2023 ANNUAL REPORT

Together We Are Strong

A 40-Year Legacy of Progress and Hope

NORD® 40 YEARS

RARE. STRONG. TOGETHER.

WELCOME MESSAGE

NORD has transformed the landscape of rare disease care, research, and advocacy for four decades.

Created in 1983 by a small grassroots coalition fighting for the Orphan Drug Act, we have since grown into a powerful force fighting for the more than 30 million Americans with rare diseases.

Our rallying cry — "Alone we are rare. Together we are strong.®" — captures a simple yet powerful truth: While rare diseases are individually uncommon, there is strength in unity. This guiding principle turned isolation into empowerment, inspiring a legacy of progress and a shared mission to ensure that no one faces the challenges of a rare disease alone.

In 2023, our progress included expanding our NORD® Rare Disease Centers of Excellence network and strengthening a collaborative diagnosis, treatment, and research model. Our commitment to health equity deepened through listening sessions with Latino communities. And the IAMRARE® Registry platform upgrade is accelerating research across more than 100 rare diseases.

Our patient support reached new heights as we provided $34.6 million in assistance to families for treatments, travel to specialists, caregiver respite, and more. In 2023 alone, we responded to nearly 150,000 requests for help.

Looking ahead, breakthrough technologies in gene therapy, artificial intelligence, and precision medicine offer unprecedented hope and, undoubtedly, new challenges. As we rise to meet these, NORD will continue to lead with the same integrity and compassion as we have for the last 40 years.

Reflecting on this milestone, I am humbled by our progress and inspired by our community's extraordinary resilience. Together, we will continue building a future where every person with a rare disease has quicker access to a diagnosis, quality medical care, approved treatments, the ability to participate in research, and increased public support and resources.

Peter L. Saltonstall
President and Chief Executive Officer

NORD® 40 YEARS
RARE. STRONG. TOGETHER.

A Challenge on Every Front

NORD's founding in 1983 is innately tied to the Orphan Drug Act, enacted that year. Prior to the federal legislation, only 38 "orphan" drugs for rare disorders had been approved. In the 40 years since, that total has skyrocketed to more than 880.

Yet for the more than 30 million Americans living with 10,000-plus known rare diseases, the need has never been greater. Lengthy and challenging diagnostic journeys, crushing financial burdens, policies that slow access, and limited treatment options continue to devastate families.

NORD remains committed to addressing these critical issues, ensuring that **no one faces a rare disease alone.**

OUR MISSION

Improving the health and well-being of people with rare diseases by driving advances in care, research, and policy.

NORD founder Abbey Meyers (seated) leads 1985 press conference in favor of Orphan Drug Act amendments, along with advocate Sharon Dobkin, Sen. Orrin Hatch (R-UT), Rep. Henry Waxman (D-CA), and Rep. Ted Weiss (D-NY).

Photo credit: *Orphan Drugs: A Global Crusade,* by Abbey Meyers

Significant Barriers to Diagnosis and Care

Accurate diagnosis takes an average of five to seven years, leading to inappropriate treatments and delayed care.[i]

39% of patients travel more than 60 miles to receive care.[ii]

Unseen Burdens of Rare Disease

Families may face annual costs exceeding $100,000, contributing to $400 billion in U.S. rare disease healthcare expenses.[iii]

Around 65% of caregivers of children with rare diseases report anxiety or depression.[iv]

Complex Treatment Development Landscape

Fewer than 5% of rare diseases have an FDA-approved treatment.[v]

Developing a new rare disease drug takes 10–15 years,[vi] partly due to the challenge of recruiting rare patients for clinical trials.

