OCTOBER 16-17, 2017
MARRIOTT WARDMAN PARK
WASHINGTON, D.C.

REGISTER BY AUGUST 25th AND SAVE UP TO $400!

Advancing the dialogue on emerging issues, policies and strategies impacting the healthcare environment, rare diseases and orphan products

BREAKTHROUGH SPEAKERS

Scott Gottlieb, M.D.
Commissioner
FDA

Mike Porath
Founder/CEO
The Mighty

WWW.NORDSUMMIT.ORG | #NORDSUMMIT
WHY YOU SHOULD ATTEND

Invitation from NORD
As major changes to the nation’s healthcare system are debated, the NORD Summit will provide you with the unique opportunity to hear from the experts and join the conversation on issues of unprecedented importance. We are committed to delivering the latest updates and emerging trends. From ethical guidelines to next-generation treatments to advancing global collaboration, this year’s topics focus on timely issues from subject matter leaders. We encourage you to attend the 2017 Rare Diseases and Orphan Products Breakthrough Summit and look forward to your participation!

Peter L. Saltonstall
President and CEO
NORD

With Special Appreciation for the 2017 Program Advisory Board Members:
NORD would like to extend a thank you to the program advisory members from the FDA who advised on the FDA elements of the program. Their dedication, time and insights contributed to this most meaningful agenda, which continues to inspire new ideas and dialogue to advance education within the rare disease community.

Eleanor Dixon-Terry
Gayatri R. Rao, M.D., J.D.
Julienne Vaillancourt, R. Ph., M.P.H.
Jonathan Goldsmith, M.D., FACP
Althea Cuff
Larry Bauer

The Largest Multi-Stakeholder Gathering in the Rare Disease Community

Previous Participant Profile

Our staff and board members who attended were thrilled with the meeting as well as yesterday’s special session for NORD members. We all came home armed with so much new information, many wonderful contacts and a wealth of exciting ideas to put into place. Thank you for creating a wonderful three-day experience for all of us!

-PSC Partners Seeking a Cure

Back by popular demand!
RARE-TO-RARE NETWORKING
Maximize your time at the event and build meaningful partnerships by utilizing our appointment-setting software to connect with attendees in advance to schedule on-site meetings.

""
# AGENDA AT A GLANCE

## Day 1: Monday, October 16, 2017

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>7:00</td>
<td>Conference Registration and Continental Breakfast</td>
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</table>
| 8:00  | **NORD’S WELCOME & SUMMIT PREVIEW** - Peter L. Saltonstall, President and Chief Executive Officer, NORD  
Marshall L. Summar, M.D., Director, Children’s National Rare Disease Institute and Chief, Genetics and Metabolism,  
Children’s National Medical Center; Chairman, Board of Directors, NORD |
| 8:15  | COMMUNITY KEYNOTE ADDRESS                                              |
| 9:00  | FDA KEYNOTE ADDRESS                                                    |
| 9:30  | ETHICAL GUIDELINES FOR PATIENT ORGANIZATIONS & INDUSTRY TO COLLABORATE |
| 10:15 | Networking & Refreshment Break                                         |
| 11:00 | ASSURING PATIENT ACCESS: FUTURE OUTLOOK FOR PATIENT ASSISTANCE PROGRAMS |
| 12:15 | LUNCH AND LEARN BREAKOUT ROUNDTABLES                                   |
| 1:30  | CHOOSE ONE OF THREE BREAKOUT SESSIONS                                  |

### Breakout Sessions

- **PROMOTING EARLIER DIAGNOSIS**
- **NEXT-GENERATION TREATMENTS & ADVANCING CLINICAL TRIALS**
- **SUCCESSFUL STRATEGIES FOR PATIENT ORGANIZATIONS**

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<thead>
<tr>
<th>Time</th>
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<tr>
<td>2:45</td>
<td>Networking &amp; Refreshment Break</td>
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<tr>
<td>3:30</td>
<td>THE CHALLENGE OF HEALTHCARE COSTS &amp; TREATMENT PRICES</td>
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<tr>
<td>4:30</td>
<td>RIGHT TO TRY, CURRENT POLICY NEWS &amp; NORD’S POLICY PRIORITIES</td>
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<tr>
<td>5:45</td>
<td>Networking Reception</td>
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## Day 2: Tuesday, October 17, 2017

