



Alexion Charitable Foundation Announces First Rare Belonging® Grants

June 17, 2020

– Funding supports efforts by National Organization for Rare Disorders (NORD®) and Global Genes to address needs of the rare disease community arising from COVID-19 pandemic –

BOSTON--(BUSINESS WIRE)--Jun. 17, 2020-- The Alexion Charitable Foundation, launched by Alexion Pharmaceuticals, Inc. (NASDAQ:ALXN) in February 2020, today announced it has awarded a total of \$1.1 million in initial grants that align with its Rare Belonging® focus. Rare Belonging seeks to advance emotional well-being and educational opportunities, and provide relief for critical needs, for those living with or affected by a rare disease. Grant recipients include two leading nonprofits dedicated to serving the rare disease community: [NORD](#) and [Global Genes](#).

“People living with rare diseases face many challenges on a daily basis. The global COVID-19 pandemic has created additional obstacles in managing their health and well-being,” said Alex Schuman, Head of Corporate Social Responsibility at Alexion & President of the Alexion Charitable Foundation. “The Alexion Charitable Foundation is pleased to support the work of two disease-agnostic organizations with programs specifically focused on helping with the nonmedical challenges faced by the rare disease community in this time of great need.”

The grant to NORD will aid the organization’s COVID-19 Critical Relief Program, designed to support people with rare diseases and their families who are facing financial challenges as a result of the COVID-19 pandemic. NORD will administer and award grants directly to qualifying individuals who apply for financial assistance.

“NORD is delighted to be among the first recipients of the Alexion Charitable Foundation’s Rare Belonging grants,” said Jill Pollander, RN, MSN, Director of Patient Services for NORD. “The global coronavirus pandemic has significantly impacted the rare disease community in many ways, including economically. The support from the Alexion Charitable Foundation is expected to help more than 500 individuals with financial assistance for nonmedical needs such as rent or mortgage payments and emergency expenses.”

The Alexion Charitable Foundation’s grant to Global Genes will support organizational members of the Global Genes RARE Foundation Alliance, as well as patients, caregivers and siblings impacted by rare diseases for which a patient organization may not yet exist. Global Genes will administer grants to organizations and individuals to support needs arising directly from the COVID-19 pandemic.

“The pandemic has exacerbated longstanding challenges faced by the rare disease community,” said Kimberly Haugstad, Chief Executive Officer for Global Genes. “We’ve seen funds traditionally earmarked to support people with rare diseases diverted to address COVID-19 generally. The Rare Belonging grant will help fill these gaps and provide critical services like telehealth psychosocial counseling, special education and distance learning, home schooling tools and resources, and career counseling to more than 1,300 people.”

The grants to NORD and Global Genes align with the Rare Belonging funding priorities, which include:

- **Mental health counseling:** Connecting the rare disease community with mental health professionals, supporting mental health tracks at conferences and related assistance.
- **Education and job skills:** Supporting funding for educational needs for children and young adults, and career reskilling for adults newly diagnosed with a rare disease.
- **Transportation and accommodations:** Providing funding for pressing needs.
- **Critical needs:** Providing financial assistance in times of critical need, such as natural disasters or significant, unplanned expenses.

In addition to the grants announced today, the Alexion Charitable Foundation initially responded to the COVID-19 pandemic in early April by providing [support for community responses](#) to address this public health crisis.

To learn more about eligibility requirements and/or to apply for a grant from the Alexion Charitable Foundation, visit <https://alexion.com/our-commitment/alexion-charitable-foundation>.

About the Alexion Charitable Foundation

The Alexion Charitable Foundation, a nonprofit 501(c)(3) foundation, is organized and operated exclusively for charitable and educational purposes. Its mission is to offer promise and cultivate a sense of belonging — particularly for people affected by a rare disease — through initiatives that advance emotional well-being, educational opportunities and economic relief. The Alexion Charitable Foundation is separate from Alexion Pharmaceuticals, Inc. and its corporate giving, patient support programs and direct engagement with various patient organizations. The Alexion Charitable Foundation makes grants on a disease-agnostic basis and does not provide funding for the costs of clinical care to treat rare diseases, such as the cost of prescription medicines. To learn more, visit the [Alexion Charitable Foundation](#).

About Alexion

Alexion is a global biopharmaceutical company focused on serving patients and families affected by rare and devastating diseases through the discovery, development and commercialization of life-changing medicines. As the global leader in complement biology and inhibition for more than 20 years, Alexion has developed and commercializes two approved complement inhibitors to treat patients with paroxysmal nocturnal hemoglobinuria (PNH) and atypical hemolytic uremic syndrome (aHUS), as well as the first and only approved complement inhibitor to treat anti-acetylcholine receptor

(AChR) antibody-positive generalized myasthenia gravis (gMG) and neuromyelitis optica spectrum disorder (NMOSD). Alexion also has two highly innovative enzyme replacement therapies for patients with life-threatening and ultra-rare metabolic disorders, hypophosphatasia (HPP) and lysosomal acid lipase deficiency (LAL-D). In addition, the company is developing several mid-to-late-stage therapies, including a copper-binding agent for Wilson disease, an anti-neonatal Fc receptor (FcRn) antibody for rare Immunoglobulin G (IgG)-mediated diseases and an oral Factor D inhibitor as well as several early-stage therapies, including one for light chain (AL) amyloidosis, a second oral Factor D inhibitor and a third complement inhibitor. Alexion focuses its research efforts on novel molecules and targets in the complement cascade and its development efforts on the core therapeutic areas of hematology, nephrology, neurology, metabolic disorders and cardiology. Headquartered in Boston, Massachusetts, Alexion has offices around the globe and serves patients in more than 50 countries. This press release and further information about Alexion can be found at: www.alexion.com.

[ALXN-G]

View source version on [businesswire.com](https://www.businesswire.com/news/home/20200617005169/en/): <https://www.businesswire.com/news/home/20200617005169/en/>

Media

Megan Goulart, 857-338-8634
Executive Director, Corporate Communications

Source: Alexion Pharmaceuticals, Inc.