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NORD® 2020  
ANNUAL REPORT  
TOGETHER  
WE ARE STRONG

20



## For 37 years, the National Organization for Rare Disorders (NORD) has built and refined a reputation for leading with integrity—and with an unbiased patient voice.

NORD has carefully and proudly engaged in decades of meaningful action on behalf of individuals affected by rare disease. Our motto is “Alone we are rare. Together We Are Strong”—and that motto has never been more relevant than it was in 2020. The COVID-19 pandemic and the uncertainty it brought to the world posed significant and distinct threats to the rare disease community.

“Together We Are Strong” is a firm belief in the collective strength and power of connection and collaboration. Throughout the pandemic, NORD has remained

dedicated to exploring new data, pathways, services and approaches—whatever it takes—to support and elevate our community now and in the future.

From day one of the pandemic, NORD has supported rare disease families and all those disproportionately affected by the pandemic. From drug shortages to

job and health insurance losses, rare disease families need the support of NORD more than ever. In the face of any and all challenges of this year, NORD continued to work tirelessly to address the needs of our rare community.

In 2020, NORD acted quickly, hosting special webinars to provide clear, useful, authoritative information to rare disease patients and caregivers on the COVID-19 virus and how to handle our emerging new normal. Together with our community, we offered numerous new tools and resources for individuals coping with this global health crisis and to organizations struggling to pivot to models that would keep them on their feet and serve their people.

## MESSAGE FROM OUR CEO

NORD is known and respected on Capitol Hill and among stakeholders in the rare disease community—and throughout the pandemic, we continued to advocate relentlessly to ensure people suffering from rare diseases had adequate and affordable coverage. In this time of crisis and uncertainty, NORD has been working to pursue policies at the federal and state levels to address COVID-19 related concerns, including the expansion of telemedicine and paid family and medical leave.

While so many in-person research efforts were paused due to pandemic restrictions, NORD was still able to advance rare disease research this year. Initiatives like our online IAMRARE® Registry Program and the NUCOAT study (featuring remote telephone interviews with patients) continued to deliver on our commitment to collaborative, projects that enable patient-fueled research and innovation. In addition, our Natural History of Metachromatic Leukodystrophy (HOME) Study launched, presenting a modern framework for dynamic data collection, allowing participants to contribute to a natural history study from home via video calls with a clinical study coordinator and a series of online surveys.

We strive to house programs to support each and every rare disease. Many of our programs are dependent on funding, donations, and partnership. We are so thankful for the programs we have now, and eagerly anticipate additional growth as we continue to assist with access to care and treatment. I encourage everyone committed to supporting the rare disease community to share NORD resources and tools, and to promote our many assistance programs to those in need.



PETER L. SALTONSTALL  
PRESIDENT AND CEO



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*The National Organization for Rare Disorders (NORD) is at the heart of driving progress for the 25 million+ Americans with rare diseases. Most rare diseases (90%) still do not have an FDA-approved treatment option, and people face an average of 5–7 years wait for an accurate diagnosis. We are committed to changing that. We provide support every step of the way to patients and families and unite our community so that together our voice is stronger.*

# WHO IS NORD?

## National Organization for Rare Disorders (NORD®)

NORD, a 501(c)(3) organization, is an independent patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 300 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.



4-STAR CHARITY ON  
CHARITY NAVIGATOR



2020 TOP-RATED  
NON-PROFIT ON  
GREATNONPROFITS



2020 PLATINUM SEAL  
OF TRANSPARENCY ON  
GUIDESTAR

# TRACKING THE IMPACT



NORD is here for you. The COVID-19 pandemic has created tremendous hardship for people with rare diseases. We have both maintained our existing resources and services, while increasing efforts in new areas needed during this unusual year.

# 9,951

patients assisted across all 50 states, DC, Puerto Rico and the Virgin Islands



# \$35,642,186

in aid provided through NORD assistance programs

# 265

rare disease diagnoses represented among those assisted by NORD



We're listening! Over 68,000 calls and 65,000 emails answered by our team in 2020



Over 22.8 million unique pageviews to the NORD website

NORD listens and creates educational materials and opportunities to best support our diverse community.

NORD's Financial Assistance Program for Rare Disease Community Members impacted by COVID-19 launched in April 2020 and has provided financial assistance to eligible patients, covering up to \$1,000 annually. Funds were provided for essential expenses, including:

- unexpected utility bills;
- cellular or internet service;
- emergency repairs to car, home or major appliances; and
- rent or mortgage payment assistance.

NORD's COVID-19 Rapid Response Program for patient organization members provided critical funding of up to \$15,000 per organization, as a stopgap measure to support patient nonprofit organizations with the burden of COVID19-related lost income.

The funding NORD has provided has gone directly back to the community:

19 

organizations had their grants approved and over \$186,000 in funding was awarded

90%

for COVID assistance programs

79%

for rapid response grants

1,600

combined participants across two surveys and published COVID-19 community reports

14

continuing Medical Education (CME) programs, in partnership with Platform Q Health

1,500+

combined attendees at two virtual conferences with over 30 sessions

# MEMBERSHIP SPOTLIGHT



325

member  
organizations  
in 40 states

39

**new**  
organizations  
joined NORD  
in 2020

449

total scholarships  
awarded to NORD  
members to attend  
the Living Rare, Living  
Stronger Forum and  
NORD Breakthrough  
Summit

27

Rare Cancer  
Coalition  
members

**Apply for NORD membership today!**  
<https://rarediseases.org/for-patient-organizations/join-membership-network/membership-criteria/>



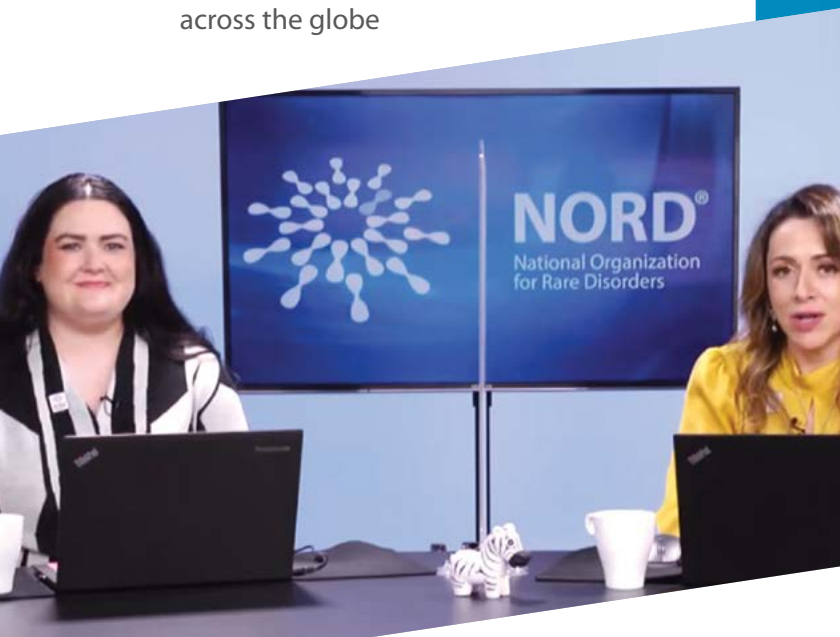
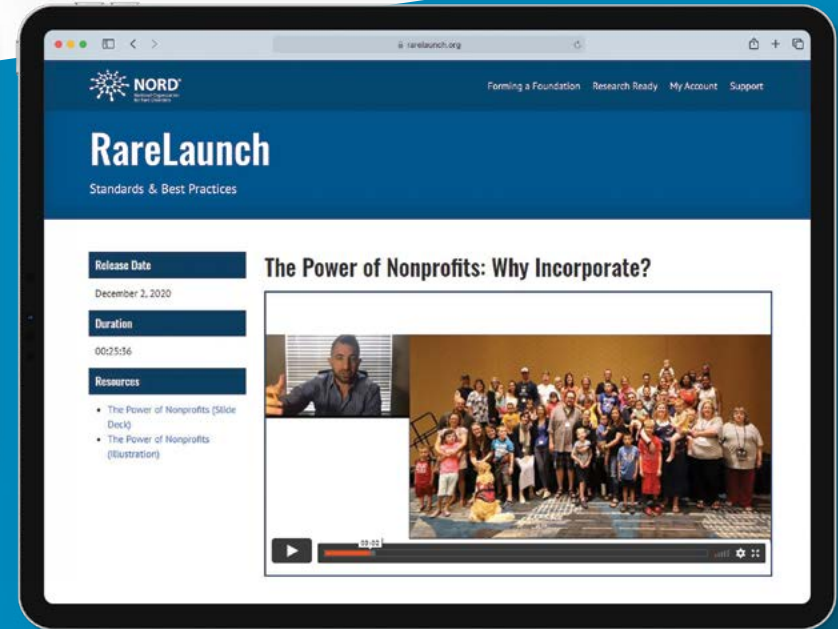
# RAPID RESPONSE: PROGRESS DURING THE PANDEMIC

The RareLaunch program, funded by the Chan-Zuckerberg Initiative (CZI), has supported the growth of disease-specific nonprofits and helped existing nonprofits consider moving into the research space through the creation of registries.

- The CZI RareLaunch program brought together 600 individuals for a two-day conference on capacity-building and nonprofit growth. From that meeting a toolkit was created that includes a number of resources for general use.

NORD and patient advocacy groups hosted an Externally-led Patient-Focused Drug Development (EL-PFDD) meeting on Krabbe Disease, in collaboration with the US Food and Drug Administration (FDA) on October 29, 2020.

- 100% virtual with live, interactive components
- The EL-PFDD meeting was attended by **226** participants via a live webcast across the globe



RareLaunch resources  
<https://rarediseases.org/nord-rarelaunch/>





# RAPID RESPONSE: CONFERENCE AND EVENTS

For the first time since NORD began hosting annual conferences more than 30 years ago, our 2020 Living Rare, Living Stronger NORD Patient and Family Forum and Rare Diseases and Orphan Products Breakthrough Summit were hosted virtually rather than in-person. In the tradition of “making lemonade when life hands you lemons,” NORD focused our virtual events on reaching a broader audience, including patients, caregivers, medical professionals, regulators, industry partners and others who may not have been able to travel to an in-person event in the past.

