NORD® Rare Summit

NORD® 35TH ANNIVERSARY

KEYNOTE SPEAKER

**Scott Gottlieb, M.D.**

Commissioner, FDA

# a new era of patient-focused innovation

## RARE DISEASES & ORPHAN PRODUCTS BREAKTHROUGH SUMMIT®

October 15-16, 2018 | Marriott Wardman Park

**#NORDSUMMIT | nordsummit.org**

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# plan your week

## SUNDAY, OCTOBER 14, 2018

1:00 NORD Patient Organization Membership Meeting*
2:00 NORD Student Chapter Membership Meeting *
5:00 Scholarship Recipient Welcome Reception**
7:00 Rare Action Network® Ambassadors Meeting*

DAY 1

## MONDAY, OCTOBER 15, 2018

7:00 Conference Registration and Continental Breakfast
7:50 **NORD'S WELCOME & SUMMIT PREVIEW** – Peter L. Saltonstall, President and Chief Executive Officer, NORD
8:00 **PATIENT/CAREGIVER OPENING ADDRESS**
8:45 How Patients Are Helping Drive Research and Drug Development
9:30 Solving the Diagnosis Challenge
10:15 Networking & Refreshment Break
10:45 **KEYNOTE ADDRESS: SCOTT GOTTLIEB, M.D., FDA COMMISSIONER**
11:30 The Growing Impact of Grassroots Advocacy
12:15 Networking Lunch or Lunch & Learn Roundtable Discussions
1:30 **CHOOSE ONE OF THREE BREAKOUT SESSIONS**

| WHAT'S NEXT FOR THE RARE CANCER COMMUNITY? | ADDRESSING ACCESS CHALLENGES FOR ORPHAN PRODUCTS | PATIENT ADVOCACY FOR DIAGNOSIS & DRUG DEVELOPMENT |
|---|---|---|

3:00 Networking & Refreshment Break
3:30 Value, Pricing and the Patient Experience: How to Achieve an Effective Balance
4:30 What We All Can Learn from Advances in Cancer Therapies
5:30 Networking Reception

DAY 2

## TUESDAY, OCTOBER 16, 2018

7:00 Continental Breakfast Opens
8:00 Day 1 Summary & Day 2 Preview
**UPDATE FROM HHS**
8:15 Patient Perspectives on Gene Therapy
9:00 **CHOOSE ONE OF THREE BREAKOUT SESSIONS**

| PRIOR AUTHORIZATION, STEP THERAPY AND OTHER ACCESS CHALLENGES | CLINICAL TRIAL SUCCESS: PATIENT ACCESS, RECRUITMENT & RETENTION | EMBRACING INNOVATION TO ADVANCE SCIENCE |
|---|---|---|

10:00 Networking & Refreshment Break
10:30 **CURRENT TOPICS FROM THE FDA**
11:30 FDA's New Patient Outreach Program and Views on Biomarkers and Pediatrics
12:30 Networking Lunch or Lunch & Learn Roundtable Discussions
2:00 Federal Policy Priorities & Election Implications
3:00 What's Ahead for Orphan Drug Development?
4:00 Predicting the Pipeline
5:00 Close of Conference
6:15 Cocktails and Conversation with Children's National Rare Disease Institute

## WEDNESDAY, OCTOBER 17, 2018

8:00 NORD Corporate Council Meeting*
8:00 NORD IAMRARE® Registry Users Meeting*

** Meetings are available to members only and not open to the public. Not a member? Contact events@rarediseases.org to join and take advantage of these meetings.*
*** By invitation only.*

