



16th Annual

Science & Advocacy *Symposium*



Image credit: Madeline Brown

Virtual Symposium
October 21 - 23, 2021

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WELCOME

Welcome to Unite 2 Fight Paralysis' 16th Annual Science and Advocacy Symposium. We had hoped to meet with you all in person this year, but once again are compelled to meet virtually given the ongoing challenges that COVID has placed in our paths.

That being said, we are excited to hear from you and have created a variety of spaces to facilitate meaningful exchanges in this virtual space. These include:

- Meet & Greet, Open Forum, and Session-themed Zoom discussions happening before and after the formal program each day
- Live Chat for questions during panel discussions following presentations
- Peer-to-Peer chat, which will allow you to form your own chat groups with other attendees
- Open Chat in our Networking Room
- Live and Moderated Chat with select Exhibitors
- Zoom video discussions with select Exhibitors

Each day of the Symposium will focus on 2 thematic sessions, with moderated discussions on the presentation topics of the day. We'll also host open-ended networking and social time to connect with your fellow attendees, exhibitors, and conference presenters.

Please read through Sam Maddox' overview of the symposium ("Navigating U2FP's Science & Advocacy Symposium") to prepare yourself for the topics at hand. Sam has provided a good bit of context for both what and why we have chosen to focus on certain areas of the research and the research system. 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.

So please take some time to review the program, and study our presenters' abstracts to prepare your questions and/or listen for key topics. This is a fantastic opportunity to pose your questions directly to the presenters and enrich the experience for all.

We are so very grateful to our sponsors this year. Please take some time to visit their virtual exhibiting booths 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 Rodreck
Executive Director, Unite 2 Fight Paralysis

SCHEDULE OF EVENTS

THURSDAY, OCTOBER 21, 2021

10:00 – 10:50 am

Exhibitor Visits & Networking

11:00 – 11:05 am

Opening Remarks & Welcome

Matthew Rodreck | Unite 2 Fight Paralysis

11:05 – 11:20 am

The Symposium in Context: Your Very Own Disaster Movie

Sam Maddox | Unite 2 Fight Paralysis

SESSION 1: ADVOCACY STRATEGIES

11:20 – 11:35 am

The Care-Cure Continuum

Jason Stoffer | Unite 2 Fight Paralysis

Quinn Brett, MA | National Park Service

11:35 – 11:50 am

North American Spinal Cord Injury Consortium (NASCI) – SCI Community Engagement

Barry Munro, LLB | Canadian American Spinal Research Organization

11:50 – 12:20 pm

Panel Discussion with Question & Answer Session

Jason Stoffer | Unite 2 Fight Paralysis

Quinn Brett, MA | National Park Service

Barry Munro, LLB | Canadian American Spinal Research Organization

Matthew Rodreck | Unite 2 Fight Paralysis - Moderator

12:20 – 12:35 pm

Advocate Spotlight

Franklin Elieh | NORCAL SCI

Jason Stoffer | Unite 2 Fight Paralysis - Moderator

SESSION 2: STRATEGIC COLLABORATIONS

12:35 – 12:50 pm

Changing the Pace of SCI Innovation: Lessons Learned on Bringing More Life Changing Technologies, Faster to People with SCI

Arushi Raina, MBA | Praxis Spinal Cord Institute

12:50 – 1:05 pm

CRO Role in Management of SCI Clinical Trials

Jim Hamer | DP Clinical

1:05 - 1:20 pm

Facilitating Meaningful Connections between SCI Researchers and the Community

Sabhya Rana, PhD | University of Florida

Warren Alilain, PhD | University of Kentucky College of Medicine

1:20 – 1:50 pm

Panel Discussion with Question & Answer Session

Arushi Raina, MBA | Praxis Spinal Cord Institute

Sabhya Rana, PhD | University of Florida

Warren Alilain, PhD | University of Kentucky College of Medicine

Jim Hamer | DP Clinical

Matthew Rodreick | Unite 2 Fight Paralysis - Moderator

1:50 – 2:10 pm

Advocate Spotlight

Jake Chalfin | Cure Advocacy Network - Pennsylvania

Nancy Nicholas, MBA | SCI Liaison, Blackmore Lab, Marquette University

Matthew Rodreick | Unite 2 Fight Paralysis - Moderator

2:10 – 2:25 pm

U2FP's Translational Work Group: Disruption to Direction

Matthew Rodreick | Unite 2 Fight Paralysis

2:25 – 2:55 pm

Translational Work Group Panel Discussion with Question & Answer Session

Murray Blackmore, PhD | Marquette University

Michael Lane, PhD | Drexel University

Lana Zholudeva, PhD | McDevitt Lab

Dennis Bourbeau, PhD | Case Western Reserve University

Matthew Rodreick | Unite 2 Fight Paralysis

Sam Maddox | Unite 2 Fight Paralysis - Moderator

2:55 – 3:00 pm

Wrap Up

3:00 – 3:45 pm

Exhibitor Visits & Networking

FRIDAY, OCTOBER 22, 2021

10:00 – 10:50 am

Exhibitor Visits & Networking

11:00 – 11:05 am

Welcome & Opening Remarks

SESSION 3: CLINICAL RESEARCH STRATEGIES

11:05 – 11:20 am

A Clinical Trial of Cognitive Multisensory Rehabilitation for Neuropathic Pain Relief in Adults with Spinal Cord Injury

Ann Van de Winkel, PhD, MSPT, PT | University of Minnesota

11:20 – 11:35 am

Hybrid-FES Exercise to Prevent Cardiopulmonary Declines in Acute High Level SCI

J. Andrew Taylor, PhD | Harvard Medical School

11:35 – 11:50 am

A Rebel's Approach to Improve Neurorecovery and Function after SCI

Ceren Yazar-Fisher, PT, PhD | University of Alabama - Birmingham

11:50 – 12:20 pm

Panel Discussion with Question & Answer Session

Ann Van de Winckel, PhD, MSPT, PT | University of Minnesota
J. Andrew Taylor, PhD | Harvard Medical School
Ceren Yazar-Fisher, PT, PhD | University of Alabama - Birmingham
Christel Mitrovitch, MS | U2FP Board of Directors - Moderator

12:20 – 12:40 pm

Advocate Spotlight

Cynthia Templeton | Push to Walk
Tommy Sutor, PhD | Hunter Holmes McGuire VA Medical Center
Matthew Rodreick | Unite 2 Fight Paralysis - Moderator

SESSION 4: SEXUAL FUNCTION

12:40 – 12:45 pm

Introduction & Explanation

Matthew Rodreick | Unite 2 Fight Paralysis

12:45 – 1:00 pm

Towards Recovery of Sexual Function after Chronic Spinal Cord Injury: Preclinical Studies in Male Rats

Lique Coolen, PhD | Kent State University

1:00 – 1:15 pm

Evidence of Response to Vaginal or Cervical Self-Stimulation in Women with Complete Spinal Cord Injury At or Above T10

Barry R. Komisaruk, PhD | Rutgers University-Newark

1:15 – 1:30 pm

Everlasting Love and Sexual Sustainability after SCI: The Need for Compassion!

Marcalee Alexander, MD | Sex, Disability & Telehealth Author

1:30 – 2:00 pm

Panel Discussion with Question & Answer Session

Lique Coolen, PhD | Kent State University
Barry R. Komisaruk, PhD | Rutgers University - Newark
Marcalee Alexander, MD | Sex, Disability & Telehealth Author
Matthew Rodreick | Unite 2 Fight Paralysis - Moderator

2:00 – 2:15 pm

Advocate Spotlight

Peter Nowell | Cure Advocacy Network - Ohio
Jake Beckstrom | Unite 2 Fight Paralysis - Moderator

2:15 – 2:30 pm

Beyond the Hype: Brain Computer Interfaces From Concept to Real World

Florian Solzbacher, MS, PhD | Blackrock Neurotech

2:30 – 2:50 pm

Question & Answer Session

Florian Solzbacher, MS | Blackrock Neurotech
Sasha Rabchevsky, PhD | U2FP Board of Directors - Moderator

2:50 – 3:00 pm

Wrap Up

Matthew Rodreick | Unite 2 Fight Paralysis

3:00 – 3:45 pm

Exhibitor Visits & Networking

SATURDAY, OCTOBER 23, 2021

10:00 – 10:50 am

Exhibitor Visits & Networking

11:00 – 11:05 am

Opening Remarks & Welcome

Matthew Rodreick | Unite 2 Fight Paralysis

SESSION 5: REGENERATION STRATEGIES

11:05 – 11:20 am

Transplanting Neural Cells to Repair Cervical Spinal Cord Injury

Michael Lane, PhD | Drexel University College of Medicine

11:20 – 11:35 am

3D-printed Spinal Cord Scaffold for Spinal Cord Injury Repair

Jacob Koffler, PhD, MBA | University of California San Diego

11:35 – 11:50 am

Gene Therapy for Spinal Cord Injury: Progress, Challenges, and Prospects

Murray Blackmore, PhD | Marquette University

11:50 – 12:20 pm

Panel Discussion with Question & Answer Session

Michael Lane, PhD | Drexel University College of Medicine

Murray Blackmore, PhD | Marquette University

Jacob Koffler, PhD, MBA | University of California San Diego

Sasha Rabchevsky | U2FP Board of Directors - Moderator

12:00 – 12:15 pm

Advocate Spotlight

Bob Yant | President & Founder, Axonis Therapeutics

Sam Maddox | Unite 2 Fight Paralysis - Moderator

SESSION 6: SPINAL STIMULATION STRATEGIES

12:35 – 12:50 pm

Epidural Stimulation for Spinal Cord Injury – Are We Ready For Non-Research Deployment?

Uzma Samadani, MD, PhD | University of Minnesota

12:50 – 1:05 pm

Neuromodulation: As Usual, Things Are More Complicated Than That

Keith E. Tansey, MD, PhD, FASNR, FASIA | Methodist Rehabilitation Center

1:05 – 1:20 pm

A Journey Toward Commercialization – Restoring Functions After SCI

Yi-Kai Lo, PhD | ANEUVO

1:20 – 1:50 pm

Panel Discussion with Question & Answer Session

Yi-Kai Lo, PhD | ANEUVO

Keith E. Tansey, MD, PhD, FASNR, FASIA | Methodist Rehabilitation Center

Uzma Samadani, MD, PhD | University of Minnesota

Matthew Rodreick | Unite 2 Fight Paralysis - Moderator

1:50 – 2:05 pm

Advocate Spotlight

Traci Fernandez, MBA | TRYAbility Neurorecovery

Rob Kozarek, MPH | University of Wisconsin Hospitals and Clinics

Matthew Rodreick | Unite 2 Fight Paralysis - Moderator

2:05 – 2:20 pm

Spinal Cord Gateways to Restore Neurological Functions

Jocelyne Bloch, MD | .NeuroRestore

Grégoire Courtine, PhD | .NeuroRestore

2:20 – 2:50 pm

ONWARD Panel Discussion

Grégoire Courtine, PhD | .NeuroRestore

Jocelyne Bloch, MD | .NeuroRestore

Dave Marver, MBA | ONWARD

Matthew Rodreick | Unite 2 Fight Paralysis - Moderator

2:50 – 3:00 pm

Wrap Up Presentation & Invitation

Matthew Rodreick | Unite 2 Fight Paralysis

3:00 – 3:05 pm

Closing Remarks

Matthew Rodreick | Unite 2 Fight Paralysis

3:05 – 3:45 pm

Exhibitor Visits & Networking

END OF CONFERENCE



CONFERENCE **T**ips

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 via our Virtual Exhibit Hall. Just click on the sponsor logo to access their virtual exhibit space. When visiting virtual exhibits, you can:

- Download sponsor information
- Watch promotional videos provided by the sponsor
- Converse with select sponsors via live chat or zoom video conference

Please take a moment to stop by the Virtual Exhibit Hall and learn more about their unique offerings for our Community.

VIRTUAL NETWORKING ROOM

We've provided a Virtual Networking Room where you can chat with other conference attendees, share contact info, and strengthen your ties with the SCI Community!

GET CONNECTED



Twitter: @U2FP_CureSCI - #U2FPsymposium21



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



Instagram: @u2fp

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. Please help us to nurture a space where we all feel included and where civility grows. Be sure to let the U2FP staff know if you hear or see anything that needs our attention. Thank you!

SPEAKER BIOS

A first-class line up of presenters from across the Scientific & Advocacy communities



Marcalee Alexander, MD | *President, Sustain Our Abilities; Sex, Disability & Telehealth MD, Author*

Marcalee Alexander is a PM&R physician that has practiced at multiple model SCI systems, served as ASIA President and Editor of Spinal Cord Series and Cases. She has centered on sexuality and SCI since 1990, having produced Sexuality Reborn and performed laboratory-based research to delineate how specific SCIs affect arousal and orgasm, thus, facilitating

better treatments. Having survived cancer in 2005, she adjusted her career path, adapting a more integrated approach to optimize sexual and quality of life for people with SCIs. Dr. Alexander is President of Sustain Our Abilities and cohosts Everlasting Love. She is the author of "Sexual Sustainability: A Guide to Having a Great Sex Life With a Spinal Cord Disorder" and the author of "More Sex, Less Drugs". Realizing the importance of accessibility to healthcare and the importance of addressing climate change for all, she is also Editor of Telerehabilitation: Principles and Practice and The Journal of Climate Change and Health.

Warren J Alilain, PhD | *Associate Professor, Department of Neuroscience, University of Kentucky College of Medicine; Founder, IOSCIRS*

Warren J. Alilain is an Associate Professor in the Department of Neuroscience at the University of Kentucky (UK) College of Medicine and his laboratory is a part of the Spinal Cord and Brain Injury Research Center. He completed his undergraduate studies at the University of California at San Diego. Following this he was a research assistant at the Veterans Administration (VA) Medical Center in San Diego where he was first exposed to the fields of neurodegenerative diseases and spinal cord injury (SCI). For his graduate and postdoctoral work he trained with the leading experts, Drs. Harry Goshgarian and Jerry Silver, and focused on rodent models of cervical SCI and the resulting respiratory



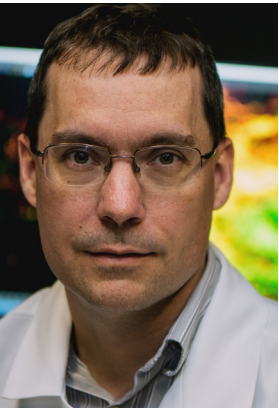
motor deficits. Dr. Alilain has continued this line of investigation in his own laboratory which he started in 2011 at MetroHealth Medical Center at Case Western Reserve University School of Medicine in Cleveland, Ohio. In 2015, he moved his laboratory to UK. In addition to cervical SCI, his research interests include neural plasticity in both injury and learning models, the therapeutic potential of stem cells, and functional electrical stimulation. Dr. Alilain's approach towards exploring strategies to restore function after SCI is through first developing a pre-clinical animal model which closely reflects the human clinical population. This includes the use of cervical contusion injuries, chronic injured animals, and "humanized" rodents in order to develop personalized therapeutic interventions. Dr. Alilain has reviewed for 20+ scientific journals and a number of federal and private funding agencies including the Craig H. Neilsen Foundation, the National Institutes of Health, National Science Foundation, the VA, and the Department of Defense. He is currently a committee member on the Research Committee of the American Spinal Injury Association. Lastly, he founded and created an online SCI seminar series now known as the International Online SCI Research Seminars (IOSCIRS) during the COVID-19 pandemic.

Jocelyne Bloch, MD | *Director, NeuroRestore & Co-Founder, ONWARD*

Jocelyne Bloch graduated in the Faculty of Medicine of Lausanne University in December 1994. She completed her neurosurgical degree in 2002, specializing in stereotactic and functional neurosurgery, and acquired an extensive experience and expertise in deep brain stimulation (DBS) and neuromodulation for movement disorders, pain and epilepsy. She is in charge of the functional neurosurgical unit at the CHUV. Very active in experimental medicine and translational neuroscience, she nourishes a profound interest in the development of new indications for DBS, and in advancing technologies and therapeutic paradigms in neuromodulation, neuro-regeneration, and cell therapy. She seeks to gather all these novel therapeutic strategies under a common umbrella that will foster optimization of



treatment options for patients suffering from neurological impairments. She is now associate Professor in the department of Neurosurgery at the University Hospital Lausanne (CHUV) and adjunct Professor in the Center for Neuroprosthetics at EPFL where together with Grégoire Courtine she is director of the Defitech Center for Interventional Neurotherapies (.NeuroRestore).



