



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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Retrophin 

plan your week

SUNDAY, OCTOBER 14, 2018

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

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

TUESDAY, OCTOBER 16, 2018

- 7:00** Continental Breakfast Opens
- 7:45** Day 1 Summary & Day 2 Preview
- 8:00** **UPDATE FROM HHS**
- 8:30** 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**
- 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
- 6:00** Music, Medicine and Moving Forward

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.

DAY 1
DAY 2

attendee demographics

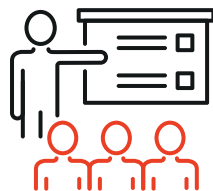
Over
12
senior FDA
officials



More than
85
speakers



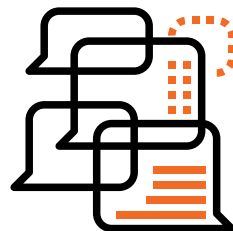
6 breakout
sessions
Over
2 Days



700
attendees
Across all stakeholders



14 Lunch and Learn
roundtable
discussions



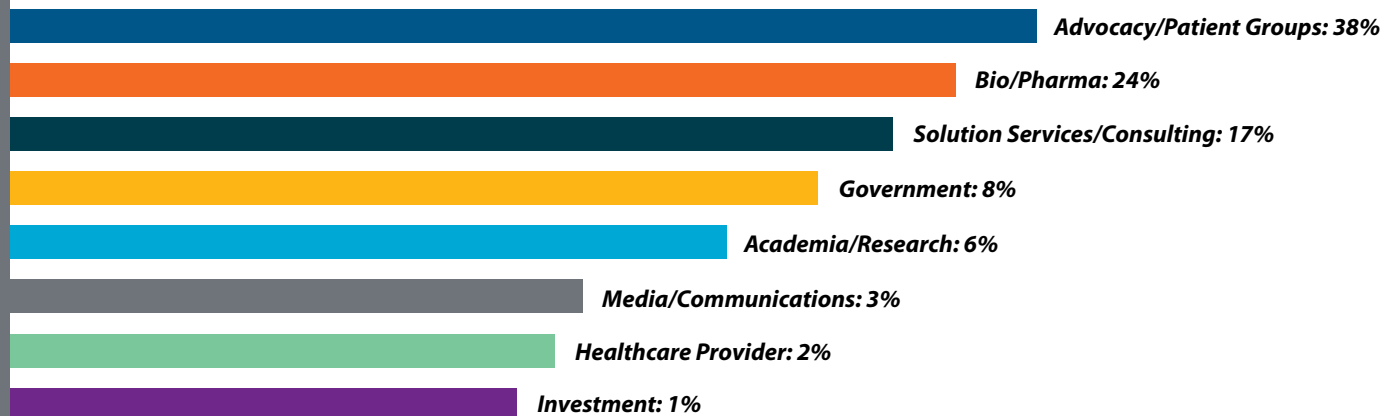
200+
networking
meetings

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 **COMMUNITY KEYNOTE: PATIENT/CAREGIVER OPENING ADDRESS**

Panelists: Christopher Anselmo

Taylor Kane

Harjot Randhawa

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.

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

Mladen Bozic, VP & Head, Global Regulatory Policy & Intelligence, Shire

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 Resetch, 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

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

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

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

Advocacy for Newborn Screening

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

5:30 NETWORKING RECEPTION



sessions day two: tuesday, october 16, 2018

7:00 CONTINENTAL BREAKFAST

7:45 DAY 1 SUMMARY & DAY 2 PREVIEW

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

8:00 UPDATE FROM HHS

8:30 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

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 Patient Advocacy, 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

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.

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.





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

10:00 NETWORKING & REFRESHMENT BREAK

10:30 CURRENT TOPICS FROM THE FDA

Senior FDA staff will present an overview of current priorities, with particular emphasis on Patient-Focused Drug Development.

Moderator: Theresa Mullins, Ph.D., CDER's Associate Director for Strategic Initiatives

Panelists: Dragos Roman, M.D., Deputy Director, Division 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, Director, Premarket Approval Section, CDRH, ODE, FDA

Christopher Leptak, M.D., Ph.D., Director, Regulatory Science Program, Office of New Drugs, CDER, FDA

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)

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

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.

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

5:00 CLOSE OF CONFERENCE

6:00 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.



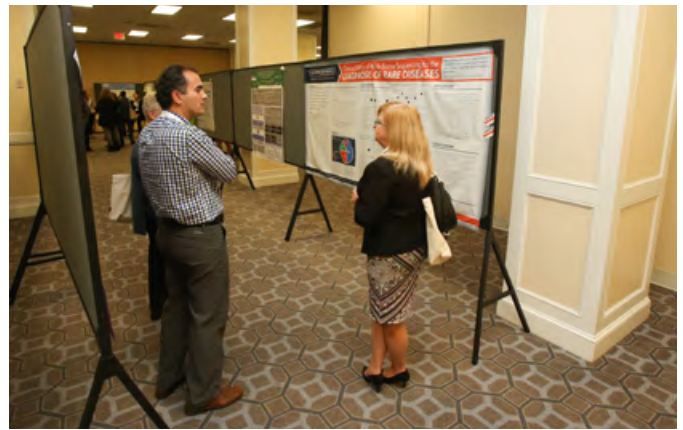


poster highlights

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!”

