

STRATEGIC PLAN, 2018-2020

Pedal with Pete

Partnering to Fund Cerebral Palsy Research

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I. Introduction

The Pedal with Pete Board of Directors offers this Strategic Plan to set the sights high for ourselves and our partners. Why? Because we are all inspired!

We are inspired by...

- 1. Pete and the many people we love and know who live with cerebral palsy (CP) every day and deserve the very best treatment and care possible.
- 2. The excellent research we have already funded and the opportunity to fund even more promising cerebral palsy research.
- 3. The strong sense of community that Pedal with Pete fosters as we partner to fund cerebral palsy research, through the events that we host (which are fun, active, meaningful, and educational) and through the relationships we build with partners.

The Board of Directors of the **Pedal with Pete Foundation (PwP)** developed this strategic plan to provide a three year view of how PwP will fulfill its mission and vision. The board will review progress semi-annually, and will review and update the plan annually as needed. The PwP Strategic Plan reflects on the mission, vision, core operating values, and assumptions underlying PwP's approach to its work.

II. Executive Summary

Pedal with Pete has two core competencies and functions to leverage and build upon:

- FUNDRAISING FOR CP RESEARCH: Over the 25 years of the Pedal with Pete Foundation's existence, we have raised over \$1.1 million dollars for cerebral palsy research through cycling and walking events. These events are so well-run and so beloved that we even get attendance when the weather is bad! As a result, **our fundraising has been reliable and consistent:** In the last 4 years, after expenses, we have averaged about \$70,000 a year in funds available to grant to cerebral palsy research.
- FUNDING CP RESEARCH: Through the years, we have granted monies to research projects to improve the lives of people impacted by cerebral palsy. Since 2010, we started working with the AACPDM, an international society of professionals, primarily doctors and researchers, who work with people who have CP, to help us select the best research projects. Because our funding is small, we are able to support SEED grants. Surprisingly, such funding is scarce in the field, so we are desperately needed! Larger research grants are not available unless the approach is piloted and proven through a seed grant. Pedal with Pete funds make a difference.



As a result of these two core competencies and functions, we have built a reputation as a crucial, consistent, discerning funder for the most promising seed grants to help people impacted by cerebral palsy.

To leverage and build upon these two competencies and functions, our strategies include:

• FUNDRAISING FOR CP RESEARCH

While continuing our critical fundraising through events, we will broaden the revenue flows to the Pedal with Pete Foundation by adding a gifting program through grant funding.

We will continue efforts to start events in other communities across the nation.

We will continue efforts to heighten awareness about the need for CP research funding, the impact that funding has on improving the lives of people affected by CP, and how individuals, organizations, and communities can help increase that funding by *partnering for cerebral palsy research* with Pedal with Pete.

We will review and revise our branding approach

• FUNDING CP RESEARCH

We will work more deeply with the AACPDM and the researchers that we fund to follow-up on how the research leads to discoveries that help improve the lives people with cerebral palsy.

We will partner with research institutions such as Nationwide Children's Hospital to publicize the positive results of their research, the need for more funding, and opportunities to support such funding through the hospital or through Pedal with Pete.

III. Background and History

In the early 1980s a young man came to Kent State University (KSU) to study marketing. He came in a wheelchair with cerebral palsy. He came because by that time, KSU had established itself as an accessible campus. The young man's name was and is Peter Zeidner, known to family and friends as Pete.

Upon graduation in 1986, Pete started job hunting and sent more than the requisite number of resumes and went on a number of interviews. Though the desired response was that attained by countless numbers of his classmates, he was offered none. Pete was disheartened. Some part-time employment was forthcoming through members of his church. It was less than satisfying because he wanted to do more, to be all that he could and to contribute more to society. What could he do?



Friends and family worked together to get Pete into a three wheeled recumbent bike. It was a godsend. He told his pastor that for the first time, he could keep up with his peers! It provided the impetus for an idea: Pete would ride to collect money for cerebral palsy research. The Elks Clubs of Ohio were of great help for the initial attempt. He rode 1,001 miles around the edges of Ohio and was able to collect \$10,000 which was contributed to Northeast Ohio Universities College of Medicine for research there.

Pete developed a grander notion: he would ride across the USA and collect \$1,000,000! With that in mind, he founded Pedal with Pete in 1993 and the requisite 501c (3) (non-profit) status was obtained. From 1993 to 1995, Pete worked to get the logistics in order. But, the logistics turned out to be overwhelming. It could not be made to happen.

Not to be thwarted, Pete the Pedal with Pete Foundation changed gears, took another route, and got back on their bikes (we know, too many metaphors).

Funds could be raised for CP research through cycling and walking events! In 1995, the first of the fundraising events was held in Kent, Ohio. It was a start and success grew with each year. Pete would ride at least part of the way with the riders each spring. Best of all, Pete found a researcher who cared about people who have CP, and was doing research to help people who live with CP every day. Dr. Leland Albright was one of the first cerebral palsy researchers, and his work to develop the Baclofen Pump was funded partially by some of the first dollars raised by Pedal with Pete!

