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

Editors: Holly Landrum and Mary Davidson

ALLIANCE MEMBERSHIP MEETING
Join consumers and professionals at our biennial membership conference, Forging Genetic Partnerships: Researchers, Policymakers and Consumers from September 11 to 13! Registration will be accepted on a space available basis. The late registration fee is $110 after August 15. You can attend for one day only for $50 per day. The Key Bridge Marriott Hotel in Arlington, Virginia will be the center of meeting activities, tours, panels, networking and events. For more information contact Tracy Gilris at 202-966-5557 ext. 205 or tgilris@geneticalliance.org.

PUBLIC POLICY, HEALTH CARE AND LEGISLATION
Advisory Committee on Genetic Testing: Health and Human Services Secretary Donna Shalala announced creation of an HHS Advisory Committee on Genetic Testing to draft policies on the development and regulation of genetic testing, building on the progress of the Genetic Testing Task Force and National Human Genome Research Institute ELSI Working Group. Central issues include assurance of patient confidentiality and test accuracy and development of informed consent standards. This Committee will work closely with the Clinical Laboratory Improvement Advisory Committee and the Medical Devices Advisory Committee. The Alliance is working to assure a strong consumer voice on this committee and solicits your thoughts and opinions about genetic testing regulatory policies.

Institute of Medicine Report on Scientific Opportunities and Public Needs: Improving Priority Setting and Public Input at the National Institutes of Health: This IOM report, released on July, 8 1998, validates an Alliance guiding principle: “Meaningful progress in research, legislation and policy requires the full participation of consumers.” Four of the report’s twelve recommendations to NIH underscore the necessity of assuring consumer involvement at advisory council and review committee levels in every institute at the National Institutes of Health. The report recommends that the public and consumers must play a more significant role in deciding about allocation of research funds. The executive and full reports are available on-line at http://www.nap.edu/readingroom/books/nih and in hardcopy from National Academy Press, 1-800-624-6242, for $30.00.

Patient Bills of Rights and Managed Care Reform: Issues critical to the consumer community are the focus of the several versions of the Patient Bill of Rights emerging from both Democrats and Republicans in the House and Senate. Take a close look at the competing legislative proposals in terms of these particular issues: extent of coverage of all insured Americans, guaranteed access to specialists and “point-of-service” options, external appeals mechanisms, disclosure restrictions and recourse and penalties for malpractice decisions. Call your state Senator or Representative or their staff to ask where they stand on these points. They need to hear from us!

CHIP Update: The Balanced Budget Act of 1997 allocated funds for a new healthcare initiative to provide health benefits to children whose families do not meet Medicaid criteria, but whose children are uninsured or underinsured. The CHIP program allows each state to extend the Medicaid income limit and develop a new plan for CHIP coverage, or a combination of the two, in an effort to expand healthcare coverage for underserved children. Several CHIP progress reports suggest that increased numbers of children are finally receiving healthcare services. However, reports also indicate that underinsured children, who may benefit from this initiative, are not receiving benefits or may not meet the eligibility requirements. For information and an application for your state’s CHIP Program, contact your local Department of Health and Human Services office. State contact information is available from the Alliance at 1-800-336-4363. For up-to-date reports on the CHIP Program, visit the Health Care Financing Administration website (http://www.hcfa.gov/chip), Families USA (http://www.familiesusa.org), Children’s Defense Fund (http://www.childrensdefense.org) and the Urban Institute (http://newfederalism.urban.org). Families USA offers a 500-page resource guide that details CHIP implementation, which is available for $30.00 at (202) 628-3030.
IRBs AND CLINICAL RESEARCH

Institutional Review Board Update: IRBs were developed to assure that research studies protect the health, well-being and confidentiality of human research subjects whose participation contributes to advances in medical science. IRBs review and approve/disapprove research proposals to be conducted in government, hospital and institutional settings and/or receive public funds. The Alliance has long supported the principle that IRB efficacy requires the representation of consumers on review panels to assure IRB sensitivity to the needs of clinical research participants they are charged with protecting.

