s Tool is not copyright protected. It is available on the ICHP website: http://www.ichp.edu/mchb/purchaser/ or by contacting John Reiss, Ph.D., ICHP, 5700 SW 34th Street, Suite 323, Gainesville, FL 32608; email: jgr@ichp.edu.

Task Force on Employment of People with Disabilities: President Clinton signed Executive Order No. 13078 on March 13, establishing the National Task Force on Employment of Adults with Disabilities. The task force will submit 4 reports over the next three years that will analyze existing programs and make recommendations to expand employment opportunities of working-age individuals with disabilities. For more information, call Becky Ogle at the President’s Committee on Employment of People with Disabilities at 202-219-6001 ext. 147.

Congratulations to Julie Gordon of MUMS: Julie Gordon, Executive Director of Mothers United for Moral Support (MUMS)/National Parent-to-Parent Network received the University of Wisconsin-Green Bay Distinguished Alumni Award. Julie reported that the ceremony gave her an opportunity to thank her mother for all the years of help, and for the wonderful example she set with her life of giving, teaching Julie that to be truly happy one must devote their life to helping others. Congratulations and keep up the good work!

LEGISLATION

Controversial Amendment to IDEA Withdrew: Senator Gregg (R-NH) proposed and withdrew the Individuals with Disabilities Education Act (IDEA) Flexibility Amendment to the Cordwell A+ Education Savings Account Act that would have authorized state and local educational agencies to establish their own discipline policies for students with disabilities. The IDEA Flexibility Amendment was opposed by The Arc and others based on concerns that it would have repealed the important due process protections and taken us back to the pre-IDEA times when children with disabilities were undereducated or totally denied an education. In a related event on April 22, a joint Congressional hearing was held to review the IDEA regulations proposed by the Department of Education. There was dialogue between the conservative Congressional members and Judy Heumann, Assistant Secretary of the Dept. of Education’s Office of Special Education and Rehabilitation Services on the interpretations of these regulations. For more information, contact Kim Musheno at The Arc at 202-785-3388.

ALLIANCE NEWS

Send in Your Nominations: It’s time again to submit nominations for The Art of Listening Award. This award is presented to the professional who best demonstrates that, “Hearing is a gift, listening is an art.” Any professional who takes the time and has the ability to listen and understand is eligible. To nominate someone who you feel meets these qualifications, write a letter to Alliance Board member Jayne Mackta, c/o the Alliance, explaining why this person should be recognized. Travel and lodging expenses for the winner and the nominator are covered. All other funding for this award, to be presented at the September 1998 Alliance Membership Meeting, is provided by a grant from the Morris J. and Betty Kaplun Foundation.

Update on Consumer Guidelines for Quality Genetic Services: The Partnership Program is happy to report that responses to the blue survey in last month’s Alert are still rolling in on a daily basis. If you didn’t get a chance to fill out a survey to identify the ten most important aspects of quality genetic services, contact Bowie Little at the Alliance, x203. We will publish the results of the Alert survey and surveys collected at a recent focus group with the consumer committee of GLaRGG in an upcoming Alert...

The Alliance ALERT is a publication of the Alliance of Genetic Support Groups. 4301 Connecticut Avenue, Suite 404, Washington DC 20008 • 1-800-336-GENE • 202-966-5557 • e-mail: info@geneticalliance.org • fax: 202-966-8553 • website address: http://www.geneticalliance.org • The Alert is funded in part by Project #2MCJ-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.
HuGEM II Update: A survey to determine confidence levels in working with families with genetic disorders is about to be mailed to a random sample of the memberships of 6 national allied health professional organizations involved with HuGEM II. As part of the project’s continuing efforts to orient the leadership of these organizations to the role of their membership in helping consumers, Kathy Hunter of the International Rett Syndrome Association and Paul Mendelsohn of Neurofibromatosis, Inc. described their positive experiences with occupational therapists to the staff of the American Occupational Therapy Association (AOTA). HuGEM’s first 3 hour pilot training workshop was received with great enthusiasm at the national AOTA conference. As a result, 13 occupational therapists have committed to training others with the help of HuGEM materials.

REQUESTS FOR RESEARCH PARTICIPANTS
The Alliance dedicates a section of the Alert to announce approved genetic disease research projects. Information on approved studies will be published in the Alert as space allows, and a copy of the study’s informed consent protocol must be included upon submission. The Alliance advocates comprehensive written informed consent protocols to promote more informed, prepared, collaborative and beneficial consumer research participation.