## Living Rare, Living Stronger®

Living Rare, Living Stronger (LRLS) Patient and Family Forum is an annual patient-focused conference providing attendees with practical tools for living their best rare lives.



710+

attendees

34

networking  
sessions and  
discussion  
groups

12

concurrent  
workshops



51

speakers, with three  
speakers from FDA,  
NIH and PCORI

48

states  
represented

41

sponsors  
and  
exhibitors



11

countries represented  
(Australia, Canada,  
China, Georgia, Italy,  
Kenya, Netherlands,  
Panama, South Africa,  
United Kingdom,  
and USA)

# RAPID RESPONSE: CONFERENCE AND EVENTS

## 2020 Rare Diseases and Orphan Products Breakthrough Summit®

The Rare Diseases and Orphan Products Breakthrough Summit is one of the largest multi-stakeholder events in the rare disease world. Every year, the conference brings together rare disease experts and leaders from patient advocacy groups, government, industry, and academia to discuss the most critical topics related to rare diseases and orphan products.



884 24

attendees

sessions



9

networking  
sessions

68

sponsors and  
exhibitors

94

speakers, including  
16 from the FDA  
and NIH

46

states  
represented

19

countries represented (Australia, Brazil, Canada, China, Denmark, France, Germany, Greece, India, Italy, Lebanon, Netherlands, New Zealand, Poland, Portugal, Sweden, United Kingdom, USA, Zimbabwe)



# EMBRACING TECHNOLOGY IN A CHANGING WORLD

## 2020 marked the 6th Edition of NORD's State Report Card®

The Report Card evolved in 2020 from a print-first design to a new, accessible digital format to serve as a tool for patients, advocates, and policymakers as they strive to advocate for state policies that best serve the needs of the rare disease community.

<https://rarediseases.org/nord-state-report-card/>

The screenshot shows the NORD website header with navigation links: ABOUT, NEWS, EVENTS, CONTACT, PODCAST, BLOG, and DONATE. Below the header is a search bar and social media icons. The main content area features the title "6th Edition STATE REPORT CARD" with a graphic of a pencil writing on a checklist. Below this is a section titled "How does your state measure up?" with a map of the United States and a "SELECT A STATE" button. To the right, there is a section titled "NORD's State Report Card®" with introductory text. At the bottom, there is a "The Issues" section with a grid of icons representing various topics: Medicaid Essential Eligibility, Medical Nutrition, newborn Screening, Prescription Drug Out-of-Pocket Costs, Protecting Patients in State Medicaid Programs, Protecting Patients in State-Regulated Insurance, Rare Disease Advisory Councils, and Stop Therapy (Fail First).

## NORDpod™ launched as the official podcast of NORD in 2020

The podcast provide a fresh platform for NORD to empower a new generation of the rare community. The connections from NORDpod have helped our community feel less alone during an isolating time in the world.

Covering many topics important to all rare disease stakeholders, the show's episodes addressed the rise and importance of telehealth, non-profit foundation and management, as well as shared myriad patient stories. The show is a partnership between NORD and OffScrip Media.

All 10 episodes of season one are available now!

### GUESTS

- Mike Porath, Founder and CEO, The Mighty
- Mary McGowen, Executive Director, the Myositis Association

- Tom Rhoads, Founder and CEO, Spencer Health Solutions
- John Hopper, Executive Director, Fibrolamellar Cancer Foundation, and Founding Chairman, the GI Cancer Alliance
- Jim Palma, Executive Director, Target Cancer Foundation, and Vice Chairman, NORD Board of Directors
- Dr. Natasha Shur, Medical Geneticist, Children's National Hospital
- Monisha Kisling, Genetic Counselor, Children's National Hospital
- Peter Saltonstall, President and CEO, NORD
- Pamela Gavin, Chief Strategy Officer, NORD
- Debbie Drell, Director of Membership, NORD
- Alice Alpert and Edgar Wonzica, caregivers to their son who is living with a rare disease
- Sarah Hill, young adult living with a rare disease

*"The voice of the patient has never been louder and the path to improved access, navigation, and dignity for all remains the most important goal worth fighting for together. We are one community united as advocates."*

MATTHEW ZACHARY, FOUNDER AND CEO OF OFFSCRIP MEDIA, AND HOST, NORDPOD



# EDUCATION GOES VIRTUAL: PUTTING PATIENTS AND FAMILIES FIRST

6

NORD-hosted webinars directly related to the coronavirus crisis provided the rare disease community with guidance on coping with their physical and mental health, as well as social concerns



NORD developed and conducted a series of brief interviews with several subject matter experts on relevant issues, viewed through the lens of the rare disease community

Virtual events allowed us to interact with our constituents in a new way, especially with those that may not have been able to travel previously due to their rare disease. NORD's virtual education efforts quickly and effectively addressed the fears and uncertainty that the rare disease community faced in 2020, providing practical tools for coping and managing life in the pandemic. The resources created will continue to serve the community in the uncertain times ahead.

NORD's continuing medical education (CME) program, in partnership with PlatformQ Health), launched 17 months ago, in June 2019. Since that time, NORD and Platform Q have completed 19 online programs, including 10 exclusively CME, seven exclusively for patients and caregivers, and two combined CME and patient education.

- The programs provide high-quality, effective education on rare disorders for healthcare providers, patients and caregivers.
- Participants consistently exhibit increases in post-test knowledge as well as self-reported positive clinical practice changes.
- The goal of NORD's CME offerings is to decrease the time to diagnosis and improve quality of care and patient outcomes.
- The initiative enables NORD to work closely with member organizations to provide patient-sensitive and accurate content.



A live tweetchat on ending isolation conducted with the Patient Empowerment Network (PEN) garnered over 2 million impressions on social media

# ALWAYS RAISING AWARENESS

## Rare Disease Day

Rare Disease Day® takes place on the last day of February each year. The main objective of Rare Disease Day is to raise awareness about rare diseases and their impact on patients' lives. NORD is the official sponsor of Rare Disease Day in the United States alongside our sister organization, the European Organization for Rare Disorders (EURORDIS), which organizes the international campaign.

# 1.4 Million

users on the website in February 2020—a 200,000 increase over February 2019

# 792k

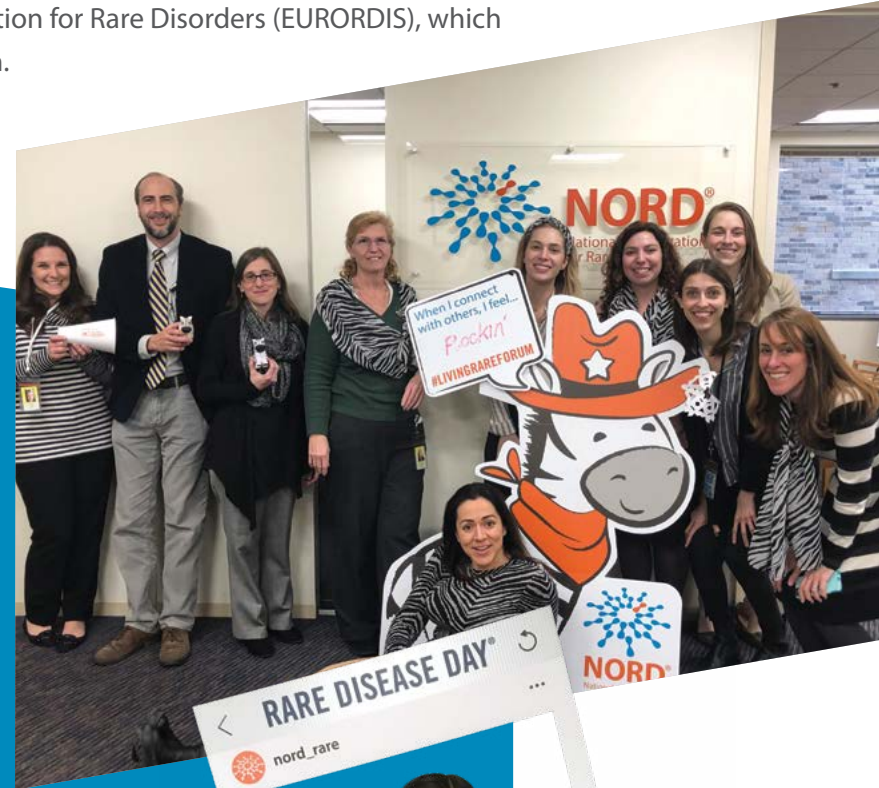
impressions from NORD social media posts

# 31,400

unique posts using #RareDiseaseDay



Hosted tweetchat with NIH that garnered ~80,000 impressions and 200 engagements



## Rare Disease Day: Mission 2020

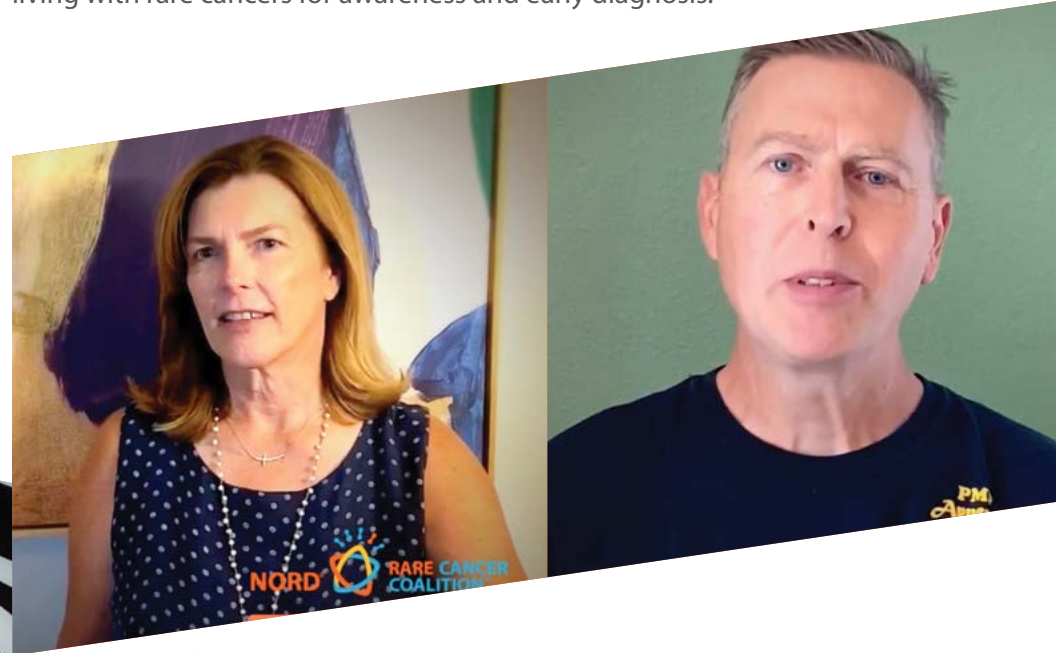
On February 29, just a few weeks before the pandemic shut most of the world, NORD hosted a day of family fun and intrigue at the International Spy Museum in Washington, DC, one of the newest family-friendly, accessible-to-all museums. NORD hosted activities and lunch for folks living with rare diseases, their families, and other rare community supporters!