In 1998, a small group in Emmetsburg, Iowa chose to begin an annual bike ride to raise funds for Pedal with Pete. Then in 1999, while participating in the Great Ohio Bicycle Adventure ride, tragedy struck. Pete was coming down a hill, swerved to avoid a vehicle, turned over the bike and broke vertebra C1 and C2 in his neck. It effectively grounded him. But his determination was not diminished. In 2001, largely upon the initiative of Pete's brother, Chris Zeidner, a highly successful ride in Columbus, Ohio was begun.

The PwP Headquarters had been located in Kent from 1993 until 2009. In 2010, the headquarters shifted to the Columbus, Ohio area.

Over the years, research to help people with cerebral palsy grew by many orders of magnitude, along with the reputation of Pedal with Pete in communities where the events were held, but more importantly, among the research community! The grants, at \$25,000 - \$35,000 each, might only fund a **seed** grant, where a researcher is exploring a new idea. But, there are almost no **seed** grant funders out there, and a researcher desperately needs to do the pilot research before they can proceed with the larger effort that might be funded by the National Institute for Health (NIH) or Center for Disease Control (CDC). Pedal with Pete makes a difference!



In late 2015, Pete's grand notion was accomplished: together, the events have contributed more than \$1,000,000 to cerebral palsy research. This is only possible because of the generous sponsor and volunteer contributions, and the participant commitment to the cycling events held in Kent and Columbus, Ohio, and Emmetsburg, Iowa. Over the course of the last 8 years, PwP has supported 21 grants. To make this milestone even more grand for PwP, Pete completed his autobiography: It Sucks to be a Gimp, Pedaling to Freedom within the same year, and turned over the subsequent publishing and profits to Pedal with Pete, and thus, cerebral palsy research.



IV. Mission

We are dedicated to raise funds for research leading to better prevention strategies, treatment protocols, or cures that improve the quality of life for people who live with cerebral palsy, their families and caregivers.

V. Vision

Our vision is a world where preventable cases of CP are prevented, where curable cases of CP are cured, and where every individual impacted by cerebral palsy can reach their fullest potential in life.

VI. By-Line

Partnering to fund cerebral palsy research

VII. Core Operating Values

All staff, board members and volunteers of PwP act with honesty, integrity, and openness in all their dealings as representatives of the organization. PwP promotes a working environment that values respect, fairness and integrity. The following core operating values influence the culture of Pedal with Pete as an effective organization serving individuals and families impacted by cerebral palsy.

Commitment to Excellence – Our stakeholders can rely on us to deliver our very best results; we will deliver the best charity events we can organize and we will fund the very best research projects that we can identify.

Commitment to the Public Good – Pedal with Pete demonstrates compassionate support for people with cerebral palsy, their families and caregivers, and also for our donors, sponsors, event participants, and volunteers.

Responsiveness – Pedal with Pete requests, evaluates, selects, and funds CP research grant proposals. PwP also partners with other organizations (e.g., Adaptive Sports Connection, AACPDM, and Pelotonia) and provide information for individuals and families impacted by CP. It is of utmost importance that every individual representing the PwP be responsive to these requests.



Respectfulness – Pedal with Pete honors the choices of people with cerebral palsy and their families. PwP also respects the commitment made by our donors, sponsors, event participants, and volunteers. We feel that when we treat one another with respect, we are listening deeply, revealing to others their value, and seeing each person not within their role but rather as another human.

Diversity – Pedal with Pete understands that people affected by cerebral palsy are part of all races, ethnicities, social economics, and religions. PwP will work with individuals from all these backgrounds in *partnering to fund cerebral palsy research*.

Integrity and Accountability – Pedal with Pete has the highest level of integrity in its management, administrative, and operational activities; we tie these activities directly to our mission, and we maintain and report our records in a timely and accurate method.

Financial Stewardship and Transparency – Pedal with Pete delivers on our mission with full transparency of the financial resources entrusted from donors, sponsors, event participants, and volunteers.

VIII. Strategic Direction and Action Items

The strategies in this plan are intended to translate our mission and vision into broadly defined goals. The plan also includes what will be done to reach the desired destination, how, and when it will be accomplished.

The following strategies will drive our goals over the next three years:

FUNDRAISING FOR CP RESEARCH

A. While continuing our critical fundraising through events, we will broaden the revenue flows to the Pedal with Pete Foundation by adding a gifting program. We will solicit these grants from corporate foundations, community organizations, and other philanthropic programs.

Action Items:

- 1. Structure a board process and program to solicit funding through grants with the goal that this revenue stream could be as productive as our event fundraising.
 - a. Identify individuals to work on this process who have the skills of project management, business writing, and the ability to develop relationships with foundations including good follow-up.
 - b. Name and appoint individuals to the role of building 1) the process and 2) the package by May 1, 2018.
- 2. One such foundation to solicit will be the Columbus Foundation. PwP is already a member organization of the Columbus Foundation with an established Donor Advised Fund. PwP will continue to actively communicate with the Columbus Foundation and



attend their events to improve awareness in the community about ways to *partner to fund cerebral palsy research* (e.g. the holiday gathering and the Big Give).

