HOPE FOR PDCD
RESEARCH FOR A CURE

2023 ANNUAL REPORT

A YEAR OF GROWTH AND COLLABORATION

HOPE FOR PDCD FOUNDATION

501(C)(3) NONPROFIT ORGANIZATION
TAX ID#: 92-0361943

MISSION

Founders Jon and Frances Pimentel with their children, Kai and Violet

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 years-long 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.

2023 BOARD OF DIRECTORS

Frances Pimentel
Founder and CEO, PDCD Mom, UX/UI Designer at Bobbie

Focus Areas:
Fundraising, Social Media, Translational Research, Education, Advocacy, and Patient Registry

Jon Pimentel, PhD.
Founder and CFO, PDCD Dad, Sr. CPU Design Engineer at NVIDIA

Focus Areas:
Fundraising, Social Media, Translational Research, Education, and Advocacy

Kim Muenzer
Secretary, PDCD Grandma and former Industrial Designer

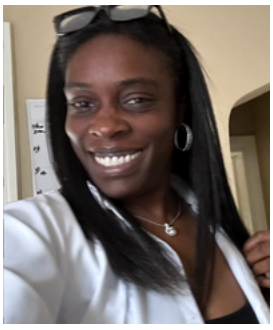
Focus Areas:
Fundraising, Education, Advocacy, and Patient Registry

Katy Cairo
PDCD Mom, Genetic Sciences, Thermo Fisher Scientific

Focus Areas:
Fundraising, Social Media, Translational Research, Education, and Advocacy

Kim Higbee
PDCD Mom and Account Manager, Carrier Enterprises

Focus Areas:
Fundraising, Social Media, Translational Research, Education, Advocacy, Research Assets, and Newborn Screening



Brandy Jackson, LPN
PDCD Mom and Licensed Practical Nurse

Focus Areas:
Standards of Care/Patient Guidelines, Newborn Screening, and Diversity Equity and Inclusion.

Nikki Kulovitz
PDCD Mom and Business Owner

Focus Areas:
Fundraising, Social Media, Education, Advocacy, Newborn Screening and Research Assets

Patricia Medlen
PDCD Patient and PDCD Mom

Focus Areas:
Fundraising, Social Media, Education, Advocacy, Standards of Care and Newborn Screening

2023 BOARD OF DIRECTORS

Molly Naccarato
PDCD Mom and CPA (inactive)

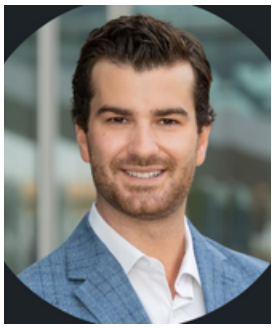
Focus Areas:
Fundraising, Social Media, Translational Research, Education, Advocacy, and Patient Registry

Layna O'Connor
PDCD Mom and Pre-construction Manager

Focus Areas:
Fundraising, Social Media, Education, and Advocacy

Carly Tasiopoulos
PDCD Mom and Account Manager, Medtronic

Focus Areas:
Fundraising, Social Media, Education, Advocacy, Standards of Care and Newborn Screening



Chris Tasiopoulos
PDCD Dad and Vice President of Business Development, Treya Partners

Focus Areas:
Fundraising, Social Media, Education, and Advocacy

Natasha Baril
PDCD Mom and and Registered Psychotherapist, Canada Liaison

Focus Areas:
Fundraising, Social Media, Education, and Advocacy

Hope for PDCD Board Site Visit to UTSW, June 2023

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 further 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 kids, 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 loved ones for the world. But we WILL change the world for our loved ones. 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.