Just like many of the spies featured in the museum, our rare community must get creative and be persistent when uncovering the facts of their own diagnosis. We celebrated Rare Disease Day at this rare intelligence gathering to uncover the truth behind our stripes!



## Rare Cancer Day™

Rare Cancer Day is an annual awareness day devoted to shining a light on rare cancers and the issues people living with them face. Led by the NORD Rare Cancer Coalition™, which is composed of 27 rare cancer-specific member organizations, Rare Cancer Day is observed on September 30 each year to highlight the challenges patients face and to unify individuals living with rare cancers for awareness and early diagnosis.



*“On **Rare Cancer Day**, I’m proud to stand with the National Organization for Rare Disorders to raise awareness of rare—and often deadly—cancers and to keep up the fight for cures. With robust federal investment, we can and will find cures for the hundreds of rare cancers affecting people in Connecticut and across the nation.”*

SENATOR RICHARD BLUMENTHAL (CT-D)

# ADVOCACY AND ACTION

At the start of the pandemic, NORD joined numerous patient advocacy groups in writing to state governors, members of Congress, senators and the administration urging federal officials to:

- Expand access to Medicaid and private health insurance coverage by reducing barriers to Medicaid enrollment and allowing Special Enrollment Periods within state exchanges and the federal exchange to enable those who are uninsured to secure health insurance coverage;
- Ensure continuity of care by offering premium assistance to those who have lost access to their employer-sponsored health insurance;
- Provide free COVID-19 testing and treatment;
- Protect patients from “surprise billing” for unexpected health care costs should they need to seek treatment during this unprecedented time; and
- Ensure that eligibility for the paid family and medical leave program includes individuals at high risk for adverse complications from COVID-19 and working members of their households.



# 27

Rare Disease Day  
advocacy events with  
2,000+ attendees

# 54

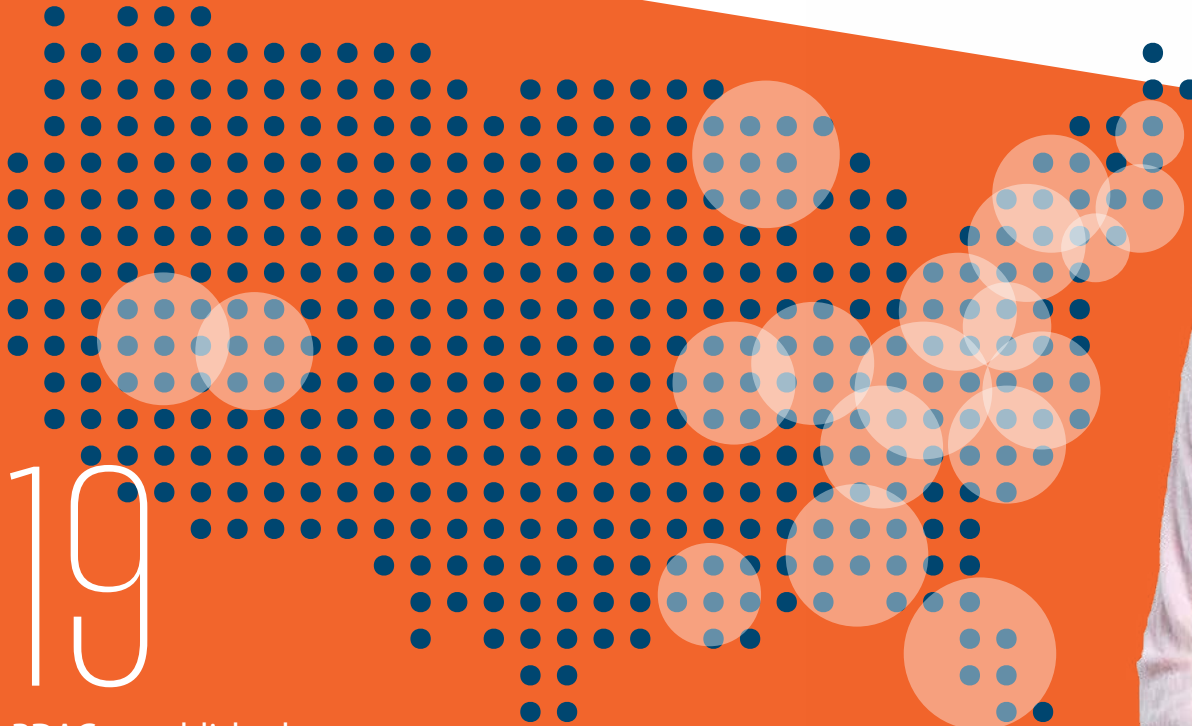
RAN volunteer  
leaders guiding  
state action

**Learn more!** View all NORD's policy  
statements and positions



## Project RDAC

A Rare Disease Advisory Council (RDAC) is an advisory body providing a platform for the rare community to have a stronger voice in state government. RDACs address the needs of rare patients and families by giving stakeholders an opportunity to make recommendations to state leaders on critical issues including the need for increased awareness, diagnostic tools and access to affordable treatments and cures. In 2020, NORD kicked off Project RDAC to support existing RDACs and increase the number of RDACs across the country. NORD hosted a meeting of existing RDACs in December 2020 to accelerate work taking place to create new councils and strengthen those already in existence.



19

RDACs established  
by the end of 2020



Rare Action Network® (RAN®) – Advocacy By the Numbers



138

RAN events held

111

Virtual rare discussion groups hosted with 940+ attendees

7

RAN Volunteer Leadership Training Academy webinars



Take Action! Join our Rare Action Network®





## FROM THE COMMUNITY

We are honored to know that we are making a positive impact. Here are just a few testimonials from the rare disease community in 2020.

Alone we are rare. Together we are strong!®

**Share your story.** Join all the individuals and families who have contributed their personal accounts of living with rare diseases.



*“Thank you so much for your assistance...Without your help, I would not have been able to afford to get my infusions any longer. Again, thank you so much. You saved my life.”*

RARE DISEASE PATIENT ASSISTED BY  
THE NORD PATIENT SERVICES TEAM

*“I love being able to be a part of something greater than myself, and a part of a larger community of rare disease advocates.”*

WASHINGTON STATE  
UNIVERSITY STUDENT  
LEADER

*“I really appreciate that NORD continues to lead with valuable, relevant information to strengthen patient communities!”*

KATE TIGHE,  
SANOFI GENZYME

*“The COVID-19 Rare Disease Premium & Limited Medical Assistance Fund Grant has been a blessing to my family. Because of it, we have one less thing to worry about. You also have given us hope in the humanity of others.”*

RARE DISEASE PATIENT ASSISTED BY THE NORD PATIENT  
SERVICES TEAM

*“It [Summit] was a fantastic conference and well organized, I have only heard positive comments!! People loved the speakers, the timely topics, the exhibit ‘hall’, and networking opportunities. The virtual approach can’t replace in-person conversations, but it can reach more people and enable important connections.”*

SUSAN D. FERNBACH RN, CO-DIRECTOR, OFFICE  
OF COMMUNITY ENGAGEMENT AND DIVERSITY,  
BAYLOR COLLEGE OF MEDICINE/TEXAS  
CHILDREN’S HOSPITAL

*“Thank you for being so supportive of organizations that are in different stages of planning and at different levels of experience. I felt an instant acceptance and camaraderie with the other rare disease nonprofit representatives...”*

JILL SALAS,  
PHACE SYNDROME

*“This pandemic has been extremely hard on people like myself, especially when we can’t go back to work like a normally abled bodies person. I told someone recently I felt forgotten and it was a great boost to my self worth to be seen by your team. I hope someday to make a donation to NORD to pay your kindness back.”*

RARE DISEASE PATIENT  
ASSISTED BY THE NORD  
PATIENT SERVICES TEAM

# BOARD OF DIRECTORS

## CLASS OF 2020

**Frederick E. (Rick) Barr, MD, MSc**  
EVP and Chief Clinical and Academic Officer  
Arkansas Children's Hospital  
Little Rock, AR

**Steven Grossman, Secretary**  
President  
HPS Group, LLC  
Washington, DC

**Susan Hedstrom**  
Executive Director  
Foundation for Prader-Willi Research  
Walnut, CA

**Jim Palma**  
Executive Director  
Target Cancer Foundation  
Cambridge, MA

**Marshall L. Summar, MD, Chairman**  
Chief, Genetics and Metabolism,  
Children's National Medical Center, and  
Margaret O'Malley Professor of Genetic  
Medicine and Professor of Pediatrics,  
George Washington University  
Washington, DC

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Alliance (FARA)  
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**Kathleen S. Holcombe**  
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Milken Institute Center for Public  
Health  
Gaithersburg, MD

**Neil Horikoshi**  
CEO and Executive Director  
Aplastic Anemia & MDS International  
Foundation  
Bethesda, MD4

## CLASS OF 2022

**Susan A. Berry, MD**  
Professor, Department of Pediatrics  
Division of Genetics and Metabolism  
University of Minnesota  
Minneapolis, MN

**Shafali Spurling Jeste, MD**  
UCLA Semel Institute  
Los Angeles, CA

**Phillip L. Pearl, MD**  
Neurophysiology, Boston Children's  
Hospital, and William G. Lennox  
Chair and Professor of Neurology,  
Harvard Medical School  
Boston Children's Hospital  
Boston, MA

**Mike Porath**  
Founder and CEO  
The Mighty  
Los Angeles, CA

**Peter L. Saltonstall**  
President and CEO  
National Organization for Rare  
Disorders  
Quincy, MA  
Ex-officio

# CORPORATE COUNCIL

## PRE-CLINICAL DEVELOPMENT

Cabaletta Bio  
Dante Labs  
EdiGENE  
Neurogene  
Orna Therapeutics, Inc  
Shape Therapeutics  
Taysha Gene Therapies

