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.

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.
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.
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.

**TRACKING THE IMPACT**

$35,642,186 in aid provided through NORD assistance programs

265 rare disease diagnoses represented among those assisted by NORD

9,951 patients assisted across all 50 states, DC, Puerto Rico and the Virgin Islands

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/
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
11 countries represented (Australia, Canada, China, Georgia, Italy, Kenya, Netherlands, Panama, South Africa, United Kingdom, and USA)
41 sponsors and exhibitors
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 attendees**
- **24 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)**
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/

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
• 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
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.

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.

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

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

31,400 unique posts using #RareDiseaseDay

792k impressions from NORD social media posts

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

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**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.
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)
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.

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
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.

“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

“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

“I [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

“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

“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

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

Alone we are rare. Together we are strong!®

16
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Executive Director
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Walnut, CA

Jim Palma
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National Organization for Rare Disorders
Quincy, MA
Ex-officio
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Cabaletta Bio
Dante Labs
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Neurogene
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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
Cytokinetiсs, Inc.
Dicerna Pharmaceuticals, inc.
Editas Medicine
Enzyvant Therapeutics
Exicure
Hansa Medical
Helixsmith
Insmed Incorporated
LEO Pharma
Lysogene
MeiraGTx
Modern Therapeutics
Momenta Pharmaceuticals
Neurocrine Biosciences
Orchard Therapeutics Ltd.
Orphazyme
Ovid Therapeutics
Passage Bio
REGENXBIO
Rocket Pharmaceuticals, Inc
Sangamo Therapeutics
Savara, Inc.
Solexigenix, Inc.
Viela Bio
X4 Pharmaceuticals
Zealand Pharma
BioMarin Pharmaceuticals, Inc.
Boehringer-Ingelheim Pharmaceuticals
Bristol-Myers-Squibb
Catalyst Pharmaceuticals
Chiesi Rare Diseases
CSL Behring
Daichi Sankyo
Deciphera Pharmaceuticals, Inc.
Dompé
Eiger BioPharmaceuticals
Foundation Medicine
Genentech, Inc.
GlaxoSmithKline PLC
Global Blood Therapeutics, Inc.
Greenwich Biosciences, Inc
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 Maltese 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
Chromosomal Disorder Outreach, Inc.
Chromosomal Disorder Outreach, Inc.
Cicatricial Alopecia Research Foundation (CARF)
CLOVES Syndrome Community
Clusterbusters, Inc.
CM 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.
CSN2A1 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
EURODIS- Rare Diseases Europe
Familial Dysautonomia Foundation
FamilieSCN2A Foundation
Family Caregiver Alliance Fanconi Anemia Research Fund, Inc.
Fat Disorders Resource Society
Fibrolamellar Cancer Foundation (FCF)
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
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 Foundation
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.
Histiocytosis Association, Inc.
Hope for Hypothalamic Hamartomas
HSAN1E Society
Hydrocephalus Association
Hyper IgM Foundation, Inc.
Hypermobility Syndrome
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.
MERO 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
Mucolipidosis 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
## STATEMENTS OF ACTIVITIES WITHOUT DONOR RESTRICTIONS FOR THE YEARS ENDED DECEMBER 31, 2020 AND 2019

### ASSETS

#### Current Assets:

<table>
<thead>
<tr>
<th>Description</th>
<th>2020</th>
<th>2019</th>
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<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>$23,512,112</td>
<td>$47,832,054</td>
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<tr>
<td>Accounts receivable, net of allowance for doubtful accounts of $200,000 and $195,000 at December 31, 2020 and 2019, respectively</td>
<td>1,358,053</td>
<td>11,775,250</td>
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<tr>
<td>Prepaid expenses</td>
<td>368,116</td>
<td>229,136</td>
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<tr>
<td>Investments</td>
<td>25,613,110</td>
<td>--</td>
</tr>
<tr>
<td><strong>Total Current Assets</strong></td>
<td><strong>50,851,391</strong></td>
<td><strong>59,836,440</strong></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Description</th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Restricted Cash</td>
<td>200,000</td>
<td>--</td>
</tr>
<tr>
<td>Investments - Deferred Compensation</td>
<td>108,394</td>
<td>136,831</td>
</tr>
<tr>
<td>Deferred Hosting Arrangement Costs</td>
<td>109,919</td>
<td>189,191</td>
</tr>
<tr>
<td>Property, Equipment and Software, net</td>
<td>1,316,605</td>
<td>1,487,761</td>
</tr>
<tr>
<td>Software Under Development</td>
<td>188,231</td>
<td>100,873</td>
</tr>
<tr>
<td><strong>Total Assets</strong></td>
<td><strong>$52,774,540</strong></td>
<td><strong>$61,751,096</strong></td>
</tr>
</tbody>
</table>

