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

Bill Demby

March 1997

A SHEEP BY ANY OTHER NAME: The latest genetic success story to raise curiosity, enthusiasm and eyebrows is, of course, the sheep cloning research in Scotland. Like other biotechnology advances, mammal cloning presents both promise and many concerns and questions. President Clinton sent a rapid mandate to the new National Bioethics Advisory Commission for deliberations on the ethical, legal and social implications of the process. We would like to hear member responses to this new research capability. You can send your opinions to the Alliance by telephone, e-mail, letter or fax. We will publish a summary in the next Alert.

CALLS FLOOD ALLIANCE: The Alliance information and referral calls this month spanned an unusual range of concerns and requests and increased three fold over the previous month. During the week of February 10, the toll-free lines were deluged with calls about genetic testing, genetic discrimination and more common, multifactorial and predispositional genetic diseases. They were a result of an article in a syndicated USA Today weekend article entitled: "Is Cancer in Your Genes?". Alliance staff and trained volunteers fielded inquiries about heart disease, different kinds of cancers, Alzheimers, arthritis and diabetes as well as increased requests from high school students doing research. As our 800 number casts a broader net via the Internet and in newspapers and numerous publications, we look forward to the assistance of trained resource volunteers and an improved phone and expanded database system. With the explosion of genetic information, the Alliance is taking giant steps to keep pace with growing public interest and need.

NETNEWS: The Office of Rare Diseases (ORD), National Institutes of Health (NIH), has launched a Home Page on the Internet. A valuable feature soon to be added is the newly developed ORD Rare Disease Clinical Research Database which is still being tested. We plan to take a cyber-tour of the site and will report back next month. Check it out for yourself: <http://rarediseases.info.nih.gov/ord>. Other new sites:
- National Tuberous Sclerosis Association: http://www.ntsa.org
- Klinefelter Syndrome and Associates: http://www.genetic.org
- Family Village, a global community of disability-related resources: http://www.familyvillage.wisc.edu

A GREAT LOSS: Neil Kurlander, former Treasurer of the Alliance, died on February 4. A gentle, generous and caring man, Neil helped many Alliance members and member organizations who needed his expertise and counsel in matters ranging from obtaining non-profit status to handling recalcitrant board members. As a member of the original Alliance Steering Committee and later as a member of the Board of Directors, he was always there when we needed him. Neil will be missed by us all.

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35 Wisconsin Circle, Suite 440, Chevy Chase, MD 20815 • 1-800-336-GENE • 301-652-5553 • e-mail: alliance@capaccess.org
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BOOK NOTES

Cultural and Ethnic Diversity: A Guide for Genetics Professionals is an excellent addition to the growing human genetics library. This book should reach not only genetics professionals, but all health care providers. The contributing authors focus on a variety of cultures, such as Amish, African American, Native American, Asian, and Latino as well as deaf, Jewish and Christian. Their message is loud and clear: how people live and make decisions is often defined by their cultural background. Although there have been several journal articles written on cultural diversity and genetics, this book is the first global attempt by several experts from diverse backgrounds to address specific ethnic and cultural beliefs and their implications for genetic services. It is long overdue!


Waist-High in The World: A Life Among the Nondisabled offers readers a penetrating and personal look into the world of adults with disabilities. Written by essayist Nancy Mairs, who uses a wheelchair as a result of progressive multiple sclerosis, this book covers subjects ranging from physical obstacles (the size of doorways) to the emotional challenges of dependency, depression, and public perceptions of people with disabilities. A gifted writer, Mairs offers insight and hope. Beacon, $20.

MATERIALS

Neurofibromatosis, A Guide for Educators. No charge, $1, s/h. The Many Faces of Neurofibromatosis, 23-min. educational video featuring medical experts, patients and families. $19.99 plus $4 s/h.

Send check or money order to National Neurofibromatosis Foundation, 95 Pine St., NYC, NY 10005.

The Tourette Syndrome Association has published a new catalog of publications and videos that contains a wealth of useful materials. A Medical ID card, a somal rearrangement. This very touching booklet is useful for those facing a similar grieving process. No charge for additional information, contact Barbara Lerner, MS, Brandeis Genetic Counseling Program, Brandeis University, Waltham, MA 02254; TEL: 617-736-3179.

A Managed Care Workshop A 2003-64907, or call 1-800-723-9166, ext. 11.

PUVA THERAPY: Everything You Might Want to Know, a course for physicians Saturday, April 5; Holiday Inn Chateau Le Moyne, New Orleans, LA. Sponsored by National Psoriasis Foundation, 6600 SW 92nd Ave., Suite 300, Portland, OR 97223-7195. Contact Julie House, 1-800-723-9166, ext. 11.

FROM THEORY INTO REALITY Genetics and Genetic Support Groups in the 21st Century Sat. April 5 from 8 am - 6 pm at Brandeis University, Waltham, MA. Presented by the Brandeis Genetic Counseling Program and the New England Regional Genetics Group (NERGG) Consumer Concerns Committee. Registration: $25. For registration forms and additional information, contact Barbara Lerner, MS, Brandeis Genetic Counseling Program, Brandeis University, Waltham, MA 02254; TEL: 617-736-3179.

