

Salt Lake City, Utah Sheraton Salt Lake City September 23 - 24, 2022



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To all of our wonderful sponsors who made this year's Science & Advocacy Symposium possible.





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Welcome

Welcome to Unite 2 Fight Paralysis' 17th Annual Science and Advocacy Symposium. We are excited to finally be back with so many of you in person this year! We look forward to facilitating meaningful exchanges among the key members of our communities engaged in our shared work. Paying attention to the following areas will help us maximize our time together.

COVID Protocols. Despite our enthusiasm to be back together, we know that Covid is not over. We strongly encourage our in-person attendees to join our board and staff in exhibiting the following safety precautions:

- · Wear a mask during the meeting
- Get fully vaccinated and boosted if not already up to date
- Wash hands and use hand sanitizer often
- Take a rapid test prior to joining the conference

Interactive Program. We have reduced the size of our printed program to save paper and utilized QR codes to create what we hope will be a more accessible and convenient way for all attendees to access key information, such as:

- Speaker Abstracts and Bios
- U2FP staff, leadership and organizational history
- Resources for the SCI Community



Scan here to download a digital version of this program and/or use the QR codes provided on the following pages.

Format. Each day of the Symposium will contain presentations from our all-star lineup of scientists and advocates. Moderated question and answer sessions will follow each grouping of 2-3 presenters. Use this program to educate yourself on what's coming up so that you can prepare to engage effectively. This is a fantastic opportunity to pose your questions directly to the presenters and enrich the experience for all.

Context. Please read through Sam Maddox's "Navigating U2FP's Science & Advocacy Symposium" in the following pages. It's a great overview and highlights the salient points that connect the various researchers to the cure enterprise. As always, we are committed to providing context both in and around the research in order for our communities to think strategically about what is happening and explore ways to have an increasingly effective voice toward expediting curative treatments for SCI. Keep these questions at the forefront:

What is happening? Where does it go next? Who can take it there? How can we help?

Sponsors. We are so very grateful to our sponsors this year. Please take some time to visit their exhibiting booths and/or talk to their representatives to discover the great work they are doing in our community. Lastly, take a few minutes to fill out our survey at the end of the symposium. We very much want to hear your impressions. And if you have any questions, reach out to us at unite@u2fp.org

Thanks for joining us this year!

Matthew Rodreick
Executive Director, Unite 2 Fight Paralysis



THURSDAY, SEPTEMBER 22, 2022 - ARRIVAL DAY

4:00 - 7:00 pm Adaptive Sports and Recreation Expo

Sheraton Salt Lake City Parking Lot

5:00 - 7:00 pm Early Registration & Check-In

Canyons Lobby

FRIDAY, SEPTEMBER 23, 2022

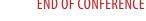
7:30 - 9:00 am	Registration & Continental Breakfast — Exhibitor Visits Canyons Lobby
9:00 - 9:15 am	Opening Remarks & Welcome Matthew Rodreick Unite 2 Fight Paralysis David P. Steinberg, MD Craig H. Neilsen Rehab Hospital - University of Utah
9:15 - 9:35 am	SCI Translational Wheel Matthew Rodreick Unite 2 Fight Paralysis
9:35 - 9:55 am	Challenges and Opportunities in the Translation Pipeline for SCI Medicine Dennis Bourbeau, PhD Louis Stokes Cleveland Department of Veterans Affairs Medical Center
9:55 - 10:15 am	The Great Divide Quinn Brett, MA U2FP Board of Directors
10:15 - 10:35 am	Panel Discussion with Question & Answer Session
10:35 - 11:05 am	BREAK — Exhibitor Visits
11:05 - 11:25 am	The Importance of the Age Factor After Spinal Cord Injury Cédric G. Geoffroy, PhD Texas A&M University
11:25 - 11:45 pm	Key Variables that Affect the Clinical Relevance of SCI Preclinial Studies Candace Floyd, PhD University of Utah
11:45 - 12:05 pm	Panel Discussion with Question & Answer Session
12:05 - 1:05 pm	LUNCH — Exhibitor Visits
1:05 - 1:20 pm	Innovation Management - Maximizing the Commercial Impact of University Inventiveness Paul Corson University of Utah
1:20 - 1:40 pm	"It Won't Work": The Perception Challenge Facing Commercial BCIs Florian Solzbacher, MS, PhD Blackrock Neurotech
1:40 - 2:00 pm	Industry Perspective on Developing a Therapeutic for Spinal Cord Injury Nana Collett, MS, MBA NervGen Pharma
2:00 - 2:20 pm	Panel Discussion with Question & Answer Session
2:20 - 2:40 pm	Who Needs Outpatient Rehab Anyway? Dale Hull, MD, MPA Neuroworx