Murray Blackmore, PhD |
Associate Professor, Department of Biomedical Sciences, Marquette University

Dr. Murray Blackmore received his undergraduate degree from Stanford University, and his graduate degree in neuroscience from the University of Minnesota. During his postdoctoral training at the Miami Project to Cure Paralysis, Dr. Blackmore studied axon regeneration and adopted High Content Screening methods to identify new gene targets to promote neural

repair. Later, as a Research Assistant Professor at the Miami Project, Dr. Blackmore used a gene therapy approach to test these new gene targets for the ability to promote axon regeneration in the injured spinal cord. Dr. Blackmore is continuing this line of research at Marquette University, using viral delivery of genes to injured neurons in rodent models of spinal injury in order to foster repair.



Dennis Bourbeau, PhD |
Research Investigator, Louis Stokes Cleveland VA Medical Center; Staff Scientist, MetroHealth Medical System; Assistant Professor, Case Western Reserve University School of Medicine

Dennis Bourbeau is a research scientist with appointments at the Louis Stokes Cleveland VA Medical Center, the MetroHealth Medical Center, and Case Western Reserve University School of Medicine. Dr. Bourbeau's research

focuses on understanding the neural mechanisms underlying control of pelvic autonomic functions, including bladder, bowel, and sexual function, and on developing approaches that use electrical stimulation to restore these functions when lost to spinal cord injuries or other neurological disorders. Such approaches would provide alternatives to surgeries or drugs. With his collaborators, he has

conducted translational studies with human study participants with spinal cord injury using electrical stimulation to inhibit unwanted bladder contractions and improve urinary continence. Other projects include electrical stimulation to inhibit unwanted reflex sphincter contractions to improve bladder emptying; wireless bladder and bowel sensors for automatic control of these electrical stimulation approaches; and electrical stimulation to improve colonic motility for individuals with chronic constipation.

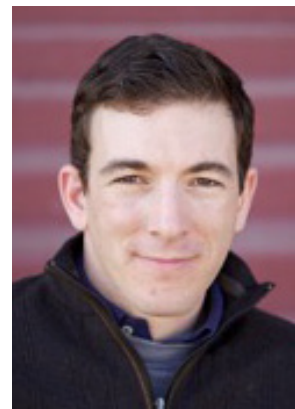
Quinn Brett, MA | *Program Analyst, National Park Service*

Quinn is an adventurer and professional athlete, tying herself to Estes Park, Colorado for the last fifteen years. When not gallivanting around the globe attempting personal goals, Quinn worked as a climbing ranger in Rocky Mountain National Park. To compliment the rescue and medical component of this job, Quinn taught Wilderness Medical Courses with Remote Medical International during the winter months. In October 2017, Quinn fell over 100 feet while climbing on El Capitan in Yosemite National Park. Quinn sustained a spinal cord injury, leaving her paralyzed from the waist down. Movement in public lands was a big part of life and vocation for Quinn. She is back with the National Park Service, broadening recreational opportunity for those with disabilities in our National Parks. Her work involves accessibility in the front country, as well as education and awareness of what makes a backcountry trail more usable.



Jake Chalfin | *Chair, PA Spinal Cord Research Advisory Committee; SCI Community Liaison, Lane Lab, Drexel University*

Jacob Chalfin first attended U2FP's Annual Symposium (formerly Working 2 Walk) in 2012 and has been a supporter of U2FP thereafter. Through his connections at U2FP, Jake and his wife teamed up with a small group of advocates in Pennsylvania and successfully lobbied for a bill that now provides \$1M in annual funding for SCI research. As a result of this bill's passage, Jake chairs the PA Health Department group, the Spinal Cord Research Advisory Committee (SCRAC), which manages



the funding process and is now in its second year. Jake also participates as a consultant with the Lane Lab SCI research department at Drexel University. This unique role provides perspective from the SCI community with the goal of creating a tangible connection between the urgent need for actionable treatments and theoretical science. Jake has a Bachelor of Science degree from Colorado State University, is a Township Supervisor and a Sales Manager for over 20 years with Laurel Valley Soils, Inc. While competing as an amateur steeplechase jockey, Jake sustained a spinal cord injury in 2010. He has a C-7 lesion ASIA B, and is paralyzed from the chest down. Post injury, Jake worked hard to live an active lifestyle traveling on vacations and participating in adaptive sports. Jake married in 2015, and he and his wife were fortunate enough to conceive through IVF and have two vibrant healthy children.

Lique Coolen, PhD | *Associate Dean, College of Arts and Sciences; Professor, Biological Sciences*



Dr. Lique Coolen is Professor of Biological Sciences at Kent State University and serves as Associate Dean in the College of Arts and Sciences. She received her Ph.D. from the University of Nijmegen in the Netherlands in 1995 and has been on faculty at the University of Cincinnati, University of Western Ontario, University of Michigan, and the University of Mississippi Medical Center. She has received numerous awards for her research and teaching, including the CJ Herrick award from the American Association of Anatomists and the Canada Research Chair in Neurobiology of Motivation and Reward.

She has published over 130 papers describing her research on spinal cord injury, drug addiction, and neuroendocrine function, and has been continuously funded by NIH and other federal agencies during the past 20 years.

Grégoire Courtine, PhD | *Director, NeuroRestore (EPFL and CHUV) & Chief Scientific Officer, ONWARD*

Grégoire Courtine was trained in Physics and Neurosciences. His passion for translational neurosciences has fueled his research in the development of neurotechnologies to improve recovery from neurological disorders. After obtaining the Chancellor Award during his post-doc at the University of California Los Angeles (UCLA), he established his own laboratory at the University of Zurich in 2008

before joining the Swiss Federal Institute of Technology Lausanne (EPFL) in 2012. He is now Full Professor of Neuroscience and Neurotechnology in the Center for Neuroprosthetics at EPFL and adjunct Professor in the department of Neurosurgery at the University Hospital Lausanne (CHUV) where together with Jocelyne Bloch he is director of the Defitech Center for Interventional Neurotherapies (.NeuroRestore). He is also Chief Scientific Officer (CSO) of GTX medical, a start-up he founded in 2014 to translate the neurotechnologies developed in his laboratory into clinical treatments.



Franklin Elieh | *Co-founder, NORCAL SCI*

Franklin was 24 when he suffered his spinal cord injury. While vacationing at a beach on the East Coast, he dove through an oncoming wave of water, not realizing there was an elevated level of sandbar behind the wave, suffering a C6, Complete, ASIA A injury. Though blessed with strong upper body motor function, he has no mobility below the chest level. He was a Santa Clara Valley Medical Center peer supporter from 2005 to 2017 and partnered with Ron Sidell and Nick Struthers as part of The Patterson Network Project before co-founding NorCal SCI. Franklin has always been employed in sales and marketing and has traveled domestically and internationally. A resident of San Jose since 1985, he graduated from San Jose State University in 1986 and has been employed in the field of sales & marketing ever since. "Back in 1989, when I suffered my injury, there were no peer support groups, no Internet, e-mail or texting. We had to literally figure things out on our own. The amount of information that today's SCI survivors must learn is exactly the same as what it was back in '89 but unfortunately, typical rehab stays are now 1/4 of what they were back when I was injured. We can help make a major difference in advancing one's 'quality of life' by communicating with them before they leave the hospital so that we can make the transition back to their home communities as comfortable as possible while showing them how they can still lead a very productive, active and fulfilling life. We want to be available to them as long as they want us."





Traci Fernandez |
Founder & Managing Partner,
TRYAbility Neurorecovery Center

Traci has owned and operated numerous organizations throughout her career and has held Executive positions at several Fortune 500 companies. Currently, Traci is a Founder and Managing Partner at TRYAbility in Chicago. TRYAbility provides Intensive Activity Based Rehabilitation services to individuals with Paralysis. TRYAbility's mission is to help patients optimize their recovery, maintain long term

health and foster a connected community. Prior to TRYAbility, Traci was a Founder and President of 3C Compassionate Care Center. As a founder of 3C, Traci successfully opened and operated two of the largest Medical Marijuana dispensaries in Illinois. Traci also was a Founder and President of Operations at iGenMedia, an application software and development company. Before opening iGen, Traci held Technical and Executive roles at Arthur Andersen, IBM and the Tribune Company. Throughout her career, Traci has excelled at both Technical and Executive positions and was twice awarded Employee of the Year for her contributions. Traci received her bachelor's degree in Information and Decision Sciences from the University of Illinois. In addition to working with U2FP, Traci founded the United Paralysis Organization after becoming paralyzed in 2008 from Transverse Myelitis. Since founding the charity, Traci has worked as an advocate, raising monies to find a cure for neurological conditions and promoting therapies for those with Spinal Cord Injuries. She currently serves on the board of directors for Unite 2 Fight Paralysis.



Jim Hamer | *Director of Spinal Cord Injury Programs, DP Clinical*

Jim Hamer works at DP Clinical, Inc., a full-service Contract Research Organization (CRO) based in Rockville, MD, specializing in SCI clinical trials. Jim has over 24 years of SCI research and clinical trial experience working with biotech, pharmaceutical and medical device companies. Jim started as a Clinical Research Associate in 1996 and monitored clinical trials in a variety of therapeutic areas including SCI studies. During this time, he also assisted in

the management of the largest benchmark acute SCI clinical trial, the Sygen GM-1 Study. During his career, Jim has managed numerous acute and chronic SCI clinical trials with pharmaceuticals,

autologous macrophages, the first in human sub-acute stem cell trials for Thoracic and Cervical SCI subjects as well as device studies. Jim understands the challenges of conducting SCI clinical trials and with his strong SCI knowledge he provides potential clients input on study design and assessments for their clinical trials. Working together on these trials to cure paralysis, Jim is hopeful that one day soon, he will witness a curative therapy approved for this debilitating injury. He currently serves on the board of directors for Unite 2 Fight Paralysis.

Jacob Koffler, PhD, MBA |
Assistant Professor of
Neurosciences, University of
California San Diego

Dr. Koffler is an assistant professor of neurosciences and the head of the Neural Engineering lab at the Department of Neurosciences, School of Medicine, UC San Diego. His lab studies axonal regeneration after traumatic injury such as spinal cord and peripheral nerve injury. His approach to promote and enhance axonal regeneration involves interdisciplinary science using 3D-printing, biomaterials, stem cells, neuroscience, and drug delivery to create biomimetic devices implanted in the injury site and integrate with the host to guide regeneration. These research programs range from feasibility studies in rodents to preclinical studies aiming to improve patients' lives.



Barry R. Komisaruk, PhD |
Distinguished Professor of Psychology,
Rutgers University-Newark

Barry R. Komisaruk is Distinguished Professor, Psychology, Rutgers University-Newark; initial appointment: 1966. Education: City University New York, B.S. Biology, 1961; Rutgers University, PhD Psychobiology, 1965; UCLA, Postdoctoral NIH Fellow, 1966. Program Director at NIH-NIGMS; Associate Editor, Journal of Sexual Medicine, Sexual Medicine Reviews. Research discoveries: first identification of brain regions activated during orgasm in women; first organic cause of PGAD (Persistent Genital Arousal Disorder) being Tarlov cysts or herniated intervertebral discs; first evidence that the Vagus nerves convey genital sensation in women with complete spinal cord injury; first



demonstration of, and mechanism underlying, the pain-blocking action of vaginal stimulation. Grant funding: NIH, NSF, NJ State, private foundations. 175 refereed research articles, 5 co-authored/edited books, including "The Science of Orgasm," published in 7 languages. Awards: Hugo F. Beigel Research Award in Sexuality; Bullough Award of the Foundation for the Scientific Study of Sexuality. Students: doctoral dissertations of 27 PhDs, 21 postdoctoral scholars.



Robert Kozarek, MPH |
Innovation and Commercialization Analyst, University of Wisconsin Hospitals and Clinics

Originally from Middleton, Wisconsin, Rob Kozarek sustained a t-4, t-5 spinal cord injury on July 11, 2006 in a car accident. He holds a bachelors and a masters in Public Health from the University of Illinois at Urbana Champaign and is currently finishing up his MBA at the University of Wisconsin. In his free time, Rob

volunteers at Shirley Ryan AbilityLab in Chicago as a peer mentor. Currently, he is working at the University of Wisconsin Hospitals and Clinics in innovation, tech transfer, and new ventures. Rob has also been involved with the Estand trial since the summer of 2019 and was implanted in November 2019. His experience with the device has been remarkable and goes far beyond what he thought was possible when he was first injured. The work being done is laying the foundation for future advances that will greatly impact the lives of people with spinal cord injuries for the better.



Michael Lane, PhD |
Associate Professor, Neurobiology & Anatomy at Drexel University College of Medicine

Michael Lane, PhD, is an associate professor in the Department of Neurobiology & Anatomy at Drexel University College of Medicine. He leads a research team consisting of two graduate students and one junior faculty member (instructor). Prior to coming to Drexel, Dr. Lane was an assistant professor in the Department of Neuroscience at the University of Florida,

McKnight Brain Institute. He also served as a lecturer in the annual NIH-funded Spinal Cord Injury Training Program at The Ohio State University from 2009 to 2013.

Yi-Kai Lo, PhD |
Chief Executive Officer, ANEUVO

Yi-Kai Lo is an entrepreneur, engineer, and scientist who started his career as an integrated circuit designer and then eventually dove deeply into the interdisciplinary field of neuroscience, neuroengineering, and bio-electronic medicine. He received his PhD in Bioengineering at the University of California, Los Angeles with the objective to investigate underlying biological mechanisms and then develop and validate relevant new devices and technologies. In 2016, he co-founded ANEUVO, a company dedicated to developing bioelectronic treatments for chronic conditions and injuries incurable through pharmaceutical agents.



Sam Maddox |
Scientific Advisory Board Director, Unite 2 Fight Paralysis

Sam Maddox is the director of the U2FP Scientific Advisory Board. He was a co-founder and former Knowledge Manager of the Reeve Foundation Paralysis Resource Center and was Reeve's primary biomedical research writer. Maddox is the author of several books, including numerous editions of the Paralysis Resource Guide. He wrote the first comprehensive history of spinal cord injury research, "Quest for Cure". Maddox wrote and published the book "Spinal Network", and founded New Mobility, the leading disability magazine in the U.S. Most recently, he published "SCI: First 90 Days", targeting newly injured individuals and their families. Maddox was a steering committee member of The Consortium for Spinal Cord Medicine, which develops evidence-based clinical practice guidelines for professionals and consumers. Maddox reported for many magazines, including Time, Money and People. Maddox is a graduate of the University of Colorado, where taught in the School of Journalism. He lives in the Los Angeles area.





Dave Marver, MBA | *Chief Executive Officer, ONWARD*

Dave Marver is CEO of ONWARD, a company creating therapies to restore movement, independence, and health for people with spinal cord injury. Prior to joining ONWARD, Dave spent almost 15 years with Medtronic in a variety of leadership positions around the world. Later, Dave served as CEO for Cardiac Science Corporation, a NASDAQ-listed company and leader in defibrillators and other cardiac equipment.

He then founded and ran a sports technology start-up, which developed two TIME Magazine Inventions of the Year. Dave has been an advisor to the World Bank's International Finance Group. He has guest lectured at the graduate business schools for Duke University, University of Washington, and University of California at Los Angeles. Dave earned a BA from Duke University and an MBA from University of California at Los Angeles. He currently resides in Lausanne, Switzerland.

Barry Munro, LLB | *Chief Development Officer, Canadian/American Spinal Research Organization*

Barry Munro is the Chief Development Officer of the Canadian/American Spinal Research Organization, which was established in 1984 to fund targeted research to maximize functional recovery and cure paralysis caused by spinal cord injury. Barry also currently holds the position of Treasurer for the North American Spinal Cord Injury Consortium, a community led organization



which has the mission to bring about unified achievements in research, care, cure, and policy by supporting collaborative efforts across the spinal cord injury community. Barry is a lawyer by trade and practiced personal injury law for over 10 years. Barry is a quadriplegic who sustained a spinal cord injury in 1987 and has been an active advocate in SCI research for over 30 years. He has served on the Board of Directors at Unite 2 Fight Paralysis for the last 4 years.

Nancy Nicholas, MBA | *SCI Community Liaison in the Blackmore Lab, Marquette University*

Nancy Nicholas received her Bachelor's of Science in Chemical Engineering from Rensselaer Polytechnic Institute in Troy, New York. She later earned a Master's in Business Administration from Seattle University. Nancy is a retired executive from the Boeing company, where she held a variety of positions starting in manufacturing research and development and culminating in program management. She sustained a spinal cord injury while mountain biking with her family in 2013. Nancy serves as the SCI Community Liaison to the Blackmore Lab at Marquette University, where she shares her lived experience and represents the SCI community in the research process.



