November 20 - 21, 1993

Holiday Inn, Old Town Alexandria, Virginia

Sponsored By:

NATIONAL ORGANIZATION FOR RARE DISORDERS (NORD)

Funded By:

- Food & Drug Administration
- Genetics Services Branch, Maternal and Child Health Bureau
- Integrated Genetics, a majority-owned subsidiary of Genzyme Corporation
- Quantum Health Resources
- RGK Foundation
- Serono Laboratories
- Sandoz Pharmaceuticals Corporation
- The Jacob and Hilda Blaustein Foundation Inc.
- The Lester and Eleanor Levy Family Fund

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HEALTH CARE IN FLUX:

How Will Families With Special Needs Fit In?
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GENERAL INFORMATION

Conference Dates
November 20-21, 1993
Saturday/Sunday

Conference Site
Old Town Holiday Inn, 480 King Street, located in Alexandria, Virginia:
the only hotel in the heart of historic Old Town Alexandria; 3 miles from National Airport; 5 miles and 15 minutes from downtown Washington, D.C., 1 mile from King Street Metro.

Registration
$85 per participant - Deadline October 8, 1993. Fee includes registration materials, Saturday coffee break, reception & banquet Saturday night, and continental breakfast Sunday. A $10 late fee will be applied to registrations made after October 8, 1993. For information about consumer scholarships, see heading.

Refund Policy
A handling fee of $15 is retained to cover administrative expenses. Refund requests must be received by mail at the Alliance office two weeks prior to the conference. No refunds will be made after November 8, 1993. Substitutions are permissible. Refunds will be mailed after the conference and will take six (6) weeks to process.

Hotel Accommodations
A limited number of rooms has been set aside for registrants at the Old Town Holiday Inn. All reservations should be made directly with the hotel by October 8, 1993. Please see the attached Hotel Reservation Form to place your reservation. Specify that you are with the Alliance/NORD "Health Care In Flux" conference in order to qualify for the group room rate ($102 single, $117 double, extra person $13, plus taxes). Check-in time is 3 p.m. Reservations made after October 8, 1993 will be accepted on a space-available basis at prevailing hotel rates. If questions, please call reservations manager at (800) 368-5047 or (703) 549-6080 between 9 a.m. and 5 p.m. Monday through Friday.

Hotel Facilities
Located near numerous gourmet restaurants, boutiques, historic landmarks, and the Alexandria waterfront. Complimentary transportation to and from National Airport and King Street Metro and local Old Town offices. Use of indoor pool & sauna at nearby Atrium Fitness Center; stationary & trail bicycles are available at no charge.

Special Accommodations
Please indicate on your conference registration form and your hotel reservation form if you desire special accommodations or services, such as handicapped rooms or interpreter.

Airline Information
Special discounted rates are being provided by U.S. Air. Special discounts include 5% off excursion rates and 10% off coach fare. For reservations, please call our official conference travel agency, Enterprise World Travel, Inc. at 1-800-888-5402 or (202)296-7050 and ask for Marlis Tessendorf. Be sure to identify yourself with the Alliance/NORD "Health Care in Flux" conference. These discounts are available for the period November 18 through 23, 1993.

Shuttle Service
Call the hotel at 549-6080 for complimentary shuttle service from the baggage claim area of National Airport. The shuttle service is also available from the King Street Metro (subway-blue or yellow line). Look for the shuttle van marked "Old Town Holiday Inn”.

Parking: Parking is available to hotel guests at a rate of $6.00 a day, and local guests can park at $1.75 an hour up to $7.00 maximum a day.

Scholarships
Partial scholarships are available for a limited number of participants. Please indicate your need on the conference registration form.

Registration Procedures
Early enrollment is recommended since conference number of participants is limited.

1. Complete attached registration form or copy by October 8, 1993.
2. Make check or money order for the registration fee payable to: ALLIANCE OF GENETIC SUPPORT GROUPS, and mail to: Alliance/NORD Conference 35 Wisconsin Circle, #440 Chevy Chase, MD 20815
3. A confirmation of your conference registration will be sent to you.
4. Make hotel reservation on your own. (See section, Hotel Accommodations, for procedure.)

Questions?
Call Joan O. Weiss, or Alliance, at 1-800-336-GENE
Laura Hughes, NORD, at 1-800-999-NORD.
What are the Goals of this Conference?

To help families with genetic and rare conditions, service providers, and policy makers understand the promise and potential problems of the proposed national health care reform; to promote collaborative efforts between consumers and professionals working together to improve the quality of health care for people with genetic and rare conditions; and to increase understanding of how government regulatory agencies, new technologies, and breakthrough therapies impact on the health care system.

Who Should Attend?

Leaders and members of support groups, health care providers, public health or health policy planners, people with an interest in health services for genetic and rare disorders, and anyone interested in learning more about the proposed national health care reform program are invited to attend.