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<tbody>
<tr>
<td>7:00</td>
<td>Continental Breakfast Opens</td>
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</tbody>
</table>
| 7:45  | **DAY TWO INSIGHTS** - Peter L. Saltonstall, President and Chief Executive Officer, NORD  
Marshall L. Summar, M.D., Director, Children’s National Rare Disease Institute and Chief, Genetics and Metabolism,  
Children’s National Medical Center; Chairman, Board of Directors, NORD |
| 8:00  | SUSTAINING ORPHAN DRUG DEVELOPMENT AND AVAILABILITY                   |
| 9:00  | CHOOSE ONE OF THREE BREAKOUT SESSIONS                                  |

### Breakout Sessions

- **THE POWER OF DATA-SHARING**
- **DEVELOPING A GLOBAL STRATEGY FOR RARE DISEASES & ORPHAN DRUGS**
- **SUCCESSFUL STRATEGIES FOR PATIENT ORGANIZATIONS**

<table>
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<tbody>
<tr>
<td>10:00</td>
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<tr>
<td>10:30</td>
<td><strong>CURRENT TOPICS FROM THE FDA</strong></td>
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<tr>
<td>10:30</td>
<td>FDA/CDER Director Janet Woodcock (via video)</td>
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<tr>
<td>10:40</td>
<td>FDA Leadership Perspectives on Orphan Drug Review</td>
</tr>
<tr>
<td>11:40</td>
<td>FDA Perspectives on Gene Therapy</td>
</tr>
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| 12:00 | Patient Voice and Engagement with the FDA  
Externally-led Patient-Focused Drug Development meetings and lessons learned  
How Patients have been Involved  
Patient Engagement in CDRH |
| 12:30 | Lunch and Learn Breakout Roundtables                                 |
| 2:00  | INVESTOR PERSPECTIVE: THE OUTLOOK FOR INVESTMENT IN ORPHAN PRODUCTS   |
| 3:00  | RARE DISEASE DRUG, BIOLOGIC AND DEVICE DEVELOPMENT: ACHIEVEMENTS AND OPPORTUNITIES |
| 4:00  | Closing Remarks                                                       |
BREAKEHROUGH SPEAKERS

Featured Keynote Speakers

SCOTT GOTTLIEB, M.D., Commissioner, FDA
Dr. Scott Gottlieb was sworn in as the 23rd Commissioner of Food and Drugs on May 10, 2017. Dr. Gottlieb is a physician, medical policy expert, and public health advocate who previously served as the FDA's Deputy Commissioner for Medical and Scientific Affairs and before that, as a senior advisor to the FDA Commissioner. He also worked on implementation of the Medicare drug benefit as a Senior Adviser to the Administrator of the Centers for Medicare and Medicaid Services, where he supported policy work on quality improvement and the agency’s coverage process, particularly as it related to new medical technologies.

MIKE PORATH, Founder/CEO, The Mighty
Mike Porath got his start in journalism at ABC News, where he was the network’s first overseas digital reporter and was awarded the Society of Professional Journalists’ top honor for his reporting in Kosovo. He has held a variety of writing, editing, producing and executive roles at media companies including ABC News, NBC News, The New York Times and AOL. Mike is also on the board of directors and fundraising chair of The Dup15q Alliance, a non-profit organization that supports people with Dup15q syndrome like his daughter.