Peter Nowell | *Co-chair, Ohio SCI Advisory Board*

Peter Nowell sustained a C4/5 incomplete spinal cord injury in 2005 as a result of a motorcycle accident. He completed his rehab at OSU Wexner Medical Center, slowly getting back to walking with a cane and driving with normal foot controls after about 12 months. Previously a Plant Manager for a plastics extrusion factory, Peter changed careers to become a cost reduction consultant for 10 years, but now dedicates his time to SCI advocacy work. About 6 years ago Peter became a certified peer mentor with the Christopher and Dana Reeve Foundation and started the central Ohio SCI Peer Mentor program with OSU. He has mentored over 50 patients, and since COVID has been running two SCI Peer support groups via zoom each month. Peter likes to travel with his wife and has had the opportunity to try many new activities since his accident; kayaking, using a snow ski-bike, hang gliding and sitting in with fellow SCI patients driving race and rally cars.





Arushi Raina, MBA |
Director of Commercialization,
Praxis Spinal Cord Institute

Arushi Raina is the Director of Commercialization at Praxis Spinal Cord Institute. She has been integral in developing, managing and overseeing the Praxis SCI Accelerate and SCI Incubate Programs, the first international incubator-accelerator programs focused on SCI technologies. Arushi has a background in healthcare, innovation and working with leadership teams. Prior to joining Praxis, she

worked as a healthcare strategy consultant, and for a traumatic brain injury start-up company. She also worked at KPMG Canada for several years in the healthcare practice, focus on public system changes and clinical program design. She holds an MBA from the Ivey Business School from Western University in Ontario, Canada, and BA honors in English and Economics from Vassar College in NY. Recognizing her leadership in healthcare, she was awarded the British Columbia Top 30 under 30 in 2020. She is a board member at Portland Hotel Society in Vancouver, BC, and a published novelist.



Sabhya Rana, PhD |
Post-doctoral Associate,
University of Florida;
Founding contributor, IOSCRS

Sabhya Rana received her B.S. in Biological sciences from University of California, Irvine (2008-2011). She worked in the lab Dr. Oswald Steward at the Reeve Irvine Research Center (2010-2013), an experience which solidified her interest in SCI research. She received her PhD in Neuroscience (2014-2018) under Drs. Carlos Mantilla and Gary Sieck at the Mayo

Clinic, where she studied mechanisms of neuroplasticity supporting respiratory recovery following SCIs. In 2019, Sabhya joined the lab of Dr. David Fuller as a postdoctoral associate at University of Florida, where she is investigating the impact of ampakines to enhance respiratory function in a pre-clinical model of SCI. Sabhya has been a founding contributor to the International Online Spinal Cord Research Seminars. She also serves on the Diversity Equity and Inclusion sub-committee and is deeply committed to supporting conversations between the SCI community and researchers in order to make meaningful strides towards a cure.

Uzma Samadani, MD, PhD |
Associate Professor, Department of
Bioinformatics and Computational
Biology, University of Minnesota

Dr. Uzma Samadani is a private practice board certified neurosurgeon in Minneapolis, MN. She has been listed as a five-time "Top Doctor in Neurosurgery" by Minneapolis-St. Paul Magazine and Minnesota Monthly. In 2018, she was on the cover of the "Top Doctors" edition with the byline "The Doctor Will Save You Now." She has also been named a "Courageous Women in Healthcare" by the Women's Health Leadership Trust. Dr. Samadani is an Associate Professor in the Dept of Bioinformatics and Computational Biology at the University of Minnesota, with a faculty appointment in Neuroscience. She is also a staff neurosurgeon at the Minneapolis Veterans Administration Medical Center. She is on the Executive Committee of the American Association of Neurological Surgeons/Congress of Neurological Surgeons Section on Neurotrauma and Critical Care and serves as Board Chair for the ThinkFirst Foundation. She is a Past-President of Women in Neurosurgery. Dr. Samadani has received more than \$5M in research grants and published more than 100 papers on brain and spinal cord injury.



Florian Solzbacher, MS, PhD |
Co-Founder, President and Executive Chairman,
Blackrock Neurotech

Dr. Solzbacher is Professor and Chair of the Department of Electrical and Computer Engineering. He also holds adjunct appointments as Professor in Materials Science and Professor of Biomedical Engineering at the University of Utah. He is a fellow of the American Institute for Medical and Biological Engineers AIMBE and a Senior Member of the Institute of Electrical and Electronics Engineers IEEE. He is Co-Founder, President and Executive Chairman of Blackrock Microsystems. His research focuses on harsh environment microsystems and materials, including implantable, wireless microsystems for biomedical and healthcare applications, and on high temperature and harsh environment compatible micro sensors. He is co-founder of several companies and member of a number of company and public private partnership advisory and reviewer boards and conference steering committees in Europe and the US. He is author of over 190 journal and conference publications, 5 book chapters and 16 pending patents.





**Jason Stoffer | *CAN Manager
& CureCast host, Unite 2 Fight
Paralysis***

Jason Stoffer lives in the Rockies of Northwest Montana with his wife and three children. He has a B.S. degree in Natural Sciences/Biology from the University of Alaska, Anchorage. Jason's love of outdoor adventure led him to work and play there as a mountaineer, long distance hiker, wild-land firefighter, search and rescue technician, EMT, and Law Enforcement Officer.

A single vehicle rollover on his commute to work one morning resulted in an L1 Spinal Cord Injury (SCI) and paraplegia. He attended Craig Hospital for inpatient rehab as well as the Brooks Cybernic Treatment Center. Jason is a strong proponent for functional recovery research. He works with U2FP as a CAN Manager and CureCast Co-host and is a Research Reviewer for CDMRP. Jason continues to pursue an active lifestyle by building a home, getting outside and engaging with his community.

**Tommy Sutor, PhD |
*Postdoctoral Research Scientist,
Hunter Holmes McGuire VA Medical Center***

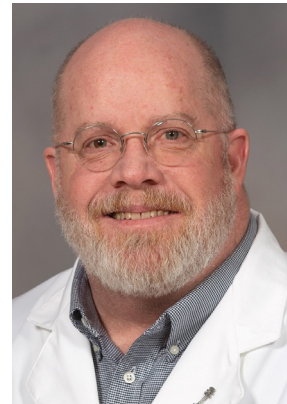
Tommy is a Postdoctoral Research Scientist in the lab of Dr. Ashraf Gorgey at the Hunter Holmes McGuire VA Medical Center in Richmond. His current research focuses on different ways that epidural and transspinal stimulation can be used to augment rehabilitation and improve function for people with spinal cord injury (SCI). His interest in SCI began when working as a trainer and Program Director of Push to Walk, a gym specializing in providing activity-based training to people with SCI and other neurological disorders. Tommy's scientific training also includes a PhD in Rehabilitation Science from the University of Florida under Dr. Emily Fox, where his primary focus was understanding breathing deficits and conducting clinical research to improve breathing after SCI. Following this, he spent a short time as a Postdoctoral Research Scientist at the Malcom Randall VA Medical Center under the mentorship of Dr. Joshua Yarrow, where he worked with animal models of SCI to understand how physical rehabilitation can be used to improve muscle and bone function. All these opportunities enabled Tommy to experience many aspects of the "bench-to-bedside" spectrum of translating findings from basic science into hands-on therapies for people with SCI. Building on all this, Tommy's career



goals are to understand how to maximize sensory and motor gains from activity-based training and physical rehabilitation, and to work with stakeholders from other aspects of the translational spectrum to understand how activity-based training may fit into multi-modal curative therapies. In addition to numerous publications and conference presentations, he is an active contributor to the Activity-Based Training Public Health Impact Working Group for Unite 2 Fight Paralysis and a member of the American Congress of Rehabilitation Medicine Spinal Cord Injury Fitness and Wellness Task Force.

**Keith E. Tansey, MD, PhD,
FASNR, FASIA | *Senior
Scientist, NeuroRobotics Lab,
Methodist Rehabilitation Center***

Keith E. Tansey, MD, PhD, FASNR, FASIA, is a Senior Scientist in the NeuroRobotics Lab of the Center for Neuroscience and Neurological Recovery at Methodist Rehabilitation Center, a Professor in the Departments of Neurosurgery and Neurobiology at the University of Mississippi Medical Center, and a Physician on the SCI Medicine and Research Services at the VA Medical Center in Jackson. Dr. Tansey has been board-certified in Neurology, Spinal Cord Injury Medicine, and Neural Repair and Rehabilitation. He has served on the boards of the American Society for Neurorehabilitation (Fellow), and the American Spinal Injury Association (Past-President and Fellow). Dr. Tansey has also recently edited a textbook, "Neurological Aspects of Spinal Cord Injury" (Springer). Dr. Tansey has studied plasticity in neural circuits for pain, autonomic function, locomotion, and upper extremity function in animal models and humans after spinal cord injury, with an interest in shaping that plasticity to improve functional recovery.



**J. Andrew Taylor, PhD |
*Principal Investigator,
Spaulding's Cardiovascular
Research Lab***

Dr. Taylor is the Principal Investigator for Spaulding's Cardiovascular Research Lab. He holds a Ph.D. in physiology from the University of Arizona. He had postdoctoral fellowships at Duke University Medical School and the Medical College of Virginia before joining the Harvard Medical School Faculty. He is currently an Associate Professor at Harvard Medical School, Associate Chair for Research in Physical



Medicine and Rehabilitation, and a Fellow of the American Heart Association. He has published over 100 research articles on topics such as the impact of microgravity on blood pressure control in astronauts, the effects of exercise on human aging, and most recently the beneficial effects of functional electrical stimulation of the legs for rowing exercise in those with spinal cord injury.



Cynthia Templeton |
Founder, Push to Walk

Cynthia Templeton has been working on the formation of an Association for the centers and professionals who provide activity based training (ABT) around the US and Canada for over 10 years. She founded Push to Walk (NJ) with her son Darren, who sustained a C5 SCI in 2004. Cynthia has seen the need for places like Push to Walk to organize themselves, share best practices and unite with one voice for the ABT programs that benefit so many people

with paralysis. Working with a core group of individuals dedicated to this mission, the Association of Neuro Activity Based Professionals (ANABP) received its 501C6 status as a trade association from the IRS. The priorities of ANABP include developing a membership base and creating a certification program for trainers. While staying involved with Push to Walk on special projects, Cynthia has been able to devote time to this important project.

Ann Van de Winckel, PhD, MSPT, PT |
Assistant Professor, Division of Physical Therapy, University of Minnesota



Ann Van de Winckel is Assistant Professor in the Division of Physical Therapy and in the Division of Rehabilitation Science, Department of Rehabilitation Medicine, Medical School, University of Minnesota. She is the Director of the Brain Body Mind Laboratory. Her research focus is to investigate brain mechanisms of how mind and body approaches may work to improve daily life of people with chronic conditions and chronic pain. She has 22 years

of experience in body awareness-related brain imaging research and research about the mechanisms of Cognitive Multisensory Rehabilitation, which is a physical therapy approach that focuses on recalibrating body awareness in adults with neurological condi-

tions and/or with chronic pain. More recently, her research has been geared towards implementing body awareness-related interventions in clinical trials and in brain research in adults with low back pain, in adults with spinal cord injury and in adults with spinal cord injury-related neuropathic pain.

Bob Yant | *President and Founder, Axonis; Former Director, Christopher and Dana Reeve Foundation; Founder, Cure Medical*

Following a 1981 accident from which Bob became a quadriplegic, Bob has dedicated himself to raising funds for basic research aimed at developing a cure for spinal cord injury. From 1982 to 2011 Bob was a member of the national board of directors of the group now known as the Christopher and Dana Reeve Foundation (until May 1999 known as the American Paralysis Association), a national, not-for-profit organization whose goal is to develop the earliest possible cure for paralysis caused by spinal cord injury. Since he began raising money for spinal cord regeneration research, Bob has raised over \$17 million. In 1989 Bob founded Research Medical, a medical supply company, which donated 10% of pre-tax profits to medical research. Research Medical also had a strong interest in hiring people who use wheelchairs, with wheelchair users comprising approximately 50% of the 50 employees in 1996, when the company was sold. Bob has been a founder or board member of 14 different charities. He served on the board of directors of the SEED (Self Employment for the Entrepeneuring Disabled) Institute, a not-for-profit group that seeks to train disabled persons to become business entrepreneurs. Bob co-founded the Newport Elementary School Foundation and the Ensign Fund. For six years Bob was the Vice President of the Newport Harbor Educational Foundation. Bob was a member of the board of directors for the Life Rolls On Foundation, which has a nationwide organization to take disabled people surfing. Bob has been very involved in his neighborhood association, serving as Treasurer, Vice President and as President. In 2007, Bob co-founded the Community Foundation of Balboa Peninsula Point. In 2008, Bob founded Cure Medical, a medical supply manufacturing company that donates 10% of net profits to spinal cord regeneration research. The success of the company has allowed significant donations to be made to spinal cord regeneration research. Bob attended the University of California at Santa Barbara and received a Bachelor of Arts degree from UC Berkeley. He lives in Newport Beach, California.



Ceren Yarar-Fisher, PT, PhD |
*Associate Professor & Director,
Rehabilitation Medicine Laboratory,
University of Alabama – Birmingham*

Dr. Yarar-Fisher is an Associate Professor at the UAB Department of Physical Medicine and Rehabilitation. Her translational research program focuses on understanding the pathophysiology of traumatic spinal cord injury (SCI) in the acute and chronic stages with the purpose of developing novel dietary and rehabilitation strategies to improve neuro-recovery, metabolism, and bowel function. Thus, her laboratory is currently developing and testing therapeutic diets and electrical stimulation programs to evaluate new ways to prevent neuronal death and promote recovery and function in the acute stages and improve body composition, gut microbiome composition, and skeletal muscle and metabolic

health in the chronic stages of SCI. She has received several NIH and NIDILRR funding to support her investigations in SCI. She recently selected as one of the 10 Outstanding Young Persons of Turkey by Junior Chamber International for her work in Academic leadership and/or accomplishment.



position at the Gladstone Institutes, working with Dr. Todd McDevitt, in efforts to build on her experience in spinal cord injury in a more translationally relevant way. Her current scientific efforts are focused on engineering human spinal interneurons from pluripotent stem cells and testing their therapeutic efficacy for promoting repair and recovery after injury and neurodegenerative disease.

Lyandysha (Lana)
Zholudeva, PhD |
*Postdoctoral Scholar in McDevitt
Lab, Gladstone Institutes*

Lyandysha (Lana) Zholudeva completed her Bachelor of Science in Chemistry with a Minor in Biophysics at Creighton University, where she worked on developing non-invasive imaging techniques for quantifying cellular metabolism. Lana then completed her graduate studies in Dr. Michael Lane's laboratory in the Department of Neurobiology & Anatomy at

Drexel University College of Medicine, focusing her work on transplantation of neural cells to repair the injured cervical spinal cord and improve respiratory function. Through this work she developed a passion for harnessing the vast therapeutic potential of stem cells by employing advanced cellular engineering techniques to tailor cells for transplantation. She then transitioned into a postdoctoral



SPEAKER Abstracts

EVERLASTING LOVE AND SEXUAL SUSTAINABILITY AFTER SCI: THE NEED FOR COMPASSION!

Marcalee Alexander, MD | *President, Sustain Our Abilities; Sex, Disability & Telehealth MD, Author*

Sexuality and SCI is a complicated topic and many variables can impact sexuality and sexual satisfaction in persons with SCI and their partners. Moreover, these issues relate not only to SCI but to other pre- and post-injury concerns such as what your sex life was like before injury, what your parents and community taught you about sex, what your level and degree of injury are, your age, your relationship status, what your sexual orientation and gender identity are, how and whether you were even educated about sexuality after injury, what medications you take, and what other medical problems you have, to name just a few.

In this presentation, Dr. Alexander will use a systematic and positive approach to assessment and treatment of sexual concerns after SCI using COMPASSION to untangle the nuances associated with ensuring sexual sustainability and satisfaction after SCI. Preinjury emotional, cultural, religious and physical issues that can affect sexuality for everyone, regardless of whether you live with a spinal cord injury or not will be discussed. The effects of specific levels of SCI on arousal and orgasm will be reviewed in a simple fashion along with how other medical concerns can affect sexual response. The impacts of medications that are prescribed, taken over the counter, and/or taken for recreation and their pro and antisexual effects will be reviewed. Finally, the need for greater attention to topics such as sexual orientation, cultural issues, sexually transmitted diseases, ensuring access to treatment for sexual concerns after SCI and treating sexual issues in people with SCIs in a more holistic approach will be discussed.

