# ANNUAL REPORT 2023



MU

# 18th Annual Science & Advocacy Symposium



### Stats

**277** attendees from 9 countries, representing over 56 unique companies or organizations

# = \$



We provided discounted registrations totaling

# \$36,697

in cumulative savings for event attendees

### Highlights



U2FP's Annual Symposium motivated me to get involved in advocacy at many different levels. I really enjoy the camaraderie between all of the attendees, and how both individuals with lived experience and researchers/clinicians are on an equal level."

> - Ian Burkhart, C5 tetraplegic President, Ian Burkhart Foundation



Scan here to watch any presentation or panel discussion from U2FP's Annual Symposium in Minneapolis 2023.



- Hosted our first-ever poster session
- Our CureCast podcast recorded real-time reactions
- Original artwork displayed by artist Lynne DeNio





Nearly **14,000** plays logged in 2023 A 57% increase over 2022!

Nearly 90,000 plays to date since CureCast first launched in 2016

Consider having your company become a sponsor of this award-winning podcast

We were proud to have the following sponsors in 2023:

### Lawyer Match + Mobius Mobility







Scan here to listen to one of our most popular episodes in 2023, The Bog, which explored the impacts of a spinal cord injury on family relationships, art and advocacy.

# **CureCast Podcast**

Having won a Direct Effect grant from the Christopher & Dana Reeve Foundation, we hired a seasoned podcast producer, Julie Censullo, and had a marketing budget for the first time. It paid off. By the end of 2023, we more than doubled our listenership! U2FP's CureCast continues to be required listening among several of the top SCI graduate research programs in the country. It's also an empowering educational tool that continues to reach tens of thousands of individuals in the SCI community.



In 2023, CureCast was made possible by a grant from the Christopher & Dana Reeve Foundation's National Paralysis Resource Center.





# **Cure Advocacy Network (CAN)**

Advocacy work is difficult. And when you've got an SCI - like almost all of our CAN advocates do - it sometimes feels impossible. We were frustrated about not passing our \$3M SCI Research Grant Bill in Wisconsin in 2023. But as lobbyists have told us, the average time for state level legislation to cross the finish line (from inception to passage) is six years. Consider this: by the end of 2023 our SCI advocates had passed nearly \$35M in research grant legislation in four states over the last eight years - not bad. (Note that by the end of 2024, that number will be over \$40M). We are keeping this big picture in mind as we continue our work in Wisconsin and have begun hatching even bigger plans for 2025 and beyond. The clock is ticking and we're aiming to stay ahead of the average.

Thanks to CAN, a total of

was appropriated towards SCI research by the end of 2023

All research funding was chosen by an Advisory Board of scientists, clinicians and those who live with the injury





CAN funding has now resulted in nearly **200** People with an SCI getting a meaningful intervention

Wisconsin SCI bill passed unanimously out of the Colleges and Universities Assembly committee

Senate version of SCI bill passed out of the Senate Committee on Health (only 1 No vote)

# Lab Rats

For the past three years, U2FP has been helping to place persons with lived experience (PLEX) of spinal cord injury into research labs to act as expert consultants - an effort we've dubbed Lab Rats. The influence of these partnerships continues to deepen, with two PLEX Lab Rats recently joining ASIA's Spinal Cord Outcomes Partnership Endeavor (SCOPE). SCOPE's mission is to enhance the development of clinical trial and clinical practice protocols that will accurately validate therapeutic interventions for spinal cord injury (SCI) leading to the adoption of improved best practices.

Additionally, five more of U2FP's PLEX Lab Rats are working with Jennifer Dulin (Texas A&M) on a study that seeks to follow the money after a ten-fold jump in human clinical trials for SCI in recent years, with no treatments to show for it. Dulin and U2FP's Lab Rats seek to understand



Researcher Murray Blackmore (left) chats with Jason Biundo (right) at the networking reception for U2FP's 2023 Science and Advocacy Symposium. Both Blackmore and Biundo participate in U2FP's Lab Rats initiative.

where the money went, what research trends were driving those investments, what outcomes were delivered and what impact those investments had. These findings will help guide future investments towards more efficient, effective and faster treatments.



