



Rare Disease Day 2022: Advancing the Conversation Around Health Equity

February 15, 2022

Each year, on the last day of February, Alexion joins together with all those in the rare disease community to recognize [Rare Disease Day](#), a global event led by EURORDIS that aims to raise awareness of rare diseases. This year, the theme for Rare Disease Day is Health Equity, and Alexion is engaging with the community in a number of ways throughout the week to advance the conversation around this critical topic.

With 400 million people around the world affected by one of more than 7,000 known rare diseases, rare is not as rare as we may think. Often, rare disease patients and their caregivers are disproportionately impacted by the gaps in our healthcare systems. There is a lack of research on many rare diseases compared to more common ones and access to specialists in rare disease is more limited. This can result in delayed and incorrect diagnoses, often at the expense of the patient's health. Even when an accurate and timely diagnosis is made, it is often just the start of a patient's journey to receiving proper care and support, as only 5% of rare diseases have an approved treatment option. In a recent [article](#) for FORTUNE, Alexion's Chief Executive Officer, Marc Dunoyer, discusses these challenges and how Alexion is committed to helping create a more equitable healthcare system for rare disease patients and their families.

This Rare Disease Day Alexion is collaborating with advocacy organizations and policy leaders to engage in conversations on the topic of Health Equity for people impacted by rare diseases. We invite you to join us at these virtual events to learn more about the collective efforts happening around the world to ensure rare diseases are seen as a public health priority.

- **February 28: Rare Disease Day at the World Expo** is a full-day event dedicated to celebrating the first ever [UN Resolution on People Living with Rare Diseases](#) and exploring the roadmap to its implementation globally. Join the Main Stage session from 10:00 AM-12:00 PM GST (1:00-2:00 AM EST) when Alexion's CEO, Marc Dunoyer, will take part in a roundtable discussion on how the UN Resolution can make an impact at a national level. [Register here](#) to attend.
- **February 28: MassBio's Rare Disease Day Conference** will focus on how we can better address health inequity and racial disparities among the rare disease community. Alexion's Vice President, Head of Corporate Affairs, Tamar Thompson, will join a panel of industry experts to discuss rare disease discovery and development programs for diseases that affect a wide spectrum of racial and ethnic backgrounds. The event will run from 10:00 AM-12:30 PM EST. Visit the [MassBio website](#) for more information and registration.
- **March 1: Alexion's Listening & Learning Series** will bring patients and caregivers together throughout the year for conversations with experts at Alexion and beyond. Join us for our first event, Health Equity – Advancing Comprehensive Care from 1:00-2:00 PM EST. Alexion's Vice President, Head of Patient Experience & Insights, Wendy Ertler, will moderate a panel discussion with Edward Neilan, MD, PhD, Chief Medical & Scientific Officer at NORD; Tammy Boyd, JD, MPH, Chief Policy Officer & Counsel at Black Women's Health Imperative; Mina Makar, Senior Vice President, U.S. Respiratory & Immunology, AstraZeneca; and Tamar Thompson, Vice President, Head of Corporate Affairs, Alexion. We invite you to register [here](#) or visit [ListenandLearn.Alexion.com](#) for additional information.

In addition to these events, Alexion will be raising awareness of the rare disease community and the health inequities they face all week across our U.S. and global social media channels. We invite you to follow us and engage with our content so that we can collectively raise the voice of the rare disease community. Because while Rare Disease Day may be one day, Alexion is committed to continuing the conversation on Health Equity every day.