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

Bill Demby

President Clinton Speaks Out on Science and Technology: During his commencement address to the graduates of Morgan State University, in Baltimore, MD, last month, the President predicted that the next fifty years will be the age of biology. Aware of the many issues being raised by recent scientific and genetic breakthroughs, he outlined guiding principles, including that none of our discoveries should be used to label or discriminate against any group or individual. Focusing on genetic discrimination, Clinton applauded genetic research while warning of the potential misuse of genetic information: "Genetic testing has the potential to identify hidden inherited tendencies toward disease and spur early treatment. But that information could also be used ... by insurance companies and others to discriminate against and stigmatize people." Prepared to meet the challenge, the President stated, "I urge the Congress to pass bipartisan legislation to prohibit insurance companies from using genetic screening information to determine the premium rates or eligibility of Americans for health insurance." For more on legislative initiatives, please see the Alert insert.

Developing Standards of Care: As the Alliance launches the Partnership for Genetic Services Pilot Program, an important project objective will involve the development of consumer guidelines for quality genetic care. These will address consumer concerns such as access to accurate information about medical conditions, the involvement of the consumer in medical decisions, and the role of peer support services. We are in the process of gathering information from the following sources: The Council of Regional Networks for Genetic Services, the New York State Genetic Service Providers, Family Voices, the Agency for Health Care Policy and Research, the American Academy of Pediatrics, the National Society of Genetic Counselors, the American Society of Human Genetics, the American College of Medical Genetics, and the New England Regional Genetics Group. Anyone with information or sources on standards of genetic care to share with the Alliance should contact Arlen Pyenson at the office: 1-800-336-GENE.

New Video: Promise and Perils of Biotechnology: Genetic Testing: Produced at the University of California San Francisco and available through Cold Spring Harbor Laboratory Press (1-800-843-4388) or Pyramid Media (1-800-421-2304). This video is professional and engaging. After defining genetic testing, it tells two true stories of people who use genetic testing for different purposes. The first is a 24-year old woman whose mother has Huntington's Disease. She shares the decision-making process that led to her being tested, and at the end of the video, the results are revealed to her and the viewer. The second story is that of a mother and daughter who have familial hypercholesterolemia. They discuss the role of testing as an instructive incentive to making critical life-style changes in their eating habits. Both stories stress the importance, impact and usefulness of genetic testing as well the role of genetic counselors in guiding clients through the process. Recommended for health care providers, medical students, and students in high school and up. A teacher's guide is provided.

The Alert periodically contains reviews of videos and books. If you have a video or book to share or would like to write reviews, please contact Mary Davidson at the Alliance office.

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HISPANIC PRENATAL HOTLINE UP & RUNNING: As part of the Maternal and Child Health Bureau's campaign to promote early and regular prenatal care, the National Coalition of Hispanic Health and Human Services Organizations (COSSMHO) is operating the National Hispanic Prenatal Hotline to provide culturally appropriate, bilingual information and local referrals to Hispanic callers. The hotline number is 1-800-504-7081. Service providers are encouraged to share information for inclusion in this extensive and growing referral database. Contact Audrey Cohen at COSSMHO, 1501 16th Street NW, Washington, DC 20036; TEL: 202-797-4353 and ask for a survey form.

CF TESTING: Alliance Executive Director Mary Davidson recently served on an NIH Consensus Conference Panel which recommended — after two days of testimony and reports about CF Testing research studies — that CF testing be offered to all pregnant women, couples considering pregnancy and CF carriers. Recommendations emphasized that testing should be optional, confidential and accompanied by appropriate education, genetic counseling and informed consent procedures. In addition, the cost of the test should be covered by insurance. They did not recommend universal newborn screening at this time because research studies do not prove clear therapeutic value of early intervention.

HOT OFF THE PRESS: Does It Run in the Family: A Consumer's Guide to DNA Testing for Genetic Disorders by Doris Teichler Zallen (Rutgers University Press, New Brunswick, NJ). According to Joan Weiss, Founding Executive Director of the Alliance, Doris Zallen has heard the public cry for more basic, comprehensive and comprehensible information about human genetics and genetic testing. Her book is a must for anyone considering genetic testing and facing its personal, familial and societal implications. Julie Gordon of MUMS National Parent-to-Parent Network has endorsed Zallen's work and recommends it for professionals who work with families as well.

