

# 2007 NORD Conference Registration Form

*If you need additional registration forms, please photocopy this form and fill one out for each person who will be attending.*

## PLEASE INDICATE:

What is your relationship to the person with the rare disorder or disability?

- Self                       Parent  
 Spouse                     Sibling  
 Relative/Friend  
 Other \_\_\_\_\_

## PLEASE INDICATE (If applicable):

- Yes, I have special needs (disability-equipped room, hearing/visual aids, dietary restrictions, etc.). Please specify:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

*(Note: If you are in need of a specially equipped room, please advise the Hilton Washington DC/Rockville Executive Meeting Center in Rockville, MD when making your reservations).*

- Yes, please list my name for any Conference Networking Programs available under the following disorder:  
\_\_\_\_\_  
\_\_\_\_\_

- Yes, I give NORD permission to indicate the above disorder on my nametag & registration materials:

NORD Member	\$ 150.00
NORD Non Member	\$ 185.00
Additional Family or Organization Member (Over age of 12)	\$ 65.00
One-Day Visit	\$ 75.00

TOTAL AMOUNT ENCLOSED: \$ \_\_\_\_\_

## Please make all checks payable to NORD

Dr./Mr./Mrs./Ms. \_\_\_\_\_  
First Name Last Name  
Title/Affiliation \_\_\_\_\_  
(Only applicable if you will be representing a support group, organization or company)

Mailing Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip Code \_\_\_\_\_

Daytime Telephone Number \_\_\_\_\_

E-mail Address \_\_\_\_\_

## Registration Deadline:

Full payment and Conference registration form must be received by Sept. 7, 2007  
Send to: NORD ♦ Attn. Donna Jackson ♦ P.O. Box 1968 ♦ Danbury, CT 06813-1968  
♦ (203) 744-0100 x 210 ♦ Fax: (203) 798-2293 ♦ E-mail: [djackson@rarediseases.org](mailto:djackson@rarediseases.org)

## (Track 1 & Track II Friday Workshops)

Please circle which Track 1 and 2 sessions you are attending.  
Select one session per time slot either from Track 1 or Track 2.

	<u>Track 1</u>	<u>Track 2</u>
Friday (9:30 am)	A B C D	1 2 3 4
Friday (10:45 am)	E F G H	5 6 7 8

## Please indicate if you will be attending the following:

Continental Breakfasts     Friday     Saturday     Sunday  
Luncheons                     Friday     Saturday

## If you prefer to use a charge card, please fill in below:

CHARGE TO: (check one of the following)

MasterCard     Visa     Amex     Discover

Card Number \_\_\_\_\_

Expiration Date: \_\_\_\_\_

Name on Card (print) \_\_\_\_\_

Signature \_\_\_\_\_



*...out of the darkness  
into the light...®*

***2007 NORD Annual Conference**  
with the National Institutes of Health (NIH) Office of Rare Diseases  
Rockville, MD  
September 28<sup>th</sup> – September 30<sup>th</sup>, 2007*

***FOCUS ON THE FUTURE***

***A Conference You Won't Want To Miss!***

**NORD** brings to the rare disease community a unique opportunity to explore resources, learn from experts, and network with others who share the same questions and concerns. General sessions will address timely issues of interest to all. Breakout workshops will provide small-group training in “nuts & bolts” skills for patients, family members, caregivers, and leaders of patient organizations. Reflecting the conference theme, *Focus on the Future*, presentations will be designed to help participants strengthen their leadership, advocacy and coping skills at this particular moment in time, with emphasis on the challenges and opportunities that lie ahead. Join NORD for an informative and dynamic conference offered in conjunction with the **Office of Rare Diseases (ORD) at the National Institutes of Health (NIH)**.

- Learn about the special challenges of rare disease research.
- Meet experts from NIH and FDA.
- Learn how to start a support group or “grow” an existing one.
- Participate in workshops with other people experiencing the same issues and concerns.