# attendee demographics

Over **12** senior FDA officials

More than **85** speakers

**6** breakout sessions

Over **2** Days

**700** attendees

Across all stakeholders

**14** Lunch and Learn roundtable discussions

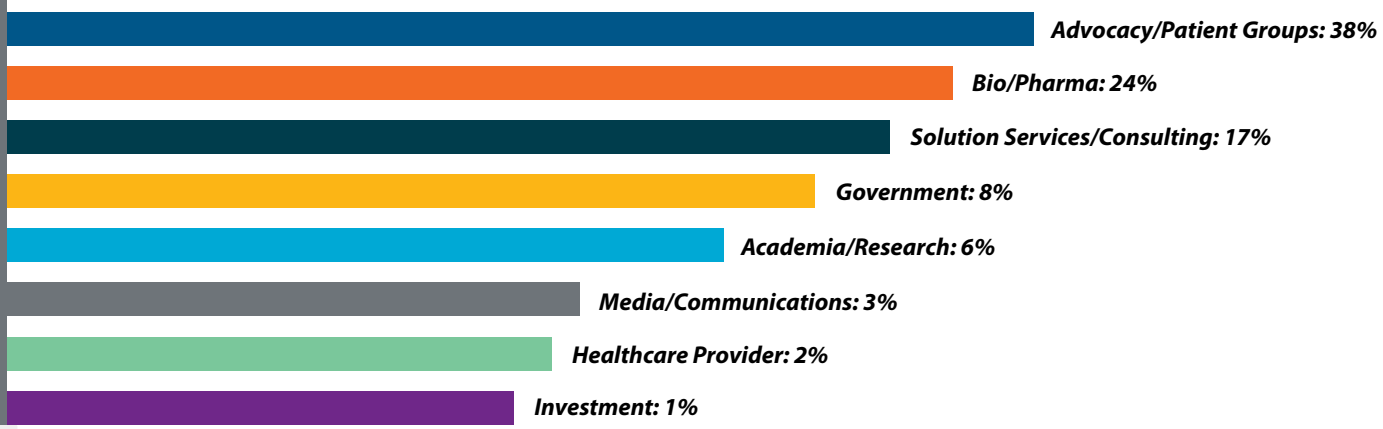
**200+** networking meetings

## the largest multi-stakeholder gathering in the rare disease community

## 2017

Previous Participant Profile

PARTICIPANTS BY ORGANIZATION



# why you should attend

## Invitation from NORD

Join rare disease innovators and pioneers at the 2018 NORD Summit to explore:

- How patients and caregivers are helping drive progress with patient-reported outcomes and real-world evidence;
- How patient-centric clinical trials can enhance recruitment and retention;
- Patient/caregiver questions, hopes and concerns about gene therapy and gene editing; and
- The impact of prior authorization and step therapy on patient access to care.

We'll also look at the possible implications of the 2018 elections and the growing impact of grassroots advocacy. You won't want to miss this opportunity to hear cutting-edge keynote speakers, network with your peers, and hear directly from senior FDA staff about their current priorities and the implementation of Patient-Focused Drug Development.

**Peter L. Saltonstall**
President and CEO
NORD

## With Special Appreciation for the 2018 Program Advisory Board Members:

NORD would like to extend appreciation to the program advisory members from the FDA who assisted with the FDA elements of the program. Their dedication, time and insights help to assure a program that is timely, relevant and meaningful to all members of the rare disease community.

Larry Bauer, Regulatory Scientist, CDER

Althea Cuff, Science Policy Analyst, CDER

Lucas Kempf, M.D., Associate Director, Rare Diseases Program

EXPANSIVE **POSTER SESSION** HIGHLIGHTING THE BRIGHTEST MINDS IN THE INDUSTRY

**85+** SPEAKERS

GROUNDBREAKING **KEYNOTES**

**INSIGHTFUL** PATIENT PARTICIPATION

PRE-EVENT **MEETING SCHEDULER** ENHANCING CONNECTIONS & PARTNERSHIP BUILDING

MULTIPLE **BREAKOUT SESSIONS** WITH SOMETHING FOR EVERYONE

ROUNDTABLE **DISCUSSIONS** KEY TOPICS OF INTEREST

# breakthrough topics + speakers

### Gene Therapy: The Patient Perspective
Patients and caregivers share their hopes, questions and concerns regarding gene therapy.

### Solving the Diagnosis Challenge
What scientific and financial challenges need to be addressed to promote earlier diagnosis for patients?

### Patient Engagement in Driving Research
Patient organizations are helping drive progress with patient-reported outcomes, real-world evidence and innovative collaborations.

### The Growing Impact of Grassroots Advocacy
Advocates in NORD's Rare Action Network talk about their challenges and successes in advocacy at the state level.

### Addressing Access Challenges
How are practices such as prior authorization and step therapy affecting people with rare diseases?

### Value, Pricing and the Patient Experience
With gene therapies and other treatment advances, the conversation about value and pricing has taken on new significance.

### What's Next for the Rare Cancer Community?
Immunotherapies, gene therapies and other advances hold great promise for those affected by rare cancers.