### LIABILITIES AND NET ASSETS

#### Current Liabilities:

<table>
<thead>
<tr>
<th>Description</th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current portion of long-term debt</td>
<td>$70,844</td>
<td>$67,463</td>
</tr>
<tr>
<td>Accounts payable</td>
<td>587,335</td>
<td>660,712</td>
</tr>
<tr>
<td>Accrued expenses</td>
<td>662,999</td>
<td>260,474</td>
</tr>
<tr>
<td>Current portion of research grants payable</td>
<td>1,098,220</td>
<td>481,474</td>
</tr>
<tr>
<td>Deferred revenue</td>
<td>248,181</td>
<td>223,059</td>
</tr>
<tr>
<td><strong>Total Current Liabilities</strong></td>
<td><strong>2,667,579</strong></td>
<td><strong>1,693,182</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Description</th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deferred Compensation</td>
<td>108,394</td>
<td>136,831</td>
</tr>
<tr>
<td>Research Grants Payable, net of current portion</td>
<td>265,000</td>
<td>265,000</td>
</tr>
<tr>
<td>Long-Term Debt, net of current portion</td>
<td>165,915</td>
<td>236,760</td>
</tr>
<tr>
<td><strong>Total Liabilities</strong></td>
<td><strong>3,206,888</strong></td>
<td><strong>2,331,773</strong></td>
</tr>
</tbody>
</table>

#### Net Assets:

<table>
<thead>
<tr>
<th>Description</th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Operating</td>
<td>5,877,691</td>
<td>3,830,508</td>
</tr>
<tr>
<td>Property, equipment and software and software under development</td>
<td>1,268,077</td>
<td>1,210,812</td>
</tr>
<tr>
<td><strong>Total without donor restrictions</strong></td>
<td><strong>7,145,768</strong></td>
<td><strong>5,041,320</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Description</th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>With donor restrictions:</td>
<td>42,421,884</td>
<td>54,378,003</td>
</tr>
<tr>
<td><strong>Total Net Assets</strong></td>
<td><strong>49,567,652</strong></td>
<td><strong>59,419,323</strong></td>
</tr>
<tr>
<td><strong>Total Liabilities and Net Assets</strong></td>
<td><strong>$52,774,540</strong></td>
<td><strong>$61,751,096</strong></td>
</tr>
</tbody>
</table>
### Changes in Net Assets Without Donor Restrictions