- a. Appoint an individual to take the lead on communicating and connecting with the Columbus Foundation coordinating our participation in the Big Give by May 1, 2018.
- B. We will continue efforts to start events in other communities across the nation.

Action Items:

- 1. Adjust our approach based on advice we received from an Advisory Panel, including an emphasis on autonomy for the new community to build their own event.
- 2. Continue to pursue opportunities with the AACPDM, Pelotonia, and TAASC to partner in starting new fundraising events by July 1, 2018.
- 3. Maintain and build on the existing relationship with Pelotonia and identify similar potential relationships in other cities.
- C. We will continue efforts to heighten awareness about the need for CP research funding, the impact that funding has on improving the lives of people affected by CP, and how individuals, organizations, and communities can help increase that funding by *partnering to fund cerebral palsy research* with Pedal with Pete.

Action Items:

- 1. Structure a regular personal-story effort so that PwP is consistently promoting how it builds community, helps people with CP, and helps the research process. This could be old stories from the past (such as how Dr. Albright endeared himself to Pete when he kneeled down in the restaurant where they were meeting to tie his shoe), or could be recent stories.
 - a. Publish a news story every two months using social media, PwP's website, newsletters, and press releases.
 - i. Designate an individual to lead this communications initiative by August 1.
 - b. PwP will evaluate the development of another video with the theme, "Partnering for Cerebral Palsy Research", that will emphasize the need for cerebral palsy research and impact such research has on improving the lives of people impacted with CP. This video will focus more on people with CP and the research. This will be used with organizations who will want to sponsor PwP or gift/grant money to PwP.
 - i. Designate an individual to lead the development of this video by 2019.
- 2. We will continue and broaden our partnerships with community organizations (schools, hospitals, places of worship), sharing the ways to *partner to fund cerebral palsy research*.
 - a. PwP will develop a program that combines Pete's new autobiography, "It Sucks to be a Gimp Pedaling to Freedom", with speakers who have CP. We will speak at area schools, hospitals, places of worship, explaining how people can *partner to fund cerebral palsy research*. PwP will conduct or participate in at least 4 events per year.
- 3. Grow the Board of Directors to help with carrying out the steps of the Strategic Plan
 - a. Add board members with abilities in grant solicitation, fundraising, and public relations
 - b. Add board member(s) with the background and time to research the long-term impacts of the grants we have funded.



- 4. Make people aware and show them innovative ways that they can donate to PwP and cerebral palsy research. For example:
 - a. Amazon Smile
 - b. United Way
 - c. Enable participants to recruit sponsorship dollars by revising the online registration capability to support this. Investigate options in 2018, and launch such a capability in time for the 2019 event season.
- D. We will review and revise our branding approach.

Action Items:

- 1. We will emphasize our tagline, "Partnering to fund cerebral palsy research" so that people who hear the name, Pedal with Pete, will know what they are supporting.
 - a. Update PwP brochures, banners, newsletters, etc. with updated branding standards by July 28, 2018.
- 2. We will work to educate people why we are Pedal **with** Pete, rather than Pedal **for** Pete, because we are all working together, with one another, *partnering*, to fund cerebral palsy research
 - a. Include this point in news stories that are published every two months.
- 3. Meet with OSU's Fisher College of Business by April 1 to determine the feasibility of having interns involved in revising our approach to branding.

FUNDING CP RESEARCH

E. We will work more deeply with the AACPDM and the researchers that we fund to follow-up on how the research leads to discoveries that help improve the lives of people impacted with cerebral palsy.

Action Items:

- 1. The Research and Education Committee will create a process by November 1, 2018 so that this is an on-going effort. We will share this information with stakeholders at least on an annual basis.
- 2. We will place a representative on the AACPDM's Community Council, influencing the direction of the AACPDM's emphasis on future research from the perspective of families and funders.
- F. We will partner with research institutions such as Nationwide Children's Hospital to publicize the positive results of their research, the need for more funding, and opportunities to support such funding through the hospital or through Pedal with Pete.

Action Items:

- 1. Continue to co-host the "Kid Fest" with Nationwide Children's Hospital with the goal of increasing participation from the community and awareness of CP.
- 2. Explore a partnership with Nationwide Children's Hospital on the April 2018 conference to spread the word about Dr. Maitre's research, which PwP helped to fund.



3. Contact Akron Children's Hospital and explore the possibility of them participating in the Kent Event (e.g., promoting the event to families of individuals with CP, conducting a Kid Fest, etc.).

The specific actions planned and fundraising targets are listed in the "Development" section of this plan.

FISCAL RESPONSIBILITY

Keep administrative and operational expenses to a minimum in order to maximize the overall amount of funds donated to CP research. However, this will not be done at the expense of overlooking new opportunities to raise monies, or other endeavors that will further our mission and vision.

IX. Development Plan - reference companion document titled "Development Plan, 2018-2020".