### Clinical Trial Success: Access, Recruitment and Retention
Practices to make clinical trials more patient-centric are increasing recruitment and retention.

### Predicting the Pipeline: FDA Forecast
The heads of FDA CDER, CBER and CDRH share their insights and predictions for orphan product development.

# keynote speaker

## 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.

# sessions day one: monday, october 15, 2018

**7:00** Conference Registration and Continental Breakfast

**7:50** **NORD'S WELCOME & SUMMIT PREVIEW**
Peter L. Saltonstall, President and Chief Executive Officer, NORD

**8:00** **PATIENT/CAREGIVER OPENING ADDRESS: THE NEXT GENERATION OF PATIENT ADVOCATES**

**Moderator:** Anita Gupta, D.O., Pharm.D., Rare Disease Survivor, Scholar at Georgetown University School of Medicine and Professor of Surgery at Rowan University School of Medicine

**Panelists:** Christopher Anselmo

Taylor Kane

Harjot Randhawa

Gabriel Low

Harjot Singh, medical student, American University of Integrative Sciences

**8:45** **HOW PATIENTS ARE HELPING DRIVE RESEARCH AND DRUG DEVELOPMENT**

The role of patients, caregivers and patient organizations in research and drug development has undergone fundamental changes in recent years. This panel will look at innovative collaborations and how these new patient roles are helping to advance research and development of therapies.

**Moderator:** Christopher P. Austin, M.D., Director, NCATS, NIH

**Panelists:** Pushkal Garg M.D., Chief Medical Officer and Senior Vice President, Clinical Development, Alnylam Pharmaceuticals

Caroline Kruse, Executive Director, Platelet Disorder Support Association

Tanisha Carino Ph.D., Executive Director, Faster Cures

**9:30** **SOLVING THE DIAGNOSIS CHALLENGE**

Delay in diagnosis remains a serious problem for all stakeholders in the rare disease community. What is the outlook for reducing time to diagnosis and what are the specific challenges—scientific and financial—that need to be overcome?

**Moderator:** 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

**Panelists:** William Gahl, M.D., Ph.D., Clinical Director, NHGRI, and Director, NIH Undiagnosed Diseases Program

Ellen Matloff, M.S., C.G.C., President and CEO My Gene Counsel

Jaimie Vickery, M.P.P., Vice President, Advocacy and Policy, Cure SMA

Helene Cederroth, President, Wilhelm Foundation—the Undiagnosed

Shannon Resetich, Head of Rare Diseases for North America, Sanofi Genzyme

**10:15** **NETWORKING BREAK**

**10:45** **KEYNOTE ADDRESS: SCOTT GOTTLIEB, M.D., FDA COMMISSIONER**

**11:30** **THE GROWING IMPACT OF GRASSROOTS ADVOCACY**

Decisions made at the state level are having an increasing impact on rare disease patients and families. Representatives of NORD's Rare Action Network® will talk about their experiences and the challenges and opportunities of advocacy at the state level today.

**Moderator:** Tim Boyd, Director of State Policy, NORD

**Panelists:** Jhoanny Cardenas, Co-State Ambassador, Florida, NORD Rare Action Network

Fran Hokkanen, Co-State Ambassador, Florida, NORD Rare Action Network

Alan Holbrook, Co-State Ambassador, Massachusetts, NORD Rare Action Network

Debbie Skolaski, State Ambassador, Texas, NORD Rare Action Network

**12:15** **NETWORKING LUNCH OR LUNCH & LEARN ROUNDTABLE DISCUSSIONS**

# sessions day one: monday, october 15, 2018 [continued]

## 1:30 – CHOOSE ONE OF THREE BREAKOUT SESSIONS

BREAKOUT A

### What's Next for the Rare Cancer Community?

*Immunotherapies, gene therapies and other advances hold great promise for those affected by rare cancers. Researchers, patient advocates and other thought leaders will share their insights, concerns and predictions.*

**Moderator:** John Hopper, President/Executive Director, Fibrolamellar Cancer Foundation

**Panelists:** Melinda Bachini, Advocacy Coordinator, The Cholangiocarcinoma Foundation

Corrie Painter, Ph.D., Associate Director of Operations and Scientific Outreach, Broad Institute of MIT and Harvard