<table>
<thead>
<tr>
<th>Patient services:</th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program fees</td>
<td>$345,353</td>
<td>$639,674</td>
</tr>
<tr>
<td>Net assets released from purpose restrictions</td>
<td>39,755,627</td>
<td>30,173,232</td>
</tr>
<tr>
<td>Patient assistance and reimbursement expense</td>
<td>(40,100,980)</td>
<td>(30,812,906)</td>
</tr>
<tr>
<td>Patient services, net</td>
<td>--</td>
<td>--</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Research grants:</th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Net assets released from purpose restrictions</td>
<td>631,258</td>
<td>535,130</td>
</tr>
<tr>
<td>Research grant expense</td>
<td>(631,258)</td>
<td>(535,130)</td>
</tr>
<tr>
<td>Research grants, net</td>
<td>--</td>
<td>--</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other revenue and support:</th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grants, contributions and bequests</td>
<td>4,122,303</td>
<td>1,111,020</td>
</tr>
<tr>
<td>Special events revenue</td>
<td>1,900,601</td>
<td>2,405,019</td>
</tr>
<tr>
<td>Registry, web subscriptions and other related fees</td>
<td>395,674</td>
<td>234,128</td>
</tr>
<tr>
<td>Interest and dividend income, net</td>
<td>328,049</td>
<td>595,629</td>
</tr>
<tr>
<td>Drug, travel and lodging program administrative fees</td>
<td>67,425</td>
<td>174,162</td>
</tr>
<tr>
<td>Net assets released from purpose restrictions - patient service administrative fees</td>
<td>3,756,095</td>
<td>4,493,330</td>
</tr>
<tr>
<td>Net assets released from time restrictions - membership dues</td>
<td>1,783,062</td>
<td>1,680,303</td>
</tr>
<tr>
<td>Net assets released from purpose restrictions - contributions</td>
<td>1,755,460</td>
<td>1,775,409</td>
</tr>
<tr>
<td>Net assets released from purpose restrictions - research grant administrative fees</td>
<td>52,000</td>
<td>34,020</td>
</tr>
<tr>
<td><strong>Total Other Revenue and Support</strong></td>
<td><strong>14,160,669</strong></td>
<td><strong>12,503,020</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other operating expenses:</th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personnel and related</td>
<td>8,470,391</td>
<td>6,630,675</td>
</tr>
<tr>
<td>Professional fees</td>
<td>1,156,404</td>
<td>740,762</td>
</tr>
<tr>
<td>Other</td>
<td>562,754</td>
<td>376,844</td>
</tr>
<tr>
<td>Occupancy</td>
<td>521,385</td>
<td>538,733</td>
</tr>
<tr>
<td>Depreciation</td>
<td>486,500</td>
<td>545,820</td>
</tr>
<tr>
<td>Data systems and equipment</td>
<td>456,801</td>
<td>328,595</td>
</tr>
<tr>
<td>Conferences, meetings and travel</td>
<td>401,986</td>
<td>1,589,511</td>
</tr>
<tr>
<td><strong>Total Other Operating Expenses</strong></td>
<td><strong>12,056,221</strong></td>
<td><strong>10,750,940</strong></td>
</tr>
<tr>
<td><strong>Changes in Net Assets Without Donor Restrictions</strong></td>
<td><strong>$2,104,448</strong></td>
<td><strong>$1,752,080</strong></td>
</tr>
</tbody>
</table>

The accompanying notes are an integral part of these statements.
STATEMENTS OF CHANGES FOR THE YEARS ENDED DECEMBER 31, 2020 AND 2019

<table>
<thead>
<tr>
<th>Without Donor Restrictions</th>
<th>With Donor Restrictions</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patient Services</td>
<td>Research Grants</td>
</tr>
<tr>
<td>Net Assets, December 31, 2018</td>
<td>$3,289,240</td>
<td>$43,315,648</td>
</tr>
<tr>
<td>Revenue without donor restrictions</td>
<td>5,159,632</td>
<td></td>
</tr>
<tr>
<td>Grants and contributions with donor restrictions</td>
<td>43,657,500</td>
<td>576,127</td>
</tr>
<tr>
<td>Net assets released from donor restrictions</td>
<td>38,691,424</td>
<td>(34,666,662)</td>
</tr>
<tr>
<td>Transfers</td>
<td>242,307</td>
<td></td>
</tr>
<tr>
<td>Total expenses</td>
<td>(42,098,976)</td>
<td></td>
</tr>
<tr>
<td>Changes in net assets</td>
<td>1,752,080</td>
<td>9,233,245</td>
</tr>
<tr>
<td>Net Assets, December 31, 2019</td>
<td>5,041,320</td>
<td>52,548,893</td>
</tr>
<tr>
<td>Revenue without donor restrictions</td>
<td>7,159,405</td>
<td></td>
</tr>
<tr>
<td>Net assets released from donor restrictions</td>
<td>47,733,502</td>
<td>(43,511,722)</td>
</tr>
<tr>
<td>Transfer</td>
<td>115,744</td>
<td></td>
</tr>
<tr>
<td>Total expenses</td>
<td>(52,788,459)</td>
<td></td>
</tr>
<tr>
<td>Changes in net assets</td>
<td>2,104,448</td>
<td>(14,630,770)</td>
</tr>
<tr>
<td>Net Assets, December 31, 2020</td>
<td>$7,145,768</td>
<td>$37,918,123</td>
</tr>
</tbody>
</table>