About the Co-Sponsors:

The Alliance of Genetic Support Groups, a coalition of voluntary genetic support groups, consumers, and professionals, serves as a forum for addressing the needs of individuals and families affected by genetic disorders. Alliance links families whenever possible to appropriate groups and genetic services and promotes the sharing and dissemination of information, strategies and technologies related to genetic services. This national federation is committed to fostering a partnership between consumers and providers of genetic services.

The National Organization for Rare Disorders (NORD) is a non-profit voluntary health organization dedicated to the prevention, treatment and cure of rare “orphan diseases” and the welfare of people afflicted by these devastating illnesses. NORD serves as the primary non-governmental source of those seeking information on over 5,000 rare diseases and referral to appropriate sources of assistance. In addition, NORD provides research grants and a networking program that links together families with the same diagnosis.

Conference Schedule

Saturday, November 20

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>9:00 - 11:00 a.m.</td>
<td>Registration</td>
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<tr>
<td>9:00 - 10:25 a.m.</td>
<td>Special Address</td>
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<tr>
<td>9:00 - 11:00 a.m.</td>
<td>Special Address</td>
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<tr>
<td>10:25 - 10:50 a.m.</td>
<td>Special Address</td>
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<tr>
<td>11:00 - 11:30 a.m.</td>
<td>Alliance Membership Meeting (open)</td>
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<tr>
<td>11:30 - 12:00 p.m.</td>
<td>NORD Membership Meeting (open)</td>
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<tr>
<td>12:00 - 1:00 p.m.</td>
<td>Lunch on your own</td>
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<tr>
<td>1:00 - 3:00 p.m.</td>
<td>Plenary Session</td>
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Welcoming Remarks:

Jayne Mackta, President, Alliance of Genetic Support Groups, and Jess G. Thoene, M.D., President, NORD

HOW PEOPLE WITH GENETIC AND RARE DISORDERS WILL FIT INTO THE NEW HEALTH CARE SYSTEM

- costs to consumers
- accessing new treatments & drugs
- genetic services
- getting care from specialists
- appealing unfair treatment
- the consumer’s role in the new system

Keynote speaker: Key Administration Spokesperson (tba)
HEALTH CARE REFORM: IMPACT ON FAMILIES WITH SPECIAL NEEDS

Abbey Meyer, Moderator
Executive Director, NORD

Panelists: Julie Beckett; Congressional Staff (tba); Robert A. Murray, M.D.; Health Care Task Force Member (tba); & Doris Zallen, Ph.D.

3:00 - 3:20 p.m. Break

3:30 - 5 p.m. Response to Panel Issues (5 discussion groups)

Consumer co-facilitators: Betsy Anderson, Priscilla Ciccarello, Jean-Paul Richard, Betsy Trombino, & Victoria Odesina

Professional co-facilitators: Barbara Bernhardt, Robin Blatt, Mary Louise Franz, Reed Pyeritz, & Luther Robinson

Some Issues for Discussion:
1. Diagnostic tests
2. Prevention
3. Drugs and other treatments
4. Medical devices
5. Medical foods (e.g., for PKU)

6. Co-payments
7. Referral to Specialists
8. Special services such as rehabilitation, home health care, and genetic counseling
9. Privacy and confidentiality issues
10. How to deal with research
11. Experimental drugs and off-label indications

5:30 - 6:30 p.m. A Media Workshop

"REPORTING IN THE GENETIC AGE"

(space limited)

6:30 p.m. Reception And Banquet

WHAT THE HUMAN GENOME PROJECT MEANS TO FAMILIES WITH SPECIAL HEALTH CARE NEEDS

Banquet Speaker
Francis S. Collins, M.D., Ph.D
Director, National Center for Human Genome Research for the National Institutes of Health

Awards Presented By Alliance & NORD

Conference Schedule

Sunday, November 21

8:00 a.m. Continental Breakfast

8:30 - 10:00 a.m. Plenary Session

THE CHANGES: WORKING WITH THE HEALTH CARE SYSTEM DURING THE TRANSITION AND IN THE FUTURE

Martha W. Volner, MSW, Moderator
Director of Health Policy, Alliance

Panelists: Betsy Anderson; Jessica Davis, M.D.; Bob Griss; Paul Mendelsohn; Marion Secundy, Ph.D.; & Rachel Warner

10:15 - 11:45 a.m. Response to Panel Issues

STRATEGIES FOR GETTING WHAT YOU NEED WHEN YOU NEED IT

(4 discussion groups plus 1 focus group on “how to make your views known to policy makers”)

Consumer Co-facilitators: Julie Beckett, Hope Charkins, Donna Gore Olsen, Paul Mendelsohn, Mary Ann Wilson

Professional Co-facilitators: Judith Benkendorf, Glenda Booth, Eric Juengst, Lynda Mulhauser, & Susan Panny

