Empowerment

ALLIANCE

OF GENETIC SUPPORT GROUPS

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

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

Supported by
the March of Dimes
Birth Defects Foundation
Empowerment -- em·pow'er·ment (n)
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 Alliance of Genetic Support Group's Symposium.

Hotel Accommodations
Rooms have been set aside for symposium registrants at the special rate of $78 per night per room, (either single or double occupancy) plus taxes. All registrations must be made through the Alliance before October 10 and be accompanied by one night's deposit. Reservations made after October 10 will be accepted on a space available basis at prevailing hotel rates. Make check or money order payable to: The Alliance of Genetic Support Groups

Funding
There are no funds available through the Alliance for scholarships. If you need funds to help defray costs, explore whether any of the following have special funds which might be tapped: your national organization or association, if one exists; your Regional Genetics Network; local service clubs such as Kiwanis, Lions, Rotary, Civitan, JayCees, or the local chapter of the March of Dimes; religious groups; women's groups and fraternal organizations. Contact the community affairs department of major companies in your local area.

It is a good idea to try to call your target to determine if grants are given. If so, ask the criteria and the procedure for applying. In many cases, you will only need a short letter describing your situation and the benefits you expect to derive from attending the symposium. If possible, include a brochure, a newsletter, a newspaper article, or some material to demonstrate your credibility. If you have tax-exempt status, include a copy of your 501C3.

For the name of a contact in your Regional Genetics Network, call the Council of Regional Networks for Genetics Services (CORN). Sonya Ross is the coordinator: 301/828-2780.
**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-Fuu, Chief, Genetics Service Branch, Bureau of Maternal and Child Health

9:00 am - 10:00 am  
Plenary Session I: NETWORK BUILDING FOR EMPOWERMENT

Panel:
- Abby Meyers, Executive Director, National Organization for Rare Disorders
- F. John Meaney, President, Coalition of Regional Genetics Networks

10:00 am - 10:30 am  
Break

10:30 am - Noon  
Workshops (5)  
EMPOWERING CONSUMERS THROUGH THE REGIONAL GENETICS NETWORKS

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
- John Carey, Associate Professor, Pediatrics, University of Utah
- Jane Feldman, Consumer, Mother of a Tay-Sachs child
- George McCoy, Consumer, Person with hemophilia

The immediate impact of hearing a diagnosis

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, donations, and membership dues.

**WORKSHOPS (5)**

**SKILLS FOR EMPOWERMENT**

1. How to Start Self-Help Groups
2. How to Start Peer Counseling Programs
3. How to Start Cross-Genetic Disorder Groups
4. How to Meet Life Cycle Needs of Your Members
5. How to Increase Public Awareness of the Genetic Disorders Represented by Your Group

5:00 pm - 6:00 pm  
Reception

6:00 pm - 8:00 pm  
Banquet

**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

The Alliance telephone number is 202/625-7853. Be sure to contact a travel agent who can help you get the best deal possible. You may have to pay a deposit in full and you will need to make your room reservation as per your instructions on the registration form. If your travel plans will result in a hotel check-in time past 6:00 pm, you must inform the Alliance so that we can guarantee your arrival. Regular check-in time is after 2:00 pm. Check-out time is by Noon. You will be responsible for all taxes and charges. The first night's deposit will be deducted from your final bill. The room rate is $78, single or double occupancy.

**REGISTRATION**

The ALLIANCE will make your room reservation as per your instructions on the registration form. If your travel plans will result in a hotel check-in time past 6:00 pm, you must inform the Alliance so that we can guarantee your arrival. Regular check-in time is after 2:00 pm. Check-out time is by Noon. You will be responsible for all taxes and charges. The first night’s deposit will be deducted from your final bill. The room rate is $78, single or double occupancy.

To take advantage of the best airfares, you may want to consider spending Saturday night in Washington, D.C. Ask the Alliance Symposium Coordinator about hotel weekday rates. The Alliance telephone number is 202/625-7853. Be sure to contact a travel agent who can help you secure the lowest possible transportation. Please complete and mail this form with your check or money order to:

- Symposium Coordinator  
  Alliance of Genetic Support Groups  
  38th and R Streets, N.W.  
  Washington, DC 20057

Please make checks payable to: Alliance of Genetic Support Groups

**Workshop Selection**

You will be assigned a place in the Friday morning workshop entitled “Empowering Consumers Through the Regional Genetics Networks” according to the Region in which you live. It is important that you indicate your 1st and 2nd choice for the Friday afternoon workshop, “Skills for Empowerment.”

**SKILLS FOR EMPOWERMENT**

1. How to Start Self-Help Groups
2. How to Start Peer Counseling Programs
3. How to Start Cross-Genetic Disorder Group
4. How to Meet Life Cycle Needs of Your Membership
5. How to Increase Public Awareness of the Genetic Disorders Represented by Your Group

**SKILLS WORKSHOP**  
Indicate #  
1st  
2nd  
Choice  
Choice

- Name in full (print or type)
- Affiliation, if any
- Address
- City  
  State  
  Zip
- Telephone  
  (h)  
  (w)
- Special Needs  
  Consumer  
  Professional
- Banquet preference  
  meat  
  fish  
  vegetable plate

**DEADLINE:** OCTOBER 10, 1988
Alliance of Genetic Support Groups
Empowerment Workshop
38th and R Streets, N.W.
Washington, D.C. 20057