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

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

The accompanying notes are an integral part of these statements.
<table>
<thead>
<tr>
<th>Cash Flows from Operating Activities (continued):</th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accounts payable</td>
<td>222</td>
<td>185,845</td>
</tr>
<tr>
<td>Accrued expenses</td>
<td>402,525</td>
<td>66,604</td>
</tr>
<tr>
<td>Research grants payable</td>
<td>616,746</td>
<td>272,396</td>
</tr>
<tr>
<td>Deferred revenue</td>
<td>25,122</td>
<td>(277,593)</td>
</tr>
<tr>
<td>Deferred compensation</td>
<td>(28,437)</td>
<td>32,779</td>
</tr>
<tr>
<td>Net cash provided by operating activities</td>
<td>1,963,827</td>
<td>2,486,041</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cash Flows from Investing Activities:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Proceeds from sales (purchase) of investments</td>
<td>1,090,282</td>
<td>(118,421)</td>
</tr>
<tr>
<td>Proceeds from sale (purchase) of investments - deferred compensation</td>
<td>28,437</td>
<td>(32,779)</td>
</tr>
<tr>
<td>Purchase of investments</td>
<td>(26,658,723)</td>
<td></td>
</tr>
<tr>
<td>Investment in software under development</td>
<td>(476,301)</td>
<td>(338,463)</td>
</tr>
<tr>
<td>Acquisition of property, equipment and software</td>
<td>(72,862)</td>
<td></td>
</tr>
<tr>
<td>Net cash used in investing activities</td>
<td>(26,016,305)</td>
<td>(562,525)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cash Flows from Financing Activities:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Principal payments on long-term debt</td>
<td>(67,464)</td>
<td>(64,245)</td>
</tr>
<tr>
<td>Net Change in Cash, Cash Equivalents and Restricted Cash</td>
<td>(24,119,942)</td>
<td>1,859,271</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cash, Cash Equivalents and Restricted Cash:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Beginning of year</td>
<td>47,832,054</td>
<td>45,972,783</td>
</tr>
<tr>
<td>End of year</td>
<td>$23,712,112</td>
<td>$47,832,054</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reconciliation of Cash, Cash Equivalents and Restricted Cash Reported Within the Statements of Financial Position:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>47,832,054</td>
<td>45,972,783</td>
</tr>
<tr>
<td>Restricted cash</td>
<td>$23,512,112</td>
<td>$47,832,054</td>
</tr>
<tr>
<td>Total cash, cash equivalents and restricted cash</td>
<td>$23,712,112</td>
<td>$47,832,054</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Supplemental Disclosure of Cash Flow Information:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash paid for interest</td>
<td>$13,405</td>
<td>$16,625</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Supplemental Disclosure of Non-Cash Transactions:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Software under development placed in service</td>
<td>$315,344</td>
<td>$335,132</td>
</tr>
<tr>
<td>Software in development in accounts payable</td>
<td>--</td>
<td>$73,599</td>
</tr>
</tbody>
</table>

The accompanying notes are an integral part of these statements.
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 indirect 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:

<table>
<thead>
<tr>
<th>Asset Type</th>
<th>Estimated Useful Lives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Building and improvements</td>
<td>5 - 20 years</td>
</tr>
<tr>
<td>Furniture and fixtures</td>
<td>5 - 10 years</td>
</tr>
<tr>
<td>Computers and computer software</td>
<td>3 - 5 years</td>
</tr>
<tr>
<td>Land has not depreciated</td>
<td></td>
</tr>
</tbody>
</table>

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:

<table>
<thead>
<tr>
<th></th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Purpose restricted</td>
<td>$41,438,384</td>
<td>$53,125,003</td>
</tr>
<tr>
<td>Time restricted</td>
<td>783,500</td>
<td>1,253,000</td>
</tr>
<tr>
<td>Perpetual in nature</td>
<td>200,000</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>$42,421,884</td>
<td>$54,378,003</td>
</tr>
</tbody>
</table>

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:

<table>
<thead>
<tr>
<th>Supporting Services</th>
<th>Programs</th>
<th>General &amp; Administrative</th>
<th>Development &amp; Communication</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient assistance and reimbursement</td>
<td>$40,100,980</td>
<td>$</td>
<td>$</td>
<td>$40,100,980</td>
</tr>
<tr>
<td>Personnel and related</td>
<td>5,208,063</td>
<td>1,997,023</td>
<td>1,265,305</td>
<td>8,470,431</td>
</tr>
<tr>
<td>Professional fees</td>
<td>763,263</td>
<td>167,636</td>
<td>225,505</td>
<td>1,156,404</td>
</tr>
<tr>
<td>Research grant expense</td>
<td>631,258</td>
<td></td>
<td></td>
<td>631,258</td>
</tr>
<tr>
<td>Other</td>
<td>322,869</td>
<td>131,658</td>
<td>108,227</td>
<td>562,754</td>
</tr>
<tr>
<td>Occupancy</td>
<td>217,275</td>
<td>245,066</td>
<td>59,044</td>
<td>521,385</td>
</tr>
<tr>
<td>Depreciation</td>
<td>451,727</td>
<td>19,263</td>
<td>15,510</td>
<td>486,500</td>
</tr>
<tr>
<td>Data systems and equipment</td>
<td>119,530</td>
<td>227,441</td>
<td>109,830</td>
<td>456,801</td>
</tr>
<tr>
<td>Conferences, meetings and travel</td>
<td>323,148</td>
<td>19,749</td>
<td>59,089</td>
<td>401,986</td>
</tr>
<tr>
<td>Total</td>
<td>$48,138,113</td>
<td>$2,807,836</td>
<td>$1,842,510</td>
<td>$52,788,459</td>
</tr>
</tbody>
</table>
3. FUNCTIONAL EXPENSES (Continued)