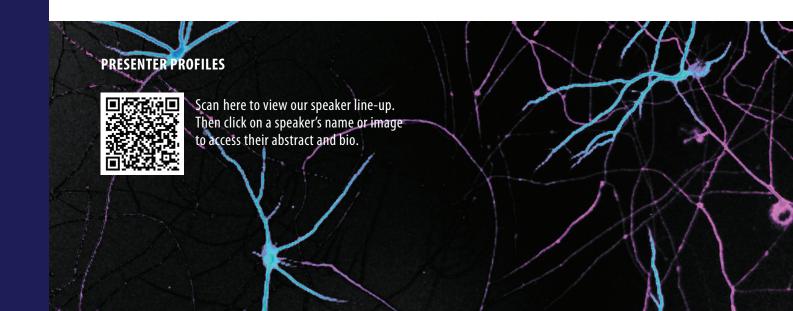
2:40 - 3:00 pm	Discussion with Question & Answer Session
3:00 - 3:30 pm	BREAK — Exhibitor Visits
3:30 - 4:55 pm	Film Screening - Move Me Special screening of Kelsey Peterson's documentary, Move Me
4:55 - 5:25 pm	Panel Discussion with Question & Answer Session Kelsey Peterson Filmmaker, Move Me
5:25 - 5:30 pm	Day 1 Wrap Up
5:30 - 7:30 pm	Networking Reception Zion Meeting Room
	DINNER ON YOUR OWN

SATURDAY, SEPTEMBER 24, 2022

7:30 - 9:00 am	Registration & Continental Breakfast — Exhibitor Visits Canyons Lobby
9:00 - 9:10 am	Opening Remarks / U2FP Introduction Matthew Rodreick Unite 2 Fight Paralysis
9:10 - 9:30 am	Bridging the Translational Gap through Effective Communication Lana Zholudeva, PhD Gladstone Institutes
9:30 - 9:50 am	A Novel Approach to Target Functional Restoration after Spinal Cord Injury Monica A. Perez, PT, PhD Shirley Ryan AbilityLab
9:50 - 10:10 am	Neuroprotection after Spinal Cord Injury Wolfram Tetzlaff, MD, PhD University of British Columbia; ICORD
10:10 - 10:30 am	Panel Discussion with Question & Answer Session* *Sponsored by ASIA's Translational Research to Inform Practice (TRIP) track
10:30 - 10:55 am	BREAK — Exhibitor Visits
10:55 - 11:00 am	Remarks from Jack Jablonski Foundation
11:00 - 11:20 am	Exposure of Unrecognized Systemic Adaptive Physiological Mechanisms has Provided a Robust Platform for Greater Recovery Post Paralysis Reggie Edgerton, PhD University of California Los Angeles (Virtual)
11:20 - 11:40 am	Neuromodulation for Whole Body Systems after Spinal Cord Injury Susan Harkema, PhD University of Louisville
11:40 - 12:00 pm	Spinal Cord Stimulation Restores Synergies After Spinal Cord Injury David Darrow, MD, MPH University of Minnesota Medical School
12:00 - 12:30 pm	Panel Discussion with Question & Answer Session