Some Issues for Discussion:
A. How to access the system during this transitional phase
B. How to get help
C. How to negotiate the government maze
D. How to protest

12:00 noon - 1:00 p.m. Plenary Session

Jayne Mackta,
Session Chairperson

Summation of Workshops

Robert C. Baumiller, SJ, Ph.D
Beverly S. Raff, Ph.D, RN, FAAN

Recommendations
Faculty

Anderson, Betsy, Director, CAPP/ National Parent Resource Center, Boston

Baumiller, Robert C., SJ, PhD, Dean, School of Health Sciences, University of Detroit Mercy

Beckett, Julie, Parent & Advocate, National Maternal & Health Resource Center, University of Iowa

Benkendod, Judith L., MS, Sr. Genetic Counselor, Div. Genetics, OB/GYN, Medical Center, Georgetown University, Washington, D.C.

Bernhardt, Barbara, MA, Co-Investigator, Ethical & Policy Issues in Cystic Fibrosis Screening, Johns Hopkins Medical Institutions, Baltimore, MD

Blatt, Robin, MPH, Genetics Education Coordinator for the Massachusetts Genetics Program, Boston

Booth, Glenda, Director of Policy, NORD, Washington, D.C.

Charkins, Hope, MSW, Executive Director, Treacher Collins Foundation, Norwich, VT

Ciccarrello, Priscilla, Chair, National Marfan Foundation, Port Washington, NY

Collins, Francis S., MD, PhD, Director, National Center for Human Genome Research for the National Institutes of Health, Bethesda, MD

Davis, Jessica, MD, Assoc. Professor of Clinical Pediatrics; Co-Director, Division of Human Genetics, Cornell University Medical College, New York City

Franz, Mary Louise, MSW, LCSW, Huntington’s Disease Project, Johns Hopkins Hospital, Baltimore, MD

Gore Olsen, Donna, Executive Director, The Indiana Parent Information Network, Inc., Indianapolis, IN

Griss, Bob, Disability Policy Analyst, United Cerebral Palsy Association, Washington, D.C.

Haffner, Marlene, MD, Director, FDA Office of Orphan Products Development, Rockville, MD

Juengst, Eric, PhD, Acting Chief, Ethical, Legal, & Social Implications Branch, NCHGR, Bethesda

Lin-Fu, Jane, MD, Chief, Genetics Services Branch, Maternal & Child Health Bureau, Rockville, MD

Mackta, Jayne, President, Alliance of Genetic Support Groups, Chevy Chase, MD

Mendelsohn, Paul David, MA, Pres., Neurofibromatosis, Inc., Lanham, MD

Meyers, Abbey, Executive Director, NORD, New Fairfield, Connecticut

Mulhausen, Lynda, MSW, LICSW, Clinical Manager/Social Worker, Children’s National Medical Center, Washington, D.C.

Murray, Robert E., Jr., MD, Chairman, Division of Medical Genetics, Howard University College of Medicine, Washington, D.C.

Odesina, Victoria, RN, MS, Sickle Cell Service, UCONN/St. Francis Hospital, NERGG, Hartford, CT

Panny, Susan R., MD, Chief, Div. of Hereditary Disorders, MD Dept of Health & Hygiene, Baltimore

Pyeritz, Reed E., MD, PhD, Chairman, Dept of Human Genetics, Allegheny Singer Research Institute, Pittsburgh, PA

Raff, Beverly, RN, PhD, FAAN, President, RN & M Consultants, Syosset, NY

Richard, Jean-Paul, Treasurer, Coalition of Heritable Disorders of Connective Tissue

Robinson, Luther, MD, Assistant Professor of Pediatrics; Director, Clinical Genetics & Dysmorphology, Children’s Hospital, Buffalo, NY

Secundy, Marian Gray, PhD, Professor, Dept of Community Health & Family Practice; Director, The Program of Medical Ethics, Howard University, Washington, D.C.

Thoene, Jess G., MD, Professor, Div. of Biochemical Genetics & Metabolism, University of Michigan School of Public Health, Ann Arbor; President, NORD

Trombino, Betsy, Program Director, Pilot Parent Partnerships, Phoenix; Consumer Chair, MSRGSN

Volner, Martha W., MSW, Director of Health Policy, Alliance of Genetic Support Groups, Chevy Chase, MD

Warner, Rachel, Reimbursement Development Coordinator, Factor Care Plus, Inc., Tampa, Florida

Weiss, Joan O., MSW, LICSW, Executive Director, Alliance of Genetic Support Groups

Wilson, Mary Ann, Administrative Director, Neurofibromatosis, Inc., Lanham, MD

Zallen, Doris T., PhD, Associate Professor of Science Studies Humanities, Virginia Polytechnic Institute, Blacksburg, Virginia