Empowerment ALLIANCE
OF GENETIC SUPPORT GROUPS

A Symposium to explore strategies of "Empowerment" through knowledge and skill-building for individuals, families and professionals involved with genetic disorders

November 4-5, 1988
Ramada Renaissance Washington, D.C.

Supported by the March of Dimes Birth Defects Foundation
Hoffmann-La Roche
Empowerment --
1. the gaining of knowledge and skills that enable;
2. the process by which one gains confidence in one's own abilities;
3. the focus of the Alliance of Genetic Support Groups' Symposium, Nov. 4-5, 1988

This symposium is open to consumers of genetics services, their families and professionals in the field. Its goal is to promote maximum health care and social and psychological functioning for genetically affected individuals and their families through a strengthened consumer-professional partnership.

PROGRAM
FRIDAY, NOVEMBER 4, 1988

7:30 am - 8:30 am Registration
8:30 am - 9:00 am THE ALLIANCE: EMPOWERING THE CONSUMER
Presenters:
Greg Weidg, President
Alliance of Genetic Support Groups
Jane Lin-Fu, Chief
Genetics Services Branch
Bureau of Maternal and Child Health

9:00 am - 10:00 am PLENARY SESSION I
NETWORK BUILDING FOR EMPOWERMENT
Panel:
Abbey Meyers, Executive Director
National Organization for Rare Disorders
F. John Meaney, President
Council of Regional Genetics Networks
10:00 am - 10:30 am Break
10:30 am - Noon WORKSHOPS (5)
EMPOWERING CONSUMERS THROUGH THE REGIONAL GENETICS NETWORKS

Workshop Leaders

Dolores Nesbitt
Great Plains Genetics Service Network (GPGSN)

Carla Lawson
Great Plains Genetics Service Network (GPGSN)

John Carey
Mountain States Regional Genetics Services Network (MSRGN)

Lori Weigle
Mid Atlantic Regional Human Genetics Network (MARHGN)

Carl Cooley
New England Regional Genetics Group (NERGCG)

Betsy Anderson
New England Regional Genetics Group (NERGCG)

Diane Baker
Great Lakes Regional Genetics Group (GLaRCG)

Barbara Michel
Great Lakes Regional Genetics Group (GLaRCG)

Stephen Amato
Mid Atlantic Regional Human Genetics Network (MARHGN)

Desiree Dodson
Southeastern Regional Genetics Group (SERGC)

Noon - 1:30 pm Dutch Treat Lunch
1:30 pm - 3:00 pm PLENARY SESSION II
IDENTIFYING NEEDS; EXPLORING SOLUTIONS
Panel:
Joan Burns, Clinical Professor
Medical Genetics and Social Work
University of Wisconsin, Madison
What makes "genetics" a common bond?

John Carey, Associate Professor
Pediatrics, University of Utah
A professional's role during diagnosis

Jane Feldman, Consumer
Mother of a Tay-Sachs child
The immediate impact of hearing a diagnosis

George McCoy, Consumer
Person with hemophilia
Living with a genetic disorder

3:00 pm - 3:30 pm Break
3:30 pm - 5:00 pm WORKSHOPS (5)

SKILLS FOR EMPOWERMENT
1. How to Start Self-Help Groups
   Leaders: Barbara Fairfield
            Deborah Maesey

2. How to Start Peer Counseling Programs
   Leaders: Barbara Bernhardt
            Janice Starr

3. How to Start Cross-Genetic Disorder Groups
   Leaders: Priscilla Ciccarelielo
            Martha MacMillan

4. How to Meet Life Cycle Needs of Your Members
   Leaders: Joan Burns
            Peter Ciccarelielo

5. How to Increase Public Awareness of the Genetic Disorders Represented by Your Group
   Leaders: Mary Ann Wilson
            John Carey

5:00 pm - 6:00 pm RECEPTION
Underwritten by Hoffmann-La Roche
Introducing
Genetics: Investigating the Mosaic of Life

6:00 pm - 8:00 pm EMPOWERMENT THROUGH THE MEDIA
Speakers:
Larry Thompson
Science Editor
THE WASHINGTON POST
Tari Susan Hartman
Marketing & Media Consultant
EIN SOF Communications
PROGRAM
SATURDAY, NOVEMBER 5, 1988

8:00 am - 8:30 am       Continental Breakfast

8:30 am - 10:00 am      PLENARY SESSION III
                        FINANCIAL EMPOWERMENT:
                        Problems, Needs, Future Directions

Panel:                  Robert Greenstein, Professor
                        Pediatrics; Division of Human Genetics
                        University of Connecticut Health Center

                        Betsy Anderson, Parent
                        Director of Health Issues
                        Federation of Children with Special Needs

                        Greg Weigle, President
                        Alliance of Genetic Support Groups

10:00 am - 10:45 am     Closing Remarks

10:45 am - 11:00 am     Break

11:00 am - 1:00 pm      Business Meeting
                        ALLIANCE OF GENETIC SUPPORT GROUPS
                        Special Report on Survey of Membership
                        to Identify Gaps in Services

                        Rita Beck Black

OPEN TO ALL

The Alliance of Genetic Support Groups is dedicated
to fostering a partnership among consumers and
professionals to increase awareness about genetic
disorders, to improve the availability and appropriateness
of genetics services, and to represent the common needs and concerns of our members.
Membership is open to individuals, support groups, and national organizations and associations.

The Alliance is funded in part by The Department of Health and Human Services, Bureau of Maternal and Child Health and Resources Development; the March of Dimes Birth Defects Foundation; donors.

SYMPHONY CO-CHAIRS
JAYNE MACKTIA
JOAN O. WEISS
Symposium Coordinator
Brett Emmerson

About the Speakers

Larry Thompson is the science editor of the Health news section of The Washington Post.

Before joining The Post in 1984 as assistant editor of the Health section, Thompson was the editor of the Science and Medicine section of the San Jose Mercury News. From 1978 to 1983, he served as the medical editor of the Call-Chronicle Newspapers in Allentown, PA. In 1977, he was a fellow of the Yale School of Medicine.

Thompson holds a bachelor of science degree in Molecular Biology from Lehigh University.

Tari Susan Hartman is past Executive Director of the Media Access Office (liaison between the entertainment industry and the disability community) and creator of the Screen Actors' Guild Committee of Performers with Disabilities. During the past decade, she has pioneered efforts to educate, motivate and activate the entertainment industry regarding increased employment of people with disabilities. Her advocacy has been focused towards changing attitudes through media portrayals, development of media access skills and the use of the media to gain empowerment. Hartman's company, EIN SOF Communications, is the first to specialize in marketing and media consultation in terms of the disability community and social issues.

Genetics: Investigating the Mosaic of Life

Hoffmann-La Roche, a leading research-intensive health care company based in Nutley, NJ is underwriting the Friday evening reception where a revised edition of a science curriculum supplement entitled "Genetics: Investigating the Mosaic of Life" will be introduced. Roche developed the supplement in conjunction with the National Organization for Rare Disorders. It is designed for use by teachers in junior high school education to provide students with a good understanding of the principles of genetics, including the causes, symptoms, and possible treatments of certain genetic disorders and the careers that involve or relate to genetic science.

March of Dimes Birth Defects Foundation
The Alliance is grateful for the enthusiastic support of the March of Dimes Birth Defects Foundation whose funding has helped to strengthen the consumer-professional partnership and to promote the