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

Bill Demby

In Memory of Jacquelyn Eoline Smith: The Alliance expresses heartfelt condolences to Tracy and Damon Smith whose infant daughter was born and passed away on May 29, 1998. We thank the Smith family and friends who generously made donations to the Alliance in memory of Jacquelyn.

HEALTH CARE AND LEGISLATION
July is Hemochromatosis Screening Awareness Month! There are still almost 1.5 million Americans with undiagnosed hemochromatosis. This condition is easily treated, and treatment can prevent organ damage if the condition is not too advanced. For more information, contact the Hemochromatosis Foundation at (518) 489-0972.

Genetic Nondiscrimination Legislation: The Alliance is keeping abreast of developments in the Senate Labor and Human Resources Committee. At this point there are fundamental differences between the two parties regarding the definition of genetic information. The Alliance advocates a definition that includes genes, gene products and family history. It is very important that senators hear consumer's concerns about this definition! The Alliance staff can provide assistance with contacting the Labor and Human Resources Committee. For discussion of this critical issue send your name, affiliation and e-mail address to “Legislative Link” at info@geneticalliance.org.

ALLIANCE NEWS
Information Resource Center: Database Updates - Thanks for your patience and cooperation as we made updates to our database! This updated information will be printed by September into a 1998 edition of the Alliance Directory of Genetic Voluntary Support Groups. Free 1995 Alliance Directory - The Alliance is offering 1995 Directories for only $5.00 to cover shipping and handling. Simply send us a letter stating your request, along with a check. The updated version of the Directory will be available by September. Share the Alert! Any portion of the Alert can be used in your newsletters. We ask only that you provide a citation and give us regular feedback on the usefulness of articles to your members, patients, or friends.

Partnership for Genetic Services Pilot Program Update: In collaboration with GLaRGG, the medical school project mailed information packets to genetics programs, medical schools and genetics coordinators in the Great Lakes area to solicit sponsor interest for Consumer Educators. Interest has been expressed from the following locations: Mayo Clinic, Wright State, Indiana Dept. of Health and the University of Chicago. Program staff are currently refining the training curriculum for the next Consumer Educator session in November '98. Anyone interested can contact Bowie at 800-232-1370 ext 203. In collaboration with MARHGN and PacNoRGG, the managed care project completed a preliminary report to the NYLCare Health Plans corporate office in New York City after a series of interviews with corporate medical staff. We are talking with Kaiser Permanente Mid-Atlantic about implementation of BRCA 1&2 guidelines in their delivery system. There has been a phenomenal response to our requests for sample resources to include with offerings to our managed care pilot sites. We would like to take this opportunity to commend your efforts toward educating and providing support for our community.

Genetics Institute for Nursing Faculty: The Alliance is helping to explore the impact of human genetics on nursing education and practice. On June 24 Joan Weiss, Alliance Founding Director, facilitated a consumer panel at the Summer Genetics Institute for Nursing Faculty in Cincinnati, Ohio. Panelists represented the following Alliance member organizations: NF, Inc.; National Marfan Fdn.; Little People of America; Mid-Atlantic Regional Genetics Network Consumer Committee; Cystic Fibrosis Fdn.; and the Huntington’s Disease Society of America.

Please Send Board of Directors Nominations: Elections are coming up this fall and we are looking for new talent and energy. Send your suggestions to Betsy Trombino, chair of the nominations committee at jbtrom@aol.com.

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: Surveys were sent to a random sample of the memberships of the seven collaborating health professional organizations to determine needs, competencies and priorities for education about genetics and related ethical, legal, and psychosocial issues. National staff of the American Physical Therapy Association met with HuGEM faculty to begin plans to educate and sensitize APTA members about genetic issues. Suzanne Richard of the Osteogenesis Imperfecta Foundation gave an inspiring account of personal experiences with physical therapists.

ALLIANCE MEMBERSHIP MEETING

Please help us get the word out about our membership meeting by including the following information in your organization’s next newsletter.