## CLINICAL DEVELOPMENT

Acceleron Pharma  
Aeglea BioTherapeutics  
Akcea Therapeutics  
Apellis Pharmaceuticals  
Applied Therapeutics  
argenx  
Ascendis Pharma  
Asklepion Pharmaceuticals, LLC  
Atara Biotherapeutics, Inc.  
Audentes Therapeutics, Inc.  
(now Astellas Gene Therapies)  
AVROBIO  
bluebirdbio  
Blueprint Medicines  
BridgeBio  
ChemoCentryx  
CRISPR Therapeutics  
Cytokinetics, Inc.  
Dicerna Pharmaceuticals, inc.  
Editas Medicine

Enzyvant Therapeutics  
Excicure  
Hansa Medical  
Helixmith  
Insmed Incorporated  
LEO Pharma  
Lysogene  
MeiraGTx  
Moderna Therapeutics  
Momenta Pharmaceuticals  
Neurocrine Biosciences  
Orchard Therapeutics Ltd.  
Orphazyme  
Ovid Therapeutics  
Passage Bio  
REGENXBIO  
Rocket Pharmaceuticals, Inc  
Sangamo Therapeutics  
Savara, Inc.  
Soligenix, Inc.  
Viela Bio  
X4 Pharmaceuticals  
Zealand Pharma

## APPROVED PRODUCT

AbbVie Pharmaceuticals  
Acadia Pharmaceuticals  
Agiros Pharmaceuticals  
Alexion Pharmaceuticals, Inc.  
Alnylam Pharmaceuticals  
Amgen  
Amicus Therapeutics, Inc.  
Amryt Pharmaceuticals, Inc.  
Astellas Pharma  
AstraZeneca  
BioCryst  
Biogen

BioMarin Pharmaceuticals, Inc.  
Boehringer-Ingelheim Pharmaceuticals  
Bristol-Myers-Squibb  
Catalyst Pharmaceuticals  
Chiesi Rare Diseases  
CSL Behring  
Daiichi Sankyo  
Deciphera Pharmaceuticals, Inc.  
Dompé  
Eiger BioPharmaceuticals  
Foundation Medicine  
Genentech, Inc.  
GlaxoSmithKline PLC  
Global Blood Therapeutics, Inc.  
Greenwich Biosciences, Inc  
Harmony Biosciences, LLC  
Horizon Therapeutics  
Incyte Corporation  
Ionis Pharmaceuticals  
Ipsen Biopharmaceuticals Companies  
Janssen Pharmaceuticals  
Mallinckrodt Pharmaceuticals  
Novartis  
Otsuka America Pharmaceutical, Inc.  
Pfizer, Inc.  
PTC Therapeutics  
Recordati Rare Diseases, Inc.  
Regeneron  
Rigel Pharmaceuticals  
Sanofi Genzyme  
Sarepta Therapeutics  
Sobi, Inc.  
Spark Therapeutics  
Stemline Therapeutics  
Strongbridge Biopharma  
Takeda Oncology

Travere Therapeutics, Inc.  
(formerly Retrophin)  
UCB Pharma  
Vertex Pharmaceuticals Worldwide  
Zogenix, Inc.

## BUSINESS MEMBER

AnovoRx  
APCO Worldwide  
Biotechnology Industry Organization (BIO)  
Children's National Health System  
Eversana  
HPS Group LLC.  
ICON  
Medidata Solutions  
Myriad Women's Health  
Parexel International  
PhRMA  
Syneos Health

# NORD MEMBERS

# 325

active member  
organizations  
in 2020

A Cure for Ellie  
A Cure in Sight  
A Twist of Fate-ATS  
Achalasia Awareness Organization  
Acid Maltase Deficiency Association (AMDA)  
Acromegaly Community, Inc.  
ADCY5.org  
ADNP-Kids Research Foundation  
Adrenal Insufficiency United (AIU)  
Advocacy & Awareness for Immune Disorders Association (AAIDA)  
Alagille Syndrome Alliance  
All Things Kabuki  
Alpha-1 Foundation  
Alport Syndrome Foundation  
ALS Association  
Alternating Hemiplegia of Childhood Foundation (AHCF)  
American Behçet's Disease Association  
American Brain Tumor Association

American Multiple Endocrine Neoplasia Support  
American Partnership for Eosinophilic Disorders (APFED)  
American Porphyria Foundation  
Amniotic Fluid Embolism Foundation (AFE Foundation)  
Amyloidosis Foundation  
Amyloidosis Research Consortium, Inc.  
Amyloidosis Support Groups, Inc.  
Angioma Alliance  
APBD Research Foundation  
Aplastic Anemia & MDS International Foundation, Inc.  
Appendix Cancer/Pseudomyxoma Peritonei Research Foundation (ACPMP)  
APS Type 1 Foundation  
Association for Creatine Deficiencies  
Association for Frontotemporal Degeneration (AFTD)  
Association for Glycogen Storage Disease  
Association of Gastrointestinal Motility Disorders, Inc. (AGMD)  
ASXL Rare Research Endowment (ARRE) Foundation  
Autoimmune Encephalitis Alliance  
Autoimmune Hepatitis Association  
Autoinflammatory Alliance  
Avery's Hope  
AXYS  
Barth Syndrome Foundation  
Batten Disease Support and Research Association  
BCM Families Foundation  
Benign Essential Blepharospasm Research Foundation, Inc.  
Bohring-Opitz Syndrome Foundation, Inc.  
BORN A HERO, Pfeiffer's Health and Social Issues Awareness

Bridge the Gap – SYNGAP Education and Research Foundation  
CACNA1A Foundation  
Canadian Organization for Rare Disorders  
Cardio-Facio-Cutaneous International (CFC)  
Castleman Disease Collaborative Network  
Cauda Equina Foundation, Inc.  
CCHS Family Network (Congenital Central Hypoventilation Syndrome)  
CHAMP1 Research Foundation  
Charcot-Marie-Tooth Association  
Child and Youth Care  
Child Neurology Foundation  
Children's Craniofacial Association  
Children's PKU Network  
Children's Tumor Foundation  
Chloe's Fight Rare Disease Foundation  
Cholangiocarcinoma Foundation  
Choroideremia Research Foundation, Inc.  
Chromosome 18 Registry & Research Society  
Chromosome Disorder Outreach, Inc.  
Chronic Recurrent Multifocal Osteomyelitis Foundation (CRMO)  
Cicatricial Alopecia Research Foundation (CARF)  
CLOVES Syndrome Community  
Clusterbusters, Inc.  
CMT Research Foundation (CMTRF)  
CMTc Alliance  
CMTc-OVM Cutis Marmorata Telangiectatica  
Congenital Hyperinsulinism International  
Consortium of Multiple Sclerosis Centers  
COPA Syndrome Foundation  
Cornelia de Lange Syndrome Foundation, Inc.  
CSNK2A1 Foundation  
Cure CMD (Congenital Muscular Dystrophy)

Cure HHT Foundation  
Cure SMA  
Cure VCP Disease, Inc.  
cureCADASIL  
CureDuchenne  
CurePSP, Inc.  
Curing Retinal Blindness Foundation  
Cushing's Support and Research Foundation, Inc.  
Cutaneous Lymphoma Foundation  
Cystic Fibrosis Foundation  
Cystic Fibrosis Research, Inc.  
Cystinosis Research Network, Inc.  
Danny's Dose Alliance  
Defeat MSA Alliance  
DeSanto-Shinawi Syndrome Corp  
Desmoid Tumor Research Foundation  
DHPS Foundation  
Dravet Syndrome Foundation, Inc.  
Dreamsickle Kids Foundation  
Dup 15q Alliance  
ECD Global Alliance  
Erythromelalgia Association  
EURORDIS- Rare Diseases Europe  
Familial Dysautonomia Foundation  
FamilieSCN2A Foundation  
Family Caregiver Alliance Fanconi Anemia Research Fund, Inc.  
Fat Disorders Resource Society  
Fibrolamellar Cancer Foundation (FCP)  
Fibromuscular Dysplasia Society of America  
Fibrous Dysplasia Foundation  
Foundation Fighting Blindness  
Foundation for Angelman Syndrome Therapeutics (FAST)  
Foundation for Ichthyosis & Related Skin Types