### **Participating labs**

Lane Lab Drexel University Blackmore Lab *Marquette University* Gensel Lab University of Kentucky Dulin Lab Texas A&M University Gaudet Lab University of Texas, Austin Ferguson Lab University of California, San Francisco (Track SCI) Schwab Lab Ohio State University McTique Lab Ohio State University DeBerry Lab University of Alabama, Birmingham Floyd Lab Emory University Lepore Lab Jefferson University **ASIA's SCOPE Committee** Zhao Lab Mayo Clinic Darrow Lab (Bottorff) Hennepin Health Revnoso Lab Case Western Reserve Poplawski Lab Cleveland Clinic



### Team U2FP

Team U2FP participants bring funds and awareness to the SCI movement for cures in a very specific way: the money they raise primarily supports our Cure Advocacy Network (CAN), where we train and mobilize SCI advocates to pass state legislation that funds curative research. We do this because it is extremely difficult to get grant funding for legislative advocacy, since it's technically considered political lobbying. Team U2FP racers help fill this funding gap while running or wheeling in one of our premiere race events!

\$35,900 was raised by Team U2FP participants in 2023!

**33** Runners + Wheelers

signed up for our races, challenging themselves physically while fundraising to advance the movement for curative therapies.





### **Race Events**

- The Bank of America Chicago Marathon (15 participants)
- The Twin Cities Marathon & 10 Mile Races (16 participants). We continue our fight for more inclusivity for wheeler participation in the Twin Cities races.
- The Freestyle Challenge (2 participants), our DIY race event where participants designed their own courses and pace. Our own Quinn Brett and Jason Stoffer, pictured on the cover, decided to take on the Grand Canyon on their adaptive trikes!



### **SPOTLIGHT ON 2024**

AB19 passed in the assembly **93 - 3** 

Paralyzed Veterans of America has become a more involved supporter of our bill

We are in talks with the Wisconsin American Legion to draft a "Resolution" to officially support the bill in addition to their lobbying support.

Governor Evers has preliminarily agreed to put our Bill in his proposed budget

Wisconsin's updated legislative map looks as if it will encourage more cooperation from lawmakers who were previously on the fence about our bill.

# CAN - Wisconson

The beginning of 2024 was a nailbiter for our Wisconsin CAN bill. After a monumental effort to get the bill introduced on the Assembly Floor, the negotiations over the bill stalled the floor procedures late into the night. Just before midnight, our SCI Research Grant Bill was passed 93-3! Unfortunately, the bill was stymied in the Senate prior to the close of session. And yet - we are extremely well-positioned to pass this bill during the upcoming session.

We have added coalition partners that support our bill to build a united front that will lead to the passage of this bill next year. But we will still need all of you at the ready to raise your voice on behalf of this important piece of legislation.

The whole experience was absolutely AMAZING. It was not only very interesting to watch the legislative process from a different perspective, but it was also very invigorating, and made me feel proud of the contribution that I am making to our community.

> - Mackenzie Wann Wisconsin CAN Advocate



### 20th Anniversary

### Science & Advocacy Symposium



Ok, so technically this is happening in 2025. BUT! We are already hard at work, preparing for the 20th Anniversary of our Symposium. We wanted to give you a small teaser for what's to come and remind you of this important event's origins:

In the spring of 2005, just 6 months after the passing of Christopher Reeve, six "bionic women" organized the first Rally in Washington on behalf of the spinal cord injury community. Three of the women – Pam Bailey, Susan Maus, and Betheny Winkler – had a spinal cord injury or disease themselves. The other three – Faye Armitage, Suzanne Poon, and Marilyn Smith – all had sons with spinal cord injuries. Their collective determination to fight for a cure led to the historic Washington Rally and the first annual Science & Advocacy Symposium (originally named "Working 2 Walk"), bringing research scientists, clinicians, investors, SCI survivors and family members together for the first time.

Next year, 2025, marks the 20th Anniversary of Unite 2 Fight Paralysis' Annual Science & Advocacy Symposium.

Our 20th Anniversary Symposium will convene in the Washington DC area
We have exciting advocacy plans that we will share at this event
A title sponsor has just been secured

### **Highlights**





### Highlights

 Launched Model Systems and Rehab Outreach work with Jason Stoffer Kicked off a new Monthly **Donor Campaign** • Applied for half a dozen grants so far this year, with more applications pending • Established relationships and/or partnerships with: Adidas High Fives Foundation No Barriers **Empower SCI** United Spinal Minneapolis Bouldering Project Charlotte's Web CBD Kyle Pease Foundation

### **Development Director**

In the fall of 2023, we hired Quinn Brett as our new development director, thanks to generous seed funding from a member of the SCI community. A record-setting mountain climber, Quinn sustained a T11 ASIA A spinal cord injury after a fall from El Capitan in Yosemite National Park in 2017. Quinn was a U2FP board member for two years before applying for this new position. Her background in education, corporate and foundation grant writing and public speaking made her an excellent fit for this role. Her passion for educating the broader community on what it means to live with a spinal cord injury has garnered more than 18,000 followers on her Instagram account (@quinndalina). Quinn has been working hard to hunt down grants, make connections with organizations and individuals aligned with our mission, and use her athletic expertise to bolster our Team U2FP fundraising events.



