

EMBARGOED UNTIL FEB. 3, 9 A.M. PACIFIC TIME

Chan Zuckerberg Initiative Awards \$13.5 Million to Drive Progress Against Rare Diseases *New Grants Support 30 Patient-Led Organizations with Funding and Capacity-Building Services*

REDWOOD CITY, CALIF. (February 3, 2020) — Today, the Chan Zuckerberg Initiative (CZI) announced \$13.5 million in funding to 30 patient-led organizations that are working to find treatments and cures for rare disease. These grants are part of CZI's [Rare As One Project](#), aimed at supporting and lifting up the work that patient communities are doing to accelerate research and drive progress in the fight against rare diseases.

Rare disease is anything but rare: as many as 7,000 rare diseases affect 400 million people worldwide. The vast majority of these diseases are not well known or understood, and fewer than five percent have any FDA-approved therapy. The knowledge and learnings of patients suffering from these diseases are key to driving breakthroughs in research and treatment, but a lack of funding and infrastructure to support such patient-led research is holding that progress back.

“No one is more committed to finding cures for rare diseases than the patients and families of those affected by these disorders,” said Priscilla Chan, Co-Founder & Co-CEO of CZI. “We are proud to support patient-led organizations as they pursue diagnoses, information, and treatment options in partnership with researchers and clinicians.”

In the first phase of the Rare As One Project, CZI launched the [Rare As One Network Request for Applications](#) in June 2019 and invited patient-led, 501(c)(3) organizations to apply, with the goal of funding 10 rare disease groups. Because of the sheer volume and demonstrated need of so many patient organizations, CZI expanded the funding to 30 different organizations, including groups dedicated to finding cures for a broad range of diseases such as rare cancers and neurodegenerative and autoimmune diseases. These organizations are led by patient advocates with a variety of backgrounds — many hold dual roles such as a stay-at-home mom, surgeon, community organizer, author, computer scientist, and more. View the [full list of grantees](#) and read about these inspiring patient leaders.

CZI is providing these patient organizations with funding, training, community mentorship, and capacity-building services to assist them in establishing a network of researchers and clinicians, convening their community, and developing a research agenda. The hope is that these organizations will share feedback with and learn from one another, and identify how to best address the most pressing needs across a spectrum of rare diseases.

“We’re excited to welcome this group of grantees — led by patients and caregivers with diverse backgrounds, perspectives, and expertise — to work together and learn together,” said Tania Simoncelli, CZI Science Policy Director and Rare As One Project lead. “We hope the support, training, and

mentorship provided through CZI's program will be transformative for these organizations and serve as a model that can be catalytic for other groups battling rare diseases."

With guidance from patient communities, rare disease experts, and advocacy organizations, the Rare As One Project will help communities of patients, researchers, and clinicians work together to advance progress against their diseases and scale these efforts.

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.

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