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

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:

<table>
<thead>
<tr>
<th>Description</th>
<th>2020</th>
<th></th>
<th></th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corporate bonds</td>
<td>$19,035,585</td>
<td>$</td>
<td>$</td>
<td>$19,035,585</td>
</tr>
<tr>
<td>Asset backed securities</td>
<td>5,686,874</td>
<td>5,686,874</td>
<td></td>
<td></td>
</tr>
<tr>
<td>US Treasury bills</td>
<td>890,651</td>
<td>890,651</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total investments</td>
<td>$25,613,110</td>
<td>$</td>
<td>$</td>
<td>$25,613,110</td>
</tr>
</tbody>
</table>

Investments - Deferred Compensation (see Note 9)

<table>
<thead>
<tr>
<th>Description</th>
<th>2019</th>
<th></th>
<th></th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mutual Fund</td>
<td>$108,394</td>
<td>$</td>
<td>$</td>
<td>$108,394</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Description</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interest and dividends</td>
<td>$238,857</td>
</tr>
<tr>
<td>Unrealized gains</td>
<td>17,088</td>
</tr>
<tr>
<td>Investment management fees</td>
<td>(38,660)</td>
</tr>
<tr>
<td>Realized losses</td>
<td>(167,668)</td>
</tr>
<tr>
<td>Investment return</td>
<td>$49,617</td>
</tr>
</tbody>
</table>

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:

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

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 occupancy 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:

<table>
<thead>
<tr>
<th>Year</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>2021</td>
<td>$70,844</td>
</tr>
<tr>
<td>2022</td>
<td>$74,395</td>
</tr>
<tr>
<td>2023</td>
<td>$78,123</td>
</tr>
<tr>
<td>2024</td>
<td>$13,397</td>
</tr>
</tbody>
</table>

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:

<table>
<thead>
<tr>
<th>Year</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>2021</td>
<td>$199,248</td>
</tr>
<tr>
<td>2022</td>
<td>$140,928</td>
</tr>
<tr>
<td>2023</td>
<td>$79,368</td>
</tr>
<tr>
<td>2024</td>
<td>$26,456</td>
</tr>
</tbody>
</table>

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:

<table>
<thead>
<tr>
<th>Donor</th>
<th>2020 Percentage of Accounts Receivable</th>
<th>2020 Percentage of Total Revenue and Support</th>
<th>2019 Percentage of Accounts Receivable</th>
<th>2019 Percentage of Total Revenue and Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>-%</td>
<td>14%</td>
<td>-%</td>
<td>20%</td>
</tr>
<tr>
<td>B</td>
<td>-%</td>
<td>-%</td>
<td>55%</td>
<td>16%</td>
</tr>
<tr>
<td>C</td>
<td>-%</td>
<td>-%</td>
<td>34%</td>
<td>-%</td>
</tr>
<tr>
<td>D</td>
<td>37%</td>
<td>-%</td>
<td>34%</td>
<td>-%</td>
</tr>
<tr>
<td>E</td>
<td>-%</td>
<td>16%</td>
<td>-%</td>
<td>13%</td>
</tr>
<tr>
<td>F</td>
<td>-%</td>
<td>11%</td>
<td>-%</td>
<td>-%</td>
</tr>
<tr>
<td>G</td>
<td>18%</td>
<td>-%</td>
<td>-%</td>
<td>-%</td>
</tr>
<tr>
<td>H</td>
<td>26%</td>
<td>-%</td>
<td>-%</td>
<td>-%</td>
</tr>
</tbody>
</table>

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:

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

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).
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.