12:30 - 1:30 pm	LUNCH TALK — Innovations in SCI Therapy: Non-invasive Spinal Neuromodulation for Motor Function Improvement Yi-Kai Lo, PhD Aneuvo Rebecca Martin, OTR/L, OTD, CPAM Kennedy Krieger Institute Chris Mason-Hale ECLIPSE Study Participant
1:30 - 1:50 pm	Potential Supra-Therapies for Spinal Cord Injury Samuel I. Stupp, PhD Northwestern University
1:50 - 2:10 pm	Mid-career Crisis of a Spinal Cord Injury Researcher: Can Humanization of Rodent Models through Sex, Age, and Bowel Outcomes Help? John Gensel, PhD University of Kentucky
2:10 - 2:25 pm	Fighting for Recovery on Multiple Fronts: The Past, Present, and Future of Clinical Trials for Spinal Cord Injury Valerie Dietz, PhD Candidate Texas A&M University
2:25 - 2:40 pm	Community Engagement Is Essential for Productive and Meaningful SCI Research Jason Biundo Boston Children's Hospital / Harvard Medical School
2:40 - 3:00 pm	Panel Discussion with Question & Answer Session
3:00 - 3:30 pm	BREAK — Exhibitor Visits
3:30 - 4:45 pm	SCI Research Advocacy Course and How to Become a Research Advocate (Workgroup A) Barry Munro, LLB Canadian/American Spinal Research Organization
3:30 - 4:45 pm	Towards Recommendations for Improving the Translational Research to Clinical Practice Pipeline (Workgroup B) Michael Lane, PhD Drexel College of Medicine Lana Zhouledeva, PhD Gladstone Institutes Dennis Bourbeau, PhD Louis Stokes Cleveland Department of Veterans Affairs Medical Center
4:45 - 5:00 pm	Wrap Up & Closing Remarks Matthew Rodreick Unite 2 Fight Paralysis
	END OF CONFERENCE





conference Tips

SPONSOR EXHIBITORS

Our sponsors help make U2FP's Annual Symposium possible - they also provide a tremendous array of resources, services and products for the SCI Community. Sponsors will be available at several exhibit tables in the Canyons Lobby area outside of the Ballroom. Please take a moment to stop by and learn more about their unique offerings for our community.

GET CONNECTED

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Facebook: https://www.facebook.com/Unite2FightParalysis/

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TikTok: unite2fightparalysis

A WELCOMING SPACE

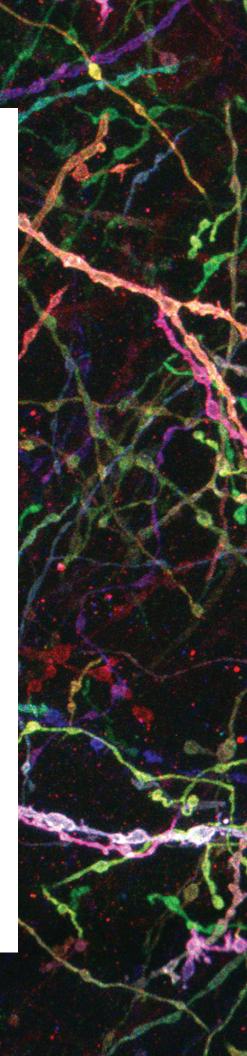
Unite 2 Fight Paralysis is committed to creating a welcoming event. We seek to create an environment where everyone feels encouraged to participate. Help us nurture a space where we all feel included and where civility grows. Please let the U2FP staff know if you hear or see anything that needs our attention. Thank you!

ABOUT U2FP



Scan here to download a digital version of this program and then use the links provided below to learn more about our:

- Leadership Team
- Scientific Advisory Board
- History & Founders



Navigating

U2FP's

SCIENCE & ADVOCACY SYMPOSIUM Sam Maddox

Welcome to the 2022 Science and Advocacy Symposium. We're grateful we can finally meet in person again here in Salt Lake City. The livestream experience of the last two years was quite successful and will be an option again this year. But there's nothing to compare with the experience of being here in person.

The aim of the Symposium is to bring you up to speed on the complicated science of repairing the injured spinal cord and on the strategies needed to move discoveries toward treatments. Science can be difficult to explain, so you are not alone if you feel a little overwhelmed. One of the unique advantages of this Symposium is that the roster and schedule are built around participation. Lay people mix it up with the experts, and vice versa. Scientists very much want to meet members of the SCI community and their families. It humanizes and focuses their work.

Keeping a Wide View

We're not there yet. No treatment has ever been approved for either acute or chronic SCI in humans — but optimism rules! There are exciting possibilities on the horizon, some already in clinical trials, others in the biotech start-up pipeline. The work is hard, and it moves slower than our expectations for it. The leap is vast from a promising SCI mouse recovery you heard about in the news to an actual treatment at your doctor's office.

Therapies start out as ideas that worked in a lab animal. Then, if something looks promising, and money is available, clinical people take over, or sometimes a company gets involved ahead of them . If trials succeed in meeting outcome expectations (this stage has never been reached in SCI) regulatory approvals are the next hurdle. Commercialization has its own challenges to scale up to meet the market, including locking down patent rights and insurance reimbursement.