Foundation for Prader-Willi Research  
 Foundation for Sarcoidosis Research  
 Foundation for USP-7 Related Diseases  
 Foundation to Fight H-abc  
 FOXG1 Research Foundation  
 FPIES Foundation  
 Friedreich's Ataxia Research Alliance  
 Galactosemia Foundation  
 Gaucher Community Alliance  
 GBS/CIDP Foundation International  
 Genetic Alliance  
 Genetic Alliance Australia  
 Global DARE Foundation  
 Global Foundation for Peroxisomal Disorders  
 Glut1 Deficiency Foundation  
 Gorlin Syndrome Alliance  
 Gould Syndrome Foundation (COL4a1/COL4A2)  
 GRIN2B Foundation  
 Gut Check Foundation  
 Guthy-Jackson Charitable Foundation  
 HCU Network America  
 HCU Network Australia  
 Helping Hands for GAND, Inc.  
 Hemophilia Federation of America  
 Hepatitis B Foundation  
 Hereditary Neuropathy Foundation, Inc.  
 Hermansky-Pudlak Syndrome Network, Inc.  
 Histiocytosis Association, Inc.  
 Hope for Hypothalamic Hamartomas  
 HSAN1E Society  
 Hydrocephalus Association  
 Hyper IgM Foundation, Inc.  
 Hypersomnia Foundation  
 Illness Challenge Foundation  
 Immune Deficiency Foundation  
 Indian Organization for Rare Diseases  
 International Advocate For Glycoprotein Storage Diseases  
 International Autoimmune Encephalitis Society  
 International FOP Association  
 National Organization for Rare Disorders (NORD®) Member Organization Partner Toolkit | 10  
 International Foundation for CDKL5 Research  
 International FPIES Association  
 International Neuroendocrine Cancer Alliance  
 International Pemphigus & Pemphigoid Foundation  
 International Rett Syndrome Foundation  
 International Sacral Agenesis/Caudal Regression Association (iSACRA)  
 International WAGR Syndrome Association  
 International Waldenstrom's Macroglobulinemia Foundation  
 iSEEK Pulmonary Hypertension Hope Center  
 Jack McGovern Coats Disease Foundation  
 Joshua Frase Foundation  
 Julia's Wings Foundation, Inc.  
 KAT6A Foundation  
 Kennedy's Disease Association, Inc.  
 KIF1A.ORG  
 Kindness for Kimberlee  
 Klippel-Trenaunay Support Group  
 KrabbeConnect  
 LAL Solace, Inc.  
 Legg Calve Perthes Foundation  
 Li-Fraumeni Syndrome Association  
 Life Raft Group  
 Liv4TheCure  
 Lowe Syndrome Association, Inc.  
 Lung Transplant Foundation  
 Lymphangiomatosis & Gorham's Disease Alliance, Inc. (LGDA)  
 M-CM Network  
 Malan Syndrome Foundation  
 Marfan Foundation  
 Martin Mueller IV Achalasia Awareness Foundation, Inc.  
 MDS Foundation, Inc.  
 MEBO Research, Inc.  
 Melanoma Research Foundation  
 Melorheostosis Association  
 Mila's Miracle Foundation, Inc.  
 MitoAction  
 MLD Foundation  
 Moebius Syndrome Foundation  
 Mowat-Wilson Syndrome Foundation  
 MPN Research Foundation  
 MSUD Family Support  
 Mucopolidosis Type IV Foundation, Inc. (ML4Fdn)  
 Muscular Dystrophy Association  
 Myasthenia Gravis Foundation of America, Inc.  
 Myhre Syndrome Foundation  
 Myocarditis Foundation  
 Myositis Association  
 Myotonic Dystrophy Foundation  
 National Adrenal Diseases Foundation  
 National Ataxia Foundation  
 National Brain Tumor Society  
 National CMV Foundation  
 National Eosinophilia Myalgia Syndrome Network  
 National Foundation for Ectodermal Dysplasias  
 National Health Council  
 National Hemophilia Foundation  
 National Median Arcuate Ligament Syndrome Foundation, Inc.  
 National MPS Society, Inc.  
 National Niemann-Pick Disease Foundation, Inc.  
 National Organization for Albinism and Hypopigmentation (NOAH)  
 National PKU Alliance  
 National PKU News  
 National Spasmodic Dysphonia Association  
 National Tay-Sachs and Allied Diseases Association, Inc.  
 National Urea Cycle Disorders Foundation  
 NBIA Disorders Association  
 NEC Society  
 NephCure Kidney International Foundation  
 Neuroendocrine Tumor Research Foundation  
 Neurofibromatosis Network  
 Neurofibromatosis Northeast  
 Neuromuscular Disease Foundation  
 NORD's™ Rare Cancer Coalition (RCC)  
 NTM Info & Research, Inc.  
 Ocular Melanoma Foundation  
 Oley Foundation  
 OMSLife Foundation  
 Organic Acidemia Association  
 Organization for Rare Diseases India  
 Osteogenesis Imperfecta Foundation  
 Our Odyssey  
 Parent Project Muscular Dystrophy  
 Parent to Parent New Zealand, Inc.  
 Patient AirLift Services (PALS)  
 PCD Foundation  
 Perthes Kids Foundation  
 PHACE Syndrome Community  
 Phelan-McDermid Syndrome Foundation  
 Pheo Para Alliance  
 Pituitary Network Association  
 PKD Foundation  
 Plan for Rare Foundation

Platelet Disorder Support Association  
Prader-Willi Syndrome Association  
(USA) PRISMS (Parents & Researchers  
Interested in Smith-Magenis Syndrome)  
Project 8p  
PSC Partners Seeking a CurePTEN  
Hamartoma Tumor Syndrome  
Foundation  
Pulmonary Alveolar Proteinosis  
Foundation, Inc.  
Pulmonary Fibrosis Foundation  
Pulmonary Hypertension Association  
PURA Syndrome Foundation  
Rare & Undiagnosed Network  
Rare Cancer Research Foundation  
Rare Kids Network  
RASopathies Network USA  
Recurrent Respiratory Papillomatosis  
Foundation  
Reflex Sympathetic Dystrophy Syndrome  
Association (RSDSA)  
Remember The Girls  
Rett Syndrome Research Trust  
Rothmund-Thomson Syndrome  
Foundation  
RYR-1 Foundation  
Sam Day Foundation  
Sanfilippo Children's Foundation  
Sara's Cure  
Sarcoma Foundation of America  
Scleroderma Foundation  
SETBP1 Society  
Shwachman-Diamond Syndrome  
Foundation  
Sick Cells  
Sickle Cell Association of Houston, Inc.  
Sickle Cell Association of Texas Marc  
Thomas Foundation

Sickle Cell Disease Association of  
America, Inc.  
Siegel Rare Neuroimmune Association  
SLC6A1 Connect  
Smith-Kingsmore Syndrome Foundation  
Snyder-Robinson Foundation  
Sofia Sees Hope  
Soft Bones, Inc.: The US Hypophosphatasia  
Foundation  
Spastic Paraplegia Foundation  
Spina Bifida Association  
Spinal CSF Leak Foundation  
SSADH Association (Succinic Semialdehyde  
Dehydrogenase Deficiency)  
Stevens Johnson Syndrome Foundation  
STXBP1 Foundation  
Sudden Unexplained Death In Childhood  
(SUDC) Foundation  
Superficial Siderosis Research  
Alliance, Inc.  
Taiwan Foundation for Rare Disorders  
Talia Duff Foundation, Inc.  
TANGO2 Research Foundation  
TargetCancer Foundation  
Tarlov Cyst Disease Foundation  
Tatton Brown Rahman Syndrome  
Community  
Team Telomere, Inc.  
Tess Research Foundation  
The Avalon Foundation  
The Bonnell Foundation: Living with  
Cystic Fibrosis  
The Calliope Joy Foundation  
The Cute Syndrome Foundation  
The EHE Foundation  
The Ehlers-Danlos Society  
The Jansen's Foundation  
The LAM Foundation

The Mastocytosis Society, Inc.  
The Multiple System Atrophy  
Coalition, Inc.  
The Snow Foundation  
Thisbe and Noah Scott Foundation  
Transplant Unwrapped  
Tuberous Sclerosis Alliance  
Turner Syndrome Society of the  
United States  
Tyrosinemia Society, Inc.  
United Leukodystrophy Foundation  
United Mitochondrial Disease Foundation  
United MSD Foundation  
Usher Syndrome Coalition  
Vasculitis Foundation  
Vestibular Disorders Association (VEDA)  
VHL Alliance

Wilhelm Foundation  
Williams Syndrome Association  
Wilson Disease Association  
Worldwide Syringomyelia & Chiari Task  
Force, Inc.  
Xia-Gibbs Society  
XLH Network Inc.  
Yellow Brick Road Project



# FINANCIALS

## STATEMENTS OF ACTIVITIES WITHOUT DONOR RESTRICTIONS FOR THE YEARS ENDED DECEMBER 31, 2020 AND 2019

### ASSETS

#### Current Assets:

	2020	2019
Cash and cash equivalents	\$ 23,512,112	\$ 47,832,054
Accounts receivable, net of allowance for doubtful accounts of \$200,000 and \$195,000 at December 31, 2020 and 2019, respectively	1,358,053	11,775,250
Prepaid expenses	368,116	229,136
Investments	25,613,110	--
<b>Total Current Assets</b>	<b>50,851,391</b>	<b>59,836,440</b>
Restricted Cash	200,000	---
Investments - Deferred Compensation	108,394	1 36,831
Deferred Hosting Arrangement Costs	109,919	189,191
Property, Equipment and Software, net	1,316,605	1,487,761
Software Under Development	188,231	100,873
<b>Total Assets</b>	<b>\$ 52,774,540</b>	<b>\$ 61,751,096</b>
<b>LIABILITIES AND NET ASSETS</b>		
<b>Current Liabilities:</b>		
Current portion of long-term debt	\$70,844	\$67,463
Accounts payable	587,335	660,712
Accrued expenses	662,999	260,474
Current portion of research grants payable	1,098,220	481,474
Deferred revenue	248,181	223,059
<b>Total Current Liabilities</b>	<b>2,667,579</b>	<b>1,693,182</b>
Deferred Compensation	108,394	136,831
Research Grants Payable, net of current portion	265,000	265,000
Long-Term Debt, net of current portion	165,915	236,760
<b>Total Liabilities</b>	<b>3,206,888</b>	<b>2,331,773</b>
<b>Net Assets:</b>		
Without donor restrictions:		
Operating	5,877,691	3,830,508
Property, equipment and software and software under development	1,268,077	1,210,812
<b>Total without donor restrictions</b>	<b>7,145,768</b>	<b>5,041,320</b>
With donor restrictions:	42,421,884	54,378,003
<b>Total Net Assets</b>	<b>49,567,652</b>	<b>59,419,323</b>
<b>Total Liabilities and Net Assets</b>	<b>\$ 52,774,540</b>	<b>\$ 61,751,096</b>



**STATEMENTS OF ACTIVITIES WITHOUT DONOR RESTRICTIONS FOR THE YEARS ENDED DECEMBER 31, 2020 AND 2019**

**Changes in Net Assets Without Donor Restrictions**

	<b>2020</b>	<b>2019</b>
Patient services:		
Program fees	\$345,353	\$639,674
Net assets released from purpose restrictions	39,755,627	30,173,232
Patient assistance and reimbursement expense	(40,100,980)	(30,812,906)
Patient services, net	--	--
Research grants:		
Net assets released from purpose restrictions	631,258	535,130
Research grant expense	(631,258)	(535,130)
Research grants, net	--	--
Other revenue and support:		
Grants, contributions and bequests	4,122,303	1,111,020
Special events revenue	1,900,601	2,405,019
Registry, web subscriptions and other related fees	395,674	234,128
Interest and dividend income, net	328,049	595,629
Drug, travel and lodging program administrative fees	67,425	174,162
Net assets released from purpose restrictions - patient service administrative fees	3,756,095	4,493,330
Net assets released from time restrictions - membership dues	1,783,062	1,680,303
Net assets released from purpose restrictions - contributions	1,755,460	1,775,409
Net assets released from purpose restrictions - research grant administrative fees	52,000	34,020
<b>Total Other Revenue and Support</b>	<b>14,160,669</b>	<b>12,503,020</b>
Other operating expenses:		
Personnel and related	8,470,391	6,630,675
Professional fees	1,156,404	740,762
Other	562,754	376,844
Occupancy	521,385	538,733
Depreciation	486,500	545,820
Data systems and equipment	456,801	328,595
Conferences, meetings and travel	401,986	1,589,511
<b>Total Other Operating Expenses</b>	<b>12,056,221</b>	<b>10,750,940</b>
<b>Changes in Net Assets Without Donor Restrictions</b>	<b>\$2,104,448</b>	<b>\$1,752,080</b>

