









2021 Annual Report The Pedal with Pete Foundation

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I. Summary

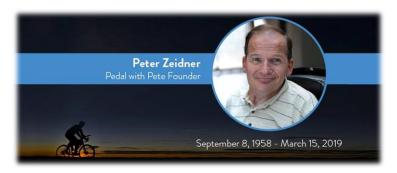
After experiencing significant impacts from Covid-19 in 2020, the Pedal with Pete Foundation made a substantial step back to a more typical operation in 2021. We executed successful, but still somewhat reduced, ride events in Columbus and Northeast Ohio, and Emmetsburg, Iowa. We used the funds that were raised to support three research grants, through our cooperation with the American Academy for Cerebral Palsy and Developmental Medicine. We also provided specially adapted bicycles to three children with Cerebral Palsy, through our cooperation with the Adaptive Sports Connection.

We are able to continue this work through the support we receive from our many dedicated donors, riders, sponsors and volunteers, many of whom have contributed for more than ten years. At the end of the year we were able to expand our Board of Directors for 2022 by adding two new members, who brought new marketing and financial management skills to the Foundation.

II. Introduction

The Pedal with Pete Foundation is a not-for-profit 501 c (3) organization with a mission to raise funds for research leading to better prevention strategies and treatment protocols to improve the quality of life of people who live with cerebral palsy, their families and caregivers. All of the work of the Foundation is carried out by volunteers, enabling over 80% of all funds raised to be directed towards the Foundation's research program. Each year the Foundation sponsors three cycling events in the Midwest to raise funds for its research program.

The Pedal with Pete Foundation was founded in Kent, OH in 1993 by Pete Zeidner. Although he



had a serious case of cerebral palsy, he rode a recumbent bicycle with joy and purpose. He combined his love of cycling, his first-hand knowledge of cerebral palsy, and his marketing knowledge to conceive of a way to raise funds for cerebral palsy research. The Foundation moved from Kent to Columbus in 2010. The cumulative amount of money raised

by the Foundation passed the million dollar level in 2015, and continues to grow.

The Foundation has been a consistent funding source of critical seed grants for cerebral palsy research. This reputation is the result of the hard work and support of the loyal volunteers, donors, and ride participants that make up the Pedal with Pete family.

III. Events





For over twenty-five years the Pedal with Pete Foundation has sponsored annual cycling- oriented events to raise funds to support our program of research grants to medical researchers seeking a cure or treatment for cerebral palsy.

A. Columbus Event:

With the advent of the coronavirus vaccine in early 2021, potential venues for the event became more available than the previous summer when everything was closed down. The event team chose the Marysville High School parking lot for our event with rest stops in Milford Center and Mechanicsburg. Pandemic restrictions limited some of the usual social activities, but we were able to provide riders with subs, pizza, chips and root beer floats at the end of the ride.

Riders chose among 6 routes of distances from 12 to 101 miles. Riding from Marysville High School put our riders in the very scenic farmland of Central Ohio safely and quickly. The event, held on Saturday, July 31st, had 567 riders, and raised \$29,103.

- Roger Schenck, Columbus Event Team Leader
- > Chris Zeidner, Route and Volunteer Leader
- ➤ Joe Florian, Marketing Leader
- ➤ Ben Wibberley, Site Leader
- ➤ Pam Grimes, Food Leader
- ➤ Fred Rogers, Route Marking Leader
- Jocelyn Zeidner, Graphic Design







B. NE Ohio Event

The ride was held on September 18th in Cleveland Metroparks. It consisted of five routes ranging from 10 to 65 miles, all of which followed Metroparks trails and roads in the Emerald Necklace park system. The event had 29 participants, and raised \$2,592.

- Lisa Boyd, Chris Garr & Jim Stroble, Northeast Ohio Event Team Leaders
 - > Carolyn Palmer
 - ➤ Mackenzie Vecchio

C. Emmetsburg Event

The event was held on September 20th, and raised \$1,340.

• Julie Naig, Emmetsburg Event Team Leader

IV. Research Program

Each spring the Foundation receives a number of research proposals from the American Academy of Cerebral Palsy and Developmental Medicine (AACPDM). These proposals are reviewed by the Foundation's Cerebral Palsy Research Team, who make a recommendation to the Foundation's Board of Directors of which projects to fund. The final decision about which projects to fund is made by the Board in June or July. Each of the projects are funded at a level between \$25,000 and \$35,000. Most of these research projects are seed research projects which typically lead to follow-up projects for further research. Such funding is a scarce yet critical part of the overall research process.

