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

Bill Demby

This Alert functions as 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

A Special Note from Joan Burns, President: It gives me great pleasure to officially welcome Mary Davidson, the new Executive Director, to the Alliance of Genetic Support Groups. She comes to our organization with a diverse background in medical social work, psychotherapy, and organizational development, and as a parent of a child with a genetic disorder. Mary has been working closely with the Board and staff for nearly two months now, and I can assure you that we are all pleased with her rapid grasp of the activities, mission and history of the Alliance. Our flourishing coalition has been carefully tended these past ten years by Joan Weiss, Founding Director. However, I can state with confidence that the Alliance continues in good hands. Why not contact Mary to introduce yourself? She is eager to get to know you and to learn about your organization. It will take all of us working together to ensure the continued growth, creativity and commitment that has always characterized the Alliance.

A Grand Time: The Alliance celebrated its tenth anniversary with a wonderful day filled with sharing and excitement on October 12 in Washington, DC. Members had an opportunity to acknowledge the many contributions of Founding Director Joan O. Weiss and to meet our new Executive Director, Mary Davidson. The computer workshop received rave reviews, and everyone agreed that networking opportunities were unparalleled. Elections were held, and the new Board takes office as of January 1.

Executive Committee
Joan Burns, President
Peggy Mann Rinehart, Vice President for Consumers
Ann C.M. Smith, Vice President for Professionals
Leslie A. Platt, Treasurer
Jayne Mackta, Immediate Past President

Medical Director: Reed Pyeritz

Directors
Jannine Cody
Debra L. Collins
Susanne Bross Emmerich
Theresa Hadley
Brad Margus
Betsy Trombino

The President has also appointed Nelson Freed to serve as Chairman of the Social Issues Committee.

“Art of Listening” Award: Guests assembled for the Gala joined a representative of the International Fibrodysplasia Ossificans Progressiva Association to recognize the outstanding listening skills of Dr. Frederick S. Kaplan, Chief of the Division of Metabolic Bone Diseases at the University of Pennsylvania Medical Center. Fibrodysplasia Ossificans Progressiva means “soft connective tissue that progressively turns to bone.” FOP is an autosomal dominant condition, and in most cases is the result of a new mutation. It is estimated that FOP affects approximately one in two million people. At the present time, researchers are aware of fewer than 200 people worldwide who have FOP. Certificates of Recognition will be mailed to all the wonderful professionals nominated for this year’s award.

And the Winner is . . . ABC News received the “Art of Reporting” Award for the production of several compelling and sensitive programs during 1996 on the ethical and social implications of genetic testing and research. A representative of Little People of America presented the award to Kathleen Kennedy, Producer of ABC News Nightline. Also present was Brad Margus whose family appeared in a segment of 20/20 focusing on the impact of Ataxia Telangiectasia.

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New on the Net: *The Gene Letter* is an Internet-Based newsletter on the scientific and societal issues in genetics. The purpose of this electronic newsletter is to inform consumers and professionals about advances in genetics and to encourage discourse about emerging medical, ethical, legal and policy dilemmas. It is funded by a grant from the US Department of Energy/ELSI Program. The editors are Philip R. Reilly, MD, JD, Dorothy C. Wertz, PhD, and Robin JR Blatt, RN, MPH. *The Gene Letter* also operates an uncensored chatroom. Check it out: WWW.geneletter.org

Another Way to Communicate: Thanks to a listing collected by Debra Collins, who coordinated our recent computer workshop for member groups with the Alliance's onstaff computer expert, Martha Volner, we will be listing the websites of Alliance members and other relevant online resources from time to time. Check them out for presentation ideas as well as information. For a listing of 105 addresses, contact the Alliance at 1-800-336-GENE.

http://medhelp.netusa.net/www/agsg.htm
http://www.albinism.org
http://www.med.jhu.edu/ataxia
http://mars.uthscsa.edu/Society
http://www.ultranet.com/~smith/CMTNet.html
http://www-bfs.ucsd.edu/dwarfism/lpa.htm
http://www.phoenix.net/~leigh/EDS
http://q.continuum.net/~wrosen/gaucher.html
http://www.boystown.org/hiirr/
http://www.emi.net/~iron-iodHemochromatosis
http://www.hht.org
http://medhelp.netusa.net/mlmv/www/nipf.htm
http://www.vicnet.net.au/~sands/sands.htm
http://www.marfan.org
http://www.kumc.edu/GEC/support smith-ma.html
http://mcrcr4.med.nyu.edu/~murphp01/taysachs.htm
http://www.turner-syndrome-us.org
http://www.kumc.edu/GEC/vhl/vhlhomep.html
http://www.medhelp.org/wda/wil.htm

