Forging Genetic Partnerships:

Researchers, Policymakers and Consumers

September 11, 12, & 13, 1998
Key Bridge Marriott Hotel, Arlington, VA

Meaningful progress in policy, research and legislation requires partnerships among all stakeholders in the genetics community and the active involvement of consumers. The biennial meeting of the Alliance of Genetic Support Groups brings together consumers and professionals to exchange perspectives, sharpen advocacy skills and combine forces to promote the interests of children, adults and families living with genetic conditions.

The goals of this exciting three day meeting — just across the Potomac River from Washington DC — are:

- to arm participants with the basic skills to become informed policy advocates and research participants;
- to stimulate partnerships with researchers, policymakers, providers and other health care coalitions; and
- to strengthen the consumer voice in research, health care delivery and public policy discussions.

Participants will equip themselves with the tools and knowledge to take a seat around the table with policy task forces, Institutional Review Boards, the media and health care providers. Join friends and colleagues for a program packed with tours of Capitol Hill and the National Institutes of Health (NIH), interactive workshops, briefings, informal exchange, exhibits, awards banquet and more. While you’re here, we hope you plan additional time to explore the monuments, parks and free museums that historic Washington has to offer!
Preliminary Program

FRIDAY, SEPTEMBER 11

9:00-11:00
Continental Breakfast and Registration

11:00-12:00
Welcome: Joan Burns, President of the Alliance of Genetic Support Groups
Opening Speaker: "Forging Partnerships for Change"
Paul Steven Miller, Commissioner of the U.S. Equal Employment Opportunity Commission and former Alliance Board member.

12:00-5:00
Tours and Briefings: On-site with Policymakers and Researchers

Capitol Hill and Congress: Visit the U.S. Senate office building where Lyle Dennis, Director of The Genome Action Coalition and Sharon and Patrick Terry of PXE International will give a briefing on the inner workings of Congress. Take a tour of Capitol Hill or have pre-arranged appointments with your Congressional representatives and visit their offices. Pre-registration is required; transportation and box lunch will be provided. An information packet will be sent out before the meeting.

OR

National Institutes of Health and National Human Genome Research Institute: Travel to the National Institutes of Health (NIH) in Bethesda, Maryland, for an introduction to the research programs and resources of the National Institutes by Stephen Groft, PharmD, Director, Office of Rare Diseases and a presentation on gene therapy by Richard Morgan, PhD, Investigator for the Clinical Gene Therapy Branch, Gene Transfer Technology Section, NHGRI. A tour of the National Human Genome Research Institute labs will follow. Transportation and box lunch will be provided; pre-registration is required. Participants will receive an information packet.

5:30-7:00
Poster Session and Reception: Renew Alliances with Consumer Partners
Enjoy a light meal while learning about our member organizations and Alliance educational projects from poster displays and information exchange about their activities and materials. This is a good opportunity to learn how other groups raise money, design websites, put together a research program, provide member support and develop public education programs.

7:00
"The Cutting Edge": A Play Demonstrating the Issues Surrounding Genetic Testing
An acclaimed dramatic presentation, written by Jason Kravits and performed by the Bethesda Academy of Performing Arts, will illustrate the impact of decision-making issues on family relationships. Tickets are free to conference attendees and $5.00 for outside guests.
8:00-9:00  Continental Breakfast

9:00-10:00  Opening: Joan Burns, President, Alliance of Genetic Support Groups
Mary Davidson, Executive Director, Alliance of Genetic Support Groups
Speaker: “Genetic Promises and Realities”
Francis S. Collins, MD, PhD, Director, National Human Genome Research Institute,
National Institutes of Health

10:00-11:00  Partnerships in Health Care Delivery: The staff of the Alliance’s Partnership for Genetic Services Pilot Program will describe the development of partnerships among managed care consumers, providers and medical schools to improve the delivery of genetics services.

Partnerships in Public Policy: Stephanie Marshall, Director of Government Affairs, National Health Council will provide an overview of genetics legislation introduced in the 105th Congress.

11:00-11:15  Coffee Break

11:15-12:45  Session I - Creating Partnerships with Health Care Providers
Moderator: Nachama L. Wilker, Program Director, Partnership for Genetics Services Pilot Program, Alliance of Genetic Support Groups
Case Managers: Your Partner Through the System
Suzanne Parker, RN, Nurse Case Manager, Aetna U.S. Healthcare

Primary Care Providers: A Link to Genetic Services
Margaretia Jackson, MD, Associate Medical Director, NYLCare Health Plans of the Mid-Atlantic

Employers: The Other Consumer
Lawrence W. Ulvila, Jr., MBA, President and CEO, Insurance Solutions

Consumers: A Guide to Navigating the System
Lauren Bridge, RNMN, Research Associate, Families as Participants and Family Voices

OR

Session II - Consumer Impact on Public Policy in Research, Health Care and Employment
Moderator: Stephanie Marshall, Director of Government Affairs, National Health Council
Consumer, Congressional, industry, and government panelists will discuss the consumer’s role in defining policies in research, health care and employment. Participants to be announced.