i Tisdale, A., Cutillo, C.M., Nathan, R. et al. The IDeaS initiative: pilot study to assess the impact of rare diseases on patients and healthcare systems. *Orphanet J Rare Dis* 16, 429 (2021). https://doi.org/10.1186/s13023-021-02061-3

ii National Organization for Rare Disorders. Ensuring access to telehealth for rare diseases, 2020. https://rarediseases.org/wp-content/uploads/2020/10/NRD-2098-RareInsights-Telehealth-Report.pdf

iii National Institutes of Health. NIH study suggests people with rare diseases face significantly higher health care costs, October 22, 2021. https://www.nih.gov/news-events/news-releases/nih-study-suggests-people-rare-diseases-face-significantly-higher-health-care-costs

iv Wu, C., Chu, X., Tang, K., Cheng, D., Ren, L. Caregiving experiences of caregivers of children with rare diseases: A qualitative meta-synthesis. Journal of Pediatric Nursing 75 (2024). https://doi.org/10.1016/j.pedn.2023.12.003

v Fermaglich, L.J., Miller, K.L. A comprehensive study of the rare diseases and conditions targeted by orphan drug designations and approvals over the forty years of the Orphan Drug Act. Orphanet J Rare Dis 18, 163 (2023). https://doi.org/10.1186/s13023-023-02790-7

vi Tufts Center for the Study of Drug Development. Impact report: Growth in rare disease R&D is challenging development strategy and execution, July/August 2019.

Turning a Movement Into Our Mission

In 2023, NORD celebrated 40 years of uniting the rare disease community in a movement to advance care, research, and policy.

A mother on a mission — Abbey Meyers — ignited this movement in the late 1970s by fighting for a treatment for her son's Tourette's syndrome. What began as a small coalition of patients and families evolved into a powerful catalyst for change, revolutionizing how rare diseases are understood, treated, and researched.

Since then, NORD has worked tirelessly to preserve this legacy and help ensure a better future for those impacted by rare diseases, and your passion and perseverance help power our work. Thank you for fighting with us. Here is just a glimpse of our shared achievements from the past four decades.

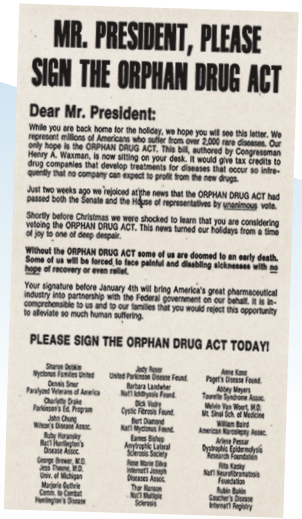
From L to R: NORD founder Abbey Meyers, NORD Chief Executive Peter L. Saltonstall, former U.S. Representative Henry A. Waxman (2013)

The 1980s: A Unified Rare Disease Movement is Born

=A NORD first

January 4, 1983: Orphan Drug Act (ODA) enacted

Led by NORD founder Abbey Meyers, advocates took out newspaper ads to reach President Reagan during the holidays and urge him to enact the Orphan Drug Act. The ads resulted in a flood of calls to the White House in support of the ODA, and shortly after New Year's Day, the president signed the bill into law.



MR. PRESIDENT, PLEASE SIGN THE ORPHAN DRUG ACT

Dear Mr. President:

While you are back home for the holiday, we hope you will see this letter. We represent millions of Americans who suffer from over 2,000 rare diseases. Our only hope is the ORPHAN DRUG ACT. This bill, authored by Congressman Henry A. Waxman, is now sitting on your desk. It would give tax credits to drug companies that develop treatments for diseases that occur so infrequently that no company can expect to profit from the new drugs.

Just two weeks ago we rejoiced at the news that the ORPHAN DRUG ACT had passed both the Senate and the House of representatives by unanimous vote.

Shortly before Christmas we were shocked to learn that you are considering vetoing the ORPHAN DRUG ACT. This news turned our holidays from a time of joy to one of deep despair.

Without the ORPHAN DRUG ACT some of us are doomed to an early death. Some of us will be forced to face painful and disabling sicknesses with no hope of recovery or even relief.

Your signature before January 4th will bring America's great pharmaceutical industry into partnership with the Federal government on our behalf. It is incomprehensible to us and to our families that you would reject this opportunity to alleviate so much human suffering.

PLEASE SIGN THE ORPHAN DRUG ACT TODAY!

May 4, 1983: NORD is established

A grassroots coalition of patient advocates launches NORD to continue their collaboration, and Abbey Meyers is named president.

