GENETICS SUPPORT GROUPS:
Volunteers and Professionals as Partners

June 2-5, 1985
Ramada Renaissance
Washington, D.C.

Sponsored by:
Georgetown University
The Johns Hopkins Medical Institutions

Supported by:
Division of Maternal and Child Health,
Genetic Diseases Program
March of Dimes Birth Defects Foundation
To promote maximum health care and social and psychological functioning for genetically affected individuals and their families through the professional-voluntary partnership.

**SYMPOSIUM OBJECTIVES**

1. To identify unmet needs of
   a. Families with genetic disorders
   b. Voluntary genetics organizations
   c. Professionals related to these organizations
2. To enhance the cooperation of voluntary genetics organizations and professionals in working towards common goals.
3. To explore the possibility of a network of the voluntary genetics organizations.
4. To encourage the development and growth of support systems in local communities appropriate to the continuing needs of individuals and their families with genetic disorders.
5. To identify how health care professionals can be most effective and helpful in working with voluntary genetics organizations.
6. To educate professionals about the ongoing needs, as well as periods of crisis, in the lives of families with genetic disorders.
7. To develop expertise for both volunteers and professionals working with supportive genetics organizations in the areas of services delivery, organizational skills, networking, education, advocacy, and self-help issues.

Program leadership will come from many voluntary organizations. A partial list includes:

- American Brittle Bone Society
- Association for Glycogen Storage Disease
- Cystic Fibrosis Foundation
- Dysautonomia Foundation
- Human Growth Foundation
- Huntington's Disease Foundation of America
- International Joseph Disease Foundation
- Little People of America
- National Association for Sickle Cell Disease
- National Down Syndrome Congress
- National Hemophilia Foundation
- National Huntington's Disease Association
- National Marfan Foundation
- National Neurofibromatosis Association
- National Organization for Rare Disorders
- National Retinitis Pigmentosa Foundation
- National Tay-Sachs and Allied Diseases Foundation
- Osteogenesis Imperfecta, National Capitol Area
- Tourette Syndrome Association
- Turner's Syndrome Society of Canada

**GENERAL INFORMATION**

**Dates**
June 2-5, 1985 (Sunday evening-Wednesday noon)

**Meeting Place**
The Ramada Renaissance, located in the heart of a most attractive shopping/business area of Washington, is just minutes from Georgetown, The White House, The Kennedy Center, museums including The Smithsonian, and the numerous landmarks and cultural attractions of the Capitol.

**Registration**
Sunday, June 2, 3:00 - 7:00 P.M.

**Fee**
Registration ........................................ $100

The registration is payable in advance and includes course materials, refreshment breaks, a complimentary ticket to the Sunday evening reception-buffet followed by sit-down dessert and coffee, and to the gala banquet on Tuesday evening, as well as bus transportation to Capitol Hill on Wednesday morning for those desiring to call on members of Congress. Only one-half the registration fee will be returned if withdrawal is made after May 15. A letter confirming enrollment will be sent to each registrant.

**Credits**
Georgetown University will provide continuing education credits to those requesting them. For detailed information, check the appropriate box on the Meeting Registration Form.

**Hotel Accommodations**
Rooms have been set aside for registrants at the Ramada Renaissance, Washington, D.C. All registrations must be made directly with the hotel by May 6 and accompanied by one night's deposit to guarantee the room at the symposium rate. Reservations made after May 6 will be accepted on a space available basis at prevailing hotel rates. Confirmation will be sent by the hotel upon request.

