2022 IMPACT REPORT

Alone we are rare.
Together we are strong.®
The Struggle is Real.

Imagine living each day with uncertainty, battling physical limitations, financial strains, and feeling isolated and misunderstood.

Picture facing a rare life-threatening and/or life-altering medical condition without access to proper care or treatments. Consider the challenge of having a loved one with an untreated condition, with no specialists available or physician familiar with their disease. Now, imagine your health declining rapidly for years without a diagnosis, despite countless medical appointments and tests. Add to this, battles with your health insurance company for medications.

Finally, ponder the exhaustion and heartache of advocating for yourself, your child or someone you love with a rare disease, while also trying to maintain a job and care for your family. For more than 25 million Americans with one or more rare diseases, this is an all-too-familiar way of life.

Individuals and families affected by rare disease(s) deserve the same equitable access to care, resources, support, and investment in research for treatments as do all other diseases.

The mission of the National Organization for Rare Disorders (NORD®) is to improve the health and well-being of people with rare diseases by driving advances in care, research and policy.

More than 93% of contributions to NORD® go to support patient programs and services.

Paving A Path Forward

For nearly 40 years, NORD has been championing advocacy and a path forward for individuals living with rare diseases. NORD’s founders led the charge in establishing the Orphan Drug Act (ODA) in 1983, the world’s first law incentivizing drug development for all rare diseases.

Every day since, NORD has tirelessly safeguarded the ODA, ensuring continued momentum in drug development while also championing programs and a path forward to improve the lives of those with rare diseases.
Defining the Problem

Rare diseases are not as prevalent as other more common diseases. A rare disease is defined as any disease, disorder, illness or condition affecting fewer than 200,000 people in the U.S.¹ Because fewer people have a given rare disease, less is known about them and it makes it harder to diagnosis, research and provide care to individuals with rare diseases.

More than 25 million Americans are living with a rare disease.² Rare disease devastates families emotionally and financially. Half of rare disease patients are children and 30% will not live to see their fifth birthday.³

With over 7,000 rare diseases, physicians face significant challenges in diagnosing, and treating individuals with a rare disease.⁴ The average time to receive an accurate diagnosis is 5-7 years with medical costs 3-5 times higher than non-rare diseases.⁵ Small patient populations make it hard to find participants for research which is needed for therapeutic development.

39% of rare disease patients travel 60 miles or more to access medical care.⁶ Most rare diseases lack disease-specific patient organizations which provide support and drive research for that specific rare disease.

Fewer than 5% of rare diseases have an FDA approved treatment.⁷

Sources:
¹ https://www.fda.gov/patients/rare-diseases-fda
² Genetic and Rare Diseases Information Center; National Center for Advancing Translational Sciences; FAQs About Rare Diseases; 11/30/2017.
⁴ https://www.fda.gov/forindustry/developingproductsforrarediseasesconditions/howtoapplyfororphanproduct-designation/ucm364750.htm
2022 HIGHLIGHTS

ADVANCING PATIENT CARE

NORD RareCare® Patient Assistance

NORD’s Patient Assistance program celebrated 35 years this year and was the first rare disease patient assistance program established in the U.S. The NORD RareCare patient assistance program is uniquely suited to serve the complex needs of rare disease patients. In 2022, NORD provided $32.6 million in financial support to individuals and families. See sidebar for Patient Assistance Impact.

Continuing Medical Education

To help improve rare disease patient care, NORD worked in partnership with Platform Q Health to educate medical professionals on rare diseases with high quality Continuing Medical Education (CME) courses. Together, NORD and Platform Q Health:

- Provided 83 educational sessions covering 35 rare disorders
- 28,768 Health Care Providers participated in CME sessions, and 14,876 CME credits were awarded.
- 93% of learners reported that the CME programs had a positive impact on their clinical practice and 91% of learners reported that CME programs had a positive impact on patient experience and outcomes.

Training the Next Generation with Students for Rare®

NORD’s Students for Rare program is actively paving the way to educate and cultivate the next generation of rare disease healthcare professionals, medical experts and others interested in a career tied to rare disease. Highlights include:

- The addition of 23 new student chapters (up to 54 from 31) which is an increase of 74%.