1984: NORD provides disease-specific information to patients and families

Before the Internet was widely accessible, families facing a rare diagnosis had limited access to information, creating a great sense of helplessness and isolation. NORD's founders were determined to address this, launching the Rare Disease Database to provide expert-reviewed information in patient-friendly language.

The voluntary assistance and support of medical experts at the National Institutes of Health (NIH) and numerous academic institutions made it possible for NORD to develop what has become the most-visited page on the website, featuring reports on more than 1,300 rare diseases.

1987: NORD establishes first rare disease patient assistance program

The first of its kind, NORD's program helps people living with a rare disease access care. In the past five years alone, we have provided $174 million in assistance for patients and caregivers.

The 1990s-2000s: Gaining National and International Momentum

=A NORD first

1999: EU adopts orphan law
NORD collaborates with patient leaders in Europe as the European Union adopts its first rare disease legislation, focused on providing incentives for orphan drugs.

2002: Rare Diseases Act signed into law
NORD successfully advocates for legislation that increases the national investment in the development of diagnostics and treatments for patients with rare diseases and disorders.

2008: NORD's first leadership transition
After 25 years, NORD President Abbey Meyers retires and is succeeded by Peter L. Saltonstall.

2008: NIH establishes undiagnosed diseases program
The National Institutes of Health (NIH), with funding support from NORD, launches a program for undiagnosed patients, and NORD later establishes a program to pay for diagnostic testing for applicants.

2009: NORD launches first U.S. Rare Disease Day®
Through its new formalized strategic partnership with EURORDIS (Rare Diseases Europe), NORD introduces Rare Disease Day® as a global awareness day in the United States and becomes the official U.S. sponsor.

Rare Disease Day

The 2010s: Building the Next Generation of Advocates

2011: NORD hosts first patient-driven forum for all rare diseases
The NORD Summit, and the first-ever forum with the Food and Drug Administration (FDA) commissioner, mark the first time that all rare disease stakeholders, from people with rare diagnoses and their caregivers to industry, regulators, physicians and more, come together to share experiences and discuss solutions.

2014: Rare Action Network® established
NORD helps ignite state-based advocacy via launch of a new network that engages more than 18,000 advocates nationwide.

2014: NORD launches first community-driven rare disease patient registry platform
As a host for patient data, NORD contributes to advancing rare disease knowledge, encouraging research, and supporting data-sharing.

2015: Students for Rare begins
The next generation of rare disease advocates and medical professionals form a network of chapters at high schools and universities across the U.S. From our first chapter at Keck Graduate Institute in Claremont, Calif., the program has grown to more than 50 chapters at the end of 2023.

2019: Caregiver Respite Program established
NORD has to-date supported more than 800 rare caregivers in 44 states, allowing them to take a much-needed break.

The 2020s: Innovation Abounds

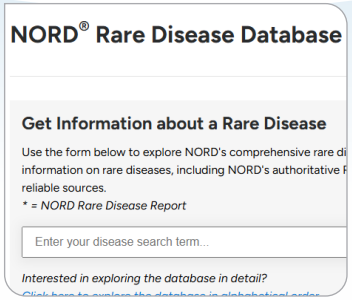
= A NORD first

2020: Project RDAC debuts

Five years after grassroots activists successfully created the first Rare Disease Advisory Council (RDAC) in North Carolina, NORD launches Project RDAC to establish more councils across the United States. Working hand-in-hand with advocates, NORD helps 13 states create RDACs between 2020 and 2023.

2020: Raising the profile of rare disease

Traffic to NORD's website (rarediseases.org) hits a record high of 2 million visits a month, and most visitors go first to the Rare Disease Database to look up a specific disorder.



2021: Partnering to advance innovation

NORD joins NIH and other partners in the Bespoke Gene Therapy Consortium to advance development of gene therapies.

NIH National Institutes of Health
Turning Discovery Into Health

2021: NORD launches first Rare Disease Centers of Excellence network

The NORD® Rare Disease Centers of Excellence, a national network of 31 medical centers and institutions, brings together world-class medical teams with the goals of helping patients and families get a diagnosis faster, access quality care, and accelerate research by rare disease experts.

