



## Rare Disease Day grant to amplify rare disease voice across borders & diseases

16 July 2020, Paris – Today, the Chan Zuckerberg Initiative (CZI) announced a grant of over \$530,000 to support the growth of the international awareness-raising campaign Rare Disease Day (RDD), awarded to EURORDIS-Rare Diseases Europe, the organisation that coordinates RDD at the international level.

This grant is awarded simultaneously to another distinct grant from CZI to the US National Organization for Rare Disorders (NORD) to support organisational capacity-building programmes. Both grants, which collectively make up \$1.3 million in funding to support the global rare disease community, are part of CZI's [Rare As One Project](#), aimed at supporting the work that patient communities are doing to accelerate research and drive progress.

### [Read the full CZI announcement](#)

CZI funding will support the development of two enhanced Rare Disease Day campaigns in 2021 and 2022 to continue to build, strengthen, and unify a movement to raise awareness of rare diseases across the globe. The campaigns will support:

- Strategic growth in the number and activity of international Rare Disease Day partners;
- The development and dissemination of core campaign materials across diseases, borders, cultures, and languages to include all those affected by rare disease; and
- The development of a global Rare Disease Day campaign in 2021, fostering recognition and celebration for the worldwide Rare Disease Day community.

“With these new grants, we’re honored to partner with two organizations that are dedicated to improving the lives of millions of individuals living with rare disease ” said **Tania Simoncelli, CZI Science Policy Director and Rare As One Project lead**. “NORD and EURORDIS are leaders in the rare disease community and provide critical support, training, and mentorship for their member organizations. As we fight Covid-19, it is more important than ever to support their efforts to lift up patient advocates and strengthen rare disease organizations, many of whom are vulnerable during this uncertain time.”

**Yann Le Cam, CEO of EURORDIS-Rare Diseases Europe**, commented, “We are pleased to count CZI among the funders of Rare Disease Day, the worldwide grassroots awareness campaign for people living with a rare disease and their families. With this grant, we will amplify the patient voice across borders and diseases to accelerate change for people around the world. Rare Disease Day is a globally coordinated movement on rare diseases, initiated in 2008 and led by EURORDIS and 60 national alliance patient organization partners working towards equity in social opportunity, healthcare, and access to therapies.”

**Peter L. Saltonstall, President and CEO of NORD**, commented, "Building capacity within rare disease organizations and providing opportunities to participate in research through natural history studies are key to supporting our collective mission to find new treatments and cures. We are thrilled that CZI is helping to make that happen by partnering with NORD and EURORDIS as we work to unite and improve the lives of over 350 million people living with rare diseases worldwide."

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## About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 900 rare disease patient organisations from 72 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services.

## About the Chan Zuckerberg Initiative

Founded by Dr. Priscilla Chan and Mark Zuckerberg in 2015, the Chan Zuckerberg Initiative (CZI) is a new kind of philanthropy that's leveraging technology to help solve some of the world's toughest challenges — from eradicating disease, to improving education, to reforming the criminal justice system. Across three core Initiative focus areas of Science, Education, and Justice & Opportunity, we're pairing engineering with grant-making, impact investing, and policy and advocacy work to help build an inclusive, just and healthy future for everyone. For more information, please visit [www.chanzuckerberg.com](http://www.chanzuckerberg.com).

## About the US National Organization for Rare Disorders (NORD)

The National Organization for Rare Disorders (NORD) is the leading independent advocacy organization representing all patients and families affected by rare diseases in the United States. For 37 years, NORD has led the way in voicing the needs of the rare disease community, driving supportive policies and education, advancing medical research and providing patient and family services for those who need them most. NORD is made strong together with over 300 disease-specific member organizations and their communities and collaborates with many other organizations on specific causes of importance to the rare disease patient community. Visit [rarediseases.org](http://rarediseases.org).

## About Rare Disease Day

A patient-led campaign, Rare Disease Day was launched by EURORDIS and its Council of National Alliances in 2008 and brings together millions of people in solidarity. EURORDIS coordinates the global community in organising Rare Disease Day, which takes place on the last day of February each year to raise awareness of the impact that rare diseases have on over 300 million people around the world. Visit: [www.rarediseaseday.org](http://www.rarediseaseday.org).