



FOR IMMEDIATE RELEASE

CLOVES Syndrome Community Receives \$450,000 Award from Chan Zuckerberg Initiative

Transformative grant will empower a patient community to accelerate collaborative research against CLOVES Syndrome, a rare genetic disorder

KENNEBUNK, ME -- (February 3, 2020) -- Rare disease is anything but rare. As many as 7,000 rare diseases affect 400 million people globally. The vast majority are not well understood, and less than 5% have approved treatments. The Chan Zuckerberg Initiative (CZI), through its Rare As One Project, has committed \$450,000 to help CLOVES Syndrome Community build capacity, expedite research and drive progress for people with CLOVES, a relatively unknown disease.

“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.”

Kristen Davis, Executive Director of CLOVES Syndrome Community, can speak firsthand to this commitment. “People with rare diseases and patient advocates are critical to understanding the day-to-day experience of living with a rare disease,” said Davis. “I have learned if the path you need doesn't exist, create one.”

Davis launched CLOVES Syndrome Community in 2009 after her daughter was appropriately — and finally — diagnosed with CLOVES, which stands for Congenital Lipomatous Overgrowth, Vascular Malformations, Epidermal Nevi & Scoliosis/Spinal Issues/Seizures. CLOVES Syndrome is a congenital disease caused by a somatic genetic mutation in a gene called PIK3CA. Symptoms vary widely amongst patients but include vascular, skin, spinal, and bone abnormalities and overgrowth. Currently, there is no cure.

PIK3CA-related overgrowth spectrum (PROS) is an umbrella term for rare syndromes characterized by malformations and tissue overgrowth caused by somatic mutations in the PIK3CA gene. Funding from CZI’s Rare As One Project will allow CLOVES Syndrome Community to launch a Collaborative Research Network, which will include people with CLOVES/PROS and their caregivers, physicians, scientists, and researchers, to work jointly on understanding the PIK3CA pathway in these diseases.

“What started as a group of the first 30 individuals to be diagnosed with CLOVES Syndrome has grown into a worldwide community of stakeholders, all working to expand opportunities for an improved quality of life for people with CLOVES and other PROS conditions. This grant will allow us to reach even more people struggling for information and options and connect them with resources that could save their life,” said Davis. “We are grateful for the opportunity provided by CZI’s Rare as One Project and are excited about the impact of this grant on our community and all rare diseases. Together we are better.”



About CLOVES Syndrome Community

CLOVES Syndrome Community supports, educates, empowers and improves the lives of those affected by CLOVES Syndrome. We believe that when patients and their families are informed and supported, they are better equipped to handle their own medical, emotional, and physical needs. CLOVES Syndrome Community does this by cultivating a thriving patient community, convening medical conferences, publishing books for children, and funding medical research. We also bring families together for Betsy's Camp, an annual opportunity for community, connection, relaxation and fun. More information can be found at <http://www.clovessyndrome.org/>

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 <https://chanzuckerberg.com/>.