NORD®

Helping individuals and families in the rare disease community access diagnostics and care

Marcia Galan and her daughter Alena,
diagnosed with Mucopolysaccharidosis type VI (MPS VI)

RareCare℠
Assistance Programs

Eliminating barriers to access is in our DNA.

NORD was founded by families struggling to obtain access to treatments and driven to advocate for changes that ultimately led to the passage of the Orphan Drug Act in 1983.

For more than 30 years, NORD has led this fight to meet modern-day needs. We ensure that those affected by rare diseases don't have to give up their hope, time or money on research for a treatment that they won't be able to access once it is on the market.

Today, NORD is the trusted and respected go-to partner for all stakeholders in addressing the most complex and challenging issues tied to rare disease research, innovation, advocacy, education and access.

RareCare℠ Assistance Programs

Medication
Free drug programs for financially eligible uninsured and underinsured patients.

Premium and Co-Pay
Branded and disease specific co-payment, co-insurance, and premium funds.

Medical Service
Access to durable medical equipment, diagnostics and other services not covered by insurance.

Travel and Lodging
Coordination and provision of necessary travel and temporary housing assistance to facilitate participation in clinical trials.

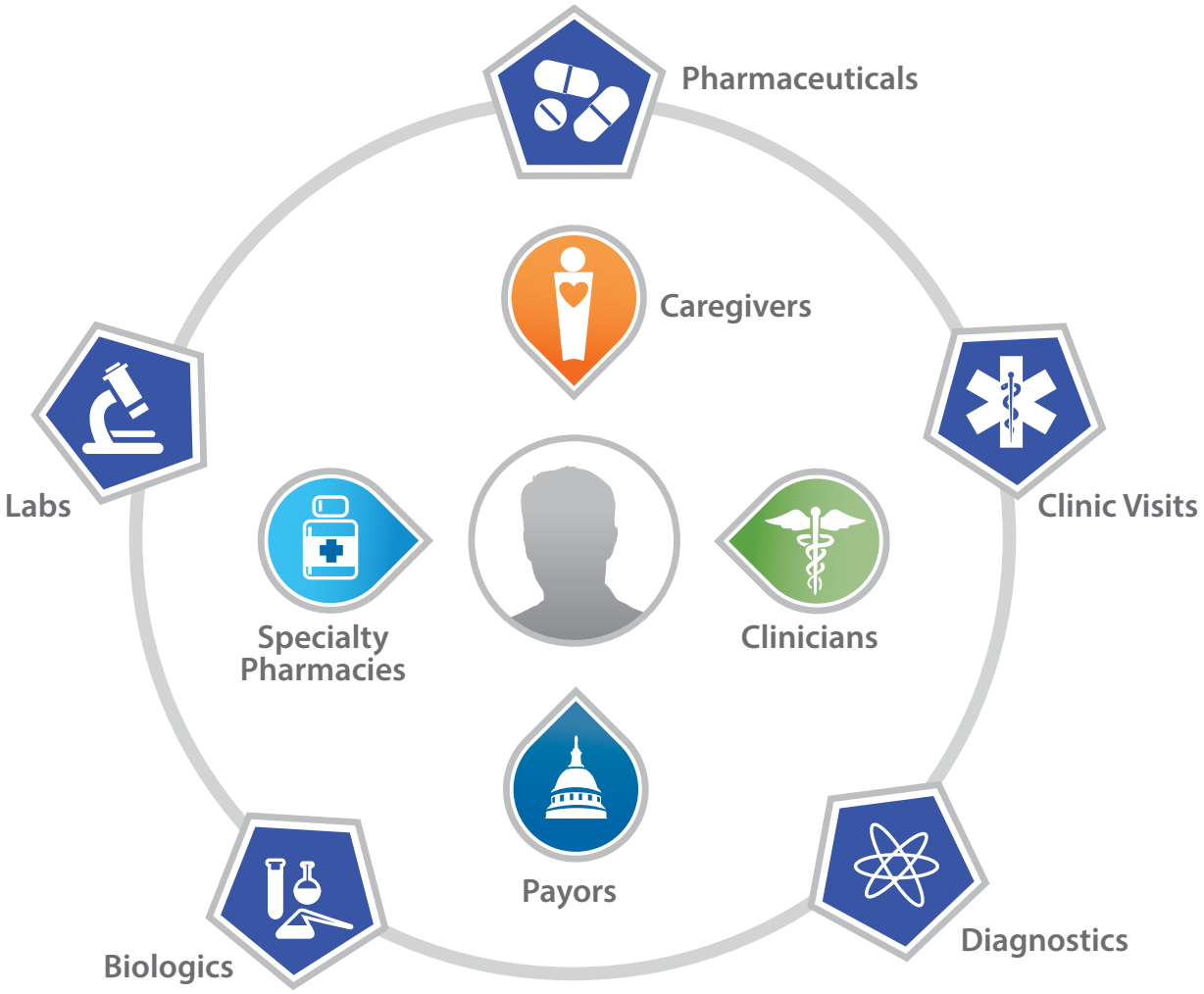
Expanded Access
Random selection programs when a limited amount of investigational drug is available.