UPCOMING MEETINGS

Great Plains Genetics Service Network (GPGEN) Annual Meeting April 3 - 5; Fargo, ND. A primary care workshop will be held at the same time. Contact Dolores Nesbit, Coordinator, The University of Iowa, Division of Medical Genetics, 200 Hawkins Dr, Iowa City, IA 52242-1083; TEL: 319-356-4860.

Great Lakes Regional Genetics Group (GLaRGG) Annual Meeting April 4 - 6; Wyndham Hotel, Cleveland, OH. Contact Louise Elbaum, Coordinator, University of Wisconsin Madison, 328 Waisman Center, 1500 Highland Ave., Madison, WI 53705; TEL: 608-265-3543; e-mail: elbaum@waisman.wisc.edu.

Wilson's Disease Association Annual Meeting April 4 - 6; Los Angeles, CA. Contact Phyllis King, P.O. Box 2305, Frazier Park, CA 93225; TEL: 805-245-0899.

Fundamentals of Phototherapy Workshop for Nurses and Technicians April 4 - 6; New Orleans, LA. Sponsored by National Psoriasis Foundation, 6600 SW 92nd Ave., Suite 300, Portland, OR 97223-7195. Contact Julie House, 1-800-723-9166, ext. 11.

A Managed Care Workshop April 10 - 12; Sheraton City Centre, Washington, DC. Co-sponsored by the Council of Regional Networks for Genetic Services (CORN) and HRSA. For information, call 404-727-1475.

AboutFace Annual Conference April 12 - 13; The Fairmont Hotel, New Orleans, LA. Contact AboutFace International, 49 Crowns Lane, 4th Fl, Toronto, Ontario, Canada MSR 3P4; TEL: 1-800-665-3223.

Genetic Testing for Cystic Fibrosis, NIH Consensus Development Conference April 13 - 15; Natcher Conference Center, Building 45, NIH, Bethesda, MD. Sponsored by National Human Genome Research Institute and the Office of Medical Applications of Research. Open to the public. For information, call 301-496-1144.

X-Linked SCID Family Conference April 18 - 19; Bethesda, MD. Co-sponsored by NIH/NIGMS/ES/IMM and the Immune Dysfunction Foundation for families and professionals to explore issues about genetic testing, treatment options and decision-making. For information, call Maddy Rutzebec: 1-800-286-4933.

National Tay-Sachs & Allied Diseases Ass'n Annual Conference May 1 - 4; Embassy Suites, San Francisco, CA. Contact NTSAD, 2001 Beacon St., #204, Brookline, MA 02146; TEL: 1-800-906-8723.

von Hippel-Lindau Annual Patient/Provider Conference May 2 - 4; Bethesda, MD. Contact VHL Family Alliance, 171 Clinton Rd, Brookline, MA 02146; TEL: 1-800-767-4VHL.

Alpha1 National Association Annual Educational Conference May 3 - 4; Boston, MA. Topics pertain to alpha-1 antitrypsin deficiency. Contact the Alpha1 National Association, 4220 Old Shakopee Rd., Suite 101, Minneapolis, MN 55437-2974; TEL: 1-800-521-3025 or 612-703-9979.

T.A.G. Patient/Parent Conference Saturday, May 17; Newark Airport Marriott, Newark, NJ. For all interested in Thalassemia Major and Intermedia. Call 1-800-935-0024.

First Annual Stickler Syndrome Conference June 6-8; Best Western, Cantonbury Inn, Iowa City, Iowa. Contact Stickler Involved People, 53 Angelina, Augusta, KS 67010; 316-775-2993.
Fundamentals of Phototherapy Workshop for Nurses and Technicians • June 6 - 8; Kansas City, MO. Sponsored by National Psoriasis Foundation, 6600 SW 92nd Ave., Suite 300, Portland, OR 97223-7195. Contact Julie Honse, 1-800-723-9166, ext. 11.

Velo-Cardio-Facial Syndrome Educational Foundation Annual Meeting • June 27 - 29; Stanford University Medical Center, Palo Alto, CA. Contact Lucy Burke, 426 Upton St., Redwood City, CA 94062; TEL: 415-365-8755; e-mail: Andipat@ix.netcom.net. The meeting is cosponsored by Stanford University Pediatrics Division of Endocrinology and by Genetic Medicine at Stanford University Medical Center.

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 Packard Children's Hospital, Stanford, CA. Contact NMF, 382 Main St., Port Washington, NY 11050; TEL: 1-800-8-MARFAN or 516-883-8040.

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

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: 1-800-3 MAGIC 3.

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 (47XXX, 48XXYY, 48XXX, 49XXXXY, 47XX etc.) Annual Conference • 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: ks47XX@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.

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

NORD Annual Conference • Sept. 25 - 28; Washington, DC. Two tracks: one for patients and families., the other for leaders of non-profit health agencies. Contact Dobry Hall, NORD, 100 Rt. 37, P.O. Box 8923, New Fairfield, CT 06812-8923; TEL: 203-746-6518.

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.

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.