Alexion Employees Raise Hands to Raise Awareness and #RallyforRare on Rare Disease Day

February 28, 2019

Employees around the globe spark social media conversations to encourage dialogue about the rare disease patient journey

BOSTON--(BUSINESS WIRE)--Feb. 28, 2019-- Alexion Pharmaceuticals, Inc. (Nasdaq:ALXN) is honored to support Rare Disease Day 2019 with the launch of #*RallyforRare*, a global social media campaign that aims to raise awareness of rare diseases. #*RallyforRare* will serve as a platform for education and conversation about rare diseases and how they impact the lives of those living with one.

Rare Disease Day is an opportunity to be part of a global call to action to better coordinate all aspects of care for people living with rare diseases. This Rare Disease Day, we show our collective support of those living with rare diseases by raising our hands to raise awareness. To join Alexion in this effort, individuals are encouraged to:

- Write #*RallyforRare* on the palm of their hand
- Take a photo of their hand
- Post their photo to social media using the hashtag #*RallyforRare*
- Follow Alexion on LinkedIn (Alexion Pharmaceuticals), Twitter (@AlexionPharma) and Instagram (@alexionpharmaceuticals) to see how others are rallying around the world!

"As a leader in rare diseases, Alexion's mission is to transform the lives of people affected by rare and devastating diseases," said Anne-Marie Law, Executive Vice President, Chief Patient and Employee Experience Officer at Alexion. "We continually push ourselves to better understand the patient experience, from the path to diagnosis to treatment and support. By raising awareness and offering education, we can better serve patients, their families and their caregivers, and begin to help redefine what it means to live with a rare disease."

In harmony with this year's themes for global Rare Disease Day, #showyourrare and 'Bridging the gap between health and social care,' #*RallyforRare* will also encourage a dialogue around the patient journey. For most patients living with a rare disease, reaching a diagnosis is only the beginning. Medical, social and support services are integral to patients' ongoing care routine, and many struggle to manage them independently and are eager to have resources. Understanding the impact a rare disease has on daily life is critical to this important conversation.

In addition to the #*RallyforRare* social media campaign, Alexion is celebrating Rare Disease Day by supporting a number of activities being held by organizations around the globe.

- In **Japan**, Alexion is participating in Rare Disease Day Japan 2019, which includes a main event in Tokyo along with local events and a photo contest throughout the country;
- Alexion employees in the **United Kingdom** are attending events throughout the month of February including Find A Cure, an annual conference with a goal of putting the spotlight on the rare disease community;
- In the **United States**, Alexion is joining the Massachusetts Biotechnology Council for its Rare Disease Day event that brings together hundreds of stakeholders, including patients, to share stories and recognize the work being done in the rare disease space.

To learn more about Alexion's commitment to redefining what it means to live with a rare disease and our corporate social responsibility platform, visit www.alexion.com/responsibility. For more information about Rare Disease Day and other ways you can help support the rare disease community, we encourage you to visit www.rarediseaseday.org.

About Rare Diseases
There are more than 7,000 known rare diseases in the world today, including atypical hemolytic uremic syndrome (aHUS), paroxysmal nocturnal hemoglobinuria (PNH), generalized myasthenia gravis (gMG), hypophosphatasia (HPP), and lysosomal acid lipase deficiency (LAL-D).[1] Based on the U.S. definition of a rare disease, these diseases affect less than 200,000 people at any given time.[2] In Japan, they affect less than 120,000 people, and in Europe, that number is even lower, with a rare disease affecting less than 1 in 2,000 people.[3,4] Because these diseases affect such a small population, there is often a lack of information and knowledge, causing some people with a rare disease to go undiagnosed or misdiagnosed for many years. In fact, the average time from when a person experiences their first symptom to when they receive an accurate diagnosis is nearly five years, and during that time they may visit more than seven doctors.[5]

Visit the following links to learn more about:

- **Atypical Hemolytic Uremic Syndrome (aHUS)** https://news.alexion.com/sites/alxn.newshq.businesswire.com/files/doc_library/file/ALXN-FS-aHUS-US-062916_Approved.pdf
- **Paroxysmal Nocturnal Hemoglobinuria (PNH)** https://news.alexion.com/sites/alxn.newshq.businesswire.com/files/doc_library/file/ALXN-FS-PNH-US-Update_December_2018.pdf
- **Hypophosphatasia (HPP)** https://news.alexion.com/sites/alxn.newshq.businesswire.com/files/doc_library/file/ALXN-FS-HPP-US-062916.pdf

- **Lysosomal Acid Lipase Deficiency (LAL-D)** https://news.alexion.com/sites/alxn.newshq.businesswire.com/files/doc_library/file/U.S._LAL-D_Fact_Sheet.pdf
- **Generalized Myasthenia Gravis** https://news.alexion.com/sites/alxn.newshq.businesswire.com/files/doc_library/file/gMG_Disease_Fact_Sheet_October_2017.pdf

About Alexion
Alexion is a global biopharmaceutical company focused on serving patients and families affected by rare diseases through the discovery, development and commercialization of life-changing therapies. 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), as well as the first and only approved complement inhibitor to treat atypical hemolytic uremic syndrome (aHUS) and anti-acetylcholine receptor (AchR) antibody-positive generalized myasthenia gravis (gMG), and is also developing it for patients with 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 second complement inhibitor, a copper-binding agent for Wilson disease and an anti-neonatal Fc receptor (FcRn) antibody for rare Immunoglobulin G (IgG)-mediated diseases. 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 and metabolic disorders. Alexion has been named to the *Forbes* list of the World's Most Innovative Companies seven years in a row and is headquartered in Boston, Massachusetts' Innovation District. The company also 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]

References

1. Orphan Drugs in the United States, accessed at https://rarediseases.org/wp-content/uploads/2017/10/Orphan-Drugs-in-the-United-States-Report-Web.pdf
2. US Food and Drug Administration's Definition of Disease Prevalence for Therapies Qualifying Under Orphan Drug Act, accessed at: http://www.ecfr.gov/cgi-bin/retrieveECFR?gp=&SID=91b7be5e87481538e33a4c0a76ba7183&n=21y5.0.1.1.6.3&r=SUBPART&ty=HTML
3. About Rare Diseases on Orphanet, accessed at: https://www.orpha.net/consor/cgi-bin/Education_AboutRareDiseases.php?lng=EN
4. Ordinance of the Minister of Health, Labour and Welfare Referred to in Paragraph (1) of Article 5 of the Order, accessed at: https://www.mhlw.go.jp/file/06-Seisakujouhou-10900000-Kenkoukyoku/0000065046.pdf
5. Engel PA, Bagal S, Broback M, Boice N. Physician and patient percepts regarding physician training in rare diseases: the need for stronger educational initiatives for physicians. Journal of Rare Diseases. 2013;1(2):1-15.

View source version on businesswire.com: https://www.businesswire.com/news/home/20190228005201/en/

Source: Alexion Pharmaceuticals, Inc.

Alexion Pharmaceuticals, Inc.
Media
Megan Goulart, 857-338-8634
Senior Director, Financial and Corporate Communications
or
Investors
Susan Altschuller, 857-338-8788
Vice President, Investor Relations