



Alone we are rare. Together we are strong.®

Pamela K. Gavin, Chief Executive Officer

Pamela Gavin leads the nation's leading and longest-standing rare disease patient advocacy organization working at the intersection of care, research and policy for all rare diseases. Pam is an accomplished healthcare executive and visionary leader with the proven ability to align multiple stakeholders to reimagine what's possible and improve the lives of the 30 million Americans living with rare diseases.

Gavin joined NORD in 2012 as its first Chief Operating Officer and most recently served as Executive Vice President. She has developed and launched many of NORD's groundbreaking initiatives, including the [NORD® Rare Disease Centers of Excellence](#), a first-of-its-kind, nationwide network of 40 medical centers, clinics and institutions dedicated to diagnosing, treating and researching rare diseases.

Additionally, Gavin led the development of [IAMRARE®](#), the first natural history patient registry platform for the rare disease patient community; the [Rare Disease Cures Accelerator](#) data and analytics platform, jointly with the Food and Drug Administration (FDA) and the [Critical Path Institute](#); and [RareLaunch®](#), NORD's patient advocacy incubator, which guides individuals and disease-specific communities on how to create and sustain an effective rare disease patient advocacy organization. Pam also led the expansion of NORD's [RareCare®](#) patient and caregiver assistance program, which under her direction has provided nearly \$175 million in financial assistance to patients and caregivers over the past five years.

Gavin was also instrumental in the launch NORD's physician Continuing Medical Education rare disease program in partnership with [PlatformQ Health](#) and NORD's [Living Rare, Living Stronger® Patient and Family Forum](#), which brings together hundreds of community members annually to gain insights and support from experts and peers living with a rare disease.

Gavin has experienced firsthand the emotional and financial burden of living and caring for a loved one with a rare disease, and the heartbreak of a child's life gone too soon. Gavin's nephew, Trevor, was diagnosed at age two with metachromatic leukodystrophy (MLD) and passed away at the early age of nine from MLD. In March 2024, MLD received its first FDA-approval to treat children with pre-symptomatic late infantile, pre-symptomatic early juvenile or early symptomatic early juvenile MLD, becoming one of the only 5% of more than 10,000 rare diseases fortunate to have an FDA approved treatment.

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Trevor's journey alongside millions battling rare diseases fuels Gavin's unwavering commitment to championing individuals and families navigating the exhaustive and frequently isolated path of a rare diagnosis and hard-earned fight for treatments.

A fierce patient advocate, Gavin believes, "We stand at the edge of transformative progress and unparalleled opportunities for the rare disease community, yet we must also acknowledge that while significant strides have been made since the enactment of the Orphan Drug Act, we have merely scratched the surface of addressing the profound impact of rare diseases on millions of individuals and families. To truly tackle this challenge, we need to adopt the same comprehensive, all-inclusive approach—combining public, private and philanthropic efforts—that has proven successful in addressing more common diseases. 'Alone we are rare. Together, we are strong' speaks to the need for everyone to join in the fight to accelerate research, treatments and cures for all rare diseases."

Before joining NORD, Gavin held several roles focused on improving healthcare safety and delivery, including as a government consultant in charge of the development of a Federal Safety Reporting Portal used by the National Institutes of Health, FDA, healthcare providers and other key segments. Her outstanding leadership was recognized with two Special Citations, a unique achievement for a non-FDA employee.

As Senior Director, Strategic Business Initiatives at the University of Pittsburg Medical Center, Gavin was responsible for bringing to market new concepts and emerging technologies that improved healthcare delivery. She was also an executive and founder of SafeCare Systems, which developed one of industry's safety management information systems, and she was a division director for the Harvard Risk Management Foundation.

Gavin received her MBA in Healthcare Management from Northeastern University and her BA in Biology from Smith College.

Pam is an avid classic car enthusiast. When she is not working, you can find her driving her Corvette Convertible to car shows or enjoying a day on the ocean sailing on Buzzards Bay off Cape Cod.

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