IOSCIRS: FACILITATING MEANINGFUL CONNECTIONS BETWEEN SCI RESEARCHERS AND THE COMMUNITY

Warren J Alilain, PhD | *Associate Professor, Department of Neuroscience, University of Kentucky College of Medicine; Founder, IOSCIRS*

Sabhya Rana, PhD | *Post-doctoral Associate, University of Florida; Founding contributor, IOSCRS*

The International Online Spinal Cord Injury Seminar Series (IOSCIRS) was launched in April 2020 as a platform for SCI researchers to stay connected and informed with the latest science during the 2020-2021 COVID lockdown. Our initiative has transformed into an ongoing seminar series. As of July 2021, we have hosted 95 talks that span the entire breadth of basic to clinical SCI focused science, hosted speakers from 9 countries and amassed an audience of ~900 subscribers. While the overarching goal of the IOSCIRS is to bring rigorous and topical SCI research to an open online forum, we recognize that the quality of SCI research can be greatly enhanced by improving diversity, equity, and inclusion (DEI) of our community. It is our belief that the unique platform of the IOSCIRS (online and without cost) allows a broader range of individuals to participate in the community. Furthermore, in an effort to provide the means for engagement of lay people and those living with SCIs in the research process, the IOSCIRS DEI committee has started various initiatives to directly partner up with the SCI community and to offer this platform to bridge discussions between researchers and individuals living with SCI. By making research more accessible to the broader community, we hope to improve the quality of SCI research and advance towards the ultimate goal of improving the lives of individuals living with outcomes for those who have sustained SCIs.

SPINAL CORD GATEWAYS TO RESTORE NEUROLOGICAL FUNCTIONS

Jocelyne Bloch, MD | *Director, NeuroRestore; Co-Founder, ONWARD*

Grégoire Courtine, PhD | *Director, NeuroRestore (EPFL and CHUV); Chief Scientific Officer, ONWARD*

Spinal cord injury alters the communication between the brain and spinal cord, leading to unrecoverable neurological deficits, including the loss of motor and autonomic functions. We found that epidural electrical stimulation utilizes large-diameter afferent fibers within the dorsal roots as a gateway to spatially and molecularly defined populations of neurons in the spinal cord. This understanding allowed us to design implantable neurostimulation systems that precisely modulate neural circuits involved in the regulation of motor and autonomic functions. We show that these systems restored mobility and hemodynamic stability after clinically complete spinal cord injury; but the number of addressable neurological functions with this therapeutic strategy is growing. Here, we will summarize our research findings, while highlighting our synergistic interactions with Onward Medical to turn these discoveries into commonly available treatments for people with spinal cord injury.

GENE THERAPY FOR SPINAL CORD INJURY: PROGRESS, CHALLENGES, AND PROSPECTS

Murray Blackmore, PhD | *Associate Professor of Biomedical Sciences, Marquette University*

Spinal cord injury interrupts axons that carry information between the brain and lower spinal cord, and fostering regeneration of these cut axons remains a central goal of spinal injury research. Two main obstacles prevent axon growth: the damaged spinal tissue contains factors that block axon advance, and many adult neurons fail to

reinitiate the intrinsic cellular programs that are needed for axon growth. This talk will focus on a gene therapy approach that aims to improve the innate growth ability of adult neurons. This is done by identifying genes called transcription factors that help to organize axon growth during early embryonic periods, and then using viral vectors to introduce these factors back into adult neurons after spinal injury. I will highlight recent advances in animal models that have identified more effective combinations of factors and that have verified highly effective gene delivery after chronic injury. Finally, I will discuss the integration of the gene therapy approach with alternative strategies. In summary, gene therapy may offer a practical and powerful means to enhance the regenerative ability of axons in the injured spinal cord.

THE CARE-CURE CONTINUUM

Quinn Brett, MA | *National Park Service*
Jason Stoffer | *CAN Manager & CureCast host, U2FP*

Within the context of their legislative work in Colorado, Quinn and Jason bumped into an unlikely obstacle: disability rights advocacy groups. In this one-on-one conversation, they discuss how care advocacy and the work of disability rights groups can be an impediment to the work of cure advocacy. They explore some of the historical and institutional drivers of this resistance and make an argument for why we should advance the work of care AND cure.



TOWARDS RECOVERY OF SEXUAL FUNCTION AFTER CHRONIC SPINAL CORD INJURY: PRECLINICAL STUDIES IN MALE RATS

Lique Coolen, PhD | *Associate Dean, College of Arts and Sciences; Professor, Biological Sciences*

Spinal cord injury has devastating effects on urogenital functions, including severe deficits in ejaculatory function in men and male rats. Surveys among spinal cord injured men place recovery of sexual function as a priority, but development of treatment options is limited by a lack of understanding of effects of spinal injury on the spinal ejaculation generator. This spinal ejaculation generator is comprised of a population of cells (called lumbar spinothalamic or LSt cells) that regulate ejaculation via release of several neuropeptides. These peptides are released from axonal projections to autonomic and motor nuclei in the lumbosacral spinal cord upon sensory stimulation of the dorsal penile nerve. Previous studies in male rats showed that intrathecal infusions of these neuropeptides facilitate ejaculatory reflexes. Moreover, we recently showed that spinal cord injury in male rats caused reduction in neuropeptide levels in the spinal ejaculation generator cells. Therefore, the leading hypothesis is that reduced neuropeptide synthesis and release following spinal cord injury is the major contributor to ejaculatory dysfunction. Studies in our laboratory currently test effects of neuropeptide receptor agonist infusions on ejaculatory function in male rats with chronic spinal cord injury with the goal to identify potential targets for treatment development. Findings thus far indicate that agonist treatments trigger ejaculatory reflexes and facilitate reflexes equally in spinal injured and control groups, with greater effects in injured animals. Together these results support the hypothesis that impairment of ejaculation may be partially due to disruption of neuropeptide synthesis in spinal ejaculation generator cells and suggest that some neuropeptides may be a potential therapeutic target for sexual dysfunction following spinal cord injury.

A CONTRACT RESEARCH ORGANIZATION'S ROLE IN MANAGEMENT OF SCI CLINICAL TRIALS

Jim Hamer | *Director of Spinal Cord Injury Programs, DP Clinical*

DP Clinical (DPC) is a Contract Research Organization (CRO) that specializes in SCI clinical trials. DPC provides a range of clinical trial services to pharmaceutical, biotech and medical device companies to support their clinical trial development and execution. We provide a full complement of clinical program services including clinical trial design, trial management, monitoring, data management, data analysis/biostatistics, regulatory, safety monitoring and medical writing for commercial, academic research centers, and government sponsors of clinical trials.

Per the FDA regulations (21 CFR § 312.52), sponsors may transfer responsibility for any or all of the obligations set forth in this regulation to a CRO. Any such transfer must be described in writing. CRO assuming any obligation of a sponsor must comply with these regulations and is subject to the same regulatory actions as a sponsor for failure to comply with any obligation assumed under these regulations.

The U.S. National Institutes of Health (NIH) defines a clinical trial as: "A research study in which one or more human subjects are prospectively assigned to one or more interventions (which may include placebo or other control) to evaluate the effects of those interventions on health-related biomedical or behavioral outcomes." Interventions may include: drugs, cells and biological products, surgical or radiological procedures, devices, behavioral treatments, etc. Clinical trials are the best way to learn what is safe and effective in treating people with spinal cord injury or other diseases. There are four phases in clinical trials, each one building upon the earlier results. Over the years, DPC has worked on all phases of clinical trials. Each phase has its own requirements and challenges, as well as defined outcome measures to establish safety and effectiveness of the product in treating the disease under study.

3D-PRINTED SPINAL CORD SCAFFOLD FOR SPINAL CORD INJURY REPAIR

Jacob Koffler, PhD, MBA | *Assistant Professor of Neurosciences, University of California San Diego*

More than 500,000 people in the United States suffer from spinal cord injury (SCI), with resulting substantial psychological and economic costs. Current methods for bioprinting functional tissue lack appropriate biofabrication techniques to build complex 3D micro-architectures essential for guiding cell growth and promoting tissue maturation. 3D-printing of central nervous system (CNS) structures has not been accomplished, possibly owing to the complexity of CNS architecture. I will discuss our novel 3D-printing method that can create complex CNS structure for regenerative medicine applications in the spinal cord. We print biomimetic hydrogel scaffolds tailored to the injury site which are scalable to human spinal cord sizes. We tested the ability of the 3D-printed scaffolds loaded with neural progenitor cells (NPCs) to support regeneration and form new 'neural relays' in a rodent model of spinal cord injury. We found that the injured host axons regenerate into 3D biomimetic scaffolds and synapse onto NPCs implanted into the device and that implanted NPCs in turn extend axons out of the scaffold and into the host spinal cord below the injury to restore synaptic transmission and significantly improve functional outcomes. Thus, 3D biomimetic scaffolds offer a means of enhancing CNS regeneration through precision medicine.

Team members

Jacob Koffler, Wei Zhu, Xin Qu, Oleksandr Platoshyn, Jennifer Dulin, John Brock, Lori Graham, Paul Lu, Jeff Sakamoto, Martin Marsala, Shaochen Chen, Mark Tuszynski

Funding sources

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Link to publication

<https://www.nature.com/articles/s41591-018-0296-z>

EVIDENCE OF RESPONSE TO VAGINAL OR CERVICAL SELF-STIMULATION IN WOMEN WITH COMPLETE SPINAL CORD INJURY AT OR ABOVE T10

Barry R. Komisaruk, PhD | *Distinguished Professor of Psychology, Rutgers University-Newark*

My research using brain imaging has provided evidence that in women, there is a sensory pathway from the vagina and cervix directly to the brain via the vagus nerves that completely bypasses the spinal cord. The evidence is that women with complete spinal cord injury (SCI) at T10 or above can feel vaginal and cervical self-stimulation, the stimulation produces a strong pain blocking action, and in some cases, the women reported experiencing orgasms from the self-stimulation. My hypothesis that only the vagus nerves could enable this response was confirmed by functional brain imaging that showed that in these women, the brain region to which the vagus nerves project is activated when they applied the vaginal or cervical self-stimulation. In our subsequent brain imaging research, we found that the region of the sensory cortex that responds to vaginal or cervical self-stimulation in able-bodied women, was also activated by direct electrical stimulation of the vagus nerve. That provides a rational basis for how the women with complete SCI can feel their vaginal and cervical self-stimulation. The question arises as to whether the vagus nerves have a similar function in men with complete SCI. We do not yet know, but there are intriguing hints. There is anecdotal information of men with complete SCI who state that while they have no genital sensation, they can feel prostate stimulation. In embryonic development, there is a component of the prostate in men that has the same origin as the cervix in women. Therefore, perhaps the vagus nerves also connect to the prostate in men. This is a hypothesis ready for testing. I will review substantial evidence that women and men, with and without complete SCI, can experience orgasms from stimulation of non-genital regions of the body. I will suggest a neurological basis for this widespread phenomenon.

TRANSPLANTING NEURAL CELLS TO REPAIR CERVICAL SPINAL CORD INJURY

Michael Lane, PhD | *Associate Professor, Neurobiology & Anatomy at Drexel University College of Medicine*

Impaired breathing is a devastating consequence of cervical spinal cord injury (SCI), and a huge burden to injured people that increases the risk of mortality. There are now several lines of evidence for small improvement in function, which scientists recognize as 'plasticity'. Plasticity is the nervous system making every effort to compensate for spinal cord injury, at times making new and useful connections, but unfortunately always limited and deficits persist. Our ongoing research in animal models is exploring new ways to enhance this plasticity and promote greater and lasting improvements in recovery.

A key component of plasticity in the injured spinal cord are a population of cells known as 'spinal interneurons'. Spinal interneurons contribute to the formation of new spinal pathways after injury and are known to contribute to improvements in walking, bladder function, and breathing. While there are many different types of these cells, our research has begun to identify those that contribute to breathing after injury. One treatment that capitalizes on this is the transplantation of 'neural' (neuronal and glial) progenitor cells, which are inherently rich in spinal interneurons. To improve on existing cell transplantation methods, our research now uses advanced cellular, molecular and genetic techniques to create specific populations of transplantable spinal interneurons - that are known to contribute to plasticity after injury - from stem cells. However, to make the correct cell types for transplantation is only the first step. Having these cells connect to the right host cells within the injured spinal cord is another hurdle. Our research is therefore combining activity-based therapies (rehabilitation) with cell transplantation to promote the development of appropriate neural networks capable of improving outcome. These preclinical studies are finding new ways to improve on prior transplantation efforts. Engineering spinal interneurons, and guiding the development and integration of these donor cells with the injured host spinal cord, can improve the beneficial effects of transplants and promote lasting improvements in functional recovery.

A JOURNEY TOWARD COMMERCIALIZATION – RESTORING FUNCTIONS AFTER SCI

Yi-Kai Lo, PhD | *Chief Executive Officer, ANEUVO*

ANEUVO is a bioelectronics medical device company focused on inventing new devices to treat chronic conditions and injuries that, until now, have defied conventional treatment. Unlike pharmaceutical approaches, which circulate drugs throughout the body, often lack anatomical/cellular specificity and adaptability for individuals, and cause undesired side effects with limited effectiveness, ANEUVO is delivering electrical neuromodulation to the nervous systems and leveraging the electrochemical molecular mechanisms associated with these chronic conditions. Electrical neuromodulation allows for better dosage control and more localized treatment by utilizing the body's innate electrical circuits and pathways. In this presentation, we will cover the journey of ANEUVO, starting from an academic lab moving toward the commercialization of its first product, with an emphasis on paralysis due to spinal cord injury and the company's current progress.

SYMPOSIUM IN CONTEXT: YOUR VERY OWN DISASTER MOVIE

Sam Maddox | *Scientific Advisory Board Director, Unite 2 Fight Paralysis*

Our guy is minding his own business, doing normal stuff, toasting a bagel, tossing the ball for the dog, posting breakfast and Fido online. But something wicked his way comes. He doesn't know but we do, on account of the dramatic score. Out of nowhere — bam, it lays down the mayhem. There's destruction, floods, fire, a few cars flying in the air, lots of screaming, and tons of explosions.

Chaos continues for days, and weeks. Can't anyone do anything? Our hero can no longer move. He's either a tragic figure or a role model for resilience. People are wringing hands and talking about bravery, which has zero to do with it. His real question is, since when did real life become a special effect? Since now, amigo! Life's a bitch and then you live!

Will the waters recede, will the flames be extinguished? Of course. Is there any way to regenerate the old ways? Buildings and highways, electric lines, yes. Life as before? No. Can our guy get unbroken? Maybe. Most of us around here are believers.

Can there be a happy ending? It's your pencil, script whatever you want . . . But seriously, this is not going to end well any time soon, not unless folks who find themselves in this mix unite and fight and understand the full scale of the problem, the numerous parts of a broken system we're stuck with, and for sure not until everybody insists that any solution must include the people most affected by it. Sound anything like your business? Then mind it.

NORTH AMERICAN SPINAL CORD INJURY CONSORTIUM (NASCIC) – SCI COMMUNITY ENGAGEMENT

Barry Munro, LLB | *Chief Development Officer, Canadian/American Spinal Research Organization*

There have been successful efforts in consumer engagement (patient-orientated research) in other conditions, such as Parkinson's disease, where the people living with the condition have become equally valued partners with stakeholders including research/clinical entities, industry, funders, and regulatory agencies.

The SCI community has fallen behind, and the time is now to educate and facilitate knowledge exchange between people with lived experience and the stakeholders across the spectrum of SCI research and care to become true partners in research.

NASCIC is leading the way for SCI community engagement in research. As part of this, NASCIC is developing an online SCI Research Advocacy Course. The goal of the course is to:

- Increase knowledge of the research process for those individuals living with SCI to become effective advisors.
- Educate researchers about how to create meaningful partnerships with individuals living with SCI.
- Facilitate placement of individuals living with SCI as advisors on research.

NASCIC's current engagement initiatives include working with the research community to facilitate the engagement of people with lived experience in their research by recruiting for consumer advisory boards, focus groups, study participants and assistance with survey distribution. NASCIC has a Project Review Committee (PRC) that evaluate and approve these projects and NASCIC recruits participants from its Project Engagement Database (PED).

To date, NASCIC has 98 consumers and caregivers in the PED and has partnered with 16 research projects. NASCIC is also a proud partner of SCITrials.org, a search engine for clinical trials which also allows consumers to build and share their profiles to facilitate the match-making process.

The evidence is clear that consumer engagement can have a profound impact on the quality of research and implementation of best practices; the time is now for the SCI community to close this gap and band together to become true partners in research.