**STATEMENTS OF CHANGES FOR THE YEARS ENDED DECEMBER 31, 2020 AND 2019**

	Without Donor Restrictions	With Donor Restrictions					Total	
		Patient Services	Research Grants	Membership Dues	Endowments	Other		
<b>Net Assets, December 31, 2018</b>	<b>\$3,289,240</b>	<b>\$ 43,315,648</b>	<b>\$ 1,307,632</b>	<b>\$85,000</b>		<b>\$798,120</b>	<b>\$45,506,400</b>	<b>\$48,795,64</b>
Revenue without donor restrictions	5,159,632							5,159,632
Grants and contributions with donor restrictions		43,657,500	576,127	1,665,303		1,664,097	47,563,027	47,563,027
Net assets released from donor restrictions	38,691,424	(34,666,562)	(569,150)	(1,680,303)			(1,775,409)	(38,691,424)
Transfers		242,307				(242,307)		
Total expenses	(42,098,976)							(42,098,976)
Changes in net assets	1,752,080	9,233,245	6,977	(15,000)		(353,619)	8,871,603	10,623,683
<b>Net Assets, December 31, 2019</b>	<b>5,041,320</b>	<b>52,548,893</b>	<b>1,314,609</b>	<b>70,000</b>		<b>444,501</b>	<b>54,378,003</b>	<b>59,419,323</b>
Revenue without donor restrictions	7,159,405							7,159,405
Grants and contributions with donor restrictions		28,765,208	195,537	2,180,562	200,000	4,436,076	35,777,383	35,777,383
Net assets released from donor restrictions	47,733,502	(43,511,722)	(683,258)	(1,783,062)		(1,755,460)	(47,733,502)	
Transfer		115,744				(115,744)		
Total expenses	(52,788,459)							(52,788,459)
Changes in net assets	2,104,448	(14,630,770)	(487,721)	397,500	200,000	2,564,872	(11,956,119)	(9,851,671)
<b>Net Assets, December 31, 2020</b>	<b>\$7,145,768</b>	<b>\$37,918,123</b>	<b>\$826,888</b>	<b>\$467,500</b>	<b>\$200,000</b>	<b>\$3,009,373</b>	<b>\$42,421,884</b>	<b>\$49,567,652</b>

**STATEMENTS OF OF CASH FLOWS FOR THE YEARS ENDED DECEMBER 31, 2020 AND 2019**

<b>Cash Flows from Operating Activities:</b>	<b>2020</b>	<b>2019</b>
Changes in net assets	\$(9,851,671)	\$10,623,683
Adjustments to reconcile changes in net assets to net cash provided by operating activities:		
Depreciation	486,500	545,820
Bad debt	5,000	
Amortization of hosting arrangement costs	79,272	71,965
Net gain on investments	(49,617)	
Donated investments	4,948	118,421
Changes in operating assets and liabilities:		
Accounts receivable	10,412,197	(9,087,648)
Prepaid expenses	(138,980)	87,862
Deferred hosting arrangement costs		(154,093)

**STATEMENTS OF OF CASH FLOWS FOR THE YEARS ENDED DECEMBER 31, 2020 AND 2019**

<b>Cash Flows from Operating Activities (continued):</b>	<b>2020</b>	<b>2019</b>
Accounts payable	222	185,845
Accrued expenses	402,525	66,604
Research grants payable	616,746	272,396
Deferred revenue	25,122	(277,593)
Deferred compensation	(28,437)	32,779
Net cash provided by operating activities	1,963,827	2,486,041
<b>Cash Flows from Investing Activities:</b>		
Proceeds from sales (purchase) of investments	1,090,282	(118,421)
Proceeds from sale (purchase) of investments - deferred compensation	28,437	(32,779)
Purchase of investments	(26,658,723)	
Investment in software under development	(476,301)	(338,463)
Acquisition of property, equipment and software		(72,862)
Net cash used in investing activities	(26,016,305)	(562,525)
<b>Cash Flows from Financing Activities:</b>		
Principal payments on long-term debt	(67,464)	(64,245)
Net Change in Cash, Cash Equivalents and Restricted Cash	(24,119,942)	1,859,271
<b>Cash, Cash Equivalents and Restricted Cash:</b>		
Beginning of year	47,832,054	45,972,783
End of year	\$23,712,112	\$47,832,054
<b>Reconciliation of Cash, Cash Equivalents and Restricted Cash Reported Within the Statements of Financial Position:</b>		
Cash and cash equivalents	47,832,054	45,972,783
Restricted cash	\$ 23,512,112 200,000	\$ 47,832,054
Total cash, cash equivalents and restricted cash	\$23,712,112	\$ 47,832,054
<b>Supplemental Disclosure of Cash Flow Information:</b>		
Cash paid for interest	\$13,405	\$16,625
<b>Supplemental Disclosure of Non-Cash Transactions:</b>		
Software under development placed in service	\$315,344	\$335,132
Software in development in accounts payable	--	\$73,599

## NOTES TO FINANCIAL STATEMENTS DECEMBER 31, 2020 AND 2019

### 1. OPERATIONS AND NONPROFIT STATUS

National Organization for Rare Disorders, Inc. (NORD) is a not-for-profit organization incorporated on May 4, 1983, under the laws of the State of New York.

NORD was formed to provide information on rare disorders and related resources, to aid government agencies in activities pursuant to the Orphan Drug Act, to encourage and promote increased scientific and clinical research on rare disorders, to support and mentor disease-specific patient organizations, and to provide services to patients and their families, especially to enhance their access to medical treatment for their diseases. NORD manages both indigent care drug programs that provide medication at no cost to those in need and financial hardship relief programs to provide individuals who meet objective criteria with insurance premium and co-payment assistance through funds raised by NORD from grants and donations from foundations, corporations and individuals.

NORD's main office is in Quincy, Massachusetts, with additional offices in Danbury, Connecticut and Washington, D.C.

NORD is exempt from Federal income taxes as an organization (not a private foundation) formed for charitable purposes under Section 501(c)(3) of the Internal Revenue Code (IRC). NORD is also exempt from state income taxes. Donors may deduct contributions made to NORD within the requirements of the IRC.

### 2. SIGNIFICANT ACCOUNTING POLICIES

NORD's financial statements have been prepared in accordance with accounting standards generally accepted in the United States of America (U.S. GAAP). References to U.S. GAAP in these notes are to the FASB Accounting Standards Codification (ASC).

#### Cash and Cash Equivalents

For the purpose of the statements of cash flows, management considers all highly liquid investments with an initial maturity of three months or less to be cash and cash equivalents. These funds include investments, overnight bank deposits, and other short-term highly liquid securities.

#### Restricted Cash

Restricted cash consists of cash restricted for the endowment (see Note 4) at December 31, 2020.

#### Accounts Receivable and Allowance for Doubtful Accounts

Accounts receivable at December 31, 2020 and 2019, include approximately \$1,023,000 and \$11,145,000, respectively, due in the next year for program grants. An allowance for doubtful accounts is based on collection experience and other circumstances which may affect the ability of NORD to collect. The allowance for doubtful accounts at December 31, 2020 and 2019, was \$200,000 and \$195,000, respectively. Accounts receivable also includes contract service receivables of approximately \$313,000 and \$631,000, respectively, representing unconditional rights to consideration and only the passage of time is required before the payment of that consideration is due. Any estimated uncollectible amounts are generally considered implicit price concessions which directly reduce accounts receivable. Changes to the estimate of the transaction price are generally recorded as adjustments to revenue in the period of the change. Subsequent changes that are

determined to be the result of an adverse change in the payer's ability to pay are recorded as bad debt expense.

#### Fair Value Measurements

NORD follows the accounting and disclosure standards pertaining to ASC Topic, Fair Value Measurements, for qualifying assets and liabilities. Fair value is defined as the price that NORD would receive upon selling an asset or pay to settle a liability in an orderly transaction between market participants.

NORD uses a framework for measuring fair value that includes a hierarchy that categorizes and prioritizes the sources used to measure and disclose fair value. This hierarchy is broken down into three levels based on inputs that market participants would use in valuing the financial instruments based on market data obtained from sources independent of NORD. Inputs refer broadly to the assumptions that market participants would use in pricing the financial instrument, including assumptions about risk. Inputs may be observable or unobservable. Observable inputs are inputs that reflect the assumptions market participants would use in pricing the financial instrument developed based on market data obtained from sources independent of the reporting entity. Unobservable inputs are inputs that reflect the reporting entity's own assumptions about the assumptions market participants would use in pricing the asset developed based on the best information available.

The three-tier hierarchy of inputs is summarized in the three broad levels as follows:

Level 1 - Inputs that reflect unadjusted quoted prices in active markets for identical assets at the measurement date.

Level 2 - Inputs other than quoted prices that are observable for the asset either directly or indirectly, including inputs in markets that are not considered to be active.

Level 3 - Inputs that are unobservable and which require significant judgment or estimation.

An asset or liability's level within the framework is based upon the lowest level of any input that is significant to the fair value measurement. All assets are valued using Level 1 inputs except as noted in Note 5.

#### Deferred Hosting Arrangement Costs and Amortization

Implementation costs, including set up and other upfront fees, that are incurred to implement a hosting arrangement service contract are capitalized. Deferred hosting arrangement costs are expensed over the term of the hosting arrangements, including any reasonably certain renewal periods. Deferred hosting arrangement costs as of December 31, 2020 and 2019, include unamortized implementation costs related to NORD's budgeting and reporting software and development software. The deferred hosting arrangement costs are expected to be amortized through March 2022. Amortization expense was \$79,272 and \$71,965 for the years ended December 31, 2020 and 2019, respectively, and is included in data systems and equipment in the accompanying statements of activities without donor restrictions.