Patient Assistance Impact

50 states supported (plus Washington, DC, Puerto Rico and Guam)

- $32.6 million in support provided to families
- $85,266 in respite care support provided to 121 patient families and caregivers
- $347,229 provided in non-medical emergency relief support to 347 patients
- 55,586 patient claims fulfilled
- 221,685 travel miles reimbursed and nearly 800 hotel night stays
- 106,414 calls and emails responded
Launched in November 2021, the NORD® Rare Disease Centers of Excellence (NORD RD CoE) program is the first national network of U.S. hospitals and medical institutions dedicated to diagnosing, treating and researching all rare diseases. In its inaugural year, these Centers teamed up to solve the greatest medical challenges and unmet needs of the rare disease community.

Year-one accomplishments include:

- **Established Working Groups**: Identified the top 10 unmet needs and barriers to care for the rare disease community and established 10 working groups focused on building solutions.
  
  > Established Co-Chairs for each group and successfully hosted monthly meetings with 75% attendance. Also, identified initial projects and delivered year-end progress reports.

- **Knowledge Sharing Platform**: Developed and successfully conducted beta launch of a knowledge sharing platform to help facilitate clinical care and research across the network.

- **Volunteer Network**: Established an active volunteer network made up of 250 medical and other healthcare professionals including: clinicians, researchers, advanced trainees, allied health professionals and support staff from across 20 areas of specialty, including pediatrics.

- **Launched Second Application Cycle**: Successfully launched a second application cycle open to any qualified medical institution. Held information webinar on November 16 and a virtual Q&A on November 30 with (54 attendees) combined. Applications due on February 23, 2023.

- **Meetings**: Held three virtual meetings with 97% attendance and 100% representation at the first in-person meeting held in October in Washington, D.C.

- **New Hires**: Hired a Program Assistant focused on Working Group and application cycle management and an Ontology Specialist to curate and validate rare diseases for the knowledge and resource sharing platform.
2022 HIGHLIGHTS

IAMRARE® Program

Helped launch 2 patient registries with All Thinks Kabuki, Kabuki Syndrome Registry and the Snow Foundation, Wolfram Syndrome Global Patient Registry

At the end of 2022, there were 17 organizations’ natural history studies that were in progress.

We reached a total of 19,921 individuals across 31 different disease specific registries, who have collectively reported data for 175,713 surveys.

In 2022, NORD, with funding from the patient member organization the APS Type 1 Foundation, issued 1 grant in the amount of $50,000.

THE FUTURE OF RARE DISEASE PATIENT CARE & RESEARCH

CONTINUED....
DRIVING POLICY & ADVOCACY

In 2022, NORD actively engaged and empowered volunteers, its Rare Action Network® of more than 18,000 people, member organizations and other community members to improve the lives of people with rare diseases and their families through public policy advocacy. Together, with the rare community NORD helped amplify the voices of those with rare diseases to advance policy change at all levels of government to:

- Protect the Orphan Drug Act
- Improve the regulatory process and development of safe and effective therapies
- Quicken access to affordable and quality health care and treatments
- Reduce the time to diagnosis from an average of 5 years or longer

TOP HIGHLIGHTS

Published 2022 State Report Card

Released the 8th edition of the NORD State Report Card which which grades each U.S. state on critical issues impacting access to care for the 1 in 10 Americans living with a rare disease. This year’s edition highlights areas of state policies that can benefit or jeopardize health care coverage, access, and affordability for rare disease patients.

Mobilized & Educated Volunteers

Coached 25 Community Ambassadors to raise awareness and build state-based coalitions nationwide. Led nearly 100 volunteers to populate NORD’s State Resource Database with local organizations and services to help patients find support close to where they live. Activated nearly 70 volunteers to execute national Rare Disease Day® events on February 28.

Advocates

More than 18,500 Rare Action Network® (RAN) advocates, representing all 50 states, signed up to receive updates and to take action on federal and state policy issues. Successfully rallied RAN network members which led to the passage of key legislation, including the establishment of Rare Disease Advisory Councils in four states (Colorado, Georgia, Connecticut, and Maine) as part of NORD’s Project RDAC.