The U2FP approach invites all interested parties along this translational pathway to the podium — scientists, clinicians, funders, industry people, regulatory people, along with advocates from the SCI community — to deconstruct the system so it operates more smoothly while remaining focused on the unmet needs of the community.

Basic Questions

To help frame the discussions at the Symposium, let's reduce spinal cord injury to a general range of problems researchers are trying to solve. Let's start with the most basic question: What does an injury actually do to the cord?

(Note: We recognize the important medical value of neuroprotection and acute SCI treatment development, however our focus is on chronic injury.)

The spinal cord is usually injured by a high impact event, a force that exceeds the protective armor of the backbone. Some nerve cells in the injury zone die right away, others die in the hours and days after the injury site seals itself off and becomes toxic to nerve cells. Trauma also disrupts the basic architecture of the spinal cord. Could we perhaps REBUILD the mangled cord structure or add cells to encourage recovery? Some spinal cord cells survive trauma but lose their axons, the long extensions like wiring. Research tells us these cells attempt to recover and resend axons but get stuck or repelled. Could we find a way to REGENERATE native cells and then direct their axons to make the appropriate connections? Other cells and nerve networks in the injured spinal cord are alive but dormant or disconnected from the information circuits between the brain and the cord. Can we REJUVENATE the spared part of the system, tapping into inherent self-repair mechanisms, or perhaps the smartness and adaptability of the spinal cord itself?

Getting Started

U2FP executive director **Matthew Rodreick** welcomes all to the Symposium and suggests a metaphoric platform or process that includes all perspectives (science, medicine, industry, funders, community). He imagines the need for effectual tension, as with spokes on a wheel, to deliver solutions for all the interested parties.

Note to SCI community: You have a very important role to play in keeping up your end of the tension — make sure the other stakeholders understand your urgency for treatments.

Dennis Bourbeau is a scientist at the Cleveland VA and Case Western Reserve. His focus is electrical stimulation to restore bladder and bowel function lost to spinal cord injury or other neurological disorders. Here he describes the work of the U2FP Translational Workgroup tasked to "drive the delivery of restorative treatments for spinal cord injury by reimagining the therapy development pipeline." The workgroup is conducting interviews with key stakeholders — researchers, clinicians, industry partners, and individuals with SCI — to identify emerging themes for how each group views the translation pipeline, its challenges, and opportunities.

Quinn Brett, U2FP board director, was injured in a climbing fall in 2017. Climbing remains as her path to self-discovery: cultivating mindfulness, evaluating fears and appreciating failure. She uses the Rocky Mountain Great Divide watershed as an analogy to the many walls and barriers of the built environment for people in wheelchairs. The Divide is a way to frame disability and the obsolete care vs. cure debate for spinal cord injury.

Animal Models

Candace Floyd, who is moving her lab from the University of Utah to Emory University next month, focuses on clinically relevant porcine (pig) models of traumatic brain injury and spinal cord injury. She discusses how key biological variables (sex, age, and species) affect outcome in preclinical SCI studies. Other variables such as diet and stress also affect study results. Therefore, keeping tabs on multiple variables is likely to improve the clinical relevance and translational potential of animal studies.

Cédric Geoffroy studies age variability for recovery after SCI at Texas A&M. Age is a factor that is not often appreciated. He describes using robotic and automated analysis to screen thousands of drugs in adult neural cells, in different species. This may reveal drugs beneficial to adult cells that were dismissed by screens of younger cells.

Down to Business

Several experts from industry and academia are here to explain how to navigate the Valley of Death between a good clinical outcome and a business that gets paid: **Florian Solzbacher** (co-founder, Blackrock Neurotech), **Paul Corson** (University of Utah tech transfer office) and **Nana Collett** (Vice President, Program Management at NervGen Pharma).

Solzbacher's company makes the electrode array (the Utah Array) used in most studies of brain-computer interface (BCI) research. His presentation is titled, "It Won't Work: The Perception Challenge Facing Commercial BCIs." The tech is solid, the results are solid, the potential market is vast. What's the hold up? It's the perception that implantable BCIs are too risky, can't be approved and can't make money. He discusses how patient advocates, potential users, caretakers, physicians and businesspeople can challenge the perception.