Featured FDA Speakers, Panelists & Moderators

RICHARD A. MOSCICKI, M.D.
Deputy Center Director for Science Operations, Center for Drug Evaluation and Research (CDER), FDA

ROBERT TEMPLE, M.D.
Deputy Center Director for Clinical Science, Center for Drug Evaluation and Research (CDER), FDA

PETER MARKS, M.D., Ph.D.
Director, Center for Biologics Evaluation and Research (CBER), FDA

JEFFREY E. SHUREN, M.D., J.D.
Director, Center for Devices and Radiological Health, CDRH, FDA

JANET WOODCOCK*, M.D.
Director, Center for Drug Evaluation and Research (CDER), FDA

Other Featured Speakers, Panelists & Moderators

CARRIE WOLINETZ, Ph.D.
Associate Director for Science Policy, NIH

ARTHUR CAPLAN, M.D., Ph.D.
Drs. William F. and Virginia Connolly Mitty Chair Director, Division of Medical Ethics, NYU Langone Medical Center

ANNE WILLIS, M.A.
Senior Director, Policy and Advocacy, Cystic Fibrosis Foundation

STEVE USDIN
Washington Editor, BioCentury

PETRA KAUFMANN, M.D.
Director of Clinical Innovation, National Center for Advancing Translational Sciences, NIH

MICHELLE DROZD, Sc.M.
Deputy Vice President, Policy and Research, PhRMA

*via special recorded video message
How can patient organizations and pharmaceutical industry collaborate?

Henry R. Moehring, President and CEO, Ethics, Virginia Connolly Mitty Chair Director, Division of Medical

compromising ethical standards?

Peter L. Saltonstall, President and Chief Executive Officer, Disease Institute and Chief, Genetics and Metabolism, Marshall L. Summar, M.D., Director, Children’s National Rare Diseases Program, Office of New Drugs, CDER, FDA

WHAT’S AHEAD FOR PERSONALIZED MEDICINE?

Dr. Larry Bauer, Regulatory Scientist, Rare Diseases Program, Office of New Drugs, CDER, FDA

9:00 FDA KEYNOTE ADDRESS
Scott Gottlieb, M.D., Commissioner, FDA

9:30 ETHICAL GUIDELINES FOR PATIENT ORGANIZATIONS & INDUSTRY TO COLLABORATE
How can patient organizations and pharmaceutical companies work together toward shared goals without compromising ethical standards?

Moderator: Arthur Caplan, M.D., Ph.D., Drs. William F. and Virginia Connolly Mitty Chair Director, Division of Medical Ethics, NYU Langone Medical Center

Fireside Chat: Henry R. Moehring, President and CEO, Alpha-1 Foundation

10:15 Networking & Refreshment Break

11:00 ASSURING PATIENT ACCESS: FUTURE OUTLOOK FOR PATIENT ASSISTANCE PROGRAMS
As Patient Assistance Programs come under fire, what can be done to assure patient access to lifesaving treatments for rare diseases?

Moderator: Jayson Slotnik, J.D., Partner, Health Policy Strategies, Inc.

Panelists:
Erin Tite, Parent of patient
Anne Willis, M.A. Senior Director, Policy and Advocacy, Cystic Fibrosis Foundation

12:15 LUNCH & LEARN BREAKOUT ROUNDTABLES
Sponsor booths open and poster presenters available at their posters; Reserve your seat when registering.

1 RARE CANCER ORGANIZATION NETWORKING
Jim Palma, Executive Director, TargetCancer Foundation

2 THE PROMISE OF IMMUNOTHERAPY FOR CANCER PATIENTS
Anne Pariser, M.D., Deputy Director, Office of Rare Diseases Research, NCATS, NIH

3 ATTRACTING YOUNG RESEARCHERS TO RARE DISEASES
Anne Pariser, M.D., Deputy Director, Office of Rare Diseases Research, NCATS, NIH

4 WHAT’S AHEAD FOR PERSONALIZED MEDICINE?
Larry Bauer, Regulatory Scientist, Rare Diseases Program, Office of New Drugs, CDER, FDA

5 ASSURING PATIENT ACCESS THROUGH PAPs
Scott Winiecki, M.D., Team Lead, Professional Affairs and Stakeholder Engagement, CDER, FDA

6 FDA ENGAGEMENT WITH PATIENT ADVOCACY GROUPS
Gayatri Rao, M.D., J.D., Director, Office of Orphan Products Development, FDA

7 INCENTIVES FOR DEVELOPING ORPHAN PRODUCTS
Gumel Liu, M.D., Ph.D., Office of Orphan Products Development, FDA

8 NATURAL HISTORY STUDIES
Vasum Peiris, M.D., M.P.H., Chief Medical Officer of Pediatrics and Special Populations, Center for Devices and Radiological Health, FDA