Together, the RAN network raised their voices to help improve access to care, joining action alerts focused on telehealth, accessing care across state lines, and protecting the Orphan Drug Tax Credit and market exclusivity provisions of the Orphan Drug Act. 1,300 new advocates joined the RAN network.

Community Sign-On Letters

RAN advocates sent nearly 7,000 messages to more than 700 lawmakers. Successfully rallied RAN network members which led to the passage of key legislation, including the establishment of Rare Disease Advisory Councils in four states (Colorado, Georgia, Connecticut, and Maine) as part of NORD’s Project RDAC.

NORD HELP Committee Rare Act in FDASLA - 84 sign ons
NORD Accelerating Kids Access to Care November 2022 - 109 organizations
NORD Title V Reauthorization November 2022 - 125 sign ons
BUILDING & EDUCATING THE COMMUNITY

NORD Rare Diseases and Orphan Products Breakthrough Summit®

The 2022 NORD Rare Diseases and Orphan Products Breakthrough Summit welcomed 755 in-person attendees in Washington, DC and 38 virtual participants. Programming aimed to bring all key stakeholders back together again to address the most critical and timely topics in rare disease, such as: “Strategies for Enhancing Diversity, Equity and Inclusion in Rare Disease Research,” “Creating a Culture of Data Sharing” and “Accelerated Approval: Doing it Right.” Representation from government partners promoted awareness of rare disease programs at NIH and FDA and included the FDA Commissioner, a Fireside Chat with three FDA Center Directors (CBER, CDER and CDRH) and the NIH Town Hall.

Living Rare, Living Stronger®
NORD Patient and Family Forum

Returning to in-person programming after two virtual years, the 2022 Living Rare Forum was held in Cleveland, Ohio. Educational sessions were centered on living your best rare life, and the forum provided educational and networking opportunities with safety as a top priority throughout the event. 299 patients and families living with rare diseases attended in-person, and 78 attended virtually. The most well-attended sessions were on the topics of “Building and Quarterbacking Your Care Team,” “Beyond Coping: Resiliency While Rare,” and “Rare Breakthroughs: Hope Now and on the Horizon.”

Raising Dollars For Rare Disease
One Step at A Time

In 2022, in its 14th year, the NORD Running for Rare® program raised over $200,000 with participation in the Boston and TCS New York City Marathons as well as three virtual Running for Rare Anywhere races.
ACKNOWLEDGEMENTS

NORD’s Rare Giving Society recognizes the extraordinary generosity of individuals and family foundations who donate $1,000 or more to NORD annually. The generosity of these members enables NORD to improve the lives of those with rare disorders.

RARE GIVING SOCIETY MEMBERS
Worthington Olson
Linda Manasee Charitable Fund
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Cinia Edwards
Erin Fitzgerald
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Toby Tschirhart
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Florence Ferguson Shine

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The Raynie Foundation
Andrew LeGrand
Edward Patterson
Colin Blanch
Richard Leebve
David Piazza
Phil-Debbie Hoelscher
Donald Rissmiller
Vahe Zeroonian
Steven Grossman
The Roger Drake Charitable Fund
Anthony Hargrove
Rachael Larson
Salve Kutlow
Jamari Foundation
The de Rothschild Philanthropic Trust
Ara D. Cohen Charitable Lead Trust

RARE GIVING SOCIETY LEGACY MEMBERS
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Kay Family Foundation
Smidt Family Foundation Trust
Gregory & Carla Matthews
The Denise D’Ascenso Foundation Inc
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- GMendel
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- Soligenix, Inc.
- Stride Bio
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- Vigil Neurosciences
- Dicerna
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- Kezar
- Lysogene
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- Santen
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- Zealand Pharma

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- BridgeBio
- Camurus
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- Jazz Pharmaceuticals
- Kiniksa
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- Pfizer, Inc.
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- Pharming
- PTC Therapeutics
- Recordati Rare Diseases
- Regeneron
- Rigel Pharmaceuticals
- Sanofi Genzyme
- Sarepta Therapeutics
- Sobi
- Spark
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- Albireo
- Alexion, AstraZeneca Rare Disease
- Alnylam