CHANGING THE PACE OF SCI INNOVATION: LESSONS LEARNED ON BRINGING MORE LIFE-CHANGING TECHNOLOGIES, FASTER, TO PEOPLE WITH SCI

Arushi Raina, MBA | *Director of Commercialization, Praxis Spinal Cord Institute*

It takes an average of 17 years to translate health research into clinical practice. SCI innovations are also challenged by a relatively small market size, further challenging the business viability of SCI technologies making it to market. To address this gap, Praxis works to accelerate innovation through the Praxis Commercialization Program, which aims to bring research innovations out of the laboratory and into the marketplace where they can benefit people living with SCI. Arushi Raina will provide an overview of the Praxis Commercialization Program, including its creation, growth, and innovative approach to bring innovation to market through the Ideation Clinic, Incubation and Acceleration Programs.

The Ideation Clinic Program focuses on supporting idea stage innovations, in partnerships with universities across Canada, while the SCI Incubate program focuses on prototype technologies looking for consumer validation and early stage commercialization support. SCI Accelerate focuses on post-prototype, MVP ready technologies who have completed early stage clinical work and are looking to scale their product and gain North American and international market access.

Arushi will share how Praxis' Programs bring meaningful and ongoing engagement of persons with lived experience to transform product development. She will also describe the importance of planning for translation in pre-clinical and clinical research, including selection of appropriate outcome measures in preparing for market entry. She will share case studies working with companies such as Spiderwort and Axonis to demonstrate how integrating consumer engagement, clinical engagement, regulatory and reimbursement support can be utilized to help innovators cross the "valleys of death" and bring new innovations to market faster that can lead to improved health outcomes and establish the platform for successful, sustainable companies. She will also discuss challenges encountered, key lessons learned, and ways SCI organizations can work collaboratively to enhance SCI innovation globally.

EPIDURAL STIMULATION FOR SPINAL CORD INJURY – ARE WE READY FOR NON-RESEARCH DEPLOYMENT?

Uzma Samadani, MD, PhD | *Associate Professor, Department of Bioinformatics and Computational Biology, University of Minnesota*

People who are paralyzed or have extreme weakness after a spinal cord injury do not have many surgical options that are proven to be helpful to them. One technology that has gathered some interest in recent years is epidural spinal cord stimulation, which involves placement of an electrode lead hooked up to a pulse generator (battery) stimulating the spinal cord below the level of injury. There have been more than 50 patients implanted with these stimulators as part of clinical trials to improve quality of life after spinal cord injury. The surgery itself can be done as an outpatient and takes about 2 hours. Some of the patients who have had stimulators implanted have recovered sufficiently to walk with a walker or exoskeleton, ride an assistive cycle, recover some bowel or bladder function and regulate their own blood pressure.

This talk will discuss the placement of devices outside of the research sphere. It will talk about the challenges spinal cord injured people have faced with regards to insurance coverage, surgical complications such as infection, difficulties with programming and failure to demonstrate improvement with the device. We will also discuss strategies for overcoming these difficulties so that more spinal cord injured people can benefit from epidural stimulation.

Collaborators

Ann Parr MD, David Darrow MD, Patricia McCracken DPT, Bryan Eddy MD, David Balsler MD

Funding

Minnesota State Office of Higher Education

Publications

1. PenaPino I, Hoover C, Venkatesh S, Ahmadi A, Sturtevant D, Patrick N, Freeman D, Parr A, Samadani U, Balsler D, Krassioukov A, Phillips A, Netoff TI, Darrow D; Longterm Spinal Cord Stimulation After Chronic Complete Spinal Cord Injury Enables Volitional Movement in the Absence of Stimulation. *Frontiers Syst Neuroscience* 2020 June 30; 14:35
2. Darrow D, Balsler DY, Netoff T, Krassioukov AV, Phillips AA, Parr AM, Samadani U., Epidural Spinal Cord Stimulation facilitates immediate restoration of dormant motor and autonomic supraspinal pathways after chronic neurologically complete spinal cord injury. *J Neurotrauma*. 2019 Jan 22

BEYOND THE HYPE: BRAIN COMPUTER INTERFACES FROM CONCEPT TO REAL WORLD

Florian Solzbacher, MS, PhD | *Co-Founder, President and Executive Chairman, Blackrock Neurotech*

Implantable BCIs are transitioning from moonshot demonstrations to tangible tools that restore lost function and address a variety of neurological disorders. With it, the focus of engineering and scientific discovery needs to be driven by the practical challenges posed by real life use. The talk will comment on realistic technological trajectories: what can we do today... and what is possible tomorrow? What recent advances will enable widespread use of BCI for restoration? Finally, what objectives and areas should public and private investments focus on?

NEUROMODULATION: AS USUAL, THINGS ARE MORE COMPLICATED THAN THAT**Keith E. Tansey, MD, PhD, FASNR, FASIA |***Senior Scientist, NeuroRobotics Lab, Methodist Rehabilitation Center*

Spinal cord injury (SCI) leaves people with different neurophysiological profiles in terms of sensorimotor function, including decreased (weakness, numbness) and increased (spasticity, neuropathic pain) activity. It should then not be surprising that there is a spectrum of responses to neuromodulation.

We studied the effect of different frequencies of tonic transcutaneous spinal stimulation on stepping in 9 individuals with motor incomplete SCI. To do so, we recorded the forces used by an exoskeletal orthosis, the Lokomat, to achieve a standardized gait pattern both with and without spinal stimulation. We also recorded electromyographic (EMG) activity in different leg muscles during these studies. Participants were first studied with no stimulation and then with a spectrum of frequencies (0-100 Hz) of stimulation altered every 6-10 steps for 300 steps in a random order before returning to no stimulation.

We found 4 kinds of responses amongst the 9 participants. In 4 subjects, stimulation resulted in the robot having to provide lesser forces during swing to achieve the stepping pattern but more forces during stance. While this effect was greater at progressively higher frequencies, there were 2 participants who could be characterized as better responders and 2 as poorer responders. In 5 other subjects, stimulation resulted in the robot having to provide lesser forces in stance and greater forces in swing. Three of these subjects could be characterized as better responders and 2 as poorer responders. In the 3 better responders, the effect of stimulation at lower and higher frequencies was less profound than stimulation at mid frequencies. In reviewing the EMG records, we found a spectrum of effects on muscles ranging from suppression of muscle activity to augmentation of gait appropriate activity to even augmentation of pathological muscle activity (spasticity).

The implications of these findings on the development of neuromodulation interventions will be discussed.

Contributors

Matthias J. Krenn, Jason White, Dobrivoje S. Stokic, Keith E. Tansey

A CLINICAL TRIAL OF COGNITIVE MULTISENSORY REHABILITATION FOR NEUROPATHIC PAIN RELIEF IN ADULTS WITH SPINAL CORD INJURY

Ann Van de Winckel | *Assistant Professor, Division of Physical Therapy, University of Minnesota*

About 148,000 Americans with a spinal cord injury (SCI) have long-term neuropathic pain. Medications do not provide enough relief, and some carry a risk of addiction. Thus, we need new treatments to reduce neuropathic pain.

One of the important functions of the brain is to receive, recognize, and respond to sensory information. For example, when stepping on a hard object, the brain identifies what is felt under the foot and then sends a signal to the muscles to pull the foot away from the object.

Injury to the spinal cord causes a disconnect in communication between body and brain. Because of the altered or lack of incoming sensory information, the brain cannot identify what it senses or where in the body the sensation comes from. Consequently, this disconnect in communication about sensory information could be the reason why adults with SCI feel neuropathic pain.

We found two brain areas, critical for pain perception that are not functioning well in adults with SCI-related neuropathic pain. Our work suggests that this altered brain functioning causes neuropathic pain and that restoring their function could reduce neuropathic pain.

To test this idea, we applied a physical therapy approach called Cognitive Multisensory Rehabilitation (CMR), previously shown to restore these brain areas in adults with stroke. Our pilot study in adults with SCI showed significant neuropathic pain relief and improved sensation and movement after 6 weeks of CMR. These improvements were maintained during the 6-week follow-up. We saw changes in the key brain areas related to pain perception after CMR. The group that did not receive the CMR did not have pain reduction or improvement in sensation and movement. The results from this research will directly impact the physical health of adults who live with paralysis from SCI, and especially those who have neuropathic pain.

Funding sources related to this presentation

Academic Investment Research Program (AIRP) – Medical School, University of Minnesota

Name of the grant project

Identifying brain mechanisms of cognitive multisensory rehabilitation for neuropathic pain relief in adults with spinal cord injury

Team members (Co-PI on this grant)

Ann Van de Winckel (Dep. Rehab Med);
Leslie Morse (Dep. Rehab Med)

Links to publications

<https://www.ncbi.nlm.nih.gov.ezp2.lib.umn.edu/myncbi/1Nmglj1umN0kf/bibliography/public/>
<https://pubmed.ncbi.nlm.nih.gov/33219267/>

HYBRID-FES EXERCISE TO PREVENT CARDIOPULMONARY DECLINES IN ACUTE HIGH LEVEL SCI

J. Andrew Taylor, PhD | *Principal Investigator, Spaulding's Cardiovascular Research Lab*

My current research seeks to define approaches to improve exercise for those with high level spinal cord injuries (hiSCI). SCI increases risk for cardiovascular disease compared to the general population, but those with hiSCI have the greatest risk factors and highest mortality. This is likely because those with injuries above T3 have the most loss of skeletal and pulmonary muscle function and cannot exercise at intensities resulting in the cardioprotective effects of regular aerobic exercise. We have refined Functional Electrical Stimulation Row Training (FESRT) coupling volitional arm and electrically controlled leg exercise, resulting in large muscle mass exercise. However, despite its potential, inability to increase ventilation beyond limits set by hiSCI restricts exercise capacity. The requirements of FESRT result in a mismatch between ventilatory capacity and skeletal muscle demand. Therefore, we explored external ventilatory support (NIV) to improve exercise capacity and found that NIV increases aerobic capacity, but only in those with hiSCI and shorter injury duration. In addition, drug treatments can improve both respiratory control and exercise ventilatory responses. For example, humans case reports suggest successful treatment of respiratory dysfunction with Buspirone. Therefore, we are pursuing

a double-blind trial of FESRT with NIV or Sham and Buspirone or Placebo in acute (<3 years), hiSCI (>T3). We hypothesize that both NIV and Buspirone will improve ventilatory exercise responses, but that combined treatment will have the greatest effect. Hence, we are examining two approaches to overcome ventilatory limitations to exercise in hiSCI - one that overcomes mechanical limitations of paralyzed pulmonary muscles and one that treats loss of respiratory control, both of which may contribute to blunted exercise responses. The ultimate purpose of this research is to optimize exercise for a population that both needs and seeks the broad range of benefits that exercise can confer.

Funding

National Heart Lung and Blood Institute, R01 HL117037

Relevant Publications

PMID: 33351539, PMID: 33099664, PMID: 32795903, PMID: 31738927, PMID: 29494290, PMID: 26784276

Team Members

Glen Picard, MS, Ryan Solinsky, MD, Matt Ely, PhD

A REBEL'S APPROACH TO IMPROVE NEURORECOVERY AND FUNCTION AFTER SPINAL CORD INJURY (SCI)

Ceren Yarar-Fisher PT, PhD | *Associate Professor & Director, Rehabilitation Medicine Laboratory, University of Alabama - Birmingham*

The treatment of SCI is limited, and patients are left with few options. To date, no pharmacologic therapy has demonstrated significant improvement effects in the neurological recovery of SCI patients. Metabolic manipulation via novel diets has long been used in treating epilepsy and is increasingly being evaluated in clinical trials for a range of neurodegenerative diseases, such as Parkinson's and Alzheimer's disease, with promising results. However, diet-based treatments have only recently been applied to experimental SCI. A better understanding of the impact of nutritional interventions in the acute stages of SCI may lead to improved outcomes and lessen the severity of the injury.

The ketogenic diet (KD), offered effective neuroprotection against secondary injury cascades and improved forelimb motor function in a rat model of SCI and improved upper extremity motor function in

patients with acute SCI. These provocative findings have led us to conduct a controlled randomized trial for determining the safety of KD in people with acute SCI, the effectiveness of KD in improving neurological recovery and functional independence in people with acute SCI, and the reproducibility of KD intervention. This study is ongoing, and our preliminary results suggest that a KD may have anti-inflammatory effects that may promote neuroprotection, resulting in improved neurological recovery in SCI.

Dietary modification, although perhaps more mundane than stem-cell research, advanced genetic manipulations, and complex electrical implants, would be the most translatable and cost-efficient, and likely the safest, approach available for treating SCI.

Funding Sources

NIH/NINR (R01) and NIH NCATS (KL2)

Links to publications

PMID: 30275980, 32366293, 33445134

Area of SCI Inquiry

Adjuvant therapies to improve neurorecovery and function in traumatic SCI.

Team Members

Erika Womack PhD; Jia Li PhD, Jan Jansen, MD; Stephen Barnes, PhD; Casey Morrow, PhD; Cassandra Renfro, MD; Kelly Berg, RD, and The Center for Injury Science Research Assistance Program



LEADERSHIP TEAM

The Board & Staff of Unite 2 Fight Paralysis

BOARD OF DIRECTORS



Mike Burris – President

Mike (of Colorado Springs, Colorado) received his B.A. from the University of Iowa and has an M.S. in Systems Management from the University of Southern California. Mike has more than 35 years of experience in the world of space exploration. He served as an Air Force intelligence officer from 1977-1982. After he left the Air Force, he went to work at Science Applications International Corp. (SAIC) before retiring as an Assistant Vice President at the end of 2011.

During his career, he worked on several space related activities such as the building of the Air Force's Consolidated Space Operations Center, the Air Force Satellite Control Network, NASA's X-43 hypersonic research vehicles, and the replacement for the Space Transportation System. Prior to joining the U2FP Board he served on three boards; he served 10-years as a school board member for the Lewis-Palmer School District #38 in Colorado during the 1990s, he was a member of the International Astronautical Congress (IAC) Space Transportation Committee from 2004-2011, and he is currently a member of Rehabilitation Institute of Chicago (RIC) Foundation Board. In July 2009 while body surfing Mike suffered a C4 incomplete SCI that, although he is ambulatory, still impacts him today. Being on the U2FP Board provides him the opportunities to advance the goals of our community and advocate for all of us to live our best possible lives.



Barry Munro – Secretary

Barry (of Toronto, Canada) is the Chief Development Officer of the Canadian Spinal Research Organization and the Ontario Neurotrauma Foundation; he also serves as director of the American Spinal Research Organization. In 1987, Barry sustained a spinal cord injury in a diving accident, which resulted in quadriplegia. He has sat on multiple boards advocating for people with disabilities and particularly spinal

cord injury research. Barry graduated from Law School in 1994 and was called to the Bar in 1996. He practiced personal injury law for over 10 years. His legal experience combined with 30 years of practical experience living with a spinal cord injury make him a formidable advocate for the disabled community. Barry has dedicated his life to assisting people living with disabilities and improving their quality of life.

Alexandar “Sasha” Rabchevsky

Alexander “Sasha” Rabchevsky (of Lexington, Kentucky) is a tenured Professor of Physiology at the University of Kentucky, College of Medicine and is a core member of the Spinal Cord & Brain Injury Research Center. He is, himself, paralyzed from the chest down as the result of a motorcycle accident in 1985 which fractured his sixth thoracic vertebrae rendering him a complete T5 paraplegic. His research efforts have ensured continued extramural funding while gaining him international recognition as a leading expert in both mitochondrial dysfunction and autonomic pathophysiology following spinal cord injury, particularly the development of a hypertensive syndrome termed autonomic dysreflexia. It is the latter condition that he himself experiences on a regular basis, and his studies have advanced our understanding of how to monitor and treat such an insidious disorder. He has and continues to serve on various study sections, both federal and private, is associate editor and reviewer of various scientific journals, and his distinct studies have been funded by the National Institutes of Health, the International Spinal Research Trust, the Paralyzed Veterans Administration, the Craig H. Neilsen Foundation, the Commonwealth of Kentucky, and the University of Kentucky.





Traci Fernandez

Traci has owned and operated numerous organizations throughout her career and has held Executive positions at several Fortune 500 companies. Currently, Traci is a Founder and Managing Partner at TRYAbility in Chicago. TRYAbility provides Intensive Activity Based Rehabilitation services to individuals with Paralysis. TRYAbility's mission is to help patients optimize their recovery, maintain long term

health and foster a connected community. Prior to TRYAbility, Traci was a Founder and President of 3C Compassionate Care Center. As a founder of 3C, Traci successfully opened and operated two of the largest Medical Marijuana dispensaries in Illinois. Traci also was a Founder and President of Operations at iGenMedia, an application software and development company. Before opening iGen, Traci held Technical and Executive roles at Arthur Andersen, IBM and the Tribune Company. Throughout her career, Traci has excelled at both Technical and Executive positions and was twice awarded Employee of the Year for her contributions. Traci received her bachelor's degree in Information and Decision Sciences from the University of Illinois. In addition to working with U2PF, Traci founded the United Paralysis Organization after becoming paralyzed in 2008 from Transverse Myelitis. Since founding the charity, Traci has worked as an advocate, raising monies to find a cure for neurological conditions and promoting therapies for those with Spinal Cord Injuries.