Gene Therapy for Ornithine Transcarbamylase Deficiency: Participants for this OTC deficiency gene therapy study are being sought by researchers at the University of Pennsylvania School of Medicine. Applicants should be between the ages of 18-25 and be either female carriers for the disorder or males with partial deficiencies. Travel expenses are covered for patients and for an accompanying support person. An 11-day hospital stay is required. Contact Marge Rose at 215-895-3584; email: mrose@childrens-seashore.org.

OCCUPATIONAL THERAPISTS GET INVOLVED
Employment Fair for Job Seekers with Disabilities: Sponsored by the President’s Committee on Employment of People with Disabilities and Johnson & Johnson, this fair, to be held in New Orleans, LA, will include positions from across the country and is open to all job seekers with disabilities. A list of employers and their hiring needs will be available at the registration desk to enable applicants to target recruiters who are seeking their particular skills. Candidates should bring a supply of resumes and arrive prepared for on-the-spot interviews, which will take place May 8, 1998, from 9:30am to 3pm. Register by calling Carol Dunlap at 202-376-6200, ext. 37 (voice) or 202-376-6205 (TTY), or if you are unable to attend, contact Nancy Hsu, ext. 210 after May 12 at the Alliance for a list of the job opportunities.

“Job Links” Now on Web: Job seekers with disabilities or employers with job openings are encouraged to visit “Job Links” at the President’s Committee on Employment of People with Disabilities website (http://www.peepa.gov/joblinks.htm) to post or respond to job openings. The Committee also operates the Job Accommodation Network (JAN), a toll-free information service on disability accommodations in the workplace and the employment supervision of the Americans with Disabilities Act—1-800-526-7234.

Postdoctoral Fellowships for Research on Fragile X Syndrome: FRAXA Research Foundation is a private, nonprofit organization which funds biomedical research aimed at finding specific treatments for Fragile X syndrome. Grant applications are accepted twice a year, on May 1 or November 1. Applicants are encouraged to submit a one-page letter of intent prior to submission of a full proposal. Contact Katherine Clapp at 978-462-1866 or email: kclapp@fraxa.org.

GETTING TO KNOW THE COUNCIL OF REGIONAL NETWORKS FOR GENETIC SERVICES (CORN)
In coming months, the Alliance will introduce the ten regional genetics networks, which are an integral part of the Council of Regional Networks (http://www.cc.emory.edu/PEDiatrics/corn/corn.htm). Each regional network offers unique and valuable resources to consumers, professionals and the public. This month we introduce to you another long standing network—the Mid-Atlantic Regional Human Genetics Network (http://www.pitt.edu/~MARHGN). Funding for CORN is provided by the Genetic Services Branch of the Maternal and Child Health Bureau.

MID-ATLANTIC REGIONAL HUMAN GENETICS NETWORK (MARHGN) MISSION STATEMENT
The Mid-Atlantic Regional Human Genetics Network is a partnership of consumers, health care providers and other professionals, government agencies, and commercial enterprises whose mission is to:

• Provide opportunities for regionally based collaboration in education, research and relevant genetic activities,
• Promote access to appropriate high quality and efficiently provided genetic services,
• Develop, facilitate and support the efficient collection and utilization of quality genetics services data,
• Serve as a central resource for current and emerging information about genetics, and
• Support the ethical provision and use of genetics services and data, including a respect for privacy and confidentiality.
MARHGN is a seven-state consortium whose mission is to expand resources and improve genetic services in the Middle Atlantic Region (Delaware, Maryland, New Jersey, Pennsylvania, Virginia, West Virginia, and the District of Columbia) through Steering Committee meetings, educational projects, collaborative research, genetics data collection, and a regional newsletter. Founded in 1982, the consortium is comprised of over 100 active members and has a mailing list of over 2000 interested persons. Geneticists, genetic counselors, public health administrators, social workers, and consumers (users of genetic services) are all represented in MARHGN.

CURRENT MARHGN COMMITTEES
- Executive Committee
- Steering Committee
- State Coordinators Committee
- Birth Defects Committee
- Consumer Committee
- Data Committee
- Education Committee
- Finance Committee/Managed Care Task Force
- Newborn Screening Committee
- Nominating/Leadership Development Committee
- Project Development Committee
- Quality Assurance-Laboratory Interest Group
- Quality Assurance-Genetic Services Committee
- Sickle Cell Committee

NEW MARHGN RESOURCE HIGHLIGHTS
- Through a collaborative effort of the NJ Medical School and the March of Dimes, materials in Arabic on genetic counseling, amniocentesis, triple screen test, and other basic topics are now available through MARHGN. Call 973-972-3302.