2021: Collaborating to improve health equity

Recognizing the inequities in our healthcare system, NORD and the Rare Disease Diversity Coalition partner to conduct a national survey of underrepresented rare disease patients and caregivers.

2023: 40 years, 40 RD CoEs

NORD celebrates its 40-year anniversary and designates nine new Rare Disease Centers of Excellence (RD CoE), bringing the total number to 40 U.S. medical centers and institutions.

NORD® 40 YEARS

RARE. STRONG. TOGETHER.

Patients and Families: NORD's Heart and Soul

The burdens of rare diseases go far beyond the medical diagnosis — families often face substantial financial strain, emotional stress, and logistical hurdles, many of which remain unseen. Recognizing these complex challenges early, NORD launched the first-ever rare disease patient assistance program just a few years after the approval of the Orphan Drug Act in 1983.

Today, our RareCare® program provides a wide range of support, including assistance with travel to see specialists, insurance premiums, educational grants, and a first-of-its kind caregiver respite program.

"I was diagnosed with Waldenström macroglobulinemia (WM) and two years passed without treatment because my labs didn't indicate treatment. One day, I saw an email from NORD offering funding for people with my disease seeking a second opinion from a specialist more than two hours away. That was me! NORD paid for my husband and I to travel to Boston to visit a specialist who was smart, engaged, and is now directing my care. It would have been a financial hardship for us to make the trip, and NORD made it possible and stress-free."*

— PATRICIA

** WM is a malignant disorder of the bone marrow and lymphatic tissues.*

Our 2023 Impact

We are dedicated to ensuring patients and families have the support and resources they need and deserve.

$34.6 million
in support provided to patients and families, including:

$27.5 million
for prescription co-pay and co-insurance payments

48,110
patient claims — for financial and travel assistance, clinical trial support, nonmedical emergency assistance, and more — fulfilled

267,243
travel miles reimbursed, allowing patients and families to access specialized treatment and participate in clinical trials

149,303
calls and emails responded to by NORD's Patient Services team

NORD® Rare Disease Centers of Excellence

A network of world-class rare disease care and research

Rare disease patients endure uncertainty and consult multiple specialists in their years-long search for a diagnosis.

To address the challenges in getting a diagnosis and finding a physician, we continue to build upon the NORD® Rare Disease Centers of Excellence (RD CoE) network. **In 2023, we designated nine new RD CoE, bringing the total to 40 U.S. medical centers and institutions in 26 states and the District of Columbia.** Our network includes eight of the top 10 children's hospitals and 18 of the top 20 research medical schools (*U.S. News & World Report*).

This growing national network connects thousands of experts in rare disease diagnosis, treatment, and research, with the aim of empowering knowledge-sharing and collaboration. We are also training the next generation of rare disease specialists and researchers.

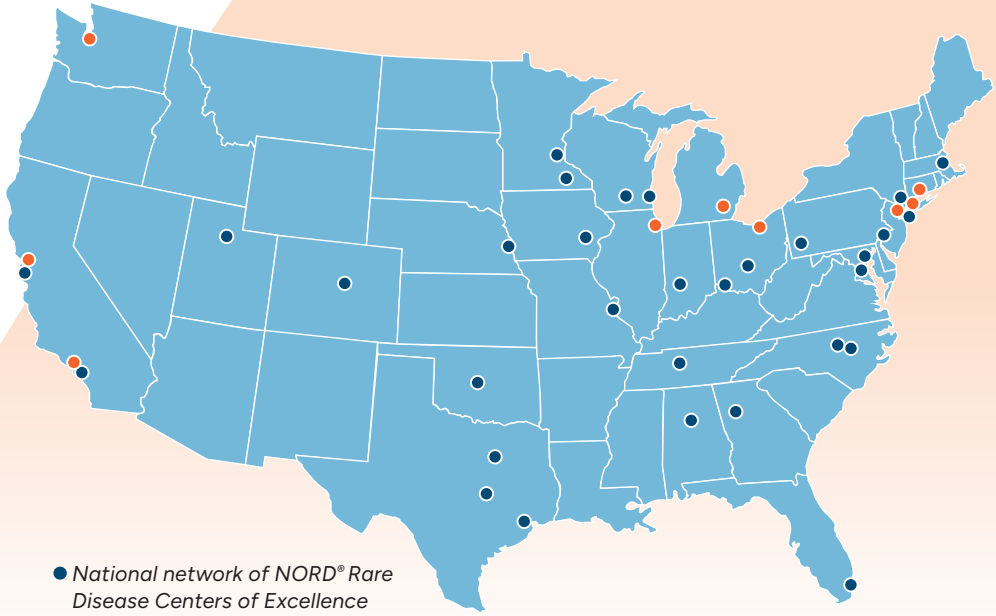
Together, we are working to solve the greatest medical challenges and unmet needs of the rare disease community with a focus on five key areas:

- **Shortening the Time to Diagnosis**
- **Increasing Multi-Site Clinical Trials**
- **Improving Access to Quality Care**
- **Training Future Rare Disease Specialists**
- **Accelerating Research and New Therapy Development**

"For years, we've been providing care for patients with rare diseases in over 40 specialty clinics. But being recognized as a NORD Center of Excellence was especially meaningful to our experts, who felt that the work they had been quietly performing in the Bronx was now being recognized on a national level. The designation energized them to continue their outstanding care."

— JOHN GREALLY, DMED, PHD, FACMG
Executive Director, New York Center for Rare Diseases at Montefiore Einstein

Our 2023 Impact



- *National network of NORD® Rare Disease Centers of Excellence*
- *Nine **NEW** Rare Disease Centers of Excellence designated (May 2023)*

Strengthening the Rare Community

The rare disease community is at the heart of NORD's mission, serving as both our inspiration and our guide. We continually create opportunities to convene and connect with our extraordinary network of individuals with rare diseases, their caregivers, and advocates to better understand and serve their needs.

In 2023, our efforts extended further, focusing on underserved populations who face additional barriers to accessing care and resources. By hosting patient and caregiver listening sessions, we developed best practices for patient advocacy organizations, medical institutions, researchers, clinicians, and others to engage with diverse communities.

Our 2023 Impact

NORD serves as the collective voice for countless rare conditions, the majority of which don't have a dedicated patient organization.

343
NORD member organizations

1,242
Rare disease champions participated in NORD's signature events: the Living Rare, Living Stronger® NORD Patient and Family Forum and NORD Rare Diseases and Orphan Products Breakthrough Summit®

$260,000+
Raised by runners through NORD's Running for Rare® program, for a total of $2.3 million raised to sustain NORD's mission since the program's creation in 2007

On Feb. 28, 2023, the global awareness event **Rare Disease Day®** captivated millions nationwide, garnering coverage in 22 media outlets, 191,000 web page visits, and 600+ heartfelt photo contributions to our Faces of Rare dedication wall.

"Before NORD, not once had I been asked about how it is trying to navigate having a rare disease and being Latino. I felt like the forgotten minority for all my life. NORD helped me mentally and physically feel heard for the first time."

— One of 71 Latino community members who participated in NORD-hosted community listening sessions throughout 2023

Advocacy in Action

NORD's origins are rooted in fighting for policies that benefit the rare disease community. Not only do we work to defend and strengthen the Orphan Drug Act (ODA) to facilitate development of new and better therapies, but we also support policies that improve access to affordable and comprehensive healthcare services. Everyone deserves care, no matter how rare their condition.

Our Policy Priorities

- Ensuring that drug approval and pricing decisions are informed by the experiences of those living with a rare disease
- Establishing Rare Disease Advisory Councils (RDACs) to educate state lawmakers and advocate for policies that benefit the rare disease community
- Protecting and expanding access to telehealth services to reduce the need for far and costly travel by rare disease patients
- Reducing or eliminating step therapy requirements to get effective treatments to patients faster with fewer hoops to jump through

Our 2023 Impact

NORD advocates on behalf of, and alongside, rare disease community members.