## THURSDAY, SEPTEMBER 27<sup>th</sup>, 2007

6:00 PM to 9:30 PM      **Conference Check-In/Registration**

7:00 PM to 9:00 PM      **Conference Welcome Reception**

*Randolph Room*

## FRIDAY, SEPTEMBER 28<sup>th</sup>, 2007

7:30 AM      **Rise & Shine – Coffee with Exhibitors**  
*Exhibit Hall open until 5:00 PM*

*Randolph Room*

7:30 AM – 8:30 AM      **Continental Breakfast**

*Plaza Foyer*

8:15 AM – 8:30 AM      **Welcome Address**  
**Abbey S. Meyers, NORD President**

*Plaza I & II*

8:30 AM – 9:15 AM      **Opening Session**  
***“Bioethics and Rare Disease Research”***

Jonathan Moreno, PhD, Professor of Medical Ethics at the University of Pennsylvania, will talk about bioethical issues in the context of rare disease research. Dr. Moreno is a member of the faculty of Penn’s acclaimed Center for Bioethics.

*Plaza I & II*

9:30 AM – 10:30 AM      **Breakout Sessions**  
**Track One: for Individuals, Families (*sessions will be repeated*)**

**A. *“Estate Planning for Special Needs Families”***

Met Life’s Brian Finn, National Organization Manager, and Kelly Piacente, Director, MetDESK, will guide you through the maze of legal and financial questions you’ll encounter when planning for the future of your special needs child, spouse, sibling, or other family member.

*Adams Room*

**B. *“Understanding Genetic Counseling”***

Many rare disorders have a known or suspected genetic cause. The diagnosis and management of these conditions often includes a referral for a genetics consultation. This workshop, led by Marsha Lanes, MS, CGC, of the NORD staff, will help patients and families learn about how genetic counseling can be helpful and what to expect from a genetic counseling session.

*Jefferson Room*

**C. *“Advice for the Caregiver”***

If someone you love has a chronic medical problem, you may be feeling overwhelmed by the number of hats you must wear—from private duty nurse to chief advocate. This workshop will focus on helpful tips and resources for caregivers, along with advice on how to protect and preserve their own health and well-being. Stefanie Putkowski, RN, BSN, of the NORD staff, will share her thoughts on the subject.

*Roosevelt Room*

**D. “So You Want to Start a Support Group”**

Sitting at the kitchen table, the idea of starting a support group seems to be an ideal way to address the needs of patients and families with a particular rare disease. How hard can it be? Jean Campbell, NORD Vice President of Development, and Michael Langan, Director of the NORD/Patient Link Mentor Project, will share their experiences related to setting up a support group.

*Wilson Room*

9:30 AM – 10:30 AM

**Track Two: for Support Group Leaders (sessions will be repeated)**

**1. “Legal Issues for Non-Profits”**

Voluntary health agencies must be certain their programs and services are within guidelines set forth by the federal government (the IRS) and charity monitoring organizations such as the Better Business Bureau (BBB). Non-profit attorney Jacqueline Henson, of McKenna, Long and Aldridge, will discuss legal requirements and how to ensure that your organization is in compliance.

*Truman Room*

**2. “Creating and Maintaining a Patient Registry”**

Patient registries are important resources in rare disease research. Using a new “how-to” handbook created by the federal Agency for Healthcare Research and Quality (AHRQ) as a guide, this workshop will focus on the patient registry as an important tool in the development of new treatments for rare diseases. Best practices in the design, creation and maintenance of patient registries will be presented.

*Monroe Room*

**3. “Public Relations 101 for Non-Profits”**

Marlin Collingwood, Managing Director, Bell Pottinger USA, and Mary Dunkle, Vice President of Communications, NORD, will discuss ways voluntary health agencies can expand their visibility, attract new supporters, and increase awareness of their particular rare disease...without breaking the bank. The emphasis will be on getting the most mileage from your dollars.

*Lincoln Room*

**4. “Developing a Board of Directors”**

One of the key components of a non-profit is its board of directors. While each board is unique, there are certain universal qualities that help determine how effective a board may be. Members of the NORD Board of Directors will talk about their experiences on the NORD Board and in their own organizations.

*Jackson Room*

10:30 AM – 10:45 AM

**Refreshments in the NORD Exhibitor Hall**

*Randolph Room*

10:45 AM– 12:00 NOON

**Breakout Sessions**

**Track One: for Individuals, Families**

**E. “Estate Planning for Special Needs Families”**

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*Wilson Room*

10:45 AM – 12: 00 NOON

**Track Two: for Support Groups**

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*Jackson Room*

12:00 NOON – 1:15 PM

**Lunch**

*Plaza Foyer*

1:00 PM – 1:15 PM

**NORD General Membership Meeting**

*Plaza I & II*

1:15 PM – 2:00 PM

**General Session**

*Plaza I & II*

**“A Promising Collaboration: Centers for Medicare and Medicaid (CMS) and Patient Organizations”**

Jeffrey Kelman, MD, Chief Medical Officer of the Center for Beneficiary Choices at the Centers for Medicare and Medicaid Services (CMS), will discuss how patient organizations and CMS can work together to help patients and families derive the greatest possible benefit from Medicare and state pharmaceutical assistance programs.