Alliance of Genetic Support Groups
Nat'l. Org. for Albinism and Hypopigmentation (NOAH)
National Ataxia Foundation
Ataxia Telangiectasia Children's Project
The Chromosome 18 Registry and Research Society
Charcot -Marie-Tooth
Little People of America
Ehlers-Danlos National Foundation
Gaucher disease
Hereditary Hearing Impairment Registry
Iron Overload Diseases Association
Hereditary Hemorrhagic Telangiectasia
National Incontinentia Pigmenti Foundation
SANDS — miscarriage, stillbirth, neonatal death
National Marfan Foundation
Smith-Magenis Syndrome: PRISMS
Natl. Tay-Sachs & Allied Diseases Association
Turner Syndrome Society
Von Hippel-Lindau Syndrome
Wilson's Disease Association

NEW ADDRESS: Hermansky-Pudlak Syndrome Network, Inc., 1 South Road, Oyster Bay, LI, New York 11771-1905. Hermansky-Pudlak Syndrome is a metabolic genetic disorder that involves a platelet dysfunction with prolonged bleeding, legal blindness and albinism. It also involves a ceroid storage disease with the most common complications being pulmonary fibrosis, granulomatous inflammatory bowel disease and kidney disease. Founder & President: Donna Jean Appell, RN; TEL: 516-922-3440; 1-800-789-9HPS; FAX: 516-922-4022; e-mail: appel@theonramp.net; website: http://www.medhelp.org/web/htsn.htm

IMPORTANT REMINDER: Be sure to call the Alliance when you change your address and/or telephone. It is frustrating to a family reaching out, perhaps for the first time, to hear that a number has been disconnected. We need to stay in touch, and we want the information we share through the *Directory of Voluntary Genetic Organizations* to be accurate.

SPECIAL OFFER: Copies of the *Directory of Voluntary Genetic Organizations* are now available for $10 each when purchased in packages of three. Call the Alliance to order this invaluable resource: 1-800-336-GENE.

REMINDER: Dues notices have been mailed out to individual and organizational members. We would appreciate your prompt renewal. Thank you.
HuGEM Results Make News: The October 25 edition of Science magazine published the results of a study conducted under the auspices of the Human Genome Model Education Project (HuGEM) of Georgetown University Child Development Center and the Alliance. Entitled “Genetic Discrimination: Perspectives of Consumers,” the article was co-authored by Alliance Founding Director Joan O. Weiss, E. Virginia Lapham and Chahira Kozma, who reported on the perceptions of 332 members of genetic support groups with one or more of 101 different genetic disorders in the family. It was found that as a result of a genetic disorder, 25% of the respondents or affected family members believed they were refused life insurance; 22% believed they were refused health insurance; and 13% believed they were denied or fired from a job. Fear of genetic discrimination resulted in 9% of respondents or family members refusing to be tested for genetic conditions; 18% not revealing genetic information to insurers; and 17% not revealing information to employers. Overall, 43% of those questioned believed they were a victim of at least one of these forms of discrimination. The level of perceived discrimination points to the need for more information to determine the extent and scope of the problem. We are pleased to report that the article generated stories about genetic discrimination in the Washington Post, Wall Street Journal, and Science News. Both the article and the issue of genetic discrimination were covered live by CNN and reported on by Reuters, Knight-Ridder, UPI and AP.

Klinefelter Study: Brenda Eskenazi, a professor at University of California, Berkeley School of Public Health, and Andy Wyrobek, a researcher at Lawrence Livermore National Laboratory, are studying whether the rate of aneuploidy (extra chromosomes) in the sperm of fathers is different, depending on whether the father did or did not contribute the extra X chromosome. They seek families with a son who is less than six years old with a karyotype of 47-XXY. The father, mother and son will be asked to participate in the study. Contact the Klinefelter Study Office at 510-642-9545 (collect calls accepted).

Potential Funding Source: The Genentech Foundation for Growth and Development provides grant support for clinical research and educational programs related to problems of growth and development in children. The Foundation is also interested in psychosocial issues related to these concerns. The Foundation requires that applicants for small educational grants submit a one page abstract which will be reviewed in a timely manner by administrative staff. Should the proposed project be consistent with the interests of the Foundation, the office will send the applicant organization a formal application package. Educational projects funded have dealt with Turner syndrome, Prader-Willi syndrome, growth hormone deficiency and related disorders.

The Foundation requires that applicants be health care professionals in the U.S. working directly in the areas of growth and development. They assume that support groups have medical advisory boards which can assist and participate in the application process. The Foundation anticipates awarding up to ten grants in 1997 of $2,000 to $5,000. Deadlines are January 23, May 15, and September 30. Letters of inquiry should arrive 2-3 months prior to these deadlines. They may be sent to Genentech Foundation for Growth and Development, Robert Blizzard, MD, President: 1224 West Main St., 7th flr., Suite 701, Charlottesville, Virginia 22903; TEL: 804-977-8192.