Jim Palma, Executive Director, TargetCancer Foundation

David Dubinski, Head of Patient Advocacy, Incyte

Karlyne Reilly, Ph.D., Rare Tumors Initiative, National Cancer Institute

BREAKOUT B

### Addressing Access Challenges for Orphan Products

*This panel will look at the roles of specialty pharmacies, pharmacy benefit managers and others within the pharmacy supply chain, along with potential access challenges for patients.*

**Moderator:** Jayson Slotnik, J.D., Principal and Founding Member, Health Policy Strategies, Inc.

**Panelists:** Brent Clough, Chief Executive Officer, Trio Health

Amy DuRoss, Chief Executive Officer, Co-founder, Vineti

Terry Cato, Senior Director, AllianceRx Walgreens Prime

Byron Neal, Director, Specialty Trade, CVS Health

BREAKOUT C

### Patient Advocacy for Diagnosis & Drug Development

*This session will address topics of particular interest to patient organizations.*

**Moderator:** Debbie Drell, Director of Membership, NORD

**Opportunities for Patient Organizations to Interact with FDA**

**Panelists:** Samir Shaikh, Deputy Director, FDA PAS: Listening Sessions

Pujita Vaidya, M.P.H., Director, Decision Support & Analysis, FDA: Patient-Focused Drug Development Meetings

**Advocacy for Newborn Screening**

Deboshree "Debi" Sarkar, M.P.H., Chief, Genetic Services Branch, Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, HRSA

Janis Sherwood, Founder, Fight ALD

**Strategic Planning with Your Medical Advisors**

Pam Mace, R.N., Executive Director and Patient, Fibromuscular Dysplasia Society of America

Monida Weldon, President/CEO, Bridge the Gap—SYNGAP—Education and Research Foundation

**3:00** NETWORKING & REFRESHMENT BREAK

**3:30** VALUE, PRICING & THE PATIENT EXPERIENCE: HOW TO ACHIEVE AN EFFECTIVE BALANCE

With gene therapies and other treatment advances, the conversation regarding value and pricing has taken on new significance. This panel will examine how to achieve a balance in orphan product pricing that reflects the value of therapies in the lives of patients.

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

**Panelists:** Mark Fendrick, M.D., Institute for Healthcare Policy & Innovation, University of Michigan

Markus Peters, Ph.D., Chief Commercial Officer, Agilis Biotherapeutics

Brendan Hayes, National Hemophilia Foundation

Patrick Collins, Senior Director, Global Healthcare Policy & External Affairs, CSL Behring

**4:30** WHAT WE ALL CAN LEARN FROM ADVANCES IN CANCER THERAPIES

More than 40% of orphan drug approvals are for rare types of cancer. How can this success and the principles adopted by the oncology community be more broadly applied to other diseases?

**Moderator:** Richard Pazdur, M.D., Director, Office of Hematology and Oncology Products, Office of New Drugs, CDER, FDA

**Panelists:** Ellen V. Sigal, Chairperson & Founder, Friends of Cancer Research

Samit Hirawat, M.D., Global Director of Development, Novartis Oncology

Deborah Morosini, M.D., VP, Clinical Affairs & Patient Engagement, Loxo Oncology

**5:30** NETWORKING RECEPTION

# sessions day two: tuesday, october 16, 2018

**7:00** CONTINENTAL BREAKFAST

**8:00** DAY 1 SUMMARY & DAY 2 PREVIEW

Peter L. Saltonstall, President and Chief Executive Officer, NORD

UPDATE FROM HHS

**8:15** PATIENT PERSPECTIVES ON GENE THERAPY

With more than 150 gene therapy Phase I, II and III clinical trials in progress, patients and caregivers representing several rare disease communities share their thoughts, hopes and concerns regarding this promising new avenue to treatment.