Alliance of Genetic Support Groups 1998 Membership Meeting:

Forging Genetic Partnerships: Researchers, Policymakers and Consumers

September 11-13, 1998 at the Key Bridge Marriott Hotel, Arlington, Virginia

A weekend of exciting events for consumers and professionals has been planned. Take a behind the scenes look at NIH and Capitol Hill; receive training in communicating with the media, policymakers, and care providers; exchange ideas and information with other support groups at a poster session highlighting the accomplishments of all our members; participate in panels on genetics research partnerships, managed care, and the impact of consumers on policy; and hear from Francis Collins, MD, PhD, Director of the National Human Genome Research Institute; Paul Steven Miller, Commissioner of the US Equal Employment Opportunity Commission; and Alice Wexler, PhD, author of Mapping Fate. This meeting is designed to empower consumers to be active policy advocates and encourage partnerships among consumers and professionals.

Registration deadline is August 15, 1998.

Contact Tracy Gilris at 202-966-5557 x205 for more information and registration forms.

Send in Your Nominations: The Art of Listening Award and the Art of Reporting Award are presented to a professional and to a reporter who demonstrate compassion and understanding of individuals and families with genetic conditions. Send your nomination letter to Alliance Past President Jayne Mackta, c/o the Alliance. Travel expenses for winners and their nominator to the September 1998 Alliance Membership Meeting are provided through a grant from the Morris J. and Betty Kaplun Foundation.

OTHER USEFUL RESOURCES

ABA Children’s SSI Project Toll-Free Numbers for Free Legal Assistance: The American Bar Association Children’s Project has compiled a list of hotline numbers for families to obtain free legal help in obtaining SSI benefits. Families can call a number specific to their state for a referral to free legal assistance, including legal services offices and private attorneys who are working for free on these cases. You can call the Social Security Administration at 1-800-772-1213 to find the number for your state, or call Holly Landrum at the Alliance, ext. 211.

UPDATES FROM OUR MEMBERS

Ambassadors for Awareness needs your help! The Great Lakes Regional Genetics Group is in the process of developing slide sets for teachers that illustrate a variety of genetic conditions. This project is a response to teacher inquiries on how to educate students about genetics. The project will help to “humanize” genetic conditions by developing slides that depict people with genetic conditions doing various activities. Each slide will be accompanied by a vignette about the person shown, written by that person or a family member, and a description of the condition written by a genetic counselor. GLaRGG is requesting help in preparing this slide set. If you are interested, please contact Susan Klenk, Dept. Med. Genetics and Birth Defects, The Children’s Medical Center, One Children’s Plaza, Dayton, OH. 45404 or call (937) 226-8480.

Research grant for SMA researchers: Families of SMA plans to fund an additional $1.2 million in research grants in 1998. The funding will include independent research grants and post-doctoral fellowship grants to study SMA. Interested parties should send a letter of intent and a one-page abstract. Send abstracts to: Families of SMA PO Box 196 Libertyville, IL 60048-0198 Fax (847) 367-7623 e-mail: SMA@interaccess.com. NO CALLS, PLEASE.

GETTING TO KNOW THE REGIONAL GENETICS NETWORKS -- PacNoRGG

This month we continue our introduction to the ten regional genetics networks and the Council of Regional Networks (CORN at http://www.cc.emory.edu/PEDIATRICS/corn/corn.htm.). Each regional network is separately funded and administered, and offers unique and valuable resources to consumers, professionals and the public. This month we introduce you to Pacific Northwest Regional Genetics Group, PacNoRGG. (http://www.ichp.edu/mchb/pacnorgg/). PacNoRGG receives funding from the Genetic Services Branch of the Maternal and Child Health Bureau.

PacNoRGG is a group of genetic services providers, consumers, public health professionals, and educators working together to improve services for families in our region - Alaska, Idaho, Oregon, and Washington, who are impacted by genetic conditions. Members volunteer their time and skills to complete the activities of the following committees and subcommittees: Consumer, Data, Education, Cancer Genetics, Ethics, Genetic Services Delivery & Public Health,
Prenatal Diagnosis, Quality Assurance-Biochemical Genetics, Quality Assurance-Cytogenetics and Screening. The activities of each committee can be viewed on the PacNoRGG Website.