The NORD Difference

- **Stewardship:** Efficient oversight and use of available funds to support maximum program occupancy
- **Compliance:** Reliable adherence to regulatory guidelines in administering programs
- **Efficiency:** Ability to approve and process applications and payments within minutes
- **Cutting-Edge:** Our custom-built, proprietary platform provides a best in class database
- **Responsive:** Extended hours and multilingual specialists ensure timely and effective assistance
- **Concierge Service:** Dedicated call center on-site provides personalized, compassionate support
- **Consultation:** Sophisticated solutions are designed and tailored to meet unique needs
- **Continuity of Care:** Once approved, we ensure coverage throughout the duration of enrollment

NORD is well-recognized and universally regarded as the expert in navigating the complex rare disease landscape.

Our individualized approach and disease-centric design ensures seamless coordination of care for best outcomes.



> *"What a wonderful relief your assistance has been. How to handle the co-payments for my cancer medication was extremely stressful, but because of NORD and the assistance you provided I can forget that stress and concentrate on the continuing battle with the cancer. Thank you providing some peace."*
>
> — RareCare Enrollee

> *"I want to thank you from the bottom of my heart for all the support you provided me over the years. Without your assistance, I would not have been able to afford this life-changing medication and would likely not have achieved the things I have today."*
>
> — RareCare Enrollee

> *"NORD is a critical organization for my practice and my patients. Without their efforts, we would not have many of the treatments and awareness of rare diseases that we all benefit from today. They will be even more important in the future as the voice for rare diseases in the changing landscape of health care."*
>
> — Marshall L. Summar, MD
> Chief, Genetics and Metabolism
> Children's National Medical Center

Provide the next-level of customer support and satisfaction by partnering with NORD.
Give us a call at (203) 744-0100.

When she was three years old, Alena was diagnosed with mucopolysaccharidosis VI (MPS VI), a rare inherited lysosomal storage disorder. Individuals with MPS VI do not produce the enzyme needed to carry out the impurities from their body, causing thickening of the bones, breathing difficulties, and ceasing normal human growth and development.

This news devastated Marcia Galan, who had adopted three year old Alena from a Russian orphanage just seven weeks earlier. Marcia, who had spared Alena from an uncertain future at the orphanage and gave her the promise of a loving home with a bright future, would now have to watch her little girl slowly deteriorate with this untimely fatal disease. Fortunately, the FDA approved an enzyme replacement therapy (ERT) to manage problems caused by MPS. Alena became the first child in the northeast to be treated with this ERT, and at seven years old was given her first infusion. Within the first year, Alena grew an astounding five inches. She now continues her treatments once a week. "Life is a special occasion," says Alena. "A lot of people don't have a medicine like I do. I want to be a doctor so that I can help them to lead a better life."

Visit our website to learn more about patients like Alena
and how NORD is fighting on their behalf, every day.

The National Organization for Rare Disorders (NORD) is an independent not-for-profit dedicated to the identification, treatment, and cure of rare "orphan" diseases through programs of education, advocacy, research and individual/family assistance services. Founded in 1983, NORD is an institution in the rare disease community with three decades of experience in advocating on behalf of the needs of the community while developing and leading innovative programs and services to support them. Our programs are made possible through membership dues, public contributions, foundation support, grants and corporate donations.

NORD®
National Organization for Rare Disorders

Alone we are rare. Together we are strong.®

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