**Moderator:** Maria Kefalas, Ph.D., Founder, The Calliope Joy Foundation

**Panelists:** Ashanthi De Silva, Patient

Carrie Koenig, Families Program Manager, Hemophilia Federation of America

Charles Priebe, Co-Founder, Sofia Sees Hope

## 9:00 – CHOOSE ONE OF THREE BREAKOUT SESSIONS

BREAKOUT I

### Prior Authorization, Step Therapy and Other Access Challenges

*Utilization management practices are creating access barriers for patients. The issues will be examined from both the patient and physician perspective.*

**Moderator:** Eric Racine, VP & Head North America Public Affairs, Sanofi Genzyme

**Panelists:** Jen Melanson, Patient

Jess G. Thoene, M.D., Active Professor Emeritus of Pediatrics, University of Michigan

Kelley Allison, Horizon

BREAKOUT II

### Clinical Trial Success: Patient Access, Recruitment, & Retention

*Experts on this topic will discuss strategies for promoting patient access to clinical trials while also maximizing recruitment and retention to increase the likelihood of clinical trial success.*

**Moderator:** Jonathan Jackson, Ph.D., Instructor in Neurology, Harvard Medical School and Director, Community Access, Recruitment and Engagement (CARE) Research Center, Massachusetts General Hospital

**Panelists:** Philip John (P.J.) Brooks, Ph.D., Program Director, Division of Clinical Innovation, National Center for Advancing Translational Sciences, NIH

Margot Johnson, VP & Group Lead for Rare Disease, Clinical Development & Operations, Pfizer

Sarah Mulcahey, M.S., Director, Clinical Program Management, Vertex Pharmaceuticals, Inc.

Nadia Bodkin, Senior Executive Vice President, Maxify Life and President and Chief Executive Officer, EDSers United

Christina Clark, Director of Development, Batten Disease Support & Research Association

BREAKOUT III

### Embracing Innovation to Advance Science

*Artificial intelligence and machine learning offer hope for addressing rare disease challenges. This session will explore these and other innovative uses of technology.*

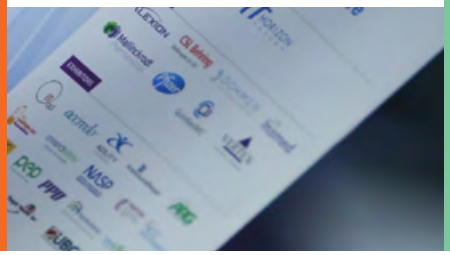
**Moderator:** Shao-Lee Lin, M.D., Ph.D., Executive Vice President, Head of Research and Development, and Chief Scientific Officer, Horizon Pharma plc

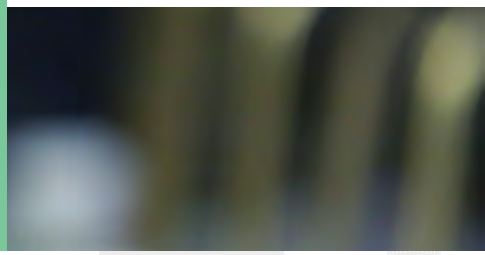
**Panelists:** Marius George Linguraru, D.Phil., M.A., M.S., Principal Investigator at Children's National Medical Center

Oodaye Shukla, Chief Data Scientist, HVH Precision Analytics

Chris Schelling, CEO & Founder, Acer Therapeutics Inc.

Christine Stanley, WuXi Nextcode





# sessions day two: tuesday, october 16, 2018 [continued]

**10:00** NETWORKING & REFRESHMENT BREAK

**10:30** CURRENT TOPICS FROM THE FDA

Senior FDA staff will discuss the evolving role of the patient and patient community in drug development process, and how best to interact with FDA.

**Moderator** Theresa Mullin, Ph.D., CDER's Associate Director for Strategic Initiatives

**Panelists:** Tejashri Purohit-Sheth, M.D., FACAAI, CQIA, CAPT, USPHS, Director, Division of Clinical Evaluation and Pharmacology/Toxicology, Office of Tissue and Advanced Therapies, Center for Biologics Evaluation and Research (CBER)

Dragos Roman, M.D., Deputy Director, Divison of Gastroenterology & Inborn Errors Product (DGIEP), Office of New Drugs (OND), CDER

Ellis Unger, M.D., Director, Office of Drug Evaluation--1, OND, CDER

Nicole Wolanski, CAPT, USPHS, Acting Deputy Director, Office of Orphan Products Development

**11:30** FDA'S NEW PATIENT OUTREACH PROGRAM, AND VIEWS ON BIOMARKERS AND PEDIATRICS

Senior FDA staff will discuss FDA's new Patient Affairs outreach program, the developing importance of biomarkers in testing new therapies, and FDA's view of new treatments for pediatric patients.