Corson is Deputy Director & Senior Director of Innovation of the PIVOT Center, University of Utah. PIVOT creates Greenhouses, a controlled environment to support the growth of invention. Greenhouses are managed by successful entrepreneurs and industry leaders who partner with university researchers and private sector stakeholders to identify opportunities, create realistic business plans, and arrange funding for technology development. The focus is on reducing risk in both technology and marketplace.

Collett addresses the many challenges for a biopharma company in developing a therapeutic for SCI — including the fact that previous attempts to treat SCI have not been successful. This creates a perception that the nervous system is not amenable to repair, and limits investments from financial markets. She discusses NervGen's need to explore unconventional funding mechanisms, and disease treatments beyond SCI, to attract

investors. (The company's peptide, NVG-291, will begin its first clinical trial in individuals with SCI in 2023.)

Who Needs Rehab?

Dale Hull was spinal cord injured in 1999, C4-5 cervical injury, initially resulting in neck-down paralysis. He spent the following two years participating in intense rehabilitation. In 2004, he and physical therapist Jan Black opened Neuroworx, a not-for-profit, outpatient rehabilitation facility in Sandy, UT. Hull discusses the critical significance of aggressive physical and occupational rehab in the first 24 months post injury. This is when people need the best tools and direction to attain maximal recovery. It is also when people should acquire adaptive skills and get counseling for mental health, relationships, and work life to assure full participation in the community.

Special Film Screening: Move Me

U2FP is proud to present a special screening of *Move Me*, the long-anticipated documentary film from **Kelsey Peterson**. The feature length film tells Kelsey's story: high-level spinal cord injury, loss, and heartbreak, and now, 10 years later, an attempt to balance hope for recovery with acceptance that life with a disability has intrinsic value and meaning. U2FP has been involved with the film from the start; the project began as The Cure Map, a cure-seeker's journey that evolved into a story of self-discovery.

After the film, U2FP CureCast co-host **Jason Stoffer** will moderate a discussion with **Peterson** and **Quinn Brett**.

Learn Together, Wire Together

Lana Zholudeva studies the therapeutic potential of stem cells at the Gladstone Institutes. Here she appears on behalf of the esteemed clinicians' group, American Spinal Injury Association (ASIA) to describe a program called Translational Research to Inform Practice (TRIP) that encourages better communication between health care people and researchers. TRIP sessions focus on a specific problem or system focus, and how it benefits people living with SCI. TRIP sessions include a basic and/or pre-clinical researcher and a clinician and/or clinical researcher.

Monica Perez is the Scientific Chair of the Arms + Hands Lab at the Shirley Ryan AbilityLab, where she studies neural mechanisms contributing to the control of voluntary movement. She hopes to develop more effective rehabilitation therapies for people with spinal cord injury. Applying the maxim "neurons that fire together, wire together" Perez uses a two-stage noninvasive stimulation to target multiple arm and leg muscles. Combined with exercise, this improves functional task performance in clinical trials.

Regeneration

Jerry Silver teaches at Case Western University. Damaged spinal cord nerve cells attempt to regrow their axons, but the trauma site becomes quite toxic and sealed off. In theory, it's possible to restart nerve growth by recoding developmental genes, using molecular decoys or drugs to remove the scar; or cultivating long axons across the injury site, perhaps along a scaffold. That brings us to Silver and the start-up company, NervGen, based on his work. He's the veteran SCI scientist and frequent U2FP Symposium presenter who has never abandoned hope for axon regeneration.

Silver has long understood the role of spinal cord scar and chondroitin sulfate proteoglycans (CSPGs) to block axons. There are ways to chemically degrade these inhibitors. Here he will discuss recent work utilizing a new, more clinically relevant, non-invasive combination treatment designed to reduce and overcome CSPGs. Results so far: a "profound effect on functional recovery" in a chronic animal model of SCI.

U2FP proposed the pairing of Silver, NervGen, Candace Floyd, and Ann Parr. The idea: test a combination of NervGen's peptide with epidural Spinal Cord Stimulation in a large animal chronic SCI model – is stim + drug better than either alone?

Combo matchmaking update: The project is on! Shortly after the 2021 Symposium, U2FP proposed the pairing of Silver, NervGen, Candace Floyd, and Ann Parr, a University of Minnesota neurosurgeon and co-project leader of the E-STAND epidural stim trial. The idea: test a combination of NervGen's peptide with eSCS in a large animal chronic SCI model — is stim + drug better than either alone? Funds were raised from several

SCI charities; animal testing will begin this fall for this unique, multidisciplinary study, using the NervGen's peptide drug (NervGen/Silver), adding epidural stimulation (Parr), in a clinically relevant pig model (Floyd).