12:45-1:45  Lunch is a networking opportunity and will be served on the hotel’s 14th floor with a panoramic view of the Potomac River and DC cityscape.
1:45-3:45  Alliance of Genetic Support Groups Membership Meeting: “Looking Toward the Year 2000”
  Joan Burns, Alliance President, will chair the business/strategy meeting. Alliance members, Board and staff will meet to discuss Year 2000 priorities, assess Alliance achievements over the past two years, hear reports about Alliance programs and review Board proposed by-laws revisions.
  Mary Davidson, Alliance Executive Director, will update members on achievements and challenges facing the Alliance and consumers.
  Michele Puryear, MD, PhD, Chief, Genetics Services Branch of MCH and Alliance program officer, will talk about consumer involvement in public policy issues.

3:45-4:00  Coffee Break

4:00-5:30  Session III - Genetics Research Partnerships: Consumer Involvement with Informed Consent, IRB, Tissue Bank and Clinical Research Issues
  Moderator: Stephen Groft, PharmD, Director, Office of Rare Diseases

  Informed Consent in Research: Robert F. Murray, Jr., MD, Chairman, Division of Medical Genetics, Howard University College of Medicine and Patrick Terry, PXE International

  Institutional Review Boards (IRBs): Freda E. Yoder, MA, Human Subjects Protection Analyst, Office for Protection from Research Risks and Jannine Cody, PhD, Chromosome 18 Registry and Research Society

  Brain and Tissue Banks: Ron Zielke, PhD, Director, Brain and Tissue Bank for Developmental Disorders, University of Maryland and Paul Mendelsohn, Neurofibromatosis, Inc., Mid-Atlantic Chapter

  Clinical Research Partnerships: John J. Mulvihill MD, Chairman, Department of Human Genetics, University of Pittsburgh, School of Public Health and Vicky H. Whittemore, PhD, National Tuberous Sclerosis Association

5:30-7:00  Free Time

7:00-9:30  Dinner and Program: “How to Tell Our Story”
  Alice Wexler, PhD, author of Mapping Fate, a personal account of her family’s experiences with Huntington’s disease.

  Awards Ceremony: “The Art of Listening” and “The Art of Reporting”
  In recognition of a health care provider and media reporter’s unique compassion and commitment to consumers and consumer issues.
SUNDAY, SEPTEMBER 13

9:00-12:00  Session IV - Personal Stories as Strategies: Making an Impact on Newsmedia, Policymakers and Care Providers

9:00-10:00  “Power of Story: Captivating your Audience”
  Peggy Mann Rinehart, Director of Communications, Division of General Pediatrics and Adolescent Health, University of Minnesota

10:00-12:00  Three 40-minute interactive training sessions: Three groups will rotate through all three sessions.
  Talking with the Media: Learn how to talk to the press and to radio/TV interviewers to get out your message - Christine Harding, President, Media Concepts
  Talking with Policymakers: Maximize your impact in giving testimony and in individual conversations with legislators - John McGing, Chromosome 18 Registry & Research Society
  Talking with Care Providers: Build a family-centered partnership with your providers - Peggy Mann Rinehart

12:00-12:30  Closing: Consumers and Professionals Together Create Powerful Coalitions for Change
  Joan Burns, President, Alliance of Genetic Support Groups
  Mary Davidson, Executive Director, Alliance of Genetic Support Groups

Meeting at a Glance

Registration Fees: include materials, three continental breakfasts, two lunches, two coffee breaks, Friday night reception and play, Saturday night banquet.

- $95 per person prior to August 15 deadline
- $75 additional family/organizational member prior to August 15 deadline
- $110 per person after the August 15 deadline

How to register:
Please complete the form and return it to the Alliance by August 15, 1998. Following this date, registration will be accepted on a space available basis. For each additional person attending the conference you may photocopy the form and fill it out or call the Alliance for additional registration forms.

Send all forms to:
Alliance of Genetic Support Groups -
Membership Meeting
Attn. Tracy Gilris
4301 Connecticut Ave. NW, Suite 404
Washington, DC 20008-2304

Please direct questions to:
Tracy Gilris
202-966-5557, ext.205

Full payment must accompany your form in order to process your registration.