



## Horizon Therapeutics plc Announces 2023 #RAREis Global Advocate Grant Recipients

*-- Fifty patient advocacy organizations from around the world awarded a \$5,000 grant to address unique challenges faced in rare disease communities --*

DUBLIN--(BUSINESS WIRE- 27 July 2023)-- Horizon Therapeutics plc (Nasdaq: HZNP) today announced the 50 awardees from around the world selected to receive the 2023 #RAREis™ Global Advocate Grant. These rare disease patient advocacy organizations will receive a one-time grant of \$5,000 to establish new programs, develop educational resources and expand their current offerings to support their disease communities.

“At Horizon, our inclusive approach to supporting patient advocacy groups helps these organizations address the most critical needs affecting their rare disease community,” said Matt Flesch, vice president, communications and patient advocacy, Horizon. “We learn from every rare disease organization we interact with and are inspired by the diversity of initiatives advancing education, treatments and more. We find great meaning and purpose in this opportunity to help many different organizations – none of whom operate within any of the disease areas where Horizon makes medicines available – advance their mission.”

The 2023 #RAREis Global Advocate Grant program was [announced in February](#) during Rare Disease Day. Horizon received nearly 190 applications, from 33 countries, representing more than 180 different rare diseases. The 50 organizations awarded the grant in 2023 represent 12 countries and focus on supporting 40 different rare diseases. Eight of the advocacy groups are recipients again this year, enabling continued programming from 2022.

### 2023 Awardees:

- Aliança Distrofia Brasil
- Alliance for Pulmonary Hypertension
- Associazione Italiana Sindrome di Beckwith-Wiedemann ODV
- Associazione Sindrome di Noonan e RASopatie ODV
- Avery's Hope
- Beck-Fahrner Syndrome Foundation
- Brazilian Association of Prader-Willi Syndrome
- Bulgarian Society of the Patients with PH
- CACNA1A Foundation, Inc
- Chordoma Foundation
- ConRett ETS
- DEBRA Ireland
- EBF3 HADDs Foundation
- European Huntington Association
- Erdheim-Chester Disease Global Alliance
- Foundation for Sarcoidosis Research



- GACI Global
- Glanzmann's Research Foundation, Inc.
- Healthcare Education Institute
- Hypertrophic Olivary Degeneration Association
- Indo US Organization for Rare Diseases
- Instituto Atlas Biosocial
- International Gaucher Alliance
- International Patient Organisation for Primary Immunodeficiencies
- Jansen de-Vries Syndrome Foundation
- Koolen de-Vries Syndrome Foundation
- Lennox-Gastaut Syndrome Foundation
- MEPAN Foundation
- Nederlandse Leverpatienten Vereniging
- NF Patients United - Global Network of Neurofibromatosis Patient Organizations
- NGO Rare Diseases of Ukraine
- Northern Ireland Rare Disease Partnership
- Osteogenesis Imperfecta Foundation
- Pediatric Epilepsy Surgery Alliance
- Progressive Familial intrahepatic Cholestasis Network
- Philippine Society for Orphan Disorders, Inc.
- Paroxysmal Nocturnal Hemoglobinuria Ukraine
- Project FAVA
- Rare Disease Ghana Initiative
- Recurrent Respiratory Papillomatosis Foundation
- SCN2A Italia Famiglie In Rete APS
- SHINE Syndrome Foundation
- Soft Bones, Inc.
- Spinal Leak CSF Foundation
- TANGO2 Research Foundation
- TBX4Life
- The E.WE Foundation
- The Rory Belle Foundation
- Uniti per la P.I.P.O. ETS
- Usher Syndrome Ireland

Applications are evaluated based on the organization's work to support the rare disease community and how the grant would further their ability to deliver on their missions and goals. For more information about #RAREis, the Global Advocate Grant and to view the full list of the recipient organizations, click [here](#).



The #RAREis Global Advocate Grant is part of Horizon's [#RAREis program](#), which is committed to improving the experience of living with a rare disease, by providing support to many organizations that offer crucial programs and services for people living with rare diseases. The Global Advocate Grant program [launched in 2022](#) to provide critical financial assistance and build equity for the rare disease community by fostering growth for advocacy organizations around the world.

### **About #RAREis**

In February of 2017, Horizon launched the #RAREis program aimed at elevating the voices, faces and experiences of people living with rare diseases, as well as highlight programs and resources for the rare disease community. The program is anchored by an [Instagram](#) page and website that showcases photos and stories of people touched by rare disease and captures elements of their patient, caregiver or advocate experience. To learn more, visit the #RAREis [Instagram](#) and [Facebook](#) page and visit the website at [www.RAREisCommunity.com](http://www.RAREisCommunity.com).

### **About Horizon**

Horizon is a global biotechnology company focused on the discovery, development and commercialization of medicines that address critical needs for people impacted by rare, autoimmune and severe inflammatory diseases. Our pipeline is purposeful: We apply scientific expertise and courage to bring clinically meaningful therapies to patients. We believe science and compassion must work together to transform lives. For more information on how we go to incredible lengths to impact lives, visit [www.horizontherapeutics.com](http://www.horizontherapeutics.com) and follow us on [Twitter](#), [LinkedIn](#), [Instagram](#) and [Facebook](#).

### **U.S. Media:**

#### **Michelle Rivas**

Senior Manager, Communications  
[media@horizontherapeutics.com](mailto:media@horizontherapeutics.com)

### **Ireland Media:**

#### **Eimear Rigby**

Associate Director, Communications  
[erigby@horizontherapeutics.com](mailto:erigby@horizontherapeutics.com)