3
new Rare Disease Advisory Councils (RDACs) were signed into law in Delaware, Indiana, and Maryland, for a total of 27 states with RDACs to inform rare disease policy at the state level

215
Patient advocacy organizations and children's hospitals joined NORD in urging federal lawmakers to support bipartisan legislation to help children who rely on Medicaid access necessary medical care outside of their home state, including rare disease specialists

77
organizations joined NORD to support the RARE Act, which would codify the FDA's longstanding interpretation for how to award orphan drug exclusivity

"I am so excited Delaware is taking on the challenge of forming a Rare Disease Advisory Council. This will open doors to increased advocacy, new and improved treatment options, and funding research for these diseases that are often overlooked. The forming of the RDAC ultimately equals more hope for those of us within the rare disease community, and we all need hope."

—JAN MEYER, Delaware RDAC member who is living with a rare disease

Partnering to Accelerate Patient-Centered Research

Patient registries are vital tools in the fight against rare diseases, centralizing hard-to-acquire data on symptoms, progression, and patient experiences. This information deepens understanding, accelerates clinical trial design, and guides researchers toward patient-centered solutions. NORD's IAMRARE® Patient Registry platform unites patients and researchers so they can work together to improve care while keeping data ownership in patients' hands.

"If it weren't for NORD, we wouldn't be where we are today. They provided protocols, templates, guidance, and step-by-step support to help us set up our registry to meet our goals and objectives. The registry helped give our organization credibility and visibility. We are now at a point where we are sharing our registry data to help inform our community and the community of scientists researching new treatments."

— **JEFF KRAMER**, President, Chondrosarcoma Foundation, an IAMRARE® registry client

Our 2023 Impact

In 2023, we launched an updated IAMRARE® patient registry platform, providing researchers with a more powerful tool to develop new treatments while continuing to empower patient organizations to play an active role in research and drug development.

15,360
patients are participating in the registries

100+
rare diseases represented across our registries

35
total live patient registries

6
new IAMRARE® patient registries launched in 2023 by the following patient advocacy groups:

- Born a Hero
- Chondrosarcoma Foundation
- CLOVES Syndrome Community
- Coalition to Cure Calpain 3
- The EHE Foundation
- Global Foundation for Peroxisomal Disorders

Educating the Rare Community

In the face of a rare disease diagnosis, knowledge can provide comfort, clarity, and the power to inspire change. Since 2019, we have equipped nearly 40,000 patients, advocates, and healthcare professionals with the education and resources they need to navigate the challenges of rare diseases and work toward solutions.

Our 2023 Impact

To foster better communication and expand access, we have made many of our resources available in English and Spanish.

227

Spanish-language reports were added to the Rare Disease Database in 2023

NORD created short videos and easy-to-save flyers, in English and Spanish, on genetic testing for rare and undiagnosed diseases *(pruebas genéticas para enfermedades poco comunes y no diagnosticadas)*.

English Video and English One-Pager
Video en español and *Folleto en español*

From Bar Napkin to Breakthrough

NORD® Students for Rare shapes medical education

Students for Rare from Perelman School of Medicine at the University of Pennsylvania and Georgetown School of Medicine. From L-R: William Gao, Yehuda Elkaim, Robin Yoon, Rolando Barajas, Eric Wan.

NORD® Students for Rare (S4R) members at Georgetown and the University of Pennsylvania turned their notes from the NORD® Rare Diseases and Orphan Products Breakthrough Summit®—first captured on the back of a napkin in 2022—into a catalyst for change, from a series of journal publications to urging faculty to rethink how rare conditions are integrated into medical school curriculum, an initiative for which they continue to advocate. With NORD's support, these and other S4R chapters around the country are working to upend the traditional medical adage "when you hear hoofbeats, think horses" to help prepare future physicians to identify and treat "zebras," the millions of Americans affected by rare disease.