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- Eversana
- ICON
- Illumina
- Medidata
- Optum Frontier Therapies
- Parexel
- PhRMA
- Syneos Health Inc

**OUR PARTNERS**
FINANCIALS
2022 REVENUE

- $39,907,322 Patient Service Contributions and Fees
- $2,269,050 Organization and Corporate Membership Dues
- $2,239,534 Special Events
- $3,076,161 Other Contributions, Grants and Service Revenue
- $248,962 Investment Income

$47,741,029 Total Unrestricted & Released Donor-Restricted Revenue

2022 EXPENSES

- Program Services $43,146,755
- General and Administrative $3,101,339
- Development and Communications $2,141,304
- Total Expenses $48,389,398
## Financials

### Statements of Financial Position December 31, 2022 and 2021

#### Assets

<table>
<thead>
<tr>
<th>Description</th>
<th>2022</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>$7,189,095</td>
<td>$13,488,659</td>
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<tr>
<td>Accounts, grants and contributions receivable, net of allowance for doubtful accounts of $25,000 at December 31, 2022 and 2021</td>
<td>$11,078,737</td>
<td>$1,240,510</td>
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<tr>
<td>Prepaid expenses</td>
<td>$232,983</td>
<td>$351,001</td>
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<td>Investments</td>
<td>$28,046,028</td>
<td>$20,808,366</td>
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<tr>
<td><strong>Total Current Assets</strong></td>
<td><strong>$46,546,843</strong></td>
<td><strong>$35,888,536</strong></td>
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<tr>
<td>Investments - Deferred Compensation</td>
<td>$106,602</td>
<td>$147,299</td>
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<tr>
<td>Investments - Endowment</td>
<td>$201,076</td>
<td>$244,364</td>
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<tr>
<td>Deferred Hosting Arrangement Costs</td>
<td>$106,140</td>
<td>$74,147</td>
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<tr>
<td>Operating Lease Right-of-Use Asset</td>
<td>$421,247</td>
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<tr>
<td>Property, Equipment and Software, net</td>
<td>$2,160,212</td>
<td>$1,520,900</td>
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<tr>
<td><strong>Total Assets</strong></td>
<td><strong>$49,542,120</strong></td>
<td><strong>$37,875,246</strong></td>
</tr>
</tbody>
</table>

#### Liabilities and Net Assets

<table>
<thead>
<tr>
<th>Description</th>
<th>2022</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current portion of long-term debt</td>
<td>$77,294</td>
<td>$74,640</td>
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<tr>
<td>Accounts payable and accrued expenses</td>
<td>$1,421,641</td>
<td>$1,435,985</td>
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<tr>
<td>Current portion of research grants payable</td>
<td>$752,777</td>
<td>$548,527</td>
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<tr>
<td>Operating lease liability - short-term</td>
<td>$207,322</td>
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<tr>
<td>Deferred revenue</td>
<td>$214,816</td>
<td>$242,900</td>
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<td><strong>Total Current Liabilities</strong></td>
<td><strong>$2,673,850</strong></td>
<td><strong>$2,302,052</strong></td>
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<tr>
<td>Research Grants Payable, net of current portion</td>
<td>$218,875</td>
<td>$393,758</td>
</tr>
<tr>
<td>Operating Lease Liability - Long-Term</td>
<td>$224,323</td>
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<tr>
<td>Deferred Compensation</td>
<td>$107,385</td>
<td>$147,299</td>
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<tr>
<td>Long-Term Debt, net of current portion</td>
<td>$13,146</td>
<td>$90,440</td>
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<td><strong>Total Liabilities</strong></td>
<td><strong>$3,237,579</strong></td>
<td><strong>$2,933,549</strong></td>
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#### Net Assets