2023 FINANCIALS

	Tax Year	
Revenue	2023	2024 (Projected)
Gross Sales	1,988	TBD
Gross Contributions, gifts, grants, and similar amounts received	426,808	TBD
TOTAL YEARLY REVENUE	**$428,796**	**TBD**

	Tax Year	
Expenses	2023	2024 (Projected)
Salaries and wages	0	0
Cost of goods sold	2,516	TBD
Information Technology	557	557
State and federal tax filing fees	225	225
Office Supplies and shipping fees	59	59
Sponsored research agreements, grant agreements, and similar amounts paid	174,885	180,384
TOTAL YEARLY EXPENSES	**$178,242.00**	**$181,225**

	Tax Year	
	2023	2024 (Projected)
TOTAL YEARLY REVENUE	428,796	TBD
TOTAL YEARLY EXPENSES	178,242	181,225
Total Yearly Operating Surplus	**$250,554**	TBD

2023 HIGHLIGHTS

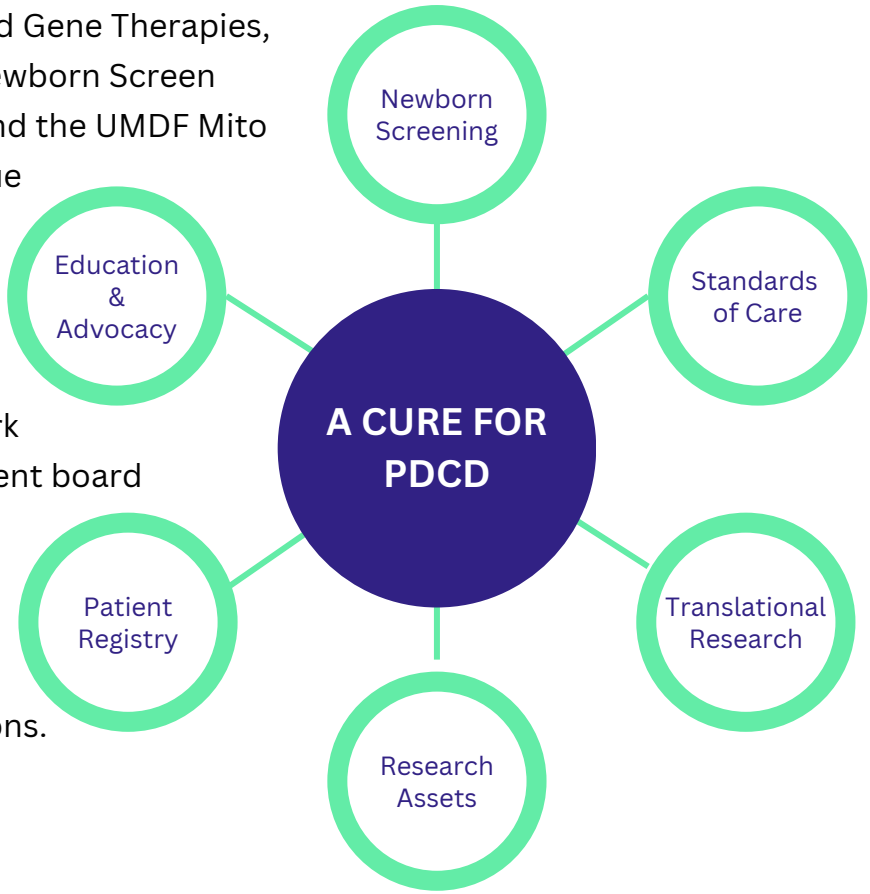
In 2023, Hope for PDCD (HOPE) initiated an informal “PDCD Alliance” with other Patient Advocacy Groups (PAG) and leaders in the PDCD space. HOPE excels in areas of transparency, education, inclusion, and pursuit of scientific knowledge. In 2023, HOPE became the first ever PAG for PDCD to initiate a Sponsored Research Agreement (SRA) for PDCD research assets, a mouse model that is currently being developed at University of Texas Southwestern. Other highlights as we reflect on the past year:

- Launched a PDCD-specific, state by state **clinician directory**.
- Made education on the use of the **ketogenic diet for PDCD** accessible via hopeforpdcd.org
- Helped **build the pipeline of the next generation of PDCD doctors** by hosting a Q and A with two mitochondrial clinicians for students at McMaster University and two additional classroom lectures by HOPE board members
- Attended **5 professional conferences**
  - The Ultragenyx Rare Entrepreneur Bootcamp
  - American Society of Cell and Gene Therapies
  - Mito Medicine Symposium
  - Global Genes
  - Newborn Screening Bootcamp by Everylife Foundation
- Distributed **3 surveys** to the PDCD community
- Collaborated and participated in **1 FDA Listening Session**
- Offered **free genetic testing** via hopeforpdcd.org
- Hosted **8+ fundraisers** across the country
- **Upleveled our advocacy** by participating in Rare Across America and building relationships with lawmakers
- ***Fully funded Stage 1: Mice Model Study campaign and launched Stage 2: Change the World for PDCD campaign!***

2024 Strategic Plan

In 2024, HOPE will continue to build the foundational infrastructure necessary for PDCD to become a “clinical-trial ready” disease. In 2024, HOPE will commission a new PDC Activity Assay (to replace an important PDC biomarker test that has been discontinued), launch a patient-owned global registry (using the same CoRDS platform as Cure Mito, enabling the 25-35% of PDCD patients that also have a Leigh Syndrome diagnosis to fill out both registries on a single platform), collect prospective data to support a successful RUSP application for Federal Level Newborn Screening, join a dedicated mitochondrial task force under C-Path (a neutral convener that focuses on drug development) and bring together the scientific community with PDCD families for a Standards of Care symposium.

Participating in capacity building training and access to resources is critical for an organization that is run entirely by parent volunteers. Last year, HOPE attended the Ultragenyx Rare Entrepreneur Bootcamp, American Society of Cell and Gene Therapies, the Everylife Foundation Newborn Screen Bootcamp, Global Genes, and the UMDF Mito Symposium. We will continue to take advantage of every learning opportunity that comes our way. We’ve created a hub and spoke model with six different work streams and a different parent board member leads each focus area. We will also continue to collaborate with other Patient Advocacy Groups and rare disease organizations.



REFLECTIONS

Violet Pimentel, age 2. Folsom, CA

"I want to express my sincere gratitude and admiration for everyone who helped us accomplish all these momentous milestones for PDCD in 2023, including but not limited to: the Cairo, Higbee, Jackson, Kulovitz, Medlen, Naccarato, O' Connor, Tasiopoulos, and Baril families; fellow PDCD PAG leaders Emma Watt, Sarah Thompson, Kelly Gilbert, and Sophia Zilbur; Dr. Rebecca Ganetzky, Dr. Sarianne Madsen, Dr. Christina Tise, Dr. Shamima Rahman; all the PDCD families that supported us this past year; our families, the Muenzers and the Pimentels who believed in us from Day 1; and most of all, thank you to Violet, she never gives up and neither will I."

FRANCES PIMENTEL

"I think the outlook from the parent of a newly diagnosed child with PDCD looks a lot different today than it did when our daughter was diagnosed, just under 3 years ago — that's Hope — on a mission for a cure and changing the landscape along the way.

MOLLY NACCARATO

REFLECTIONS

“There are various stages of grief you go through as a rare disease parent. For me, I had to grieve the child I thought I was going to have. That grief has now morphed into determination for curing PDCD through the Hope for PDCD Foundation. I’m lucky to be able to work alongside other rare disease parents who share that same determination. As a collective, we will change the world for PDCD.”

KATY CAIRO

“Facing my daughter's devastating diagnosis of PDCD this year was tough, but I didn't let it break me. Instead, I turned that pain into action. I quickly stepped up into a leadership role, diving into advocacy, policy change, and building ties with lawmakers. I refuse to stop until we find a cure for PDCD. The change begins with us!”

NIKKI KULOVITZ

“For the last few years, I have lived with extreme guilt over passing PDCD on to my son. Thanks to relationships built through Hope for PDCD, I have been able to pull myself out of a dark hole and turn guilt into passion and perseverance. 2023 was my acceptance Era and I’m looking forward to changing the world for PDCD in 2024.”

ANNIE MEDLEN

“This group has given me clarity and a voice. The sheer volume and passion of all the parents gives me hope. No matter our gender, race or nationality, in this situation we can all relate and fight for a common cause. This makes me feel good. This makes me feel strong.”

BRANDY JACKSON

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