

UNITE 2 FIGHT PARALYSIS

ANNUAL REPORT

2019



HIGHLIGHTS IN 2019

CURE ADVOCACY NETWORK (CAN) \$3M Ohio SCI Research Bill - PASSED

- Advisory Board includes:
 - 6 individuals from the SCI Community (Jeni Belt, Chairperson)
 - 9 leading SCI Researchers & Clinicians (Dr. Phil Popovich, Chairperson)
- We've finalized our grant structure and Request For Proposals are now actively circulating in Ohio!
- Up to \$1,500,000 in each fiscal year allotted for spinal cord research

The \$10M Wisconsin SCI Research Bill - INTRODUCED

- Our legislative champion, Rep. Jimmy Anderson (who has an SCI) is working to gain inclusion in the Governor's Budget for the next session.
- * *Special thanks to the Canadian Spinal Research Organization for covering travel expenses for CAN these last 2.5 years!*

Take a moment to look over these highlights, as well as much of the work that is already in progress for this current year. Your support has helped U2FP bring the SCI Community's voice into new places, conversations, decisions and forums that are making a real impact. Thank you!

But until we have cures for the chronic injury, we need to go further. We need to refine our voice, grow the chorus of influences and continue to UNITE the community who live with the injury 2 those who FIGHT, research, fund, invest and advocate to cure PARALYSIS. And we need your help so that we can do it together.

SUBMERGED DOCUMENTARY (aka The Cure Map)

Note from Kelsey: This film has been on quite the journey over the past three years - thanks to your support! I'm glad I trusted the story, because here we are, standing on a huge milestone within this process.

- *SUBMERGED* has been awarded funding by ITVS Open Call
- ITVS Open Call gives independent producers up to \$350,000 to complete production for a standalone broadcast length documentary to air on public television.
- Since 1991, ITVS has funded 533 Open Call programs, including the most recent Oscar-nominated film, *Minding the Gap*.
- We expect and are excited to see this film reach completion in Summer 2021.

WORKING 2 WALK 2019

- 45% of attendees from SCI Community (Injured or Family)
- 45% received reduced or no-cost Admission: **this is critical to the value of our Symposium and we are grateful for your support!**
- 64% were first time attendees
- Livestream offered (for free!) for the first time.

SPOTLIGHT ON 2020

OUR GOALS

for 2020 include making progress in the following areas of our work:

Cure Advocacy Network (CAN)

INTER-STATE COLLABORATIVE

- With 5 states and \$12M in SCI Research funding passed, we're now facilitating collaborative meetings between Minnesota, Ohio and Pennsylvania to share knowledge, best practices and explore collaborative potential.

WISCONSIN

- Mount a campaign with our advocates to gain inclusion in the Governor's Budget
- PASS the Bill in the next legislative session '20-21

Colorado & Texas - NEW STATES!

- Our advocates Elizabeth Dierdorf (TX; monthly donor), Jesus Centeno (TX) and Quinn Brett (CO) are working to identify Bill authors and generate support

PENNSYLVANIA

- We continue to support our advocates with the formation of the Advisory Council chaired by CAN advocate Jake Chalfin (monthly donor)

NEUROMODULATION QUARTERLY CALLS

- **Potential for a Participant Registry.** The quarterly conference calls we facilitate with scientists working in human beings on neuromodulation studies, are poised to take a big step forward: we are working on how the scientists can collect more uniform information from their studies that can be collaboratively shared, understood and analyzed.

ACTIVITY BASED EXERCISE ASSOCIATION

- The newly formed Activity Based Exercise Association that U2FP helped inaugurate and facilitate has identified research partners **who are submitting funding applications and IRB approval to conduct a public health impact study on the effects of exercise in the SCI population.** We hope to demonstrate the positive effects that exercise has for individuals with SCI so that we can build the case for coverage.

ELEVATING THE SCI COMMUNITY'S INFLUENCE

- U2FP has been invited to present on our advocacy work at the **2020 Kentucky Spinal Cord and Head Injury Research Trust (KSCHIRT) Symposium**
- Report on a Goal Prioritized Strategy for all stakeholders at Working 2 Walk 2020, with our Title Sponsor, the Craig H. Neilsen Rehabilitation Hospital

CONFERENCE REPRESENTATION

U2FP was invited to speak on advocacy issues at the following venues:

- American Spinal Injury Association (ASIA) - April 2019
- NIH's "SCI 2020: Launching a Decade for Disruption in Spinal Cord Injury Research" (as part of the NASCIC delegation) - February 2019
- National Neurotrauma Society - July 2019
- And interviews with New Mobility and Cure Nation.

Sustaining Supporters

Adam Cole (*a member of the SCI community who left a sizable donation as a bequest*)

Sue & Jay Pendleton
Therese Dvorak
Alan Tholkes
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Lauren Bailey
David Dvorak
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Working 2 Walk 2019 Sponsors

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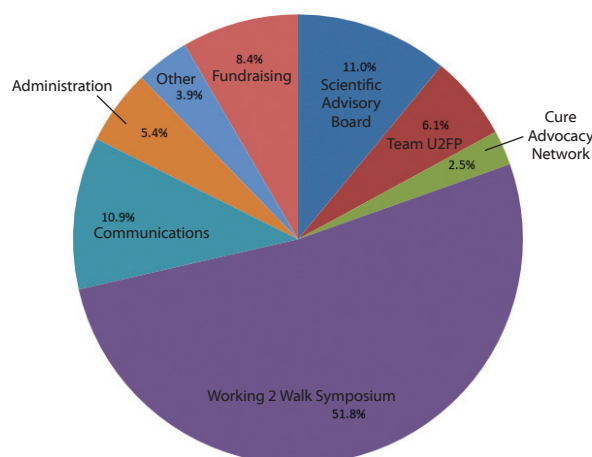
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Organizations

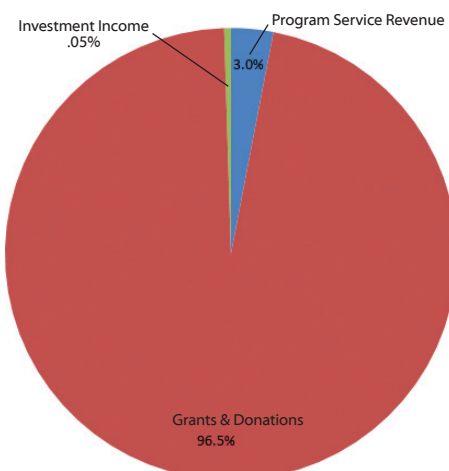
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2019 Expenditures



2019 Revenue



**These pie charts reflect pre-audited financial information for Unite 2 Fight Paralysis*

Unite 2 Fight Paralysis relies almost exclusively on public contributions and grants to provide our services.