COORDINATION OF RARE DISEASE RESEARCH: Consumers and researchers, meeting for two days to enhance collaborative efforts and share perspectives, acknowledged the need to build a better partnership between research and participant communities, developing better communication, education and clarification of respective needs. There was also recognition of the need for increasing consumer involvement in research design and oversight. The consumer experience in rare disease research was well represented by Alliance staff, Mary Davidson and Mary Ann Wilson, and support group Executive Directors, Vicki Whitmore of Tuberous Sclerosis, Tom Moran of the Immune Deficiency Foundation, Sue Levi-Pearl of Tourette Syndrome Association and Brenda Duffy of Neurofibromatosis Inc., Mid-Atlantic. The contrasting perspectives of researchers and consumers surfaced in discussions around consumer concerns about genetic privacy, discrimination, tissue sample anonymity and informed consent protocols. There was also much discussion raised by research concerns about tissue sample availability, the difficulty of compliance with growing public requirements and the potential impact on the advance of genetic research. A full report based on panel recommendations will be issued in the near future and will set collaborative goals which will be reviewed in the fall and again in 12 months. The Alliance position statement on rare disease research is available by e-mail request.

YOU CAN HELP THE ALLIANCE GROW
We would like to encourage individuals to become members of the Alliance. Would you please promote this outreach by printing the following announcement in your own publication?

The (name of your group) is an organizational member of the Alliance of Genetic Support Groups. Our membership in this umbrella organization provides us with referrals from families as well as linkage to the professional medical community. The Alliance presents the concerns of genetic support group members to the public, the press and to policy-makers on the national level. You can broaden your view of genetic support groups and the issues critical to you by becoming an individual member of this flourishing coalition. An individual membership is $25, which includes 10 issues of the Alliance Alert as well as a vital connection to people and programs on the cutting edge of genetics. Donations are tax deductible. Contact the Alliance at 800-336-GENE or write to The Alliance of Genetic Support Groups, 35 Wisconsin Circle, Suite 440, Chevy Chase, MD 20815.
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.

**Autism Society of America National Conference** • July 8 - 12; The Hilton at Walt Disney World Village, Orlando, FL. For information, call 1-888-648-2033.

**The National Marfan Foundation Annual Conference** • July 9 - 13; Stanford Health Services and the Center for Marfan Syndrome and Related Connective Tissue Disorders in association with Lucile Salter Packard Children's Hospital, Stanford, CA. Contact NMF, 382 Main St., Port Washington, NY 11050; TEL: 1-800-8-MARFAN or 516-883-8040.

**United Leukodystrophy Foundation Conference** • July 10 - 13; South Point Conference Center, DeKalb, IL. Contact ULF, 2304 Highland Dr., Sycamore, IL 60178; TEL: 1-800-728-5483.

**International Conference on Mental Retardation: Genes, Brain and Behavior** • July 10 - 13; College of Staten Island, NY. Contact A. Snider, Institute for Basic Research, 1050 Forest Hill Rd., Staten Island, NY 10314; TEL: 718-494-5299.

**Annual CDGS Family Conference** • July 12; Kahler Hotel, next door to Mayo Clinic, Rochester, MN. Contact Donna Yunes, 4 Wryan Rd., Derry, NH 03038; TEL: 603-434-3064; e-mail: cdgforum@ultranet.com

**Treacher Collins Syndrome Symposium** • July 14; NYU Medical Center, NYC. Co-sponsored by The Institute of Reconstructive Plastic Surgery, The Treacher Collins Foundation and Forward Face - the Charity for Children with Craniofacial Conditions. Date for pre-registration has passed, but try anyway. Call Patricia Chibbaro at 1-800-FWD-FACE or 212-263-5205.