**For Further Information**
Symposium Coordinator
Moore Clinic - Genetics
Johns Hopkins Hospital
Baltimore, Md. 21205
(301) 955-3122

**Program Director**
Joan O. Weiss, M.S.W.
Senior Social Worker
Medical Genetics
The Johns Hopkins Hospital

**Faculty Directors**
Robert C. Baumiller, S.J., Ph.D.
Georgetown University
Victor A. McKusick, M.D.
The Johns Hopkins Medical Institutions

**Program Coordinator**
Jane E. Karkalits, M.A.S.S.
Adjunct Assistant Professor
Georgetown University Medical School

**Planning Committee**
Barbara Bernhardt, M.S.
Kathleen Kirk Bishop, M.S.W.
Leonard Borman, Ph.D.
Joan Burns, M.S.W., M.S.
Debby Koth
George McCoy
Abbey Meyers
Robert F. Murray, Jr., M.D., M.S.
Ernest Ott
Susan R. Panny, M.D.
Reed E. Pyeritz, M.D., Ph.D.
Beverly S. Raff, Ph.D.
Sonya I. Ross, B.S.
Nina Scribanu, M.D.
Candice Stevens
Greg Weigle
Mary Ann Wilson

**Program Secretary**
Peggy Hyer
# PROGRAM

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tr>
<td>3:00 to 7:00 P.M.</td>
<td>Registration</td>
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<tr>
<td>6:30-8:00 P.M.</td>
<td>Cash Bar</td>
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<td>Reception-Buffet Supper (included in registration fee)</td>
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<td>8:00-9:30 P.M.</td>
<td>GENERAL SESSION: GREETINGS AND INTRODUCTIONS</td>
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<tr>
<td></td>
<td>Joan O. Weiss, M.S.W. (Program Director)</td>
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<tr>
<td></td>
<td>Vince L. Hutchins, M.D. (Division of Maternal and Child Health)</td>
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<td></td>
<td>Arthur J. Salisbury, M.D. (Vice-President for Medical Services)</td>
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<td></td>
<td>March of Dimes Birth Defects Foundation (Director)</td>
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<td>Victor A. McKusick, M.D. (William Osler Professor of Medicine)</td>
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<td></td>
<td>Robert C. Baumiller, S.J., Ph.D. (Professor of Obstetrics and Gynecology)</td>
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<td>BEVERLY SILLS (Interviewed by Sandy Rovner) Health Columnist</td>
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<tr>
<td>9:00 - 10:00 A.M.</td>
<td>THEME I: STRENGTHENING VOLUNTARY ORGANIZATIONS</td>
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<td>Chairperson: Joan O. Weiss, M.S.W. (Symposium Program Director)</td>
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<td>Panel: Priscilla Ciccariello (National Marfan Foundation)</td>
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<td>Daniel Margulies (Little People of America)</td>
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<td>Jean Paul Richard (Osteogenesis Imperfecta-National Capitol Area)</td>
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<td>Raymond Starr (National Down Syndrome Congress)</td>
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<td>10:15 A.M.-11:45 A.M.</td>
<td>WORKSHOPS: THEME I (See separate listing)</td>
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<td>11:45 A.M.-1:15 P.M.</td>
<td>LUNCH BREAK</td>
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<td>1:15 P.M.-2:45 P.M.</td>
<td>WORKSHOPS: THEME I (Morning repeated)</td>
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<td>3:00 P.M.-4:30 P.M.</td>
<td>WORKSHOPS: THEME I (Repeated)</td>
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<tr>
<td>4:30 P.M.-6:00 P.M.</td>
<td>Resource Material Display (March of Dimes Birth Defects Foundation)</td>
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<tr>
<td>6:00 P.M.</td>
<td>Dutch Treat Dinners</td>
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<td>8:00-10:00 P.M.</td>
<td>Resource Material Display (continued)</td>
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<tr>
<td>8:30-9:30 A.M.</td>
<td>THEME II: SELF-HELP GROUPS: AN EMERGING SOCIAL RESOURCE</td>
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<td>Chairperson: June Vavasseur (National Association for Sickle Cell Disease)</td>
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<td>Speaker: Frank Riessman, Ph.D. (National Self-Help Clearinghouse)</td>
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<td>Comments: Jane Paritzky (National Capitol Tay Sachs Foundation)</td>
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<td>Leonard Sawisch (Little People of America)</td>
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<td>9:45-10:45 A.M.</td>
<td>WORKSHOPS: THEME II (See separate listing)</td>
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<td>11:00 A.M.-12 P.M.</td>
<td>WORKSHOPS: THEME II (repeated)</td>
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<td>12:00-1:30 P.M.</td>
<td>LUNCH BREAK</td>
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<td>1:30-2:30 P.M.</td>
<td>THEME III: NETWORKING, PRESENT AND FUTURE</td>
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<td>Chairperson: Leonard Borman, Ph.D. (The Self-Help Center, Evanston, Ill.)</td>
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<td>Panel: R. Stephen Amato, M.D., Ph.D. (Mid-Atlantic Regional Human Genetics Network (MARHGN))</td>
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<td>Betsy Anderson (New England Regional Genetics Group (NERGG))</td>
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<td>Ruby Horansky (National Organization for Rare Disorders (NORD))</td>
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<td>Susan R. Panny, M.D. (Marylanders Advocating Services for Hereditary Disorders (MASH))</td>
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<td>2:45-4:00 P.M.</td>
<td>WORKSHOPS FOR THEME II AND THEME III (See separate listings)</td>
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<tr>
<td>4:15-5:30 P.M.</td>
<td>WORKSHOPS FOR THEME III (See separate listing)</td>
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<td>4:00-6:00 P.M.</td>
<td>Resource Material Display (continued)</td>
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<tr>
<td>7:00-9:30 P.M.</td>
<td>Marjorie Guthrie Memorial Banquet with invited Congressional guests</td>
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<td>8:30-10:00 A.M.</td>
<td>SUMMING UP</td>
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<td>Barton Childs, M.D. (Professor Emeritus of Pediatrics)</td>
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<td>Networking Workshop Chairpersons</td>
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<tr>
<td>10:00 A.M.-12:00 P.M.</td>
<td>Visit to Capitol Hill for those wishing to visit Congresspersons (buses provided)</td>
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<td>Informal, pre-arranged follow-up groups or meetings</td>
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<td>Resource Material Display (continued)</td>
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<tr>
<td>12:00 noon</td>
<td>Check Out Time and End of Symposium</td>
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Sunday, June 2