#### Software Under Development

Software under development includes the cost to advance and update NORD's proprietary software. The cost related to software or modules not placed in service as of December 31, 2020 and 2019, was \$188,231 and \$100,873, respectively, and is reflected as software under development

in the accompanying statements of financial position. When the software update or advance is implemented, it is placed in service, depreciated, and the asset is transferred to property, equipment and software in the accompanying statements of financial position.

#### Marketing and Advertising Costs

NORD expenses marketing and advertising costs as they are incurred.

#### Research Grants Payable

Research grants are recorded when awarded by NORD. Payments are made when certain milestones are met by the researchers. The final payment is made when the research is considered substantially completed. Research grants expected to be paid during the subsequent fiscal year are shown as current liabilities in the accompanying statements of financial position. Non-current research grants payable are expected to be paid in 2022 or beyond.

#### Property, Equipment and Software and Depreciation

Property, equipment and software are recorded at cost when purchased or developed or at fair value at the time of donation. Renewals and betterments are capitalized, while repairs and maintenance are expensed as they are incurred.

Depreciation is computed using the straight-line method over the following estimated useful lives:

	Estimated Useful Lives
Building and improvements.....	5 - 20 years
Furniture and fixtures .....	5 - 10 years
Computers and computer software .....	3- 5 years
Land is not depreciated.	

NORD accounts for the carrying value of its property and equipment in accordance with the requirements of Impairment and Disposal of Long-Lived Assets. As of December 31, 2020 and 2019, NORD has not recognized any reduction in the carrying value of its property and equipment in consideration of the requirement.

#### Net Assets

##### Net Assets Without Donor Restrictions

Net assets without donor restrictions are those net resources that bear no external restrictions and are generally available for use by NORD. NORD has grouped its net assets without donor restrictions into the following categories:

Operating - Represents resources available to carry on the operations of NORD.

Property, equipment and software and software under development - Represents the activities relating to NORD's property, equipment and software and software under development, net of related debt, if any.

##### Net Assets With Donor Restrictions

Net assets with donor restrictions represent amounts received or committed with donor restrictions that have not yet been expended for their designated purpose (purpose restricted) or amounts for use in future periods (time restricted).

Net assets with donor restrictions also include endowment funds which are perpetual in nature (see Note 4). Earnings from this fund may be used for operations unless otherwise stipulated by the donor. In accordance with Massachusetts law, all earnings, including interest and dividends, and appreciation of a donor-restricted endowment are restricted until appropriated by the Board of Directors, and are released to net assets without donor restrictions based on NORD's spending policy.

As of December 31, 2020 and 2019, net assets with donor restrictions are restricted for the following:

	2020	2019
Purpose restricted	\$41,438,384	\$53,125,003
Time restricted	783,500	1,253,000
Perpetual in nature	200,000	
Total	\$42,421,884	\$54,378,003

#### Revenue Recognition

In accordance with Accounting Standards Update (ASU) No. 2018-08, Not-for-Profit Entities (Topic 958): Clarifying the Scope and the Accounting Guidance for Contributions Received and Contributions Made, NORD must determine whether a contribution (or a promise) is conditional or unconditional for transactions deemed to be a contribution. A contribution is considered to be a conditional contribution if an agreement includes a barrier that must be overcome and either a right of return of the assets or a right of release of a promise to transfer assets exists. Indicators of a barrier include a measurable performance-related barrier or another measurable barrier, a stipulation that limits discretion by the recipient on the conduct of an activity, and stipulations that are related to the purpose of the agreement. Topic 958 prescribes that NORD should not consider probability of compliance with the barrier when determining if such awards are conditional and should be reported as conditional grant advance liabilities until such conditions are met. At December 31, 2020, NORD had conditional promises to give subject to matching and measurable performance barriers of \$1,257,656. These conditions are expected to be satisfied in 2021, at which time they will be recognized as revenue. NORD had no conditional grants at December 31, 2019.

NORD reports gifts and grants of cash and other assets as revenue and net assets with donor restrictions if they are received or unconditionally committed with donor stipulations that limit the use of the asset. When a donor restriction expires, that is, when a stipulated time restriction ends or purpose restriction is accomplished, net assets with donor restrictions are reclassified to net assets without donor restrictions and reported in the statement of activities without donor restrictions as net assets released from restrictions. Revenue from grants and contributions without donor restrictions is recorded when received or unconditionally committed by the donor.

Patient service program and administration fees are recorded as net assets with donor restrictions. When expense criteria are met, patient service program and administration fee revenue is recorded as net assets released from purpose restrictions under patient services in the statement of activities without donor restrictions.

Research grant contributions are received and held as donor restricted contributions until a research grant award is given and are reclassified as net assets released from restrictions in the statement of activities without donor restrictions. Research grants administration fee revenue is withheld from the grant award and released from restriction upon award date. The research grants administration fee revenue is considered peripheral to the research grant award transaction and are not considered an exchange transaction as no direct benefit is received by the research grant funder.

Sponsorships, included in registry, web subscriptions and other related fees in the statement of activities without donor restrictions, are recorded upon receipt and are recorded as net assets with donor restrictions. When expense criteria are met, revenue is recorded as net assets released from restrictions - contributions in the statement of activities without donor restrictions.

Membership dues, which are non-refundable, represent contributions restricted to the time period representing the membership period. The value of any membership services provided in exchange for membership rights are considered peripheral to the transaction. Membership dues are recorded as net assets with donor restrictions based upon the implied time restriction related to the effective membership period. Membership dues are reclassified to net assets without donor restrictions over time as time restrictions lapse and are reported in the statement of activities without donor restrictions as net assets released from time restrictions - membership dues.

NORD is and may be named beneficiary of trusts and wills. The amounts to be received, if any, cannot always be determined and are therefore not reflected in the accompanying financial statements because the donors' wills have not yet been declared valid by the probate court, and the value of the amounts to be received is not yet determinable. Bequests are recorded at a point in time when received. NORD received bequests of \$684,606 and \$5,723 for the years ended December 31, 2020 and 2019, respectively, which are included in grants, contributions and bequests in the accompanying statements of activities without donor restrictions.

NORD evaluates its revenue contracts with customers based on the five-step model under FASB's ASU No. 2014-09, Revenue from Contracts with Customers (Topic 606): (1) Identify the contract with the customer; (2) Identify the performance obligations in the contract; (3) Determine the transaction price; (4) Allocate the transaction price to separate performance obligations; and (5) Recognize revenue when (or as) each performance obligation is satisfied.

Drug, travel and lodging program fees, patient services program fees and registry, web subscriptions and other related fees represent service revenue earned under contractual agreements with customers and is recorded over time as services are provided. Revenue is reported at the stated contract price with adjustments for any consideration for explicit and implicit price considerations. Advance payments on these fees are recorded as deferred revenue until contract obligations are met at which point they are recognized as revenue.

All other revenue is recorded when earned.

#### Income Taxes

NORD accounts for uncertainty in income taxes in accordance with ASC Topic, Income Taxes. This standard clarifies the accounting for uncertainty in tax positions and prescribes a recognition threshold and measurement attribute for the financial statements regarding a tax position taken or expected to be taken in a tax return. NORD has determined that there are no uncertain tax positions which qualify for either recognition or disclosure in the financial statements at December 31, 2020 and 2019. NORD's information returns are subject to examination by the Federal and state jurisdictions.

#### Estimates

The preparation of financial statements in accordance with U.S. GAAP requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosure of contingent assets and liabilities at the date of the financial statements and the reported amounts of revenues and expenses during the reporting period. Actual results could differ from those estimates.

#### Expense Allocation

Certain expenses are incurred which support the work performed under more than one grant or contract. Such expenses are allocated among the various grants and contracts based upon management's calculation of the amount attributable to each grant or contract. Expenses incurred for specific grants or contracts are charged directly to the applicable project.

The financial statements contain certain categories of expenses that are attributable to program and supporting functions and are allocated on a reasonable basis that is consistently applied. The expenses that are allocated include occupancy and depreciation, which are allocated based on estimates of square footage occupied, as well as personnel and related, which are allocated based on an estimation of time spent, head count and level of effort spent on NORD's program and supporting functions.

#### Subsequent Events

Subsequent events have been evaluated through July 2, 2021, which is the date the financial statements were available to be issued. Except as disclosed in Note 14, there were no events that met the criteria for recognition or disclosure in the financial statements.

### 3. FUNCTIONAL EXPENSES

Expense allocation by function and classification is as follows for the years ended December 31:

	2020			
	Supporting Services			Total
	Programs	General & Administrative	Development & Communication	
Patient assistance and reimbursement	\$40,100,980	\$	\$	\$40,100,980
Personnel and related	5,208,063	1,997,023	1,265,305	8,470,391
Professional fees	763,263	167,636	225,505	1,156,404
Research grant expense	631,258			631,258
Other	322,869	131,658	108,227	562,754
Occupancy	217,275	245,066	59,044	521,385
Depreciation	451,727	19,263	15,510	486,500
Data systems and equipment	119,530	227,441	109,830	456,801
Conferences, meetings and travel	323,148	19,749	59,089	401,986
Total	\$48,138,113	\$2,807,836	\$1,842,510	\$52,788,459

### 3. FUNCTIONAL EXPENSES (Continued)

	2019			
	Supporting Services			
	Programs	General & Administrative	Development & Communication	Total
Patient assistance and reimbursement	\$30,812,906	\$	\$	\$30,812,906
Personnel and related	3,441,946	2,135,039	1,053,690	6,630,675
Professional fees	437,613	242,471	60,678	740,762
Research grant expense	535,130			535,130
Other	235,162	50,206	91,476	376,844
Occupancy	284,649	175,268	80,816	538,733
Depreciation	509,778	21,811	14,231	545,820
Data systems and equipment	81,781	163,025	83,789	328,595
Conferences, meetings and travel	1,122,833	142,277	324,401	1,589,511
Total	\$37,461,198	\$2,928,097	\$1,709,081	\$42,198,976

### 4. ENDOWMENT

During 2020, NORD received a \$200,000 endowment restricted in perpetuity. NORD follows the Massachusetts Uniform Prudent Management of Institutional Funds Act (UPMIFA). NORD developed a formal endowment spending policy whereas the corpus shall not be used to pay current expenses, other than investment service fees. The corpus shall be invested and returns may be used by NORD on an annual basis, starting three years after the funds are invested. The annual spending will be calculated as the greater of zero or half of the average annual return over the prior three years, calculated from the calendar year-end balance. NORD may decide, at its discretion, to delay or forego the annual withdrawal from the portfolio. NORD will not spend endowed funds from the endowment until after March 2024, three years after the initial investment. There were no amounts appropriated for spending from endowment funds during 2020 and no unspent appreciation of endowment funds as of December 31, 2020.