**Moderator:** Lucas Kempf

**Panelists:**Andrea Furia-Helms, M.P.H., Director, Patient Affairs Staff, Office of Medical Products and Tobacco

Christopher Leptak, Director, OND Regulatory Science Program, CDER

Susan McCune, M.D., Director, Office of Pediatric Therapeutics, Office of the Commissioner

**12:30** NETWORKING LUNCH OR LUNCH & LEARN ROUNDTABLE DISCUSSIONS

**2:00** FEDERAL POLICY PRIORITIES & ELECTION IMPLICATIONS

Members of NORD's federal policy team and advocacy partners will discuss current issues and policy priorities for the community. They will also talk about possible scenarios following the November elections.

**Moderator:** Paul Melmeyer, M.P.P., Director of Federal Policy, NORD

**3:00** WHAT'S AHEAD FOR ORPHAN DRUG DEVELOPMENT?

In a fireside chat format, orphan drug investors and corporate CEOs will talk about gene therapy, personalized medicine, the impact of mergers & acquisitions, scientific innovation, and other topics that will play a role in emerging directions for orphan product development.

**Moderator:** David Scheer, President, Scheer & Company, Inc.

**Panelist:** Stephen Aselage, Chief Executive Officer, Retrophin, Inc.

Sean P. Nolan, Former President and CEO, AveXis, Inc.

Jessica Chutter, Chair, Biotechnology Investment Banking, Morgan Stanley

Greg LaRosa, SVP, Head Scientific Strategy, Rare Disease RU, Pfizer, Inc.

Charlie Albright, CSO, Editas Medicine

**4:00** PREDICTING THE PIPELINE

The division heads of FDA CBER, CDER and CDRH share their insights and predictions for orphan product trends, opportunities and challenges over the coming months.

**Moderator:** Wayne L. Pines, President, Health Care, APCO Worldwide

**Panelists:** Janet Woodcock, M.D., Director, Center for Drug Evaluation and Research, 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

Jessica Chutter, Chairman of Biotechnology Investment Banking, Morgan Stanley

**5:00** CLOSE OF CONFERENCE

**6:15** COCKTAILS AND CONVERSATION WITH CHILDREN'S NATIONAL

You are invited to join the Children's National team immediately following the conclusion of the NORD Summit for cocktails and conversation. Marshall Summar, M.D., and members of the Children's National Rare Disease Institute will be there to celebrate the Summit and the work going on in the institute.

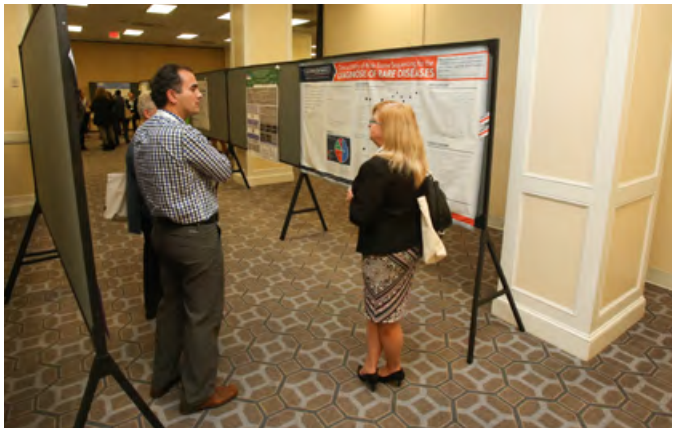
Children's National
Rare Disease Institute

# poster highlights

## Life-Transforming Treatments

An opportunity is provided 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



## Poster Submissions

Academics, researchers, industry, government agencies, health care professionals, patient organizations and any other interested parties who 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."

For more information, please contact: Carrie Lucas, events@rarediseases.org.