Rejuvenation

This involves waking up nerve cells that are alive and home where they should be, but not functioning in harmony with spinal cord circuitry. This sets up the major Symposium discussion on spinal cord stimulation (SCS). We are pleased to include presentations from **Reggie Edgerton** and **Susan Harkema**, pioneers in neuromodulation who led the team that implanted an epidural stimulation device 13 years ago in a motor-complete paraplegic who could then stand with the stim on. That result ignited the neuromod field and launched many new projects, and several device development companies. **David Darrow** follows, reviewing his contribution and experiences implanting spinal cord stimulators using a novel patient-centric approach.

Edgerton, considered the grandpa of spinal cord stimulation, has been at the research bench for nearly six decades. His work at UCLA underpins the entire field. He will be introduced at the Symposium by **Jack Jablonski**, injured in 2011 during a Minnesota high school hockey game. The Jack Jablonski Foundation has supported Edgerton's work for several years.

Spinal cord stim is based on the notion that spinal cord nerve cells have a kind of automatic programming for messaging motor/muscle cells; the cord can be independently smart and active, even with no connection to the brain. Spinal cord activation can occur to some degree with intensive physical therapy, but much more so by applying pulses of electrical energy by way of an implanted device or via skin surface electrodes — in both cases, some people, not all, have gained meaningful voluntary function that often remains when the stim device is turned off. Apparently, stimulation is more than a jolt of electricity, it encourages what scientists call plasticity — the cord circuitry adapts and rewires itself permanently.

Here Edgerton will dive into spinal cord physiology with an eye on how the cord manages movements, posture, and locomotion. He suggests that "sensory ensembles" (input from touch, sight, hearing, taste, etc.) contribute to highly specific functions.

Up next, **Harkema**. She and Edgerton go way back — she was a postdoc in his UCLA lab before moving to University of Louisville where she runs the large spinal cord neuromodulation program for the Kentucky Spinal Cord Injury Research Center. Her group has implanted 45 epidural stim units and has published numerous papers detailing standing, stepping and volitional movement.

One of the surprising results of SCS studies, Harkema notes, is that stimulation has a positive effect on whole-body homeostasis. For example, studies have shown that SCS greatly improves blood pressure management. The first clinical approval for a spinal cord stim implant won't be standing or stepping, it will likely be orthostatic hypotension (the dizziness related to sitting or standing up too fast).

Darrow started an epidural stimulation clinical trial in 2017 (E-STAND) while still a neurosurgery resident at the University of Minnesota (funded by a state program created by advocates supported by U2FP and launching the Cure Advocacy Network). Results to date are quite good — standing, autonomic improvement, bowel and bladder recovery, some volitional movement. What sets Darrow's approach apart from the Louisville group is that he skipped the rehabilitation component. His participants are not required to relocate or pre-train before or after implantation; they get a 90-minute outpatient surgery and go home with a device that allows them to dial in their own stimulation patterns.

In his Symposium talk, Darrow explains that muscles don't work alone to create movement; they work together in groups, or muscle synergies. Stimulation restores dormant muscle synergies after SCI, but they are not

the same as those found in nondisabled individuals. Darrow suggests that SCS produces a "new normal" spinal network for volitional control.

(During the 2021 Symposium, we heard from Uzma Samandani, a neurosurgeon and collaborator with Darrow on E-STAND. She continues to put epidural spinal cord stim devices in her SCI patients, sending them home with a device to modify stim parameters, and getting everything reimbursed by insurance.)

Aneuvo: Following a panel discussion with Edgerton, Harkema and Darrow, start-up company Aneuvo presents data from its ongoing clinical trials for non-invasive spinal cord stimulation. Co-founder **Yi-Kai Lo** will be joined by clinician **Rebecca Martin** from the Kennedy Krieger Institute in Baltimore, along with trial participant **Chris Mason-Hale**. She recently ran an 8-week trial combining skin-surface spinal cord stim with people with incomplete SCI using Aneuvo's device with intensive walking-based training. Result: better walking speed and endurance.