**Contact MARHGN for other publications and resources. First copy is free of charge.**

GET INVOLVED WITH MARHGN!
- Request for proposal guidelines for subcontract awards from MARHGN for 1999-2000 will be available in the Fall of 1998 and will be due December 1998. Call MARHGN for application and details.
- Limited funding for travel expenses is available for first time attendees and active committee members for MARHGN activities. MARHGN invites consumers to be involved and active in the committees listed above.
- If you would like to be placed on the MARHGN mailing list to receive the quarterly newsletter, or want to verify your mailing address, contact MARHGN.

UPCOMING MARHGN ANNUAL MEETING: The Fall 1998 MARHGN annual meeting, “In the Public Eye: Genetics, the Internet, and the Media,” will be held Saturday-Monday, September 26-28, 1998, at the Sheraton City Centre Hotel in Washington, DC. Consumers and professionals are invited. Contact MARHGN for details.

CONTACT MARHGN:
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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, telephone number and e-mail address.


Families on the Frontier of Dying • May 21-22. The Ritz-Carlton, Philadelphia, PA. Presented by the Center for Bioethics, University of Pennsylvania Health Systems. Limited number of partial scholarships available. Contact Sally Nunn at snunn2@mail.med.upenn.edu or write to the Center for Bioethics, UPHS, 3401 Market St., Suite 321 Philadelphia, PA 19104.

National Neurofibromatosis Foundation International Consortium • June 7-10. Hotel Jerome, Aspen, CO. For details, contact Fran Morris at 212-344-6633.

National Down Syndrome Society National Conference • June 9-11. Lake Lawn Lodge, Delavan, WI. Call 1-800-221-4602 for details.
Alliance 1998 Membership Conference
FORGING GENETIC PARTNERSHIPS: RESEARCHERS, POLICY-MAKERS & CONSUMERS
September 11-13, 1998
Key Bridge Marriott Hotel, Washington D.C.
Conference Speakers: Alice Wexler, Ph.D. and Francis Collins, M.D., Ph.D.


9th Bi-Annual Maple Syrup Urine Disease • June 17-19. Willow Valley Resort, Lancaster, PA. Contact Kevin & Dawn Hahn, 1854 Agape Court, East Earl, PA 17519.


Annual Conference on Polycystic Kidney Disease • June 19-21. Crystal Gateway Marriott Hotel, Arlington, VA. Contact Tim Mastin at 1-800-PKD-CURE.

National Urea Cycle Foundation Annual Membership Meeting • June 19-21. Grand Milwaukee Hotel, Milwaukee, WI. Contact NUCDF at 1-800-38-NUCDF.

Huntington's Disease Society of America 13th Annual Convention • June 19-21. Marriott City Center Hotel, Denver, CO. Contact Amy Schoenbery at 212-242-1968, ext. 18.

Foundation for Ichthyosis and Related Skin-Types (FIRST) National Family Conference • June 19-21. Hilton, Cherry Hill, NJ. Contact FIRST at 1-800-545-3286.


19th Annual International Conference of the Cornelia de Lange Syndrome Foundation, “Thousands of Lakes, Millions of Dreams” • July 2-5. Minneapolis Hilton and Towers, Minneapolis, MN. Contact Gretchen Vakiener, 1-800-753-CDLS.

14th Annual National Marfan Foundation Conference • July 8-12. New York Hospital/Cornell Medical Center and the Roosevelt Hotel in New York City. Contact NMF at 1-800-8-MARFAN.

Williams Syndrome Association National Convention, “Together in Harmony, Fulfilling Dreams” • Radisson South and Plaza Tower, Minneapolis, MN. Contact the Williams Syndrome Association at 248-541-3630.


Alliance Board of Directors: 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; Jannine Cody, Ph.D.; Brenda Margus, M.B.A.; Theresa Hadley, M.S.W.; Betsy Trombino; Debra Collins, M.S.; Susanne B. Emmerich; Nelson Freed. Alliance Medical Advisor: Reed E. Pyeritz, M.D., Ph.D. Alliance Executive Director: Mary E. Davidson, M.S.W.