Monday, June 3

Tuesday, June 4

Wednesday, June 5
WORKSHOPS

THEME I WORKSHOPS
STRENGTHENING VOLUNTARY ORGANIZATIONS

• 1 How to recruit, expand, retain membership.
• 2 How to encourage leadership in your group.
• 3 How to stimulate communication within your group.
• 4 How to develop good public relations and favorable publicity.
• 5 Role and function of the governing board.
• 6 How to raise funds.
• 7 How to apply successfully for grants.
• 8 When and how to provide referral services.
• 9 How to improve medical/life insurance coverage.
• 10 The role of the professional/medical advisory board.
• 11 The role of voluntary groups in support of research.
• 12 How to sensitize local health professionals to the social-emotional needs of consumers.
• 13 How to involve the clergy in genetics support groups.
• 14 How to find and make use of national resources for your group.

THEME II WORKSHOPS
SELF-HELP GROUPS: AN EMERGING SOCIAL RESOURCE

• 1 Self-Help/Peer Counseling
• 2 Self-Help for Families in Crisis
• 3 Self-Help and Life Cycle Needs
• 4 Self-Help for Parents
• 5 Self-Help for Grandparents
• 6 Self-Help for Siblings
• 7 How to Start a Self-Help Group

THEME III WORKSHOPS
NETWORKING, PRESENT AND FUTURE

1 Networking: Toward a Strategy for Lobbying
2 Networking: Toward a Strategy for Educating Health Professionals
• 3 Networking: Toward a Strategy for Educating the Public
4 Networking: Toward a Strategy for Introducing Genetics Education in the Schools
5 Networking: Is there a Task Force for Genetics Support Groups in Our Future?