Rebuilding

Samuel Stupp is Professor of Materials Science and Engineering, Chemistry, Medicine, and Biomedical Engineering at Northwestern University. Restoring broken spinal cord architecture is a necessary part of nerve cell regrowth. Stupp's work with injectable super-tiny scaffolds and "danc-

Dietz found that of 1149 interventional SCI clinical trials listed at clinicaltrials.gov, 80 percent designated as "completed" do not have results posted. Wouldn't it be good to know if a human study met its endpoints? ing molecules" in a spinal cord model garnered worldwide media attention late last year. Stupp reported that his little nano-bridges delivered molecules inside a spinal cord injury site that improved function and promoted repair. In animals, he saw locomotor recovery, axonal regeneration, and reduced glial scarring. His 2021 study reported on a "mild" mouse injury. Here he will discuss newer results with a

more severely injured animal and will speculate on his hopes to take this scaffold strategy to humans.

John C. Gensel is Acting Director of the Spinal Cord and Brain Injury Research Center at the University of Kentucky College of Medicine. He studies inflammatory responses to spinal cord injury. Here he addresses his "mid career crisis:" Having spent 20 years working with suboptimal animal models, will that path actually help humans with SCI? Or do we need to refine the model to encourage data gathering that better reflects such factors

as age and sex. In other words, can the mouse model be humanized?

Valerie Dietz is a PhD candidate at Texas A&M University who talks about clinical trials for SCI. There are more trials than ever yet still we have no treatments. Could the way trials are conducted and reported be part of the problem? She found that of 1149 interventional SCI clinical trials listed at clinicaltrials.gov, 80 percent designated as "completed" do not have results posted. Wouldn't it be good to know if a human study met its endpoints? Some of those results show up in published literature but this is a major omission that must be addressed.

Jason Biundo was injured in 2019 in a climbing accident. That life-changing event shifted his research interests to the SCI field; he joined the Zhigang He lab at Boston Children's Hospital. Here, Jason advocates for the SCI community to be involved in the research process. Biundo serves on a consumer advisory board organized by the North American SCI Consortium (NASCIC) to design more relevant, patient-focused outcome measures for clinical trials for functional movements (see next session, Advocacy Workshop.)

Workshops

Barry Munro, one of the founders of NASCIC and Chief Development Officer of the Canadian Spinal Research Organization, leads the discussion on how people living with paralysis can improve the research process by becoming part of laboratory science. Hint: you don't need a PhD but it helps to know how things work — there's training coming for that. NASCIC is developing an SCI Research Advocacy Course to prepare individuals with SCI and caregivers to serve as research advocates. Munro, who is also on the Board for U2FP, will describe our "lab rats" program, which is actively placing people with SCI in labs.

Matthew Rodreick formed a translational workgroup (called T4) including scientists, clinicians, industry partners, and individuals with SCI to better understand the biomedical therapy development system and how research is and is not translated to therapies. The mission: "Drive the delivery of restorative treatments for spinal cord injury by reimagining the therapy development pipeline." Members of the group (Michael Lane, Lana Zholudeva, and Dennis Bourbeau) will raise questions and provoke conversation with attendees about the barriers, challenges, incentives and opportunities as defined from over 70 interviews conducted by the group with SCI stakeholders.

If you want to reach out to us, email Matthew Rodreick, matthewrodreick@u2fp.org

Resources

Scan here to view all of the below information with direct links to each of these resources.





The NASCIC Research Advocacy Course is designed to educate and empower individuals with spinal cord injury, researchers and clinicians, and caregivers who wish to become more involved with Clinical Research relating to SCI at all levels.



The goal of the SCITrialsFinder.net website is to allow individuals with spinal cord injury (SCI), their families and health care professionals to get common language information about clinical trials as developed by experienced clinical investigators. apply to clinical trials quickly and directly in the web site.



SciTrials.org provides the community with a way of finding clinical trials that are relevant to each individual in the fastest way possible by enabling individuals to search via location and injury details; receive email updates on new trials of interest to them; find answers for the most common questions about trials; access clinical information distilled into everyday language; apply to clinical trials quickly and directly in the web site.



The MSKTC works closely with researchers in the 14 Spinal Cord Injury (SCI) Model System Centers to develop resources for people living with spinal cord injury and their supporters. These user-friendly resources are grounded in evidence and available in a variety of formats such as printable PDF documents, videos, and slideshows.