Christel Mitrovitch

Christel Mitrovich is a proud San Diego native and graduate of San Diego State University where she earned her MS in Exercise Physiology. Christel is Director of Operations for Reneu Health, Inc., a Southern California team of clinical kinesiologists specializing in restorative exercise and activity-based therapies. Since beginning her career in 2002, Christel has helped to advance the field of neuro-recovery and expand the reach of post-traditional rehabilita-

tion services through her leadership and educational development of new practitioners. Christel has worked side-by-side top researchers and practitioners in the field of SCI rehabilitation, logging several years as a Facility Director for the NeuroRecovery Network and lending her expertise to numerous research projects. Over the years, Christel has worked closely with countless patients and their families

and made many friends in the SCI community. She has dedicated her career to advancing the field of neurorehabilitation, working to develop and bring new treatment options to those fighting paralysis. Christel is honored to join the Unite 2 Fight Paralysis Board of Directors and looks forward to contributing all she can to find a cure.

Johnnie Edwards

Johnnie Edwards (BA, JD) is a native of Birmingham, Alabama who now resides in the outskirts of Birmingham, in Helena, Alabama. She is the wife and Co-Pastor at Live By Faith Christian Center along with her husband, Pastor James Edwards. They have six adult children ranging from the ages of 35-21 years old. The youngest of the six suffered a paralyzing T6-7 injury in September of 2018. Dr. Edwards attends all Physical Therapy sessions with her son and is very involved in the healing process as his caretaker. Johnnie received her Bachelors from Faulkner University in Birmingham, Alabama, and a Doctorate of Law from the Birmingham School of Law. She is a published author, has been an advocate in the past for single mothers, and is chair and founder of the organization, "To the Polls To Vote". Johnnie is very passionate about advocating for the SCI community.



Jim Hamer

Jim (of Germantown, Maryland) is the Director of the Spinal Cord Injury (SCI) Program at DP Clinical, Inc., a full-service Contract Research Organization (CRO) based in Rockville, MD, specializing in SCI clinical trials. Jim has over 24 years of SCI research and clinical trial experience working with biotech, pharmaceutical and medical device companies. During his career, Jim has managed numerous acute and chronic SCI clinical trials with pharmaceuticals, autologous macrophages, the first in human sub-acute stem cell trials as well as device studies. Jim has worked with numerous KOLs in the SCI field and companies on SCI clinical trials which has broadened my experience, desire and passion to seek cures for the acute and chronic SCI community. Jim understands the challenges of conducting SCI clinical trials and with his strong SCI knowledge he provides potential clients input on study design and assessments for their clinical trials. Working together to cure paralysis, Jim is hopeful that one day soon, he will witness a curative therapy approved for this debilitating injury.



Quinn Brett

Quinn Brett grew up in New Hope, Minnesota. After graduating with a degree in Psychology and Leadership from the University of Minnesota she bee-lined to Estes Park, Colorado where she had visited as a youth and found her first outdoor industry job at the YMCA of the Rockies. Athletics and movement have always been a big part of Quinn's life, from running the Twin Cities Marathon, triathlons, ultra-runs and rock climbing. In 2008, Quinn returned to school to obtain a Masters Degree in Educational Psychology as well as a social studies secondary teaching certificate. Traveling and the mountain lifestyle led her away from teaching in a classroom setting, and instead she acquired her Emergency Medicine training and Search and Rescue

Training. She got hired as a climbing ranger in RMNP in the summer months, educating visitors on Public Land use and rescuing visitors with everything from twisted ankles to life-threatening injuries in precarious places. In the winter months she taught Wilderness EMT courses and traveled on various climbing expeditions. Quinn has established new routes and speed records on mountains across the globe, as well as all over the American West. In 2017, Quinn took a large climbing fall on El Capitan in Yosemite National Park, sustaining a T11 ASIA A Spinal Cord Injury. Her love to move through outdoor wilderness space continues as does her passion for educating others on spinal cord injury and research.



STAFF

Matthew Rodreick

Executive Director

Matthew (of Minneapolis, Minnesota) entered the SCI community after his son Gabe sustained a C5 injury while body surfing in Costa Rica. After leaving his position as Emergency Department Operations Supervisor for the Fairview Health System, he and Gabe traveled the world in search of the best therapeutic options, only to end up back in Minnesota advocating for cure research. Matthew led a coalition of

Minnesota SCI community advocates and researchers to leverage the state legislature in pursuit of public funding for SCI research. In 2012 he made a short documentary film featuring then Minnesota Viking punter and Twitter celebrity Chris Kluwe, spending a day in a



wheelchair. The screening of "Chris Kluwe Rolls A Mile In Someone Else's Wheels" kicked off their 2013 legislative campaign. The bill was passed in 2015 as the MN SCI/TBI Research Grant Program, and Matthew then formalized this advocacy victory by creating U2FP's Cure Advocacy Network (CAN). U2FP's CAN has since passed similar legislation in Washington, Pennsylvania and Ohio; and is actively working in Wisconsin, Colorado and Texas. He credits U2FP with providing the knowledge, focus and energy to see the real possibility of an end to the debilitating effects of paralysis.

Sam Maddox

Scientific Advisory Board Director

Sam Maddox (of Los Angeles, California) is former Knowledge Manager and spinal cord injury research writer for the Reeve Foundation. He is the author of several books related to chronic health and paralysis, including four editions of the Paralysis Resource Guide, published by the Reeve Foundation. In 1992 Maddox wrote the first comprehensive history of spinal cord injury research, "The Quest for Cure: Restoring Function After Spinal Cord Injury". He wrote and published the widely acclaimed resource book "Spinal Network", and is founder of New Mobility magazine. Maddox was a panel member on The Consortium for Spinal Cord Medicine, which develops and disseminates evidence-based clinical practice guidelines to professionals and consumers. He is currently writing and producing books as a resource for the newly injured: "SCI: First 90 Days". He has been a reporter for many magazines, including Time, Money and People. Maddox is a graduate of the University of Colorado, where he taught in the School of Journalism.



Jake Beckstrom

Cure Advocacy Network Manager

Jake Beckstrom is from Watertown, Minnesota. At the age of 16, Jake had a diving accident in a backyard pool and sustained a C4-6 spinal cord injury. A lifelong love of hunting, fishing, and the outdoors led him to pursue a path of environmental sustainability. He received a B.S. in Environmental Science at Southwest Minnesota State University, and in 2015, he received a law degree and master's degree in Environmental Law and Policy at Vermont Law School. Jake is eager to use his experience in public policy and advocacy to work with the Cure Advocacy Network to lobby for smarter spinal cord injury research funding and find a cure for paralysis.





Jason Stoffer
*Cure Advocacy Network Manager |
CureCast Host*

Jason Stoffer lives in the Rockies of Northwest Montana with his wife and three children. He has a B.S. degree in Natural Sciences/Biology from the University of Alaska, Anchorage. Jason's love of outdoor adventure led him to work and play there as a mountaineer, long distance hiker, wild-land firefighter, search and rescue technician, EMT, and Law Enforcement

Officer. A single vehicle rollover on his commute to work one morning resulted in an L1 Spinal Cord Injury (SCI) and paraplegia. He has now turned his energies toward SCI cure advocacy and participates as a co-host on the CureCast podcast.



Lucia Webb
Operations Director

Lucia Webb (of Minneapolis, Minnesota), graduated from Carleton College in 2016 with a degree in Dance and American Studies. Since graduation, she has pursued a variety of professional and artistic endeavors. Most recently, she worked as Events Coordinator at First Universalist Church. Lucia is passionate about social justice and believes that a new, more equitable world is possible. Originally from Portland,

Oregon, she loves swimming in lakes, backpacking, reading, and birdwatching. Lucia is excited to join the U2FP team, and is honored to work for such an important cause.



Ryan Romine
Program Manager

Ryan (of Minneapolis, Minnesota) has worked in managerial and administrative roles at mission driven organizations for the last 15 years. He has a strong background in communications, customer service, and project management. Impressed by U2FP's vision to end paralysis rather than simply accommodate it, Ryan is honored to lend his efforts in the comprehensive fight for a cure.

Kathy Christopherson
Finance Manager

Kathy Christopherson (of Minneapolis, Minnesota) was born and raised in New England. She enlisted in the US Navy as a medic after high school and moved to the Minneapolis area with her husband after being discharged from the service.

Kathy attended the University of Minnesota and earned a Bachelor of Science degree in Accounting. She has worked in accounting management for the last 30 years - half of that time with non-profits serving disabled and refugee clients. Kathy believes that there is nothing more satisfying than lending your efforts to a mission-driven organization, even in a small way. She is honored to be part of the Unite 2 Fight Paralysis family and our mission to find cures!



Jordan Bolton
Social Media Strategist

Jordan Bolton (of Apple Valley, Minnesota) was paralyzed from the neck down while a student at Lake Region State College in North Dakota. He suffered a C-4 and C-5 Spinal cord injury one night during a party with his basketball teammates and was given only a 5% chance of any recovery. After being airlifted to Minnesota, Jordan got to work, committing to an intense daily training schedule while also getting his Associate of Arts degree in the process. Prior to his injury in February 2018, he was a full time collegiate basketball player, working on getting a degree in law. Jordan served in student senate, honors society, and diversity club. Since his injury, Jordan tries to motivate people who follow his recovery journey on social media. Jordan is excited to use his social media influence to help U2FP grow the movement for cures!



ABOUT Unite 2 Fight Paralysis

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 spinal cord injuries 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.

Motivated by the knowledge and energy gained at the Rally, Susan, Betheny and Marilyn founded Unite 2 Fight Paralysis (U2FP) in late 2005, and a unique advocacy organization was born. In 2006 U2FP introduced their Annual Science & Advocacy Symposium (originally named “Working 2 Walk”), bringing research scientists, clinicians, investors, SCI survivors and family members together for the first time. This annual conference continues to foster knowledge, collaboration and power for all the stakeholders committed to achieving a cure for spinal cord injury.

Through U2FP’s Annual Symposium and our other initiatives, Unite 2 Fight Paralysis has had an enormous impact with and for the SCI Community. We have promoted:

- Increased collaboration among research scientists;
- A committed advocacy effort that has led to the passage of the Christopher & Dana Reeve Paralysis Act, as well as SCI Research Grant bills in Minnesota, Washington, Pennsylvania & Ohio;
- Partnerships between scientists and investors;
- Ongoing dialogues between researchers and those living with spinal cord injury;
- Individual and collective fundraising campaigns by community members to support research;

- Development of a strong core of community advocates who are empowered by their knowledge and support for each other;

Working in partnership with SCI Sucks, in 2012 U2FP created its first Scientific Advisory Board (SAB), comprised of experts in the field of neuroscience who evaluate research targeted toward repair of the chronic spinal cord injury. The SAB began work on November 1, 2012, and to date have reviewed over \$10.7 million in targeted research funding. Their reports offer educated, reliable guidance for community members to provide financial support for research.

The Cure Advocacy Network was established in 2016 following the successful passage of the Minnesota SCI/TBI Research Grant Fund. U2FP supports, trains and leads advocates to initiate state legislative efforts to fund SCI research across the United States. We have initiated these efforts in multiple states and have secured funding in 4 so far (Minnesota, Washington, Pennsylvania, Ohio). We will have added almost \$20M by the end of 2021, with 61 people with chronic injury having had an intervention.

Through the years Unite 2 Fight Paralysis has stayed true to its roots. We are governed and staffed by people who have a personal connection to paralysis; we live with it every day. We focus our time and energy on understanding the science, and bringing key players together who can advance the best therapies as quickly as possible. We are the Voice of the Cure.

Unite 2 Fight Paralysis is a 501c3 nonprofit organization, and donations are tax-deductible to the full extent of the law.

VOICE OF THE CURE A U2FP Vision

WHAT IS THE CURE – DEFINING THE VISION

Unite 2 Fight Paralysis uses the tagline, “Voice of the Cure”. What does the word “cure” mean to us? Our vision of a cure includes:

1. Restoration of one’s fully functional and healthy body, including relief from pain and spasms, return of bowel, bladder and sexual function, and recovery of normal sensation in addition to motor control. Once cured a person should be able to live independently, free of assistive devices, caregivers, catheters, etc.
2. Belief that curative therapies will come in stages, and support for advancing research into each stage as it becomes more promising.
3. Understanding that recovery will come through combinations of therapies that may vary just as much as the nature of spinal cord injuries. To this end we promote and support collaborations amongst scientists, investors, advocates, clinicians, and regulatory agencies.
4. Commitment over the long term to successive stages of recovery by helping to build the capacity necessary to optimize that recovery while refusing to be satisfied until all bodily functions are restored.

WHAT IS THE CURE – NAVIGATING THE VISION

U2FP fights for a cure for the invisible ones, the severely disabled, the families who support them, and everyone who believes that it’s possible, and more importantly urgent, to restore health and opportunity to these compromised lives.

A cure does not mean that a person receives a “magic potion” injection one day and is up and running around the next. We know that after any kind of intervention to stimulate regeneration, extensive rehabilitation will be required to properly connect the motor and sensory pathways and restore function.

Let us never forget about those with complete injuries and little or no return, those who cannot use their hands or live independently, those who have no family support and are shuffled off to nursing homes, those on ventilators who require 24/7 assistance, those who do not have the time and/or money to spend the hours necessary to maximize recovery.

We don’t want to start a “pity party”, but we do want to increase the awareness of these realities by bringing our community into effective relationships with critical decision-makers. We believe this is the best tactic to demonstrate:

- that paralysis is a progressive and burdensome condition,
- that research science shows great promise and needs financial support,
- that restoring function will save millions of dollars for SCI survivors, their families, and society.



SCIENTIFIC ADVISORY BOARD

Cure research can be overwhelming and confusing. Many smaller foundations want to fund promising research, but lack the scientific expertise to vet their funding decisions. The U2FP Scientific Advisory Board is here to fill this gap. We make that expertise available to these important members of the paralysis community.

The U2FP Scientific Advisory Board (SAB) is directing dollars from SCI foundations to research that is Relevant to Chronic Injury, Replicable, Translatable and Innovative.

Relevant to Chronic Injury Giving preference to chronic injury research allows for a greater impact to the vast majority of individuals currently living with a spinal cord injury.

Replicable Research needs to be replicated in order to move toward clinical trials. We want to identify opportunities to replicate research that shows promise for innovative treatments.

Translatable Research that is applicable to the chronic injury and has the potential to move from animal models to human trials.

Innovative We wish to identify research that is asking bold questions with conservative interpretations, rather than conservative questions with bold interpretations.



Phillip G. Popovich, PhD, *Chair*

Dr. Popovich is the Chair and Professor in the Department of Neuroscience and Director of the Center for Brain and Spinal Cord Repair at Ohio State University. His laboratory is an interdisciplinary research group dedicated to studying the complexities of CNS injury, inflammation and tissue repair. Inflammation can have devastating consequences in the spinal cord, and the lab is striving to develop novel therapies that will manipulate or over-ride normal immune

function. In addition, the Popovich lab performs replication work for the NIH. Replication is a core principle of the scientific method. To establish validity, the results of an experiment performed by one group of scientists must be evaluated by an independent group of scientists. The second group attempts to repeat the experiment of the first group, based on the original description. If the outcomes are similar, replication has been achieved and the first experiment is validated. Dr. Popovich's work in the replication process will bring a detail-oriented perspective to evaluating scientific projects.

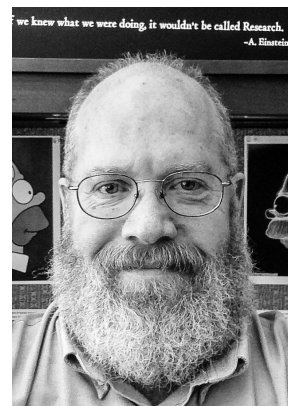
Moses V. Chao, PhD

Dr. Chao is a Professor of Cell Biology, Physiology, and Neuroscience, and professor of Psychiatry at the York University School of Medicine. He is the former President of the 42,000-member Society for Neuroscience (SFN), made up of the world's leading brain and spinal cord scientists. Dr. Chao's lab at the Skirball Institute of Biomolecular Medicine focuses on the study of molecular neurobiology and understanding the mechanisms that lead to a. the generation of neural cells and their targets, and b. the mechanisms that allow axons to project to their targets, form synapses, and signal to one another. Dr. Chao believes strongly in the necessity for more discovery science to solve the challenges of neurodegenerative disease and trauma. He brings a wealth of knowledge and experience in the field of neuroscience to our Advisory Board, and we appreciate his service.