PacNoRGG is one of the three regional networks working with the Alliance Partnership Program and consumers are actively involved in all activities. Consumers write articles for the newsletter, Genetics Northwest, help plan regional conferences, develop educational materials, guide the website and plan the annual meeting. PacNoRGG conferences feature family panels. Approximately 110 regional and local genetics-related support groups or chapters are listed in the PacNoRGG Directory of Genetic Support Groups and will soon be posted on the website.

Consumer Publications Available for Order — Many publications are available online.

- Maternal Serum Marker Screening, A Test for Pregnant Women (booklet, Spanish translation in development)
- Multiple Serum Marker Test: A Blood Screening Test for Any Pregnant Woman (fact sheet, Spanish available)
- Preventing Neural Tube Defects, for Couples at Increased Risk (fact sheet, Spanish available)
- Testing for Huntington Disease: Making an Informed Choice (booklet)
- There's No Reason to Face it Alone, Questions You May Have For Your Health Care Provider (brochure, Spanish available)
- Why Do DNA Testing or Banking? (fact sheet)
- Will I Have a Healthy Baby? (brochure in Cambodian, Chinese, Korean, Laotian, Russian, Spanish, Vietnamese)
- Carbamyl Phosphate Synthetase Deficiency - A Guide For Parents (booklet)
- Ketone Utilization Disorder (Beta-ketothiolase Deficiency) - A Guide For Parents (booklet)
- Glutaric Acidemia Type II - A Guide for Parents (booklet)
- Medium Chain ACYL-CoA Dehydrogenase Deficiency: MCAD-A Guide For Parents (booklet)
- Isovaleric Acidemia - A Guide For Parents (booklet)

Alaska, Idaho, Oregon, and Washington consumers are invited to become active PacNoRGG members and to sign up for the Genetics Northwest mailing list!

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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.

Annual Cystinosis Foundation Conference • July 2-4. Ann Arbor, MI. Call Jean Hobbs Hotz at 1-800-392-8458.


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.


National Down Syndrome Society Conference: The Future is Ours • July 9-11. Lake Lawn Lodge Resort, Develan, WI. Call 1-800-221-4602.


Dental & Genetic Aspects of Ectodermal Dysplasias • July 9. Chapel Hill, NC. Followed by:


Aicardi Syndrome Family Conference • July 17-19. Holiday Inn Conference Center, Fairborn, OH. Contact Denise Park at 937-368-2137.

20th Annual Prader-Willi Syndrome Association • July 22-25. Columbus, OH. Contact PWSA at 1-800-926-4797.

4th Annual MAGIC Foundation Convention • July 23-26. Chicago Marriott Oak Brook Hotel, Oak Brook, IL. Contact MAGIC at 1-800-3-MAGIC-3.

Late Onset Tay Sachs Foundation Annual Conference • July 23-25. Wyndam Franklin Plaza Hotel. Contact Bobbi Fishbein at 1-800-672-2022.


Alzheimer’s Association 7th National Alzheimer’s Disease Education Conference • July 26-29. Indianapolis Convention Center, Indianapolis, IN. Contact Michael Pirages at 312-335-5764.

Scleroderma Foundation Annual Conference: Celebrating New Horizons • July 30-August 1. DoubleTree Hotel at Post Oak, Houston TX. Call 1-800-722-HOPE.

Batten Disease Support and Research Association International Family Conference • July 30-August 2. Omni Richmond Hotel, Richmond, VA. Contact Debbie Lowther at 919-774-1933.

National Association of Pseudoxanthum Elasticum • July 31-August 2. Denver, CO. Call NAPE at 303-355-3866.

Families of Spinal Muscular Atrophy Annual Family & Professional Conference • July 31-August 2. Hyatt Regency Technology Center, Denver, CO. Contact Families of SMA at 1-800-886-1762.


New Treatments in Genetic Disorders • September 26. Brandeis University, Waltham MA. Hosted by NERGG, the Brandeis Univ. Genetic Counseling Program, and the Developmental Evaluation Center at Boston Children’s Hospital. Contact the Conference Coordinator at 781-736-3179.


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.; Brad 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.