9 DEVICES FOR RARE PEDIATRIC DISEASES
Vasum Peiris, M.D., M.P.H., Chief Medical Officer of Pediatrics and Special Populations, Center for Devices and Radiological Health, FDA

10 SAFETY ISSUES IN RARE DISEASE DRUG DEVELOPMENT
Kathryn O’Connell, M.D., Ph.D., Medical Officer, Rare Diseases Program, Office of New Drugs, CDER, FDA

11 RARE PEDIATRIC DISEASE PRIORITY REVIEW VOUCHERS & DESIGNATIONS
Larry Bauer, Regulatory Scientist, Rare Diseases Program, Office of New Drugs, CDER, FDA

12 NAVIGATING CBER
Ilan Irony, M.D., Deputy Director Division of Clinical Evaluation and Pharmacology/Toxicology, CBER, FDA

13 GENE THERAPY POLICIES AT CBER
Ilan Irony, M.D., Deputy Director Division of Clinical Evaluation and Pharmacology/Toxicology, CBER, FDA

14 CREATIVE PROTOCOL DESIGNS TO ACCELERATE REGULATORY APPROVALS
Jules T. Mitchell, MBA, Ph.D., President, Target Health Inc.

15 ASSESSING THE VALUE OF ORPHAN DRUGS
Heather Golding, Vice President Legal and Compliance, Sobi North America

16 A CONVERSATION WITH JONATHAN GOLDSMITH, CBER RARE DISEASE OFFICE
Jonathan C. Goldsmith, M.D., F.A.C.P., Associate Director Rare Diseases Program, Office of New Drugs, CDER, FDA

17 BOARD MANAGEMENT FOR PATIENT ORGANIZATIONS
Heather Golding, Vice President Legal and Compliance, Sobi North America

18 MANAGING VOLUNTEERS IN PATIENT ORGANIZATIONS
Heather Golding, Vice President Legal and Compliance, Sobi North America

19 SOCIAL MEDIA STRATEGIES TO MAKE YOUR MESSAGE HEARD

20 ROLE OF PATIENT ORGANIZATIONS IN ADVOCATING FOR NEW DRUG APPROVALS
Amy R.U.L. Calhoun, M.D., Medical Director, Division of Medical Genetics, Sted Family Department of Pediatrics, University of Iowa Carver College of Medicine and Medical Consultant, Iowa Newborn Screening Program

21 EDUCATING MEDICAL PROFESSIONALS ABOUT RARE DISEASES

22 GENOME SEQUENCING & RARE DISEASE DIAGNOSIS

DAY 1 MONDAY, OCTOBER 16, 2017
### Breakout A: Promoting Earlier Diagnosis

**The Physician Perspective**
Debra Regier, M.D., Ph.D., Director of Education, *Children's National Rare Disease Institute*
Amy R.U.L. Calhoun, M.D., Clinical Assistant Professor, Division of Medical Genetics, Stead Family Department of Pediatrics, University of Iowa Carver College of Medicine and Medical Consultant, Iowa Newborn Screening Program

**Advancing Diagnosis**
Michael Patrick Gray, M.P.H., Senior Director of Medical Services, *Pulmonary Hypertension Association*
Derek Blackway, Senior Manager, Communications & Advocacy, *Guthy-Jackson Charitable Foundation*

### Breakout B: Next-Generation Treatments & Advancing Clinical Trials

**The Promise of Gene Therapy**
Maria Kefalas, Co-Founder, *Calliope Joy Foundation*

**Share for Rare—a Collaborative Platform Model**
Petra Kaufmann, M.D., Director of Clinical Innovation, National Center for Advancing Translational Sciences, NIH

**Development of Novel Endpoints Using Mobile Technologies**
Theresa Strong Ph.D., Director of Research Programs, *Prader-Willi Research*

### Breakout C: Successful Strategies for Patient Organizations

**Track Moderator:** Jennifer Knapp, Executive Director, *Adrenal Insufficiency United*, Oregon Rare Action Network State Ambassador, NORD

**The Power of State-Level Legislation**
Erica Barnes, Founder/President, *Chloe's Fight Rare Disease Foundation*, Minnesota Rare Action Network State Ambassador, NORD

**Effective Family Partnerships with the Medical Care Team**
MaryBeth Hollinger, R.N., Director of Education, Support and Advocacy, *MitoAction*
Colleen Clarke Muraresku, M.S., C.G.C., Children’s Hospital of Philadelphia

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**2:45** Networking & Refreshment Break

**3:30** The Challenge of Healthcare Costs & Treatment Prices
A look at the many factors impacting healthcare costs and treatment prices today.