**Prader-Willi Syndrome Association (USA) National Conference** • July 17 - 19; Orlando, FL. Contact PWSA (USA) National Office, 2510 S. Brentwood Blvd., Suite 220, St. Louis, MO 63144-2326; TEL: 1-800-926-4797; e-mail: pwsausa@aol.com

**The MAGIC Foundation for Children's Growth Annual Convention** • July 17 - 20; Ramada O'Hare Hotel, Chicago, IL. Educational segments covering Growth Hormone Deficiency, Precocious Puberty, Congenital Adrenal Hyperplasia, Turner Syndrome, Russell-Silver Syndrome, thyroid disorders & McCune-Albright Syndrome. Contact The MAGIC Foundation for Children's Growth, 1327 N. Harlem Ave., Oak Park, IL 60302; TEL: 1-800-3MAGIC 3.

**Genetics & Ethics in the 21st Century** • July 18 - 20; The Given Institute of the University of Colorado, Aspen. Contact Office of Continuing Medical Education: 1-800-882-9153 or 1-303-372-9050.

**National Foundation for Ectodermal Dysplasias National Conference** • July 18 - 20; Portland, OR. Contact NFED, 219 E. Main St., P.O. Box 114, Mascoutah, IL 62258-0114; TEL: 618-566-2020; e-mail: nfed2@aol.com

**National Niemann-Pick Disease Foundation Annual Family Conference** • July 18 - 20; Rochester, MN. Contact National Niemann-Pick Disease Foundation, N1590 Fairview Lane, Fort Atkinson, WI 53538; TEL: 414-563-8677.

**Sotos Syndrome Support Association Annual Conference: All Over-growth Syndromes** • July 18 - 20; Novi, MI. Contact Ken Datte, 6884 McCain Rd., Spring Arbor, MI 49283; TEL: 517-750-2314.

**Klinefelter Syndrome and Associates (47XXY, 48XXXY, 49XXXXY, 47XXX, etc.) Annual Conference** Batten Disease Support and Research Association Annual International Conference • July 25 - 27; San Antonio, TX. Contact BDSRA, 2600 Parsons Ave., Columbus, OH 43207; TEL: 1-800-448-4570.

July 25 - 27; North Shore Hilton, Chicago (Skokie), IL. A multi-disciplinary KS Clinic will be held prior to the conference. Contact K.S. and Associates, P.O. Box 119, Roseville, CA; TEL: 773-761-5298; e-mail: ks47XXX@ix.netcom.com

Support Organization for Trisomy 18, 13, & Related Disorders (S.O.F.T.) Annual Conference • July 30 - Aug. 3; Salt Lake City, Utah. Scientific Session: Congenital Heart Defects and Malformation Syndromes, July 30. Contact Center for Pediatric Continuing Education, Primary Children's Medical Center: 1-800-910-7262 or 801-588-4060.

Late Onset Tay-Sachs Conference • Aug. 1 - 3; Wyndham Franklin Hotel, Philadelphia, PA; Contact Late Onset Tay-Sachs Foundation, 1303 Paper Mill Rd., Erdenheim, PA 19038-7025; TEL: 1-800-672-2022.

Parents of Galactosemic Children Conference • Aug. 8 - 9; DoubleTree Hotel, Austin, TX. Sponsored by TEXGENE, Texas Dept. of Health, and March of Dimes Defects Foundation. Contact Rhonda Bauer, 53 Pamela Lane, College Station, TX 77845; TEL: 409-731-8365.

National Down Syndrome Congress Annual Conference • Aug. 8 -10; Pointe Hilton Resort on South Mountain, Phoenix, AZ. Contact Paul Murphy at 1-800-232-6372; e-mail: ndsc@charitiesusa.com

Workshop on Machado-Joseph Disease • September (date not available yet); Santa Catarina, Brazil. Contact Dr. Iscia Lopes-Cendes, Institute of Neurosciences, Montreal General Hospital, Room L12-132, 1650 Cedar Ave., Montreal, Quebec PQ H3G 1A4, Canada; TEL: 514-937-6011, ext. 4519.

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.

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.

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

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.

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.

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., Boston, MA 02116; TEL: 617-423-4112.