Keith Tansey, MD, PhD

Dr. Tansey earned his BS and MS in Biology and Biomechanics from Stanford University and his MD and PhD in Neuroscience from the University of Texas Southwestern Medical Center. He then completed his Residency in Neurology at Washington University in St. Louis and then Fellowships there and at the University of California at Los Angeles in Neurorehabilitation and Spinal Cord Injury Research. He was board certified in Neurology and then subspecialty board certified in Spinal Cord Injury Medicine and Neural Repair and Rehabilitation. Dr. Tansey serves on the Board of the American Society for Neurorehabilitation and as a Board Officer for the American Spinal Injury Association and the International Society for Restorative Neurology. He recently published a book, "Neurological Aspects of





Spinal Cord Injury” with two colleagues from Heidelberg Germany. Dr. Tansey has grants to study neural plasticity after spinal cord injury in animal models and humans from the National Institutes of Disability and Rehabilitation Research, the Department of Defense, the Veterans Administration, and the Neilsen Foundation.

Steven Kirshblum, MD

Dr. Kirshblum is nationally recognized for his work in the area of spinal cord injury rehabilitation and research. He joined Kessler Institute in 1990 and currently serves as Medical Director

of the West Orange campus, as well as the Director of the Spinal Cord Injury Program. Dr. Kirshblum received his medical degree from the University of Health Sciences/Chicago Medical School and completed a residency in physical medicine and rehabilitation at Mt. Sinai Hospital in New York City, where he was a chief resident. He became board certified in 1991 and was one of the first physicians in the country to receive special certification in spinal cord injury medicine in 1998. One of the most widely respected physicians in his field, Dr. Kirshblum has delivered more than 500 lectures nationally and internationally. He is the President of the Academy of Spinal Cord Injury Professionals, Chair of the International Standards Committee for the American Spinal Association and a member of numerous advisory boards and foundations for spinal cord research.

Brian Kwon, MD, PhD, FRCSC

Dr. Kwon is the Canada Research Chair in Spinal Cord Injury and a Professor in the Department of Orthopaedics at the University of British Columbia (UBC). As a surgeon-scientist, he is particularly interested in the bi-directional process of translational research for spinal cord injury – both “bench to bedside” and “bedside back to bench”. He has worked extensively on establishing biomarkers of human SCI to facilitate human trials and is leading a national biobanking effort

in acute SCI. In his laboratory he has developed novel preclinical small and large animal models of SCI that can serve as the testing ground for therapeutic strategies and for conducting bedside back to bench translational studies. He has also led initiatives to establish a framework for how promising therapies for SCI should be evaluated in the laboratory setting prior to translation into human patients.



John Houle, PhD

Dr. Houle is a professor in the Department of Neurobiology & Anatomy at Drexel University College of Medicine, and director of the Spinal Cord Research Center. Prior to coming to Drexel, he taught at the University of Arkansas for Medical Sciences (UAMS), also serving as the director of the Division of Cellular and Molecular Neurobiology and the Neuroscience Research Core Facility at UAMS. Dr. Houle has long been interested in neurotransplantation strategies to promote structural and functional recovery after spinal cord injury. Research in his laboratory is designed to examine multiple aspects of the neuronal and glial cell response to spinal cord injury, with the intent of designing a combinatorial treatment strategy for regeneration leading to functional recovery. Dr. Houle’s career has been a pursuit of understanding how the regenerative response of injured neurons is regulated, why some neuron groups are strong regenerators while others exhibit very limited regenerative effort, and how we might enhance regeneration in acute and chronic injury conditions.



Paul Lu, PhD

Dr. Paul Lu is an Associate Adjunct Professor of Neuroscience at the University of California San Diego (UCSD) and a Research Health Science Specialist at the Veterans Administration San Diego Healthcare System. His research, motivated in part by his own spinal cord injury, focuses on neural stem cells. He explains that injured neurons of the host nervous system regenerate into stem cell transplants, forming neural connections. In this way, the injured spinal cord forms new relay circuits through the injury site to partially restore function. Dr. Lu received his PhD in molecular biology from the University of California Davis, and performed his post-doctoral research in the laboratory of Dr. Mark Tuszynski at UCSD. While much basic work remains to be done with this neural repair strategy, Dr. Lu and his colleagues hope to translate this work eventually into humans with spinal cord injury.



BACKGROUND

In September of 2012, Unite 2 Fight Paralysis - in partnership with SCI Sucks - initiated a Scientific Advisory Board. Its purpose was and is to provide investors in the SCI community with peer-reviewed recommendations on where to direct critical funding and information on specific research interests.

The SAB is made possible, in part, due to contributions from The Allergan Foundation, Cure Medical and the Hong Kong Spinal Cord Injury Foundation.

Navigating

THE SYMPOSIUM'S SCIENCE PRESENTATIONS Sam Maddox

Unite 2 Fight Paralysis' Annual Science and Advocacy Symposium is the best way to get up to speed about the science to repair the injured spinal cord. This is also the place for members of the spinal cord injury community to join in to help accelerate progress.

First, what happened to Working 2 Walk? The name was around for 16 years, but it's time for a change (Annual Science and Advocacy Symposium) because "walk" is not the most appropriate action verb. We're still advocating for cures, just recognizing that walking isn't the only goal.

You are the Symposium

As in past years, the Symposium is not just a show-and-tell for research science projects; it's also a research science interaction and an inquiry into the inefficient biomedical system that moves ideas from laboratories to doctors' offices. The SCI community plays an important role, more now than ever, in keeping things moving, keeping things real, reminding the scientific community – with your voice and your presence – that there is urgency for new treatments.

Our livestream is intuitive and effortless; it lets you mix it up with the scientists, and vice versa. Scientists, for the most part, don't interact with people with lived experience of SCI, so they are eager to meet the community. It helps humanize and motivate their work. (Note: U2FP is actively placing injured persons in SCI labs. Participation details to be shared at this year's Symposium.) So please join in. Let the scientists know what is important for you, and if you don't understand something, ask!

Keeping a Wide View

Discovery science is a big part of the Symposium, but it's only part of a greater strategy required to produce new therapies. Don't expect to hear the cure de jour in these presentations. U2FP sees a long continuum within a risky and imperfect system. Therapies start out as lab ideas that need financial backing, from government or charity. Then, if something pans out, preclinical people hand off animal results to clinical people. Human clinical trials are long and costly, and most never make it to the finish line. But, if trials get funded and go well, regulatory approvals are the next hurdle. Commercialization has its own challenges, including the crucial ingredient of insurance reimbursement.

The U2FP approach brings all the players along the translational pathway to the podium — scientists, clinicians, funders, industry people, regulatory people, along with advocates from the SCI community — to reimagine how the system can operate more smoothly while remaining focused on the needs of the community.

Cures And Cares

This year we're adding a semantic discussion: What does the word "cure" mean and is it the right word for what people are looking for? To suggest that cure means a return to full normal function as before spinal cord trauma is a tall order. U2FP sometimes uses "cures," plural, which can be defined as the development of a meaningful treatment even on a scale less than walking and based on what people say they want. Examples might include a quad gaining hand function, being better able to breathe, restored sexual function and new ways for all SCI people to address pain, or infection, or metabolic health.

Over the years we've heard it said that cure is wishful, medical-model denial, incompatible with a psychologically healthy individual living in an unjust social construct. No need to argue that. The first day of the Symposium will feature the cure word, with Barry Munro, Jason Stoffer and Quinn Brett, three individuals living with SCI. They're going to steer the dialog away from the old duality of cure versus care, setting up the context of realistic medical progress that benefits everyone.'

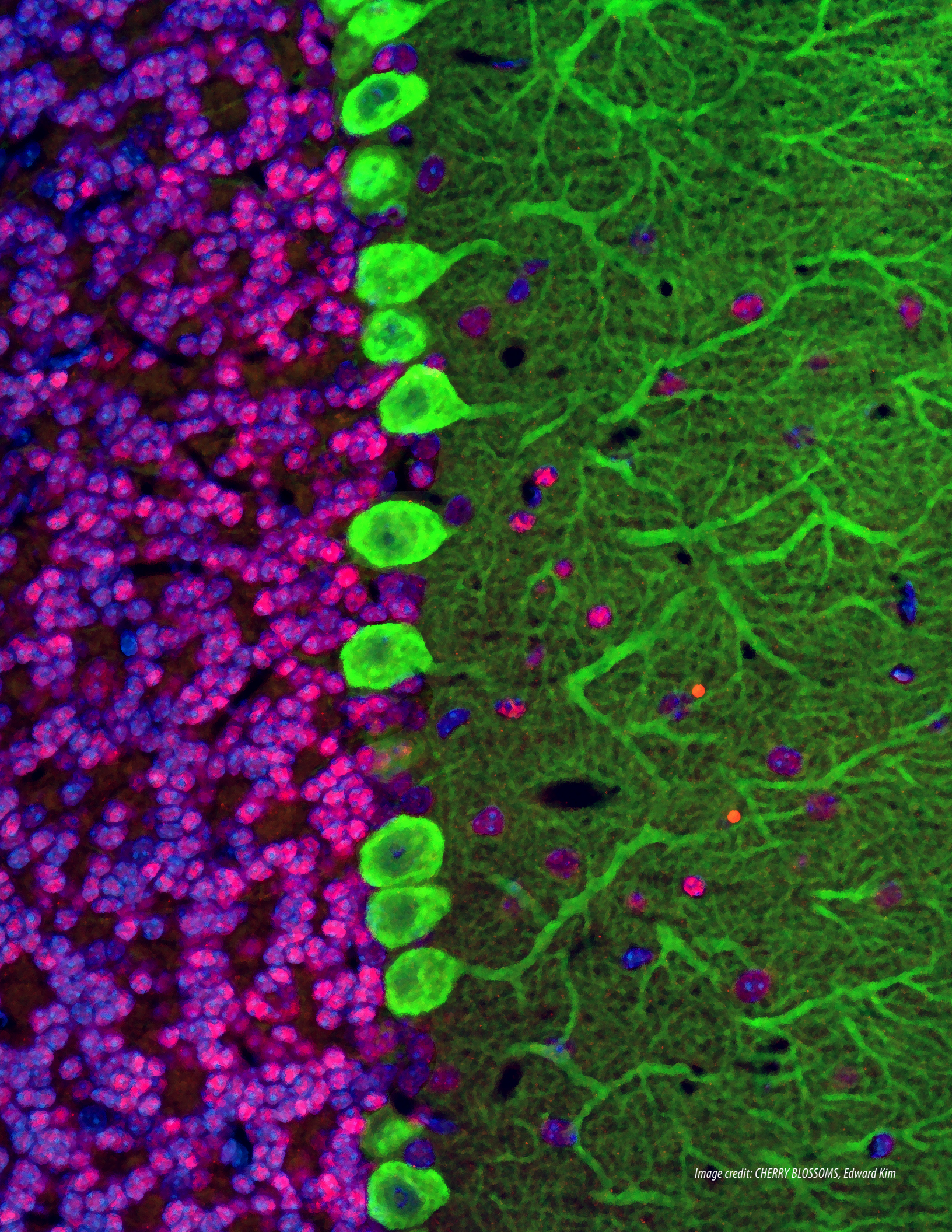
Three Rs for Recovery:

To frame the Symposium research agenda, let's start with the most basic question: What does an injury do to the cord? (Ed. note: we fully appreciate the need to study acute spinal cord injury. U2FP's focus is on chronic injury.)

The spinal cord is usually injured by a high impact force that exceeds the protective armor of the backbone, or by way of congenital dysfunction, tumors, stroke, neurological disease, surgical error, etc. Some nerve cells in the damage zone die right away, and they're gone. Nearby, others are in peril, and many succumb hours and days later as the injury site becomes toxic to cells. What if we were to REPLACE lost cells or rebuild the mangled cord structure to encourage recovery?

Some spinal cord cells survive trauma but lose their axons, the long extensions akin to wiring. Many of these cells attempt to recover and project axons – but they get stuck. Could we unstick them, maybe bump up their power, REGENERATE them, and then direct growing axons to reconnect appropriately?

Many cells and cell networks in the injured spinal cord are alive but disconnected from the primary information circuits between brain and cord. Can we REJUVENATE the spared parts of the spinal cord, tapping into inherent self-repair mechanisms, or perhaps the innate smartness of the spinal cord itself?



Cells and Scaffolds

Cell transplantation is a potential strategy that seems simple enough; a new cell replaces a missing or broken one. It's not so easy. Which cells are best to use, and when should they be transplanted? Where is the best place to put them, and what are the transplanted cells really doing — merging into the body or acting as compost? Stem cells also come with a major caution: because these cells are capable of vigorous growth, they are capable of tumorous growth.

Check out the Regeneration Strategies session, with presentations and discussion about adding cells to the injured spinal cord. Panelists include Michael Lane, a spinal cord injury researcher at Drexel University, who has focused on defining and enriching specific stem cell types. For example, the group used embryonic stem cells to engineer a subset of cells called V2A interneurons (connecting motor nerves and sensory nerves). In an animal model of cervical spinal cord injury, implanted V2A cells were

wired into the correct motor pathways and significantly restored breathing function.

Scientists are eager to meet the community. It helps humanize and motivate their work.

Jacob Koffler from the University of California - San Diego, is on the panel too. He helped design 3-D

printed customized scaffolds to implant in the spinal cord. The scaffolds contain substances that reduce inflammation to protect growing nerve cells and feature tiny channels to encourage growing nerve fibers to move toward neurons on either side of an injury. After six months, rats that received the scaffold and stem cells showed the growth of new neurons extending into the rest of the spinal cord. The animals regained some movement in their back leg joints. The published scaffold results came out two years ago in *Nature Medicine*.

Rejuvenation

Let's turn to rejuvenation, which you might think of as the rousing of nerve cells that are still alive and home where they should be, but maybe asleep, and not functioning in harmony with spinal cord nerve circuitry. In the simplest terms, how might these cells be brought back online?

One answer opens the discussion to spinal cord stimulation, based on the idea that spinal cord nerve cells can be independently smart and active, despite missing their connection to the brain. The cells have a kind of automatic programming (called a pattern generator) for messaging motor/muscle cells; this can be switched on to some degree with intensive physical therapy, but much more so by applying pulses of electrical energy.

The stimulation reaches the dormant spinal cord by way of an implanted device or via skin surface electrodes — in both cases, some people have gained meaningful voluntary function that often remains after the stim

device is off. Apparently, stimulation is more than a jolt of electricity, it encourages what scientists call plasticity — the cord circuitry remodels itself permanently.

Stim, Stimming, Stimmed

Spinal cord stim is almost certainly going to be available clinically, in large part due to the biotech startup Onward. The company (a major sponsor of the Symposium) is represented in the persons of co-founders Grégoire Courtine and Jocelyne Bloch from Lausanne University in Switzerland, and Dave Marver, CEO. They will explain their current multi-center clinical trial for noninvasive spinal cord stimulation, testing skin surface stim to see if it improves movement and strength in the hands and upper limbs of people with incomplete cervical spinal cord injury (C2-C8). They'll describe the pathway to getting stim on the market.

Also presenting at the 2021 Symposium is Yi-Kai Lo, who heads a new neuromodulation company called ANEUVO. The LA based start-up has an eye on the spinal cord stimulation market, and has also experimented with stimulation of the intestinal tract.

Clinical Stim, Now.