Institutional Review Boards: A Time for Reform, a report from the Office of the Inspector General, Department of Health and Human Services: This report, published on June 11, 1998, documents concerns about variability of Institutional Review Board (IRB) effectiveness in providing sufficient protections of human subjects in clinical research studies. The report was based on testimonies to the House Reform and Oversight Committee concerning the efficacy of IRBs in clinical research. Proposed recommendations suggest the need to reform the IRB process to provide better protection for research study participants and to provide greater consumer and public contribution to the IRB process. The full report is available on-line at http://www.dhhs.gov/progorg/org as a PDF file and must be viewed with the Adobe Acrobat Reader. To receive a free hardcopy call 202-619-1142.

Office of Rare Diseases (NIH) Report on the Rare Diseases and Conditions Research Activities 1997: This publication includes a summary of recent scientific advances in rare disease research and information about specific research projects in 20 NIH Institutes. The report is available on-line at http://www.rarediseases.info.nih.gov/ord. A limited number are available in hardcopy from ORD at 301-402-4336.


IRBs in the Shifting Sands of Public Opinion: Public Responsibility in Medicine (PRIM&R) and Applied Research Ethics National Association’s (ARENA) annual conference will take place in San Diego, CA on November 8-9, 1998. Issues that will be covered include the recent reports issued by the Inspector General, NIH and the NBAC; genetics; privacy of patient records and informed consent. Please contact the PRIM&R/ARENA office for information at 617-423-4112 or e-mail prmr@aol.com.

IN MEMORY OF
Frank Greenberg, MD, a brilliant geneticist and caring physician, died last month after a long illness. All of us who knew Frank will miss his wise consultations, his warmth and humor and his zealous dedication to the profession of medical genetics. We are appreciative that Frank chose the Alliance of Genetic Support Groups as one of his favorite charities. If you would like to contribute to his memory in this way, please earmark your contribution to the Frank Greenberg, MD, Alliance Memorial Fund.

ALLIANCE NEWS

Welcome to New Alliance Members!
The following organizations have recently become members of the Alliance: 9 TIPS (Trisomy International Parent Support), 22q and You Center, Ara Parseghian Medical Research Foundation, Children’s Liver Alliance, Chromosome 9p- Network, Dystonia Medical Research Foundation, Familial GI Cancer Registry, GeneCare Medical Genetics Center, Glaucoma Research Foundation, Goldenhar Fund, Huntington’s Disease Society of America, Mid-Michigan Chapter, Marsden Walker Family Support Group, Mosaic Trisomy 16 Registry and Resource Group, Pacific Southwest Regional Genetics Group (PSRGN), P.A.G.E.R. (Pediatric/Adolescent Gastroesophageal Reflux Association), Prune Belly Syndrome Network, Southeast Regional Genetics Group (SERGG), Y-Me National Breast Cancer Organization.

HuGEM II Update: Come hear the HuGEM presentation and visit our poster display at the Alliance Membership Meeting! HuGEM faculty, in addition to consumers from Alliance member organizations, are now scheduled through the end of this year for the following training workshops and presentations: the American Dietetic Assn.-Oct. in Kansas City; the National Assn. of Social Workers- Nov. in Greensboro, NC; the American Speech and Hearing Assn.- Nov. in San Antonio; and the American Psychological Assn.- Dec. in Bethesda, MD.

OTHER USEFUL RESOURCES

The Center for Studying Health System Change Annual Report: This publication looks back on significant health related events of 1997. This includes documentation about the changes in healthcare services and delivery, based largely on surveys of consumers, physicians and employers. To obtain a copy of this annual report contact the Center for Studying Health System Change, 600 Maryland Avenue SW, Suite 550, Washington, DC 20024, 202-484-9258, http://www.hschange.com.