STEM CELL FACTS is a useful publication for understanding the basics of stem cells. It is put out by the International Society for Stem Cell Research (ISSCR). The ISSCR is an independent, nonproft organization providing a global forum for stem cell research and regenerative medicine



This data sheet is a quick reference on demographic and condition statuses for 35,675 persons with SCI in the United States. Data were collected through 2021 by federally funded SCI Model Systems and five Form II (follow up) centers and entered into the National SCI Database.

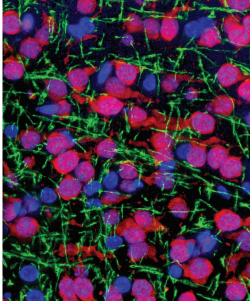
ABOUT the Art



CRACKS IN THE UNIVERSE

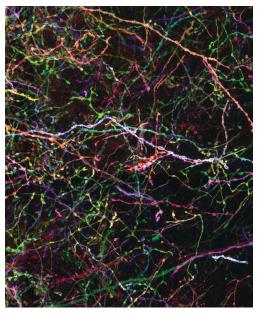
by Kristen Verhey, Ph.D.

A neuron cell body with several fine extensions (dendrites, colored blue) to transmit information along nerve circuits.



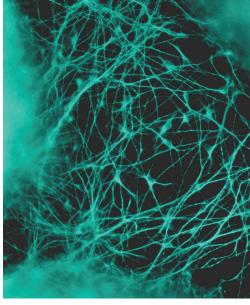
THOUGHTS OF CHERRY PIE

by Tyler Burns
Neuronal nuclei (red) within the mouse cerebral cortex, surrounded by a mesh of axons wrapped in myelin (green).



CIRCUIT CITY

by Dawen Cai, Ph.D.
A tangle of individual nerve circuits in a genetically modified mouse brain, mapped here in red, blue, and green.



UPS AND DOWNS

by Monica Bame, Ph.D.
Skin cells are reversed into embryonic stem cells that can form any cell of the body, including neurons of the brain.

AN ENTIRE HOSPITAL CREATED TO

CHALLENG IMPOSSIBLE

Together with our patients we don't see injuries, only new possibilities.

It's what happens when you combine 57 years of exceptional patient care with a facility built to provide an inspiring and healing environment.

With world-renowned physicians and clinicians, Craig H. Neilsen Rehabilitation Hospital is proud to share our exceptional capabilities and outcomes in spinal cord injury, traumatic brain injury, dual diagnosis, polytrauma, burns, and amputations. Today, we are the leading destination in the mountain west for treating complex cases.

For more information, contact: Janel Mortenson, Clinical Manager, at **801.581.3639** or visit **UOFUHEALTH.ORG/NEILSEN**









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Unite 2 Fight Paralysis'

ANNUAL SCIENCE & ADVOCACY SYMPOSIUM



NEILSEN

FOUNDATION

Neilsen Foundation funding is dedicated to supporting both programs and scientific research to improve the quality of life for those affected by and living with spinal cord injury.

www.chnfoundation.org



The ASPIRE study is currently enrolling participants who are at least 22 years of age and have a traumatic, chronic* spinal cord injury between C2 and T2, but who maintain limited function of the upper extremities. Participants must be willing to cooperate with the study requirements, including compliance with the treatment plan and completion of all office visits.

To learn more, visit Aneuvo.com/aspire-study





Caution: Investigational device. Limited by United States law to investigational use.

^{*}Chronic injury shall be defined as either (1) 12 months since initial injury or (2) a preceding six months of no significant change in motor function (<2.72 points in ISNCSCI Upper Extremity Motor Score).



www.gtservices.net

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CPN assists people affected by paralysis and other neurological conditions to help put them on the road to independence. We enable trailblazing spinal cord research and are an advocate of making the world aware of the need to conquer paralysis.

Contact us at info@conquerparalysisnow.org
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Push to Walk

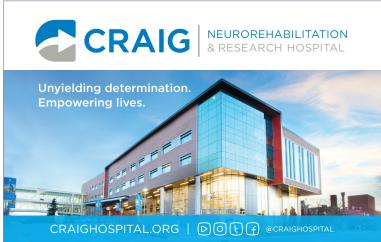


Our Mission

The mission of Push to Walk is to provide individualized workouts and resources to people with spinal cord injuries and other forms of paralysis to optimize current quality of life and to prepare for future medical advancements.



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