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

# rare-to-rare networking + highlights

## Bringing the Community Closer

### 1:1 Appointments Elevate Networking Opportunities!

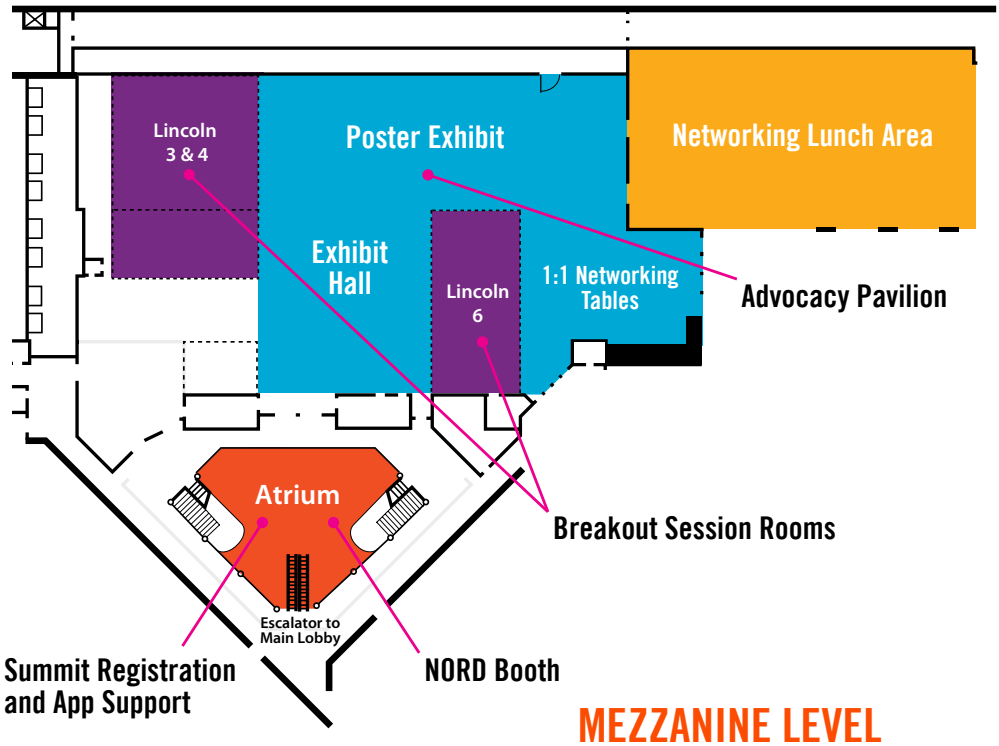
Maximize your time at the event and build meaningful partnerships by utilizing our appointment-setting software to connect with attendees in advance to schedule on-site meetings.

- 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

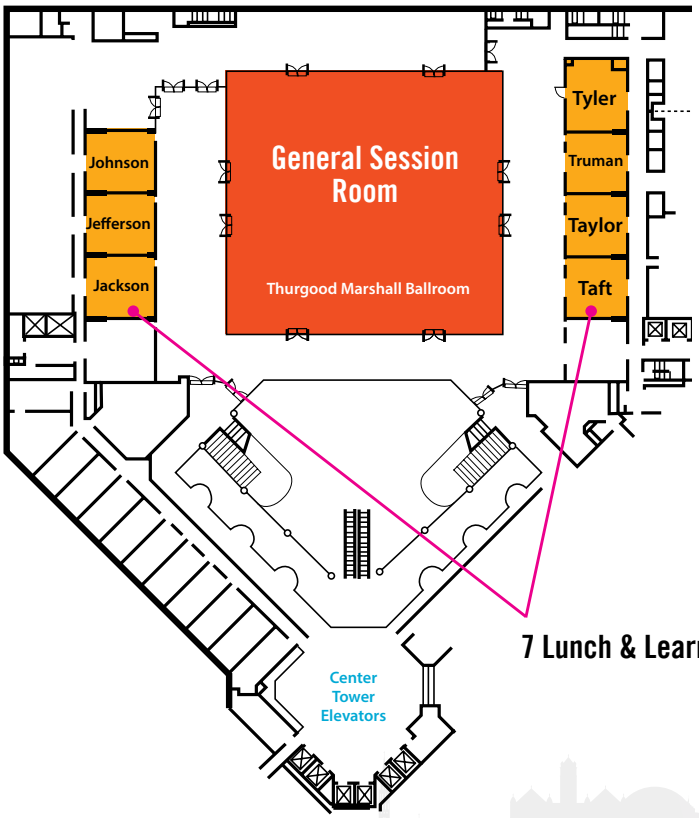
> *"Our staff and board members who attended were thrilled with the meeting as well as yesterday's special session for NORD members. We all came home armed with so much new information, many wonderful contacts and a wealth of exciting ideas to put into place. Thank you for creating a wonderful three-day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


