

Sponsorship Proposal

CHANGE THE WORLD FOR PDCD

MISSION







Hope for PDCD was founded by PDCD patients and parents in 2022 with an urgent mission: to cure a fatal disease known as Pyruvate Dehydrogenase Complex Deficiency. All financial gifts are invested wisely: 100% of every dollar donated goes to research and advocacy efforts for PDCD. Hope for PDCD has quickly grown into a collective of volunteer parent board members, scientific advisors, and industry partners. Hope for PDCD aims to fund a multi-million dollar research project into new therapeutics for PDHA1 mutations, newborn screening, standards of care, the first ever PDCD-specific patient registry, biomarkers and clinical endpoints. Hope for PDCD serves the PDCD patient community by offering a state-by-state clinician directory, free genetic testing, resources on the ketogenic diet and more. Find out more at hopeforpdcd.org

VISION

We envision a world where children with PDCD are screened for diagnosis at birth, instead of families undergoing months to yearslong diagnostic odysseys. We envision a world where children with PDCD have access to effective treatments at birth, instead of suffering lactic acidosis for months to years without treatment. We envision a world where children and adults with rare diseases and disabilities have equitable access to care and play, no matter what part of the world they live in.

CORE VALUES

01. Empower PDCD Families

We hold researchers accountable with milestones and reporting and, in turn, we hold ourselves accountable to our most important stakeholders: PDCD families. As a PDCD-patient run advocacy group we seek to own PDCD-related assets and provide input on our disease whenever possible. We seek to make decisions as a community, empower PDCD families with knowledge and encourage them to ask hard questions.

02. Build a Better Future for PDCD

Our goal is to build something that future generations can improve upon. We appreciate the incredible progress in genetic and precision medicine over the last few decades, but we acknowledge that we still have much farther to go. We understand that any potential therapeutics we help develop will be the first of its kind. For the families of PDCD, gene therapy is not about "fixing" our loved ones, but giving them the best therapeutic science has to offer.

03. Stronger Together

We know that as a mostly spontaneous disease, PDCD does not favor any single population over another. We advocate for fairness and equality for all of our babies. We believe we will reach a cure by working with a cross functional team of stakeholders from academia, industry, and the families themselves. Finally, we rise above political and cultural differences to collaborate on our most important shared goal, a good outcome for patients with PDCD.

04. Never. Give. Up

We wouldn't change our kids for the world. But we WILL change the world for our kids. Our kids face impossible odds everyday. Our work with Hope for PDCD is a tribute to them. We know this disability and rare disease life is not easy. We take breaks when we need to. We accept a bad day, bad month, bad year, and then we get back up and get in the fight to achieve the impossible - a cure for PDCD.

SPONSORSHIP LEVELS



Fish Friends | \$500 - \$999

- Business or donor name listed sponsorship page on hopeforpdcd.org (+1,000 unique monthly visitors)
- Link to business website
- Thanked on social media
- Will be added to a commemorative Change the World for PDCD t-shirt



Butter Bronze | \$1,000 - 4,999

- Everything listed above, plus:
- Commemorative Hope for PDCD tumbler
- Acknowledged at Family Standards of Care and Research Symposium (date TBD)



Coconut Silver | \$5,000 - 9,999

- Everything listed above, plus:
- Logo placement sponsorship page on hopeforpdcd.org (+1,000 unique monthly visitors)
- 2 tickets + Logo presence at Family Standards of Care and Research Symposium (June 2024, PA)



Avocado Gold | \$10,000 - 24,999

- Everything listed above, plus:
- 4 tickets + Logo presence at Family Standards of Care and Research Symposium (June 2024, PA)



MCT Oil Platinum | \$25,000 or above

- Everything listed above, plus:
- 6 tickets + Logo presence at Family Standards of Care and Research Symposium (June 2024, PA)

BUDGET PROPOSAL





Expense Category	Amount (\$)
Manufacturing a toxicology AAV batch and conducting GLP safety studies (UTSW)	\$1,500,000
Newborn Screening (N of 1 Prospective Study + Connetics Consulting for RUSP)	\$80,000
PDC Biomarkers (Develop new PDC Activity Assay at CHOP)	\$75,000
Investigating New Therapeutic Models	\$244,500
Patient Registry with CORDS	\$500
Standards of Care and Family Symposium	\$100,000
Total Budget	\$2,000,000

Note: The overall estimated budget represents the total funding required over the next two years to organize and execute successful clinical outcomes for PDCD.

GIVING TUESDAY BUTTER CHALLENGE

We believe that our social media butter challenge has the potential to become the next ice bucket challenge for ALS. From retroactive newborn screen studies conducted in Ohio and Colorado, we know that PDCD affects 1 in 40,000 live births (making it more common than ALS). In addition, early implementation of a ketogenic diet is critical to a good outcome for children with PDCD. We hope that you will join us in our \$2M campaign to Change the World for PDCD, kicking off this Giving Tuesday and continuing on through 2024. On Giving Tuesday we will host our second annual "Butter Challenge" where we challenge all our PDCD families and followers to eat butter, make a donation, and pass it on to help us "spread" the word about this devastating childhood disease and the keto diet.

Ways to Support PDCD on Giving Tuesday:

- Make a donation on Hope for PDCD's <u>Give Butter</u>
 <u>Campaign</u>, large or small, it all adds up.
- Post a picture or a video of you, your friends or your family eating some butter*, tag @hopeforpdcd foundation and use the hashtags #EatButterGiveButter and #GivingTuesday. In your post, tell everyone why you donated to Hope for PDCD Foundation.
- Nominate three more people to do the same.
- Add our fundraiser to your Instagram profile
- Promote purchasing our "Keto Does it Butter" t-shirt. All proceeds from the t-shirt go to life-saving research and advocacy

Highlights of the 2022 Butter Challenge:

- raised \$18,000 for PDCD research
- out of 800+ applications, was selected as one of the eight Most Creative Campaigns by our donation platform, Givebutter
- "spread" from the United States to four other countries

























THANK YOU FOR YOUR CONSIDERATION

We know your time is valuable. We deeply appreciate your thoughtful consideration of a sponsorship or donation to support children fighting PDCD. Together we can make a difference. Together we can change the narrative for children with rare disease and change the outcome of this devastating childhood neurological disease.



Hope for PDCD Foundation

- www.hopeforpdcd.org
- **§** 818-497-6243