**Moderator:** Steve Usdin, Washington Editor, *BioCentury*

**Panelists:**
- Michelle Drozd, Sc.M., Deputy Vice President, Policy and Research, PhRMA
- Bill Martin, Vice President, Pharma Strategy and Account Management, *Express Scripts*
- James Geraghty, Entrepreneur in Residence, *Third Rock Ventures*

**4:30** RIGHT TO TRY, CURRENT POLICY NEWS & NORD’S POLICY PRIORITIES

**Moderator:** Kate Rawson, Senior Editor, The RPM Report: Regulation, Policy and Market Access and “The Pink Sheet”, Prevision Policy LLC

**Panelists:**
- Martha Rinker, J.D., VP Policy, NORD
- Kurt R. Karst, Director, Co-Founder and Primary Author of FDA Law Blog, *Hyman, Phelps & McNamara, PC*
- Paul Melmeyer, Director of Federal Policy, NORD
- Tim Boyd, M.P.H., Director of State Policy, NORD

**5:45** Networking Reception
DAY 2  TUESDAY, OCTOBER 17, 2017

7:00  Continental Breakfast Opens  
NETWORKING APPOINTMENT TIMES AVAILABLE

7:45  DAY TWO INSIGHTS
Peter L. Saltonstall, President and Chief Executive Officer, NORD
Marshall L. Summar, M.D., Director, Children's National Rare Disease Institute and Chief, Genetics and Metabolism, Children's National Medical Center; Chairman, Board of Directors, NORD

8:00  SUSTAINING ORPHAN DRUG DEVELOPMENT AND AVAILABILITY

9:00  CHOOSE ONE OF THREE BREAKOUT SESSIONS

**BREAKOUT SESSION I**  
**THE POWER OF DATA-SHARING**

- **CENTERS OF EXCELLENCE**
  - Marshall L. Summar, M.D., Director, Children's National Rare Disease Institute and Chief, Genetics and Metabolism, Children's National Medical Center; Chairman, Board of Directors, NORD
- **PARTICULAR RELEVANCE OF DATA-SHARING TO RARE DISEASES**
  - Carrie Wolinetz, Ph.D., Associate Director for Science Policy, NIH
  - Sheetal Telang, Senior Director, Therapeutic Strategy, Head of Global Site Identification, Therapeutic Science & Strategy Unit, QuintilesIMS
- **DATA-SHARING & RARE CANCERS**

**BREAKOUT SESSION II**  
**DEVELOPING A GLOBAL STRATEGY FOR RARE DISEASES & ORPHAN DRUGS**

- **Track Moderator:** Durhane Wong-Rieger, CEO, Canadian Organization for Rare Disorders and Chair, Rare Diseases International
- **GLOBAL RESEARCH AND DEVELOPMENT AND ACCESS STRATEGIES**
  - Julie Raskin, Congenital Hyperinsulinism International
  - Steve Roberds, Ph.D., Chief Scientific Officer, Tuberous Sclerosis Alliance
- **THE CURRENT SITUATION IN INDIA**
  - Ramaiah Muthyala, M.D., President & CEO, Indian Organization for Rare Diseases