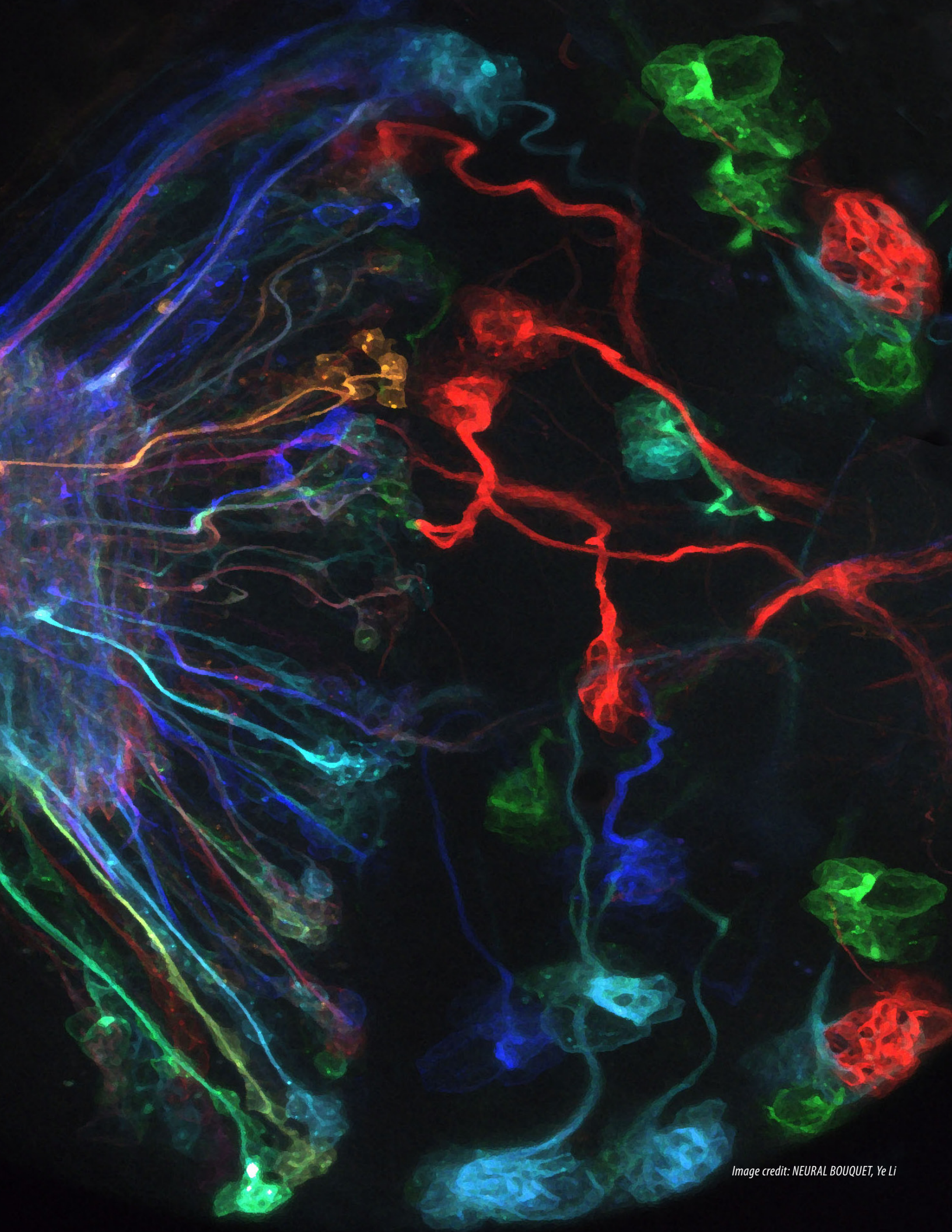
Neurosurgeon/scientist Uzma Samadani represents the avant-garde of clinical spinal cord stim. She's worked experimentally with colleagues at the University of Minnesota on a trial called ESTAND. They continue implanting epidural stimulators in people with SCI. It's surgically similar to what has been done in other stim implant trials, but without the weeks of heavy-duty physical therapy before and after surgery.

Samadani is now taking things a step further — she is putting epidural spinal cord stim devices in her SCI patients and having success getting them reimbursed by insurance companies. Here's what she says about her talk: "The surgery itself can be done as an outpatient and takes about two hours. Some of the patients who have had a stimulator implanted have recovered sufficiently to walk with a walker or exoskeleton, ride an assistive cycle, recover some bowel or bladder function and regulate their own blood pressure."

Keith Tansey will round out the stim panel. He is physician/scientist in the NeuroRobotics Lab at the Center for Neuroscience and Neurological Recovery in Jackson, Miss. Tansey also serves on the U2FP Scientific Advisory Board. He will speak about how people actually respond to spinal cord stimulation. It's not a cure and it's not a one size fits all remedy. Here is how he frames it: "I'm sort of the guy who says proof of principle does not transform instantly into the standard of care."

Regeneration

This is the functional regrowth of spinal cord nerve fibers (axons) traveling down the cord, responsible for major muscle activity. Injury causes the axons to shrink back toward the cell body. Nerve cell bodies want to grow their axons after injury, and very much try to. But axons are



confronted by an injury site that has become quite toxic and sealed off to growth. And it's not just the inhibitory environment. The nerve cells don't seem to have the juice to grow with the vigor they had when they were embryonic, when the developing nervous system was first wired up.

So, the challenges are to unblock the axon pathways and to repower the cells. Downstream, of course, the growing axon must eventually hook up with the appropriate target to restore functional circuits.

Samadani is putting epidural stim devices in her SCI patients and getting them reimbursed by insurance companies.

In theory, it's possible: growth machinery can be restarted by recoding developmental genes; barriers can be overcome by using molecular decoys or drugs to remove scar; long axons can be cultivated to extend far across the injury site, perhaps

along a scaffold. The final part—making functional connections between the spinal cord and muscle targets that might be 18 inches away—that is proving to be a challenge, but they're working on it.

This is very difficult biology and let's be clear, it's a long way from human use. What's clear to scientists is that a single approach probably won't be the answer; regeneration will almost certainly be in the form of combination therapies along the stages of axon growth.

The theme of regeneration — and collaboration — is woven through the Symposium agenda.

Collaboration Matchmaking

At the 2020 Symposium, U2FP featured a panel called Accelerating Translation with Porcine Models of Spinal Cord Injury: An Invitation to Collaborate. Candace Floyd, a neuroscientist from the University of Utah, was joined by University of Toronto scientist Molly Shoichet and University of Texas researcher Nick Jefferies. Shoichet described a new formulation for a scar-busting drug (chondroitinase, or chase) that promotes regeneration much better than other less stable versions of chase. Jefferies talked about his well-developed veterinary model for spinal cord injury; he has used chase to help paralyzed dogs.

Here's the collaborative payoff: Shoichet and Jefferies, who did not know of each other's work before U2FP's Symposium last year, got together this year, and got a grant to try her new chase formula in his paralyzed dogs.

Another collaboration, again facilitated by U2FP, involves 2021 Symposium sponsor NervGen. The biotech was formed in 2018 around the idea that a peptide drug (from the Jerry Silver lab at Case Western) promotes spinal cord axon regeneration by blocking a bad molecule called protein tyrosine phosphatase sigma. The peptide is getting close to the clinical trial stage, but has not been tested in animals larger than rodents.

So, Floyd connected with Marc DePaul, research director at NervGen. They cooked up an idea. A third combinator hypothesis was brought to the table — how about using spinal cord stimulation as an adjunct to the peptide? Floyd and DePaul met neurosurgeons Ann Parr and David Darrow from the University of Minnesota (leaders of the E-STAND trial.) The stim piece fell into place.

The group, joined by Silver, is currently lining up funding for a multidisciplinary combination chronic SCI study, using the peptide drug (NervGen/Silver) to free spinal cord axons from their bonds, plus epidural stimulation (Darrow/Parr) to optimize their growth and plasticity — using a clinically relevant large animal model (Floyd).

Incubating Innovation

A Saturday panel, Discovery to Market, is about the process of bringing an idea from the lab to the marketplace and clinic. Featured are Onward, represented by Courtine, Bloch, and Marver; and Blackrock Neurotech, the Utah firm that makes the implant arrays used for brain-computer-interface studies, in the person of Florian Solzbacher, co-founder and chairman.

Sex Research: Beyond Fertility

This year, U2FP is exploring a more specific area of SCI research: the neurobiology of sexual function. Not baby making. Pleasure.

The choice to focus specifically on sexuality research follows a series of CureCast episodes with U2FP Executive Director Matthew Rodreick and co-host Jason Stoffer, along with their guests Kelsey Peterson, Quinn

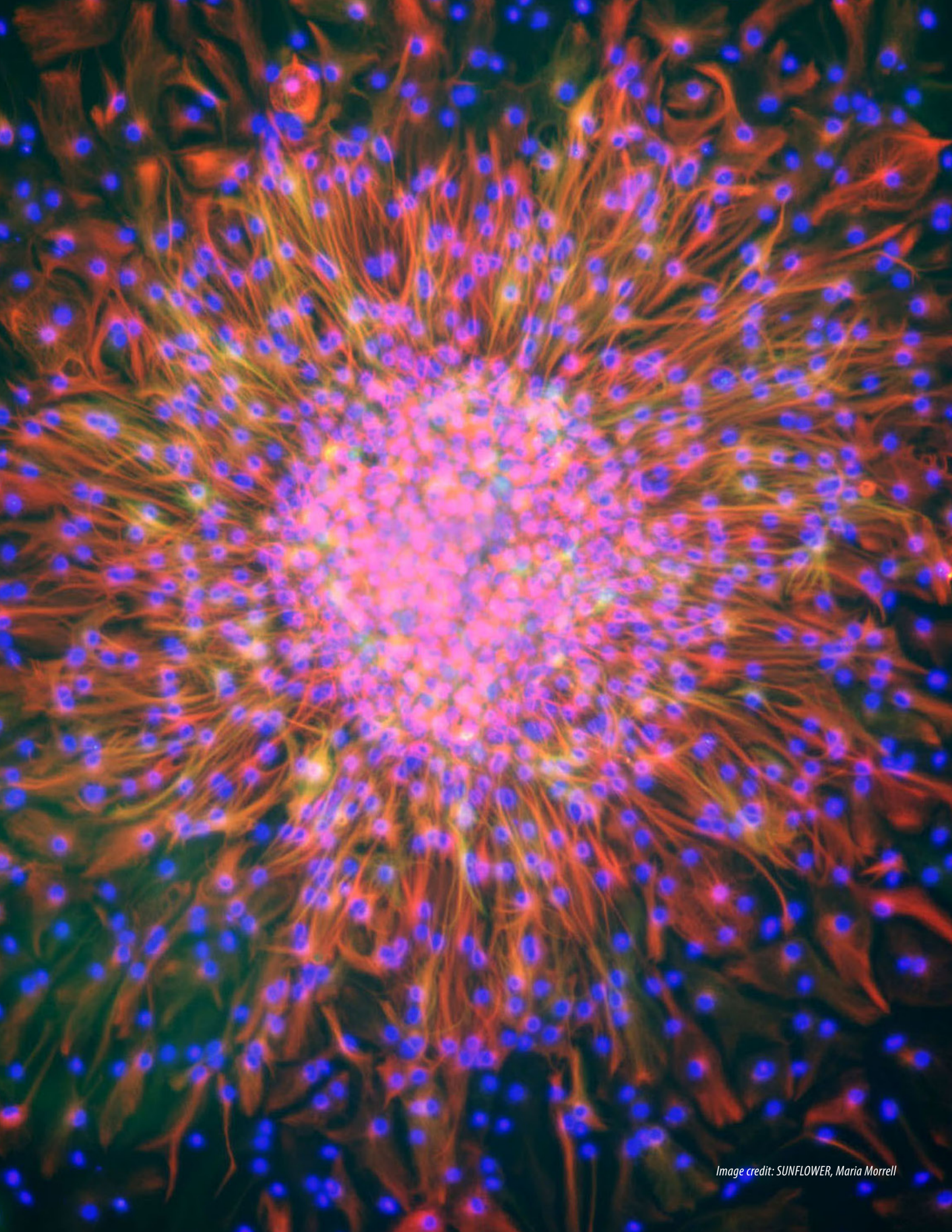


Image credit: SUNFLOWER, Maria Morrell

Brett, and Thomas Cloyd. They get personal and explicit about their experiences with sex after injury, their partners, perceptions, and feelings. The science part is being explored with a full interview with distinguished sex scientist Barry R. Komisaruk. Look for that SexCast soon, and check out the rest of the series here.

Here are the three scientists presenting work in the SCI realm that involves ejaculation and orgasm.

The aforementioned Komisaruk is a professor of psychology at Rutgers. I first heard about him 15 years ago in a non-medical publication (Wired) about reengineering female orgasm. Komisaruk described work that induced orgasm in quadriplegic women.

Komisaruk bases a lot of his work on brain imaging, showing that in women, a sensory pathway connects the vagina directly to the brain via the vagus nerve, completely bypassing the spinal cord. In a study of five women who had their vagus nerve activated by electrical stimulation, three reported experiencing orgasms. Said Komisaruk: "It was very emotional. Some of the women cried. It was a surprise to me and them because their doctors had told them after their injury that their sex life is over; they wouldn't be able to feel genital sensations."

What about men and the vagus nerve? The case isn't as strong as it is for women. Komisaruk thinks there could be a prostate-to-brain connection via the vagus nerve, but it needs more study. Meanwhile, he says he will present evidence that men and women, with and without complete SCI, can experience orgasms from stimulation of non-genital regions of the body.

Marcalee Alexander is a PM&R physician and educator who has researched sexuality and SCI, including arousal and orgasm. Her Symposium presentation is called "Everlasting Love and Sexual Sustainability after SCI: The Need for Compassion!"

Of course, sexuality may have been complicated before injury (one's level of experience, or orientation, or cultural or religious pressures, etc.) but injury can reset the notion of a sex life. Also, unfortunately, many SCI clinicians are uncomfortable talking about sex, and may do their patients a disservice with less than optimistic views — sex is dead, forget about a family, etc.

"Education of the patient with regard to his or her sexual potential and the need to be flexible in his or her sexual repertoire is followed by self-ex-

ploration and practice," Alexander wrote. "Routine follow-up is suggested after the patient's initial sexual exploration."

Lique Coolen is a biology professor at Kent State University and has for many years been focused on male ejaculation. Twenty years ago, Coolen's lab discovered what is called the spinal ejaculation generator. This is the population of cells in the lower spinal cord that regulate ejaculation via release of several neuropeptides after sensory stimulation of the penile nerve.

Generator + chemical mechanism? Could there be a biological switch for ejaculation? Yes, that's the hypothesis. Coolen's studies

in rats demonstrated that injury does indeed reduce the specific peptides, but that reinfusion triggers an ejaculation reflex. This, says Coolen, "suggests that some neuropeptides may be a potential therapeutic target for sexual dysfunction following spinal cord injury."

Sounds promising, but do rats work the same as humans? Coolen says the peptides and generator anatomy are identical across species, suggesting that human response will replicate the animal model.

Ejaculation efficiency is for sure important for sperm quality and fertility — what about pleasure? That's a big unknown at this point, says Coolen. The pathways to the brain, as Komisaruk showed in women, can be activated, although this appears less likely in males.

Coolen has plenty of leads to follow, she's got good grant support to move forward, and thinks the best solutions for sexual functional repair may eventually come by way of combination therapies, for example, add the peptide + regeneration + spinal cord stimulation.

A single approach won't be the answer; regeneration will almost certainly be in the form of combination therapies.

ABOUT THE ART

CHERRY BLOSSOMS

Edward Kim, Research Technician, Zhu Lab, Departments of Internal Medicine & Cell and Developmental Biology, University of Michigan Medical School

Located at the lower back of the brain, the cerebellum controls motor, sensory and cognitive functions. In this section, large specialized Purkinje cells (green) interact with smaller granule cells (pink). The blue nuclear staining shows numerous cells present in the cerebellum. This image depicts the beautiful and highly organized structure of the cerebellum.

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NEURAL BOUQUET

Ye Li, Graduate Student (Cai Laboratory), Department of Cell and Developmental Biology, University of Michigan Medical School

A major goal of the Obama BRAIN initiative is to understand how the individual neurons in the brain connect to one another to allow organized transmission of signals that are required for learning and memory. But that is nearly impossible to do in the human, so researchers turn to simpler models. A species of fruit fly (*Drosophila melanogaster*) has a brain of about 100,000 neurons and exhibits many complex behaviors, making it a perfect model to start with. The Cai lab has developed a new tool (FLY Brainbow) to map individual neurons of the fly brain with different colors so that their projections can be tracked. Additionally, when the cells divide, their progeny will be the same color. Here, groups of identically colored cells can be seen to form a common projection path, forming these delicate and colorful bouquets.

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ROSE GARDEN

SunJung Kim, Ph.D., Postdoctoral Fellow, Center for Organogenesis and Internal Medicine, Division of Molecular Medicine and Genetics, University of Michigan Medical School

This is a picture of an embryonic mouse brain, in a region called the cortex. Nuclei of the neural progenitor cells are stained reddish pink. These cells are proliferating to give rise to many other cells (with blue stained nuclei). The green stain marks the intercellular junctions between cells. Proper cell division in this tissue is critical for correct brain development. The human cortex at this stage has a similar structure and function; thus mouse models