New Booklet Series for Families with HD

- Huntington's Disease: A Guide for Families provides an overview of the disorder by discussing topics such as symptoms and stages, being at-risk, treatment and other issues.
- Coping with Speech and Swallowing Difficulties in Huntington's Disease: A Guide for Families helps families to understand why these problems occur and what can be done at home to help manage them. This 25-page booklet also shows how a speech-language pathologist and other professionals can assist in improving the quality of life for the person with HD.

Single copies of these booklets are available free of charge. Additional copies cost $1 each. To order, contact Huntington's Disease Society of America, 140 West 22nd Street, 6th Floor, NYC, NY 10011-2420; TEL: 212-242-1968. Toll-free HD Information Line: 1-800-345-HDSA.

Volunteers may work for free, but they don't work for nothing! (Thanks to Erma Bombeck) The Alliance is recruiting volunteers in the Washington, DC area to work at the office a few hours a week. Call Mary Davidson if you have any local contacts who may wish to help others by helping out at the office: 1-800-336-GENE.
UPCOMING MEETINGS

New England Regional Genetics Group (NERGG) Annual Meeting • December 5 - 6; The New England Center, University of New Hampshire, Durham. Contact Joseph Robinson, Coordinator, P.O. Box 670, Mt. Desert, ME 04660; TEL: 207-288-2704.

James Watson Lecture and Awards Ceremony • Jan. 14, 1997; National Academy of Sciences, Washington, DC. Dr. Frances Collins will deliver the James Watson Lecture. Senators Nancy Kassebaum and Edward Kennedy will receive Congressional Awards. ABC News, CNN and the Washington Post will be recognized for their consistent quality of coverage of genetics and genomics issues. Contact The Genome Action Coalition, 317 Massachusetts Ave NE, Suite 100, Washington, DC 20002.


Hermansky-Pudlak Syndrome Network Family Conference • January 18 - 19, 1997; Long Island Marriott, Uniondale, LI, NY. Contact HPS Network, Inc., 1 South Road, Oyster Bay, NY 11771-1905; TEL: 516-922-3440; 1-800-789-9HPS; e-mail: appell@theonramp.net

March of Dimes Birth Defects Foundation Perinatal Nursing Conference • February 6 - 7; 1997, Sheraton Chicago, IL. For information, call 312-435-4007.

Joint Clinical Genetics Meeting • Feb. 28 - March 2; Ft. Lauderdale, FL. March of Dimes Meeting: Prenatal Diagnosis; The American College of Medical Genetics Meeting: Advances in the Practice of Clinical Genetics. March 3: Billing and Reimbursement Workshop sponsored by The ACMG; March 3 - 4: Neurogenetics Short Course sponsored by National Society of Genetic Counselors in conjunction with the ACMG. Contact The ACMG, 9650 Rockville Pike, Bethesda, MD 20814-3998; TEL: 301-530-7127.

Research!America Advocacy Awards Dinner • March 12; National Academy of Sciences, Washington, DC. Contact Research!America, 1522 King Street, Alexandria, VA 22314; TEL: 703-739-2577.

Pacific Northwest Regional Genetics Group (PacNoRGG) Annual Meeting • March 12 - 14; Benson Hotel, Portland, Oregon. Contact Kerry Silvey, Coordinator, PacNoRGG Office, CDRC, Clinical Services Bldg., 901 E. 18th Ave., Eugene, OR 97403-5254; TEL: 541-346-2610; e-mail: kerry_silvey@ccmail.uoregon.edu

Great Plains Genetics Service Network (GPGSN) Annual Meeting • April 3 - 5; Fargo, ND. A primary care workshop will be held at the same time. Contact Dolores Nesbitt, 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: 805-245-0889

FROM THEORY INTO REALITY — Genetics and Genetic Support Groups in the 21st Century • Saturday, April 5 from 8 am - 6 pm at Brandeis University, Waltham, MA. An overview of the new genetics, its technologies and their relevance to support groups, this conference will offer a combination of lectures, panel discussion, and hands-on workshops in molecular genetics, cytogenetics, and computer laboratories. It is directed towards genetic support group leaders, board members, directors, coordinators, and anyone else thinking about running a genetic support group. Presented by the Brandeis Genetic Counseling Program and the New England Regional Genetics Group (NERGG) Consumer Concerns Committee. Registration: $25. For more information, contact Barbara Lerner, MS, Brandeis Genetic Counseling Program, Brandeis University, Waltham, MA 02254; TEL: 617-736-3179.

First Annual Stickler Syndrome Conference • June 6-8; Best Western, Canterbury Inn, Iowa City, Iowa. Contact Stickler Involved People, 53 Angelina, Augusta, KS 67010; 316-775-2993.