



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 Weigle, *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 (NERGG)

Betsy Anderson

New England Regional Genetics Group (NERGG)

Diane Baker

Great Lakes Regional Genetics Group (GLaRGG)

Barbara Michel

Great Lakes Regional Genetics Group (GLaRGG)

Stephen Amato

Mid Atlantic Regional Human Genetics Network (MARHGN)

Desiree Dodson

Southeastern Regional Genetics Group (SERGG)

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

PROGRAM FRIDAY, NOVEMBER 4, 1988

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 Massey
2. How to Start Peer Counseling Programs
Leaders: Barbara Bernhardt
Janice Starr
3. How to Start Cross-Genetic Disorder Groups
Leaders: Priscilla Ciccariello
Martha MacMillan
4. How to Meet Life Cycle Needs of Your Members
Leaders: Joan Burns
Peter Ciccariello
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 BANQUET

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, dona-

SYMPOSIUM CO-CHAIRS

JAYNE MACKTA

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 and improved portrayal 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