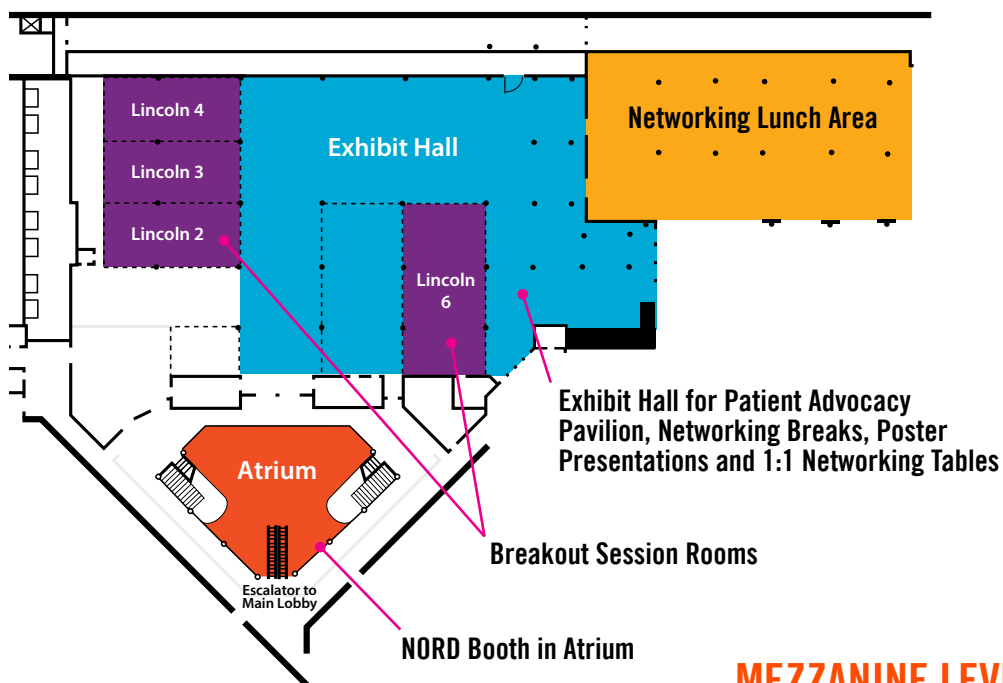
— PSC Partners Seeking a Cure



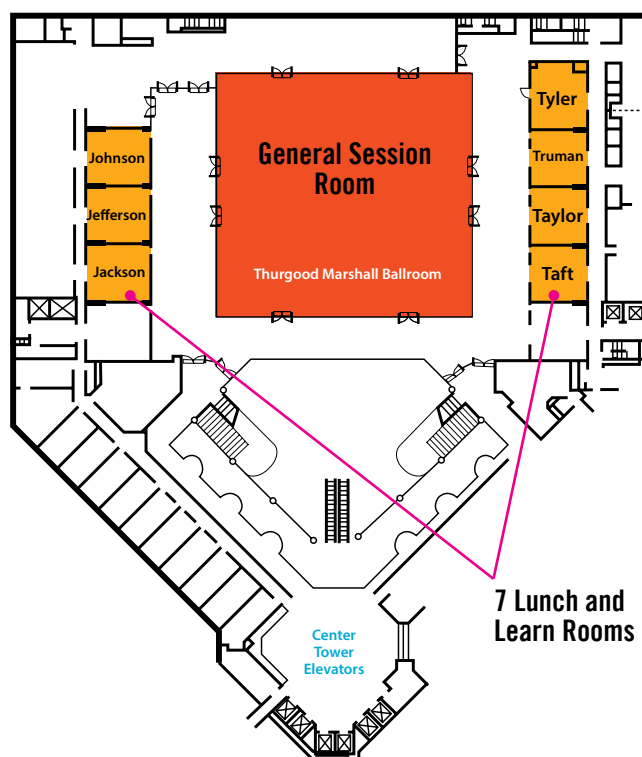


conference and exhibit floorplan

EXHIBIT HALL LEVEL



MEZZANINE LEVEL



event sponsorship

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 how to position your company as a sponsor or exhibitor, contact Alexa Moore amoore@rarediseases.org or Derek Gavin dgavin@rarediseases.org

GOLD

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SILVER

ADVOCACY

 **SAREPTA**
THERAPEUTICS

 **ALEXION**

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Biotherapies for Life®

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PHARMA

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 **Mallinckrodt**
Pharmaceuticals

 **Pfizer**

 **VERTEX**

BRONZE

ADDITIONAL SPONSORS + EXHIBITORS

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 **HvH**
PATIENT PRECISION ANALYTICS

 **illumina**

 **NORD** **RARE CANCER**
COALITION

 **Pheo Para**
ALLIANCE
Pheochromocytoma & Paraganglioma

 **PRECISION**
FOR MEDICINE
ONCOLOGY AND RARE DISEASE

 **rareLife solutions**
collaboration + science + technology

 **RETROTOPE**

 **The Smith Family**
CLINIC
for GENOMIC MEDICINE

 **sobi**
Pioneer in Rare Diseases

 **WEP**
Clinical

MEDIA PARTNERS

 **FRONTLINE**
MEDICAL COMMUNICATIONS

 **RareDR**
Rare Disease Report

STAT

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

sponsorship info

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NORD VP of Development
617-934-6397
amoore@rarediseases.org

Derek Gavin
NORD Director of Business Development
617.279.7304
dgavin@rarediseases.org



venue information + accommodations

venue

Marriott Wardman Park

2660 Woodley Rd NW,
Washington, D.C. 20008

Phone Reservations: 1-877-212-5752 (mention NORD)
Please book your hotel room by September 21, 2018.

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

	ADVANTAGE RATE <i>Register by 8/25/18</i>	STANDARD RATE <i>Register by 10/15/18</i>	REGISTER ONSITE
NORD Patient Organization Members	\$349	\$649	\$749
Registered 501(c)3 Non-Profits/Patients/ Academics/Physicians	\$399	\$699	\$799
Government	\$499	\$499	\$599
NORD Corporate Council Members	\$1,699	\$2,099	\$2,199
Industry (Pharma, Service Providers, Co-Pay Foundations)	\$2,199	\$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.

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