### 5. INVESTMENTS

At December 31, 2019 and 2020, investments, summarized using the inputs under the ASC Topic, *Fair Value Measurements* standard, consist of the following:

Description	2020			
	Level 1	Level 2	Level 3	Total
Corporate bonds	\$	\$19,035,585	\$	\$19,035,585
Asset backed securities		5,686,874		5,686,874
US Treasury bills		890,651		890,651
Total investments	\$	\$25,613,110	\$	\$25,613,110

Investments - Deferred Compensation (see Note 9) Mutual Fund	\$108,394	\$	\$	\$108,394
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Description	2019			
	Level 1	Level 2	Level 3	Total
Investments - Deferred Compensation (see Note 9) Mutual Fund	\$136,831	\$	\$	\$136,831

Investment return consists of the following for the year ended December 31, 2020:

	2020
Interest and dividends	\$238,857
Unrealized gains	17,088
Investment management fees	(38,660)
Realized losses	(167,668)
	\$49,617

Investment return is included in interest and dividend income, net in the accompanying statement of activities without donor restrictions at December 31, 2020.

## 6. PROPERTY, EQUIPMENT AND SOFTWARE

Net property, equipment and software consisted of the following as of December 31:

	2020	2019
Land	\$505,203	\$505,203
Building and improvements	857,182	857,182
Computers and computer software	3,181,529	2,866,185
Furniture and fixtures	31,731	31,731
	<u>4,575,645</u>	<u>4,260,301</u>
Less - accumulated depreciation	3,259,040	2,772,540
Net property, equipment and software	<u>\$1,316,605</u>	<u>\$1,487,761</u>

## 7. LONG-TERM DEBT AND LINE OF CREDIT

NORD has a mortgage note payable to a bank that is secured by certain property. Payments of principal and interest at 4.9% are due in monthly installments of \$6,739 through February 2024, the note's maturity. Subsequent to year-end, the interest rate was adjusted from 4.9% to 3.5% effective March 27, 2021 (see Note 14). Interest paid on the note was \$13,405 and \$16,625 for the years ended December 31, 2020 and 2019, respectively, which is included in other in the accompanying statements of activities without donor restrictions. The balance outstanding on the note was \$236,759 and \$304,223 as of December 31, 2020 and 2019, respectively.

The note agreement contains various covenants with which NORD must comply. At December 31, 2020 and 2019, NORD was in compliance with the covenants.

The future principal payments are as follows:

2021	<u>\$70,844</u>
2022	<u>\$74,395</u>
2023	<u>\$78,123</u>
2024	<u>\$13,397</u>

NORD has a line of credit with a bank which allows for borrowings up to \$750,000 and is renewable annually by the bank. The line of credit through May 31, 2021, was extended subsequent to year end through July 30, 2021 (see Note 14). Borrowings under the agreement are due no later than the expiration date and interest is payable monthly at the London Interbank Offered Rate (LIBOR) Daily Floating Rate plus 2.5%. The line of credit is secured by NORD's property. No amounts were drawn on the line of credit during 2020 or 2019.

## 8. LEASE AGREEMENTS

NORD leases office space under operating leases in Massachusetts and Washington D.C., which expire in June 2022 and April 2024, respectively. Monthly payments under the terms of the agreements were \$6,614 during 2020 and 2019. In future years, payments range from \$6,614 to \$10,440. The facility leases require NORD to maintain certain insurance coverage and pay for its proportionate share of real estate taxes and operating expenses, as defined in the agreements. Rent expense was \$258,868 and \$255,691 for the years ended December 31, 2020 and 2019, respectively, which is included in occupancy in the accompanying statements of activities without donor restrictions. One of the facility leases is recorded on the straight-line method over the lease term. The rent accrued in excess of the rent paid, approximately \$19,000 and \$26,000, is included in accrued expenses in the accompanying statements of financial position as of December 31, 2020 and 2019, respectively.

Future minimum base lease payments under these agreements are as follows:

2021	<u>\$ 199,248</u>
2022	<u>\$ 140,928</u>
2023	<u>\$ 79,368</u>
2024	<u>\$ 26,456</u>

Both lease agreements contain renewal options.

## 9. EMPLOYMENT BENEFIT PLANS

NORD maintains a tax-deferred pension plan under Section 403(b) of the IRC. Employees may contribute to the plan, however, employer contributions are not allowable under the plan.

NORD also maintained a defined contribution pension plan under Section 401(a) of the IRC. NORD contributed 5% of each participant's annual salary into the plan. In 2020, the 401(a) plan was terminated and participants were given the option to receive a pay out of the funds or transfer the funds into the 403(b) plan. NORD's contributions for the years ended December 31, 2020 and 2019, totaled \$297,849 and \$250,201, respectively, which are included in personnel and related in the accompanying statements of activities without donor restrictions.

NORD maintains deferred compensation plans for certain members of its senior management team. NORD makes annual discretionary contributions to these plans as determined by the Board of Directors. The total amounts accrued for these plans as of December 31, 2020 and 2019, are \$108,394 and \$136,831, respectively, which are included in investment - deferred compensation and deferred compensation in the accompanying statements of financial position. The liability is classified as long-term since NORD intends to pay the balances to certain retired employees in accordance with the plans. These employees will receive payments upon retirement, which is expected to be more than one year from the statements of financial position date. NORD's contribution expense under the plans was \$47,154 and \$32,779 for the years ended December 31, 2020 and 2019, respectively, which is included in personnel and related in the accompanying statements of activities without donor restrictions.



## 10. CONCENTRATIONS

NORD maintains its operating cash balances in various banks. The Federal Deposit Insurance Corporation (FDIC) insures balances at each bank up to certain amounts. At certain times during the years ended December 31, 2020 and 2019, cash balances exceeded the insured amounts. NORD has not experienced any losses in such accounts. NORD believes it is not exposed to any significant credit risk on its cash and cash equivalents.

Accounts receivable and revenue and support concentrations are comprised of the following private donors at December 31:

Donor	2020		2019	
	Percentage of Accounts Receivable	Percentage of Total Revenue and Support	Percentage of Accounts Receivable	Percentage of Total Revenue and Support
A	-%	14%	-%	20%
B	-%	-%	55%	16%
C	-%	-%	34%	-%
D	37%	-%	-%	16%
E	-%	16%	-%	13%
F	-%	11%	-%	-%
G	18%	-%	-%	-%
H	26%	-%	-%	-%

## 11. CONTINGENCY

In the ordinary course of NORD's business, NORD is from time-to-time involved in disputes concerning business and employment matters of NORD. While damages in connection with these disputes are possible, NORD denies any wrongdoing in these cases and is taking the appropriate legal steps in defense of these disputes. It is management's opinion that any potential settlement would not be material to the accompanying financial statements.

Beginning in March 2020, the COVID-19 pandemic in the United States has caused business disruption and a reduction in economic activity. While the disruption is expected to be temporary, there is uncertainty around the duration and the impact it will have on NORD's operations and financial position. Any financial impact to NORD, if any, cannot be reasonably estimated at this time.

## 12. UNEMPLOYMENT INSURANCE

NORD is self-insured for unemployment claims for two of their locations. NORD holds a prepaid account to fund the insurance through the Unemployment Services Trust. Claim liabilities are requested from the states through the Trust. As of December 31, 2020, and 2019, the balance in the prepaid unemployment insurance account was \$143,380 and \$124,579, respectively, which is included in prepaid expenses in the accompanying statements of financial position. The unemployment insurance account is available to fund future unemployment claims.

## 13. LIQUIDITY AND AVAILABILITY OF FINANCIAL ASSETS

NORD regularly monitors liquidity required to meet its operating needs and other contractual commitments, while also striving to maximize the investment of its available funds. NORD has various sources of liquidity at its disposal, including cash and cash equivalents and a line of credit in the amount of \$750,000 (see Note 7).

For purposes of analyzing resources available to meet general expenditures over a twelve-month period, NORD considers all expenditures related to its ongoing activities of its mission as well as the conduct of services undertaken to support those activities to be general expenditures. In addition to financial assets available to meet general expenditures over the next twelve months, NORD anticipates collecting sufficient revenue to cover general expenditures not covered by donor restricted resources.

As of December 31, 2020 and 2019, the total financial assets held by NORD that could readily be made available within one year of the statements of financial position date to meet general expenditures are as follows:

	2020	2019
Cash and cash equivalents	\$23,512,112	\$47,832,054
Accounts receivable, net	1,358,053	11,775,250
Investments	25,613,110	
	50,483,275	59,607,304
Less - amounts with donor-imposed restrictions	(41,438,384)	(53,125,003)
Financial assets available to meet cash needs for general expenditures within one year	\$9,144,891	\$6,482,301

## 14. SUBSEQUENT EVENTS

On March 27, 2021, NORD's mortgage interest rate was modified from 4.9% to 3.5% (see Note 7). On May 31, 2021, NORD's line of credit was extended through July 30, 2021 (see Note 7).



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To the Board of Directors of  
National Organization for Rare Disorders, Inc.:

**Report on the Financial Statements**

We have audited the accompanying financial statements of National Organization for Rare Disorders, Inc. (a New York corporation, not for profit) which comprise the statements of financial position as of December 31, 2020 and 2019, and the related statements of activities without donor restrictions, changes in net assets and cash flows for the years then ended, and the related notes to the financial statements.

***Management's Responsibility for the Financial Statements***

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

***Auditor's Responsibility***

Our responsibility is to express an opinion on these financial statements based on our audits. We conducted our audits in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audits to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

***Opinion***

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of National Organization for Rare Disorders, Inc. as of December 31, 2020 and 2019, and the changes in its net assets and its cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America.

**AAFCPAs, Inc.**

Westborough, Massachusetts  
July 2, 2021



ALONE  
WE ARE RARE.  
TOGETHER  
WE ARE STRONG.



**NORD**<sup>®</sup>  
National Organization  
for Rare Disorders

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