**FRIDAY, SEPTEMBER 28<sup>th</sup>, 2007** *(continued)*

- 2:00 PM – 3:00 PM      **General Session**      *Plaza I & II*  
**“Social Security and Rare Diseases”**  
Newly appointed Social Security Administration Commissioner Michael Astrue will share his thoughts on what he hopes to accomplish as head of the SSA. Specifically, he will address the concerns of the rare disease community related to issues such as eligibility for benefits for people with disabilities.
- 3:00 PM – 3:15 PM      **Refreshments in the NORD Exhibitor Hall**      *Randolph Room*
- 3:15 PM – 4:00 PM      **General Session**      *Plaza I & II*  
**“Special Challenges of Rare Disease Research”**  
From finding funding to recruiting patients, rare disease research poses challenges that are different from those encountered in the study of more common diseases. Panelists with extensive experience in rare disease research talk about this and how patients and patient organizations may help.
- 4:00 PM – 4:45 PM      **General Session**      *Plaza I & II*  
**“Internationalism and Other Trends in Developing Diagnostics and Treatments for Rare Diseases”**  
Stephen Groft, PharmD, Director, National Institutes of Health  
Office of Rare Diseases  
Debra Lewis, Acting Director, Food and Drug Administration  
Office of Orphan Products Development

**SATURDAY, SEPTEMBER 29<sup>th</sup>, 2007**

- 7:30 AM      **Rise & Shine – Coffee with Exhibitors**      *Randolph Room*  
*Exhibit Hall open until 5:00 PM*
- 7:30 AM – 8:45 AM      **Continental Breakfast**      *Plaza Foyer*
- 8:45 AM – 9:00 AM      **Welcome Address**      *Plaza I & II*  
Maria Hardin, NORD Vice President of Patient Services

**SATURDAY, SEPTEMBER 29<sup>th</sup>, 2007** *(continued)*

- |                       |   |                      |
|-----------------------|---|----------------------|
| 9:00 AM – 9:45 AM     | <b><u>General/Panel Session</u></b><br><b><i>“Building Credibility For Non-Profits”</i></b><br>This panel will provide hands-on advice for working effectively as a non-profit organization in a for-profit world. Some patient organizations have been accused of being too closely aligned with companies. How can you avoid the appearance or reality of impropriety?        | <i>Plaza I, II</i>   |
| 9:45 AM- 10:30 AM     | <b><u>General/Panel Session:</u></b><br><b><i>“What Can You Do to Encourage Research on Your Disease?”</i></b><br>Some patients and patient organizations seem to have more success than others in working effectively with medical researchers. This session will explore what works and what doesn't, and how the patient community may facilitate research on rare diseases. | <i>Plaza I, II</i>   |
| 10:30 AM -10:45 AM    | <b>Refreshments in the NORD Exhibitor Hall</b>  | <i>Randolph Room</i> |
| 10:45 AM – 11:30 AM   | <b><u>General/Panel Session</u></b><br><b><i>“We Can Make a Difference: The Power of Patients in Advocacy”</i></b><br>Patients and patient organizations have played a powerful role in the development of health-related public policies, and can do even more in the future. It's time to “show up” so we won't be “shut out”!  | <i>Plaza I, II</i>   |
| 11:30 AM – 12:00 Noon | <b>Wrap-up of morning sessions: Q&amp;A</b>   | <i>Plaza I, II</i>   |
| 12:00 Noon – 1:15 PM  | <b>Lunch</b>  | <i>Plaza Foyer</i>   |
| 1:15 PM – 2:30 PM     | <b><u>General/Panel Session:</u></b><br><b><i>“Orphan Diseases: The Next Chapter”</i></b><br>As we prepare to celebrate 25 years of the <u>Orphan Drug Act</u> and NORD, this panel will focus on the challenges and opportunities that lie ahead for the rare disease community.   | <i>Plaza I, II</i>   |