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<tr>
<th>Without donor restrictions:</th>
<th>2022</th>
<th>2021</th>
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</thead>
<tbody>
<tr>
<td>Operating and board designated endowment</td>
<td>$6,460,678</td>
<td>$7,812,601</td>
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<tr>
<td>Property, equipment and software</td>
<td>$2,059,374</td>
<td>$1,355,820</td>
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<tr>
<td><strong>Total Without Donor Restrictions</strong></td>
<td><strong>$8,520,052</strong></td>
<td><strong>$9,168,421</strong></td>
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<tr>
<td>With donor restrictions:</td>
<td>2022</td>
<td>2021</td>
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<tr>
<td>----------------------------------------------------------------------------</td>
<td>-------------</td>
<td>-------------</td>
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<tr>
<td>37,784,489</td>
<td>25,773,276</td>
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<td><strong>Total Net Assets</strong></td>
<td><strong>$46,304,541</strong></td>
<td><strong>$34,941,697</strong></td>
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**Total Liabilities and Net Assets**                                        **$49,542,120** | **$37,875,246**
### STATEMENTS OF ACTIVITIES WITHOUT DONOR RESTRICTIONS FOR THE YEARS ENDED DECEMBER 31, 2022 AND 2021

<table>
<thead>
<tr>
<th></th>
<th>2022</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Changes in Net Assets Without Donor Restrictions</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient services:</td>
<td></td>
<td></td>
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<tr>
<td>Program fees</td>
<td>$301,072</td>
<td>$182,934</td>
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<tr>
<td>Net assets released from purpose restrictions</td>
<td>32,627,130</td>
<td>48,069,350</td>
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<tr>
<td>Patient assistance and reimbursement expense</td>
<td>(33,039,894)</td>
<td>(44,198,311)</td>
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<tr>
<td>Patient services, net</td>
<td>(111,692)</td>
<td>(170,732)</td>
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<tr>
<td>Research grants:</td>
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<td></td>
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<tr>
<td>Net assets released from purpose restrictions</td>
<td>198,624</td>
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<tr>
<td>Research grant expense</td>
<td>(198,624)</td>
<td>--</td>
</tr>
<tr>
<td>Research grants, net</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Other revenue and support:</td>
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<td></td>
</tr>
<tr>
<td>Grants, contributions and bequests</td>
<td>$2,683,947</td>
<td>$3,363,185</td>
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<tr>
<td>Special events revenue</td>
<td>2,239,534</td>
<td>1,888,596</td>
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<tr>
<td>Registry, web subscriptions and other related fees</td>
<td>781,560</td>
<td>1,000,570</td>
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<tr>
<td>Investment return, net</td>
<td>292,249</td>
<td>64,185</td>
</tr>
<tr>
<td>Drug, travel and lodging program administrative fees</td>
<td>102,071</td>
<td>44,877</td>
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<tr>
<td>Investment return - endowment, net</td>
<td>(43,287)</td>
<td>22,863</td>
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<tr>
<td>Net assets released from time restrictions - membership dues</td>
<td>2,269,050</td>
<td>1,828,085</td>
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<tr>
<td>Net assets released from purpose restrictions - research grant administrative fees</td>
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<td>--</td>
</tr>
<tr>
<td><strong>Total Other Revenue and Support</strong></td>
<td>$47,741,029</td>
<td>$59,754,155</td>
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<tr>
<td>Other operating expenses:</td>
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<tr>
<td>Personnel and related</td>
<td>$10,723,039</td>
<td>$10,006,667</td>
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<tr>
<td>Professional fees</td>
<td>1,155,992</td>
<td>1,180,693</td>
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<td>Occupancy</td>
<td>495,394</td>
<td>497,517</td>
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<tr>
<td>Data systems and equipment</td>
<td>514,067</td>
<td>487,430</td>
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<tr>
<td>Other</td>
<td>431,493</td>
<td>467,025</td>
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<tr>
<td>Depreciation</td>
<td>477,010</td>
<td>457,604</td>
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<tr>
<td>Conferences, meetings and travel</td>
<td>1,383,887</td>
<td>436,255</td>
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<tr>
<td><strong>Total Operating Expenses</strong></td>
<td>$48,389,398</td>
<td>$57,731,502</td>
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<tr>
<td><strong>Changes in Net Assets Without Donor Restrictions</strong></td>
<td>($648,369)</td>
<td>$2,022,653</td>
</tr>
</tbody>
</table>

Alone we are rare. Together we are strong:

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