

## **Anglonordic Charity of the Year**

### **About Beacon for rare diseases**

Beacon for rare diseases is a UK-based non-profit organisation that is building a united rare disease community with patient groups at its heart. The charity just celebrated its 10th year!

Beacon's patient group trainings help these often small and voluntary organisations to form, grow, and professionalise. It is through their events and trainings that patient groups have the opportunity to connect and collaborate with others across the rare disease space. Beacon for rare diseases firmly believes that no one should face their rare journey alone.

### **Beacon's vision**

A world in which no one faces their rare journey alone.

### **Beacon's mission**

To build a united rare disease community with patient groups at its heart.

### **About rare diseases**

According to a study on rare diseases published by Wakap et al. (2020), there are 6,172 unique rare diseases. Globally, rare diseases affect between 3.5% and 5.9% of the population. This means that anywhere between 263 million and 446 million people are living with a rare disease in the world.

There is a common thread that connects all rare disease patients and families, regardless of location. Medical understanding, knowledge and research of rare diseases are limited. Patients and their families often fall victim to misdiagnosis, delayed treatment, poor care coordination and a lack of support. Having a rare disease can be an isolating experience not only for the patient, but also his or her family. Rare conditions and those they affect should not be overlooked by doctors and researchers. Beacon wants to see the day when no one is handed a Google printout and is simply told to go home and deal with it. Learn more about rare diseases now: <https://www.rarebeacon.org/rare-diseases/what-are-rare-diseases/>

### **How to work with Beacon**

Engage with the rare community on a national and international level! If your organisation wants to be patient-centric and deliver services that meet the needs of rare individuals, then get involved in Beacon's work and mission. You'll reinforce your position as a vital player in the rare disease space and raise the profile of your company in the life-sciences sector.

Cross-sector collaboration between rare disease patient groups and corporate organisations is crucial to building a united community that works for the benefit of all rare conditions. If you are looking for charities to support, consider making a charitable donation or corporate contribution to Beacon. Beacon helps patient advocacy groups to grow in skill, knowledge and

confidence so that they become strong partners in research and effective advocates for their condition. Beacon's trainings have successfully transformed countless patient groups into self-assured experts who offer immense value to industry, pharma and healthcare professionals.

Whether you'd like to pledge financial support or offer your time, services and resources, Beacon would be incredibly grateful to have your generous backing. To discuss potential funding opportunities, please email their Senior Corporate Fundraiser, Laura at [laura@rarebeacon.org](mailto:laura@rarebeacon.org)

She'd be happy to walk you through Beacon's projects and explain how you can support them!

Learn more: <https://www.rarebeacon.org/support-us/corporates-and-trusts/>

### **Drug repurposing opportunities with Beacon for rare diseases**

Beacon for rare diseases is a fierce supporter of repurposing drugs to create new, pioneering therapies for rare conditions. Beacon is a proud member of two international consortiums that are working to repurpose drugs to treat some of the world's rarest and most neglected conditions. MCDS-Therapy is working to develop the first therapy for the ultra-rare bone disease, metaphyseal chondrodysplasia type Schmid (MCDS), and REMEDI4ALL is a new flagship EU-funded research initiative to drive the repurposing of medicines across the UK and Europe.

Learn more about MCDS-Therapy: <https://www.rarebeacon.org/research/mcbs-therapy/>

Learn more about REMEDI4ALL: <https://www.rarebeacon.org/news/beacon-joins-the-remedi4all-consortium/>

If you'd like to engage with the rare community to discuss the power and potential of drug repurposing, attend and sponsor Beacon's Drug Repurposing for Rare Diseases Conference. Drug Repurposing for Rare Diseases highlights the best examples of rare repurposing in the field to encourage patient groups to get involved in research. The conference sparks cross-sector conversation and collaboration to ensure that new, repurposed treatments reach patients faster.

Learn more: <https://www.rarebeacon.org/the-drug-repurposing-for-rare-diseases-conference/>

Coming up...

Beacon's Rare Disease Showcase!

The Rare Disease Showcase is event series that celebrates the innovative rare disease projects taking place across the UK and wider world. It introduces rare disease stakeholders to each other and invites them to share their experiences, work, research and expertise with the wider community. By sharing and combining the rare community's skills, Beacon is creating an unstoppable movement that brings real change to those living with rare disease.

Beacon's showcase is essential to breaking down barriers between patients, industry, healthcare professionals and researchers. The team has a range of partnership packages that are suitable

for every budget, which includes opportunities to speak and exhibit. To find out more, get in touch with Beacon's Chief Operating Officer, Mary Rose at [maryrose@rarebeacon.org](mailto:maryrose@rarebeacon.org)