Quinn Brett, above, on her 22-mile rim-to-rim journey through the Grand Canyon in the fall of 2023.

# **Model Systems and Rehabilitation Outreach**

Not long after joining U2FP's staff, Quinn Brett was reminiscing with Jason Stoffer about how they met as inpatients right after their injuries. They were reflecting on all the questions they had, all the uncertainty and fear and curiosity about the state of functional recovery research that remained unanswered during their early days with the injury. So Ouinn and Jason hatched an educational outreach plan and hit the road, connecting with Model System Rehabilitation hospitals to help augment their current patient education curriculum. This includes updating individuals on the current state



of functional recovery research, sharing advocacy opportunities that will empower them, while providing realistic management around hope for recovery.



### Highlights

- Visited five Inpatient Rehabilitation Hospitals: Craig Hospital in Denver, CO; Craig H. Neilsen Rehabilitation Hospital in Salt Lake City, UT; Minneapolis Veterans Affairs Hospital; EA Therapeutics in Rochester, MN; Health Partners in Minneapolis, MN.
- Connected with 46 persons with lived experience (PLEX) of spinal cord injury
- Met with 74 staff members at those institutions Distributed copies of Kate Willette's book 'Don't Call It A Miracle: The Movement to Cure Spinal Cord Injury'
- Shared U2FP's resources such as our CureCast podcast, invited families to our Annual Symposium, and suggested they sign up for our email Newsletter.
- Provided Jason and Quinn's personal contact info so injured individuals have someone with lived experience they can connect with about functional recovery research.



# **2023 Financial Report**

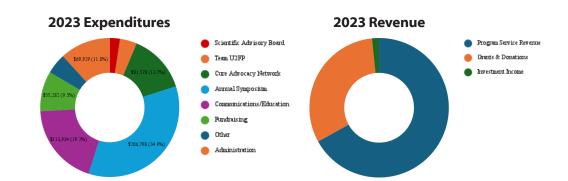
In 2018 Unite 2 Fight Paralysis was given over \$100,000 in a bequest from an individual in the SCI community. These funds were put into a reserve where they could gain interest but remain liquid. Shortly after I came on as U2FP's Financial Manager in 2020, Matthew began strategizing with the board and staff on smart ways to leverage that money to increase our impact for the SCI community. In the last four years, U2FP has tripled its operating budget while continuing to grow our reserve accounts. Our overhead expenses are lower than anywhere I've ever worked (and that's saying something after 50 years in finance!) and our commitment to the mission of curing paralysis is more central than ever.

2023 saw Unite 2 Fight Paralysis once again meet our budgeted surplus. We could not have accomplished this without the ongoing support of all our donors. This is especially true of the donors listed on the next page, the majority of whom come from the SCI community. Thank you!

Kathryn Christopherson

Scan here to view U2FP's 2023 financial documents as listed on our donation page: Audited Financial Statement, 990 Form, Guidestar Pro Report.





\*These pie charts reflect audited financial information for Unite 2 Fight Paralysis. Unite 2 Fight Paralysis relies almost exclusively on public contributions and grants to provide our services. We apologize for any oversight in listing donors. Please contact our office to update our records.





#### **Sustaining Supporters**

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#### 2023 Symposium Sponsors

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### **Special Thanks to our Donors!**

Institute for Functional Restoration **Craig Hospital** DP Clinical **Conquer Paralysis Now** The Miami Project **Cure Paralysis** Push to Walk EA Therapeutic Health Regions Neuroscience Center ONWARD Spinal Cord and Brain Injury **Research Center at University** of Kentucky Coloplast NeuroHope

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U2FP sincerely appreciates the generosity of all our donors. The donors listed above made cash or in-kind gifts or grants totaling \$250 or more over the past 12 months and/or contribute regularly as Monthly Donors.