> *"With one in 10 Americans having a rare disease diagnosis, no matter what specialty medical students choose, they're going to encounter rare diseases. Healthcare providers don't need to know every disease, but they need to recognize when a case doesn't fit the usual picture and make the appropriate referrals."*
>
> —**ERIC WAN**, Students for Rare member and white paper co-author, Georgetown University School of Medicine

The Voices of Our Community

We asked those living with rare diseases and their families to envision the future of rare disease care. What changes right now would make the most significant difference in their lives? What progress do they most hope to see over the next decade? Here's what they shared:

"As my son Rob, an artist and advocate, has become an adult, I've realized that emphasis on rare disease doesn't extend into adulthood. It's primarily focused on newborn screening, and while that's very important, there's so much more to living a rare life than early diagnosis. Rare diseases can present and be diagnosed at any age. How we live is as important as our diagnosis."

— JENEVA S.

"I envision a future where people are diagnosed quickly and easily to allow for prompt and appropriate medical surveillance. The ultimate dream is that an affordable treatment is available that helps affected individuals live their best lives."

— SARAH F.

"I want more robust incentives for companies developing rare disease drugs."

— RAYMOND H.

"I would like all rare diseases to get more attention in universities' medical and allied health studies programs! Rare providers and patients would collaborate on lived experiences and the reality of symptoms versus what's in textbooks, enhancing patients' quality of life and health outcomes."

— CONNIE M.

Responses have been edited for clarity.

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** through Jan. 31, 2023*

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Thank you to the members of our Rare Giving Society and all of our generous donors for your unwavering support and commitment to our mission. Your contributions make a lasting impact on the rare disease community.

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Savara Inc.
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Viridian Therapeutics
Wave Life Sciences
Zevra Therapeutics

Approved Product
AbbVie Pharmaceuticals
Agios
Alexion–AstraZeneca Rare Disease
Alnylam
Amgen
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Ascendis Pharma
Astellas
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BioCryst
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BioMarin
Blueprint Medicines
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UCB Pharma
Vertex Pharmaceuticals
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Xeris Pharmaceuticals

Business Member
Biotechnology Industry Organization (BIO)
EVERSANA
ICON
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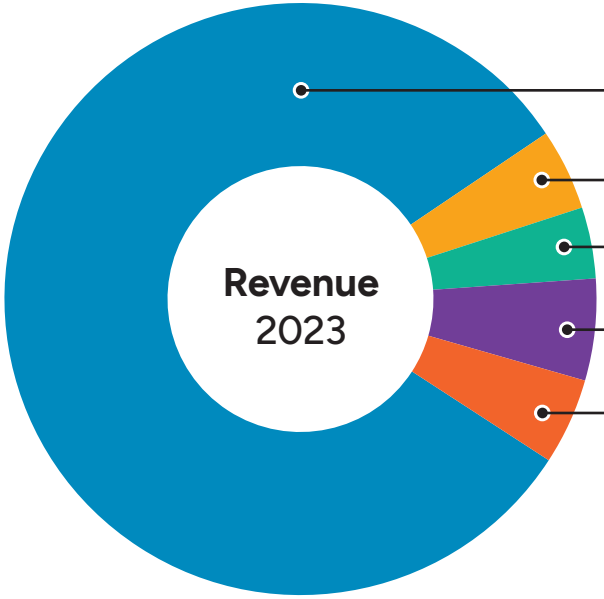
Optum Frontier Therapies
PhRMA

**now Spyre Therapeutics*

FINANCIALS



$43,111,448 Patient service contributions and fees

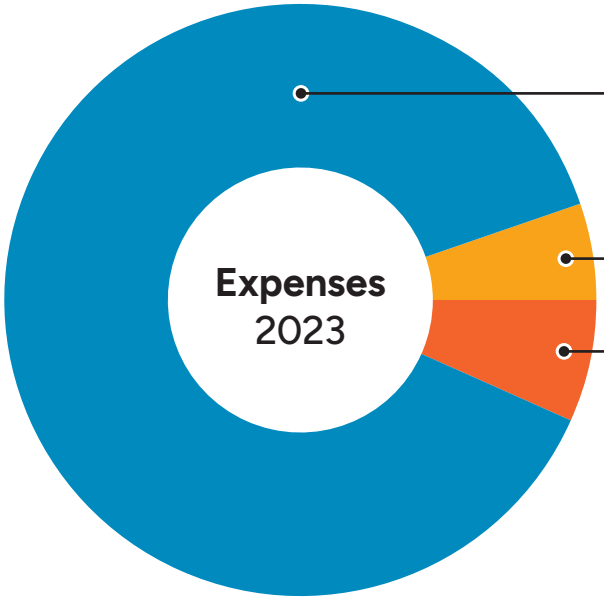
$2,379,036 Special events

$2,069,250 Organization and corporate membership dues

$2,849,654 Other contributions, grants, and service revenue

$2,443,676 Investment income

$52,853,064 Total unrestricted revenue and net assets released from purpose and time restrictions