# conference and exhibit floorplan

## EXHIBIT HALL LEVEL




## MEZZANINE LEVEL



# event sponsorship

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Inspire

illumina

Immune Deficiency Foundation

INCA International Neuroendocrine Cancer Alliance

INVITAE

IWMF

IPSEN
Innovation for patient care

The Jack McGovern Coats Disease Foundation

LDRTC

The MSA Coalition
Multiple System Atrophy
Support · Education · Research · Advocacy

MLD foundation

NF Neurofibromatosis Northeast

Pheo Para Alliance
Pheochromocytoma & Paraganglioma

PhRMA
RESEARCH · PROGRESS · HOPE

Platelet Disorder Support Association

PRECISION FOR MEDICINE
ONCOLOGY AND RARE DISEASE

NORD RARE CANCER COALITION

RARE DISEASES INTERNATIONAL

rareLife solutions
collaboration + science + technology

RETROTOPE

Rho

Sangamo THERAPEUTICS

The Smith Family CLINIC for GENOMIC MEDICINE

sobi
Pioneer in Rare Diseases

SOLIGENIX

STRONGBRIDGE BIOPHARMA

The Transverse Myelitis Association

UNITED MSD FOUNDATION
MULTIPLE SULFATASE DEFICIENCY

WEP Clinical

WuXiNextCODE

## MEDIA PARTNERS

Applied CLINICAL TRIALS

BioBuzz
be more connected

CheckOrphan
rare, orphan and neglected diseases

CheckRare

CLINICAL LEADER

FRONTLINE MEDICAL COMMUNICATIONS

Gene Therapy Net

THE HILL

INSIGHT PHARMA REPORTS

The MIGHTY

PHARMA BOARDROOM

Pharmaceutical Executive

PharmaVOICE

Policy & Medicine

RareDR Rare Disease Report

STAT

# event sponsorship

## sponsorship and exhibit opportunities

Sponsorship and exhibit opportunities provide unique access to decision-makers and align your brand with the premier thought-leaders and innovators in rare disease. Custom sponsorship packages offer prominent brand exposure and meaningful prospect interactions via a one-on-one networking software.

For more information on sponsorships, contact Alexa Moore, NORD VP of Development, 617-934-6397, amoore@rarediseases.org or Derek Gavin, NORD Director of Business Development, 617-279-7304, dgavin@rarediseases.org.

**NEW! patient advocacy pavilion** A newly added patient advocacy pavilion on the Summit exhibit level offers patient organizations an opportunity to feature their work and efforts within the rare disease community at a greatly reduced rate. The pavilion is designed to draw attention to their amazing work, offer exclusive networking and engagement, as well as media and marketing opportunities.

**cocktail reception host** Showcase your brand by hosting the prime networking event for all Rare Summit participants. Sponsors create a custom experience in the exhibit hall through entertainment, craft cocktails and menu planning.'

**breakfast, luncheon or network break host** Continue to engage in conversation during scheduled programming breaks in the exhibit hall. Welcome attendees to a custom F&B station at your exhibit booth.

**branding enhancements** Elevate your brand by displaying your logo prominently on branded giveaway items* that enhance the overall conference experience. Options include: WiFi host, hotel room keys, lanyards, water bottles, 1:1 appointment tool, registration bag insert.

* Coordinated by NORD

# venue information + accommodations


*Please book your hotel room by September 21, 2018.*

## venue

**Marriott Wardman Park**
2660 Woodley Rd NW,
Washington, D.C. 20008
**Phone Reservations:**
1-877-212-5752
(mention NORD)

## accommodations

**To receive NORD's discounted hotel rate:**
**Online:** https://book.passkey.com/gt/216339708?gtid=ef9abdbd88318f27747d42e20ded47b6
**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 21, 2018.

## 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, 2018. 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.*

# pricing + registration

## pricing

| | STANDARD RATE *Register by 10/15/18* | REGISTER ONSITE |
|---|---|---|
| NORD Patient Organization Members | $649 | $749 |
| Registered 501(c)3 Non-Profits/Patients/ Academics/Physicians | $699 | $799 |
| Government | $499 | $599 |
| NORD Corporate Council Members | $2,099 | $2,199 |
| Industry (Pharma, Service Providers, Co-Pay Foundations) | $2,499 | $2,599 |

## register at nordsummit.org

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, Mastercard, AMEX, Discover) or checks accepted.

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

## scholarship applications

NORD is pleased to provide patient organizations and students 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 and download the application.**