**BREAKOUT SESSION III**  
**SUCCESSFUL STRATEGIES FOR PATIENT ORGANIZATIONS**

- **Track Moderator:** Debbie Drell, Director of Membership, NORD
- **FUNDRAISING STRATEGIES FOR RARE DISEASE ORGANIZATIONS**
  - Valerie Navy-Daniels, Chief Development Officer, Foundation Fighting Blindness
  - Danielle Pinders, Officer and Event Coordinator, Foundation for Angelman Syndrome
  - Kelly Sitkin, Chief Advancement Officer, American Brain Tumor Association
- **PCORI FUNDING OPPORTUNITIES AND RESOURCES FOR RARE DISEASE ORGANIZATIONS**
  - Julie Beitz, M.D., Office of Drug Evaluation III, Office of New Drugs, CDER, FDA

10:00  Networking & Refreshment Break  
NETWORKING APPOINTMENT TIMES AVAILABLE

10:30  CURRENT TOPICS FROM THE FDA

- **Moderator:** Robert Temple, M.D., Deputy Center Director for Clinical Science, CDER, FDA
- **Time:** 10:30
- **FDA/CDER Director Janet Woodcock (via video)**
  - Janet Woodcock, M.D., Director, Center for Drug Evaluation and Research, FDA
- **Time:** 11:10
- **FDA Leadership Perspectives on Orphan Drug Review**
  - Billy Dunn, M.D., Director, Division of Neurology Products (DNP), Office of New Drugs, CDER, FDA
  - Wilson Bryan, M.D., Director, Office of Tissues and Advanced Therapies, CBER, FDA
  - Amy Barone, M.D., M.S.C.I., Oncology Center of Excellence, FDA

10:40  How Patients Have Been Involved

- Andrea Furia-Helms, M.P.H., Health Programs Coordinator, Office of Health and Constituent Affairs, FDA

11:40  FDA Perspectives on Gene Therapy

- Ilan Irony, M.D., Deputy Director Division of Clinical Evaluation and Pharmacology/Toxicology, CBER, FDA

12:00  Patient Voice & Engagement with the FDA

- Pujita Vaidya, M.P.H., Office of Strategic Programs, FDA
- How Patients Have Been Involved
- Andrea Furia-Helms, M.P.H., Health Programs Coordinator, Office of Health and Constituent Affairs, FDA
- Patient Engagement in CDRH
- Anindita “Annie” Saha, Director, External Expertise and Partnerships, CDRH, FDA
**2:00 INVESTOR PERSPECTIVE: THE OUTLOOK FOR INVESTMENT IN ORPHAN PRODUCTS**
David Scheer, President, Scheer & Company, Inc.

**3:00 RARE DISEASE DRUG, BIOLOGIC AND DEVICE DEVELOPMENT: ACHIEVEMENTS AND OPPORTUNITIES**
Moderator:
Wayne L. Pines, President, Health Care, APCO Worldwide
Richard Moscicki, M.D., Deputy Center Director for Science Operations, CDER, FDA
Peter Marks, M.D., Ph.D., Director, Center for Biologics Evaluation and Research, FDA
Jeffrey Shuren, M.D., J.D., Director, Center for Devices and Radiological Health, FDA

**4:00 CLOSING REMARKS**
Peter L. Saltonstall, President and Chief Executive Officer, NORD

**6:00 MUSIC, MEDICINE AND MOVING FORWARD**
A Cocktail Reception Hosted by Children’s National Rare Disease Institute to celebrate the NORD Summit
Life-Transforming Treatments
An opportunity throughout each of the networking breaks and luncheons to view original research, innovations and advancements as numerous posters are displayed, illustrating key themes:

• INNOVATIVE RESEARCH
• MEDICAL EDUCATION ADVANCEMENT
• PATIENT COMMUNITY BUILDING
• OTHER LIFE-TRANSFORMING TREATMENTS & ADVANCEMENTS

For questions regarding the poster submissions, please visit www.nordsummit.org.

Bringing the Community Closer
1:1 Appointments Elevate Networking Opportunities!
Maximize your time at the event and build meaningful partnerships by utilizing our appointment-setting software to connect with attendees in advance to schedule on-site meetings.

• Customized profiles for you and your organization
• Access attendee lists to find potential interesting clients, contacts or partners
• Software automatically recommends potential matches using keywords
• Easy scheduling for face-to-face meetings at the event; reserved space handled by NORD
• Ability to confirm or deny meeting requests
• Secure, confidential messaging
• Customize your personal agenda for the conference
• Automated personal schedule that can be exported to Outlook, iCal, or printed as a PDF
• Easy access using mobile or desktop
Who attends?