**SATURDAY, SEPTEMBER 29<sup>th</sup>, 2007** *(continued)*

2:30 PM – 3:00 PM	<b>Refreshments in the NORD Exhibitor Hall</b>	<i>Randolph Room</i>
3:00 PM – 4:00 PM	<b><u>General Session:</u></b> <b><i>“Town Hall Meeting with Abbey”</i></b> Abbey Meyers will answer questions and talk about lessons learned over her more than 25 years of advocacy on behalf of all rare disease patients and patient organizations.	<i>Plaza I, II</i>

**SUNDAY, SEPTEMBER 30<sup>th</sup>, 2007**

8:30 AM – 10:00 AM	<b>Continental Breakfast</b>	<i>Plaza Foyer</i>
9:00 AM – 9:15AM	<b>Morning Address</b> Jean Campbell, Vice President of Development, NORD	<i>Plaza I, II</i>
9:15 AM – 10:00 AM	<b><u>General Wrap-Up Session</u></b> <b><i>“Ask the VPs”</i></b> NORD’s vice presidents will explain what they do and field related questions from individuals or representatives of patient organizations. The informal discussion will feature tips on fundraising, advocacy, communications, patient services and finance.	<i>Plaza Foyer</i>

# Conference Information

## Welcome Reception

Join us on Thursday evening September 27<sup>th</sup>, 2007, in the Randolph/Randolph Foyer rooms from 7:00 PM to 9:00 PM for complimentary refreshments and conversation with fellow attendees.

## Exhibitor Hall

This is a unique opportunity to be introduced to new and inventive products and services for the special needs community. You don't want to miss this display in the *Randolph Room from Thursday at 7:00 PM to Saturday at 4:00 PM*. NORD is very grateful to these companies and organizations for supporting this conference. Please be sure to stop by and visit our exhibitors. *All refreshment breaks will be held in the Randolph Room/Exhibitor Hall.*

## Rise & Shine

If you are an "early riser", this is the perfect opportunity for you to have your morning cup(s) of coffee and meet our exhibitors while checking out their products and services. A great way to start your day! Rise & Shine will be held Friday and Saturday mornings in the *Randolph Room* beginning at *7:30 AM sharp*.

## General Conference Information

The NORD Conference will be held at the **Hilton Washington DC/Rockville Executive Meeting Center, Rockville, Maryland, located at 1750 Rockville Pike, Rockville, Maryland 20852**. For the comfort of all attendees, conference-meeting rooms, exhibit hall, and common areas are designated as non-smoking. Casual attire is appropriate for the entire conference. Our speakers are looking forward to seeing you at their respective workshops and general sessions. Be sure to make the most of the conference by attending all general sessions and the breakout sessions of your choice.

## Scholarships

A limited number of partial scholarships for conference registration will be made available for NORD members only. These awards are based on financial need and are given on a first-come, first-serve basis. To inquire about the availability of partial scholarships, please send your written or emailed request to the NORD Development Office ([djackson@rarediseases.org](mailto:djackson@rarediseases.org)) along with your conference registration form. *Recipients of these scholarships will be contacted by September 5, 2007.*

## How to Register

Read the registration form carefully. Please complete the form and return it to NORD by September 7<sup>th</sup>, 2007. Following that date, registration will only be accepted on a space available basis. Be sure to indicate any of your special needs in the appropriate section of the form. A separate form should be filled out for each person attending the conference. You may photocopy this form or request additional copies from NORD.

## Send all forms to:

**NORD Development Office**  
**Attn: Donna Jackson**  
**PO Box 1968**  
**Danbury, CT 06813-1968**  
**Phone: 203-744-0100 ext 210**  
**Fax: 203-798-2293**  
**Email: [djackson@rarediseases.org](mailto:djackson@rarediseases.org)**

## Hotel Reservations

A limited number of rooms have been set-aside for conference attendees at The Hilton Washington DC/Rockville Executive Meeting Center, Rockville, Maryland. The special room rate for NORD conference attendees is \$119 (plus tax) for a single or double. All reservations must be made directly with the hotel by September 5, 2007, to receive this special room rate. Any reservations made after that date will NOT receive the conference room rate. To reserve a room, call the hotel reservations directly at 1-800-445-8667 and mention (code OR3) to get the special rate. If you need a room equipped for people with disabilities, be sure to mention it at the time you make your reservation. There is no room charge for children under 18 when they occupy the same room as their parents or grandparents.