$46,637,492 Programs

$2,704,860 Development and communication

$3,512,800 General and administrative

$52,855,152 Total expenses

Statements Of Financial Position Dec. 31, 2023 and 2022

ASSETS	2023	2022
Current assets:		
Cash and cash equivalents	8,100,409	7,189,095
Accounts, grants and contributions receivable, net	20,885,685	11,078,737
Prepaid expenses	371,112	232,983
Investments	32,890,768	28,046,028
Total current assets	**$62,247,974**	**$46,546,843**
Investments—deferred compensation	129,004	106,602
Investments—endowment	230,004	201,076
Deferred hosting arrangement costs	108,039	106,140
Operating lease right-of-use asset	529,596	421,247
Property, equipment and software, net	1,909,847	2,160,212
Total assets	**$65,154,464**	**$49,542,120**
LIABILITIES AND NET ASSETS		
Current liabilities:		
Current portion of long-term debt	—	77,294
Current portion of research grants payable	445,729	752,777
Accounts payable and accrued expenses	2,676,954	1,422,424
Operating lease liability—short-term	226,535	207,322
Deferred revenue	513,639	214,816
Total current liabilities	**$3,862,857**	**$2,674,633**
Research grants payable, net of current portion	226,650	218,875
Operating lease liability—long-term	314,510	224,323
Deferred compensation	129,004	106,602
Long-term debt, net of current portion	—	13,146
Total liabilities	**$4,533,021**	**$3,237,579**
Net assets:		
Without donor restrictions:		
Operating and board designated endowment	9,296,108	6,460,678
Property, equipment and software	1,898,398	2,059,374
Total without donor restrictions	**$11,194,506**	**$8,520,052**
With donor restrictions	49,426,937	37,784,489
Total net assets	**$60,621,443**	**$46,304,541**
Total liabilities and net assets	**$65,154,464**	**$49,542,120**

Statements of Activities and Changes in Net Assets For the years ended Dec. 31, 2023 and 2022

	2023 *Without donor restrictions*	2022 *Without donor restrictions*
OPERATING REVENUE		
Program fees	439,208	301,072
Grants, contributions and bequests	3,767,673	2,683,947
Program administrative fees	132,718	102,071
Investment return, net	2,414,748	292,249
Special events revenue	2,379,036	2,239,534
Membership dues	—	—
Registry and other fees	752,405	781,560
Research grants	—	—
Investment return—endowment, net	28,928	(43,287)
Net assets released from purpose restrictions	36,814,517	34,698,160
Net assets released from time restrictions	6,123,831	6,685,723
Total operating revenue	**$52,853,064**	**$47,741,029**
OPERATING EXPENSES		
Patient assistance and reimbursement	35,012,233	33,039,892
Personnel and related	11,769,993	10,723,039
Professional fees	2,118,263	1,155,992
Conferences, meetings and travel	1,575,781	1,383,887
Depreciation	754,550	447,010
Data systems and equipment	580,005	514,067
Occupancy	534,328	495,394
Other	480,865	431,493
Research grants	29,134	198,624
Total operating expenses	**$52,855,152**	**$48,389,398**
Changes in net assets from operations before employee retention tax credit and gain on sale of property	(2,088)	(648,369)
Employee retention tax credit	1,927,961	—
Gain on sale of property	748,581	—
Changes in net assets from operations	**$2,674,454**	**($648,369)**

THANK YOU

Thank you for your support, and please consider staying involved by volunteering your time, donating to sustain our mission, or exploring other ways to partner.

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