The Summit provides a collaborative environment for researchers from academia, drug and device companies, patient organizations and advocates, policy experts and government organizations responsible for rare disease research and orphan product oversight.

**BREAKTHROUGH INDUSTRIES & FOCUS AREAS INCLUDE:**

- Patient Services
- Advocacy
- Clinical Development
- R&D
- Reimbursement
- Health Policy / Affairs
- Regulatory Affairs
- Corporate Communications

Sponsorship of NORD’s Rare Diseases and Orphan Products Breakthrough Summit exposes your organization to hundreds of stakeholders, decision makers and influencers committed to the identification, treatment, and the cure of rare diseases. This is through accomplished programs of education, advocacy, research, and patient services.

**For more information contact:**

**Alexa Moore**  
VP of Development, National Organization for Rare Disorders  
617-934-6397 | amoore@rarediseases.org

**Derek Gavin**  
Director of Development, National Organization for Rare Disorders  
617.249.7304 | dgavin@rarediseases.org | NORDsummit.org | #NORDSummit
### Conference Pricing

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<td>Students, Residents and Fellows</td>
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<td>Physicians, Pharmacists and Nurses (2-day Summit)*</td>
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*This price is offered to individuals attending the CME program offered by NORD during the conference. Please visit rarediseases.org/CME for more information.

For additional pricing information, please contact NORDREG@MeetingExpectations.com.

Registration fee includes continental breakfast, lunch, refreshments, wine and cheese reception and conference materials.

Credit Card (Visa, MC, AMEX, Discover) or checks accepted. Please make checks (in U.S. funds drawn on a U.S. bank) payable to:

National Organization for Rare Disorders, Inc.  
Department 5430  
P.O. Box 4110, Woburn, MA 01888-4110

**PLEASE NOTE:** All advertised discounts are taken from the full, standard rate.

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**VENUE**

**Marriott Wardman Park**  
2660 Woodley Rd NW,  
Washington, DC 20008  

**Phone Reservations:** 1-877-212-5752 (mention NORD)  

**SUBSTITUTION AND CANCELLATION**

Any cancellations received in writing on or before 14 days prior to the start date of the event will be refunded, less a $399 administrative charge. No refunds will be made after October 1, 2017. Your registration may be transferred to another member of your organization up to 24 hours in advance of the summit.

In case of a conference cancellation beyond our control*, you will receive a refund for your conference registration fee only. NORD reserves the right to alter this program without prior notice. **Please Note:** Speakers and agenda are subject to change. In the event of a speaker cancellation, every effort to find a suitable replacement will be made.

*Events beyond our control include: severe weather conditions, natural and man-made disasters and any other similar events.

**ACCOMMODATIONS**

To receive NORD’s discounted hotel rate:  
**Online:** [https://aws.passkey.com/go/NORD17](https://aws.passkey.com/go/NORD17)  
**Phone reservations:** 1-877-212-5752 (mention NORD)

**Book Now!** Marriott Washington Wardman Park is accepting reservations on a space and rate availability basis. Rooms are limited so please book early. All travel arrangements are subject to availability. Please make sure you book your room by September 22, 2017.

**Scholarship Applications**

NORD is pleased to provide patient organizations with scholarships to help with the cost of attending the Summit. Scholarships are awarded on a first-come, first-served, as-needed basis with priority given to NORD patient organization members and students.

**To apply, please go to [www.nordsummit.org](http://www.nordsummit.org) and download the application.**

**Poster Submissions**

Academics, researchers, industry, government agencies, health care professionals, patient organizations and any other interested parties that have conducted rare disease or orphan product research studies or public health projects are invited to submit a poster abstract to the NORD Summit. The overall theme of the poster session is “Life-Transforming Treatments.” Suggested specific topic areas within that over-arching theme that the planning committee would like to address include: Innovative Research, Medical Education Advancement, Patient Community Building, and other topics. For more information please contact: Katherine Morgan, kmorgan@meetingexpectations.com