New Grant Fuels Major Initiative to Support Rare Disease Caregivers Through Genetic Testing Access

This grant helps CAN reinforce its commitment to supporting caregivers—by working to remove barriers to diagnosis & care for families affected by rare diseases.

Caregiver Action Network logo

WASHINGTON, DC, UNITED STATES, May 5, 2025 /EINPresswire.com/ -- Caregiver Action Network (CAN) is thrilled to announce a new strategic initiative made possible through a generous grant from the Alexion Charitable Foundation (ACF) as part of its Rare Belonging® program. This grant will enable CAN to expand its commitment to caregivers of rare disease patients by providing critical support and resources to help families navigate the complexities of genetic testing and diagnosis.

For over thirty years, CAN has been at the forefront of advocating for and supporting rare disease caregivers. Through this grant, CAN will launch a direct-to-caregiver initiative aimed at accelerating the diagnostic process for rare conditions, with a particular focus on immunological, neurological, and metabolic disorders. These conditions—such as Severe Combined Immunodeficiency (SCID), Huntington's disease, and Phenylketonuria (PKU)—often go undiagnosed for extended periods, especially in underserved communities. CAN's initiative will break down barriers to communities with known healthcare disparities.

> "Through the Alexion Charitable Foundation grant & our partnership with Probably Genetic, CAN is helping caregivers access the resources they need to get a faster diagnosis & access critical care."
>
> *Marvell Adams Jr.*

"For decades, CAN has stood beside caregivers who are

navigating the challenges of rare diseases," said Marvell Adams Jr., CEO of Caregiver Action Network. "We know that the diagnostic odyssey is not just about the patient—it profoundly impacts caregivers who are desperately seeking answers. Through the Alexion Charitable Foundation grant and our new partnership with Probably Genetic—an organization specializing in at-home genetic testing—we are expanding our commitment to ensuring that caregivers have access to the resources they need to shorten the diagnostic journey and access critical care options. A diagnosis is often the gateway to vital treatment and care," added Adams. "With this initiative, we are tackling one of the biggest obstacles caregivers face—lack of information—head-on."

The Alexion Charitable Foundation (ACF) is dedicated to ensuring equitable access to care, services, and resources for underserved communities in the rare disease space. Through the Rare Belonging® program, ACF funds initiatives that support rare disease patients and their caregivers, helping them navigate the challenges that come with complex and often misunderstood conditions.

New Strategic Partnership with Probably Genetic
As part of this initiative, CAN is proud to announce a new strategic partnership with Probably Genetic, an organization specializing in identifying rare genetic diseases through accessible, at-home DNA testing. Probably Genetic has helped diagnose over 50% of their users with previously unexplained symptoms, offering families long-awaited clarity and connection to life-changing treatments and support systems.

"For too many families affected by rare diseases, the path to answers remains unnecessarily long," said Lukas Lange, PhD, Co-founder and CEO of Probably Genetic. "The fact that more than 70% of rare diseases have genetic origins gives us a powerful pathway to earlier diagnosis and more timely care. Our partnership with CAN represents a commitment to making genetic testing accessible to more who need it, fundamentally changing the trajectory for patients and the caregivers who advocate tirelessly for them."

With this grant and new partnership, CAN reinforces its long-standing commitment to supporting caregivers—not only by providing emotional guidance and resources but by actively working to remove barriers to diagnosis and care. This initiative represents a bold step forward in the fight against delayed diagnoses and inadequate support for families affected by rare diseases.

For more information about Caregiver Action Network and this initiative, visit https://www.caregiveraction.org/genetic-testing/.

About Caregiver Action Network (CAN):
Caregiver Action Network is the nation's leading family caregiver organization, dedicated to improving the quality of life for millions of caregivers. CAN provides education, peer support, and resources at no cost to family caregivers across the United States. Its programs support caregivers of individuals with chronic conditions, disabilities, and rare diseases, including those

navigating the complexities of genetic testing and diagnosis.

About Alexion Charitable Foundation (ACF):
The Alexion Charitable Foundation (ACF) is committed to ensuring that members of the rare disease community have equitable pathways to care, services, and resources. Through the Rare Belonging® program, ACF funds nonprofit initiatives that support individuals, caregivers, and families impacted by rare disease, helping address some of their most pressing needs.

About Probably Genetic:
Probably Genetic is revolutionizing the diagnostic journey for patients with severe, complex diseases. Using cutting-edge machine learning and at-home genetic testing, the organization helps undiagnosed patients find answers and access appropriate care. Probably Genetic partners with patient advocacy groups and research organizations to connect individuals with critical medical resources, accelerating the path to treatment and support.

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