During 2021 the Foundation funded three research grants:

Cardiorespiratory Analytics in Neonatal Intensive Care Unit and Risk for Cerebral Palsy

Investigators: Lisa C. Letzkus, PhD RN CPNP-AC; Genevieve Ray Lyons, MD; Karen Fairchild, MS

Why is this Research Important?

Identification of Neonatal Intensive Care Unit patients at highest risk for cerebral palsy early in the Neonatal Intensive Care Unit stay can allow for earlier, targeted rehabilitation services starting when the brain is most highly plastic and rapidly developing.

Initial Observations	Core Questions
• Heart rate and oxygen characteristics are routinely collected in the Neonatal Intensive Care Unit.	1
 Abnormal heart rate and oxygenation characteristics in infants predict multiple adverse outcomes. Data is available for 1917 infants going back to 2009. 74 of the 1917 infants for whom data is available were diagnosed with cerebral palsy 	

Shared Decision Making in Cerebral Palsy through Goal-based Patient Reported Outcome Measures

Investigators: Unni G. Narayanan, MBBS, MSc, FRCS(C); Laurie Glader, MD; Paul Gross; Darcy Fehlings MD, MSc, FRCP(C); Herbert Kerr Graham, MD, FRCS; Garey Noritz, MD; George Ibrahim, MD, PhD; Pamela Jane Thomason, PT; Brandon George Rocque MD

Why is this Research Important?

Patients, caregivers and parents are not always satisfied with the outcome of a recommended therapy or surgery because the expectations of doctors, patients, caregivers and parents differ.

Initial Observations	Core Questions	
 From a doctor's/hospital's perspective a procedure may be a success, but if it leaves the patient and caregiver unhappy, it wasn't a success. There are existing patient priority-informed outcome measures (called CPCHILD, GOAL, CPCHECKList). 	 What is the current state of shared decision making among parents/caregivers of children with cerebral palsy? What is the patient and the parent perspective of the effectiveness and outcome of the interventions? Can existing data collected from various questionnaires be used to determine the perception of shared decision making by parents/caregivers using the Shared Decision Making Questionnaire? 	

The role of the Extracellular Matrix in Cerebral Palsy Muscle Dysfunction

Investigators: Kristen Stearns-Reider, PhD, PT; Eileen Fowler, PhD, PT; Rachel Thompson, MD

Why is this Research Important?

Muscle stiffness and contractures are a main concern in cerebral palsy, as they limit mobility. The cause of muscle stiffness is not known.

Initial Observations	Core Questions	
Muscle stiffness and contractures exists. The cause could be due to changes in extracellular matrix of patients with cerebral palsy.	 Is there a difference in the tissue (extracellular matrix) between individual cells of typically developing patients and those who are affected by cerebral palsy? Is fibrosis in the tissue between individual cells (extracellular matrix) a cause of the stiffness and contractures? 	

V. Other Activities



In cooperation with the <u>Adaptive Sports Connection</u>, The Pedal with Pete Foundation awarded three customized bicycles to Ohio children with cerebral palsy.

The President of the Foundation, along with representatives of Nationwide Children's Hospital and the Patches of Light Foundation gave a presentation at the Family Voices Leadership Conference titled: "Small Gift, Big Impact - The Benefit of Developing Community Partnerships to Support Families in Crisis"

VI. Financial Information

The key financial metrics for the Pedal with Pete Foundation for 2021 were:

Income Statement 2021		
Income	Amount	
Donations	\$26,086	
Ride Events	\$39,687	
Investment Income	\$1,475	
Misc. Income	\$2,926	
Total Income	\$70,174	
Expenses	Amount	
Ride Expenses	\$7,992	
Research Grants	\$75,000	
Bikes for Kids	\$5,750	
Administration	\$4,490	
Total Expenses	\$93,232	
Net for 2021	-\$23,058	

Balance Sheet as of 12/31/2021		
Assets	Amount	
US Bank - Checking	\$22,199	
US Bank - Savings	\$0	
PayPal	\$0	
Total Assets	\$22,199	
Total Liabilities	\$0	
Equity	\$0	
Assets-(Liabilities + Equity)	\$22,199	

VII. Board of Directors

The 2021 Board of Directors of the Pedal with Pete Foundation were:

Nick Farmer, President

Phil Rosen, Vice President

Lauri Kaplan, Secretary

John Manley, Treasurer

Mei Gong, Director

Sabine Kuhn, Director

Roger Schenck, Director

Mimi Singh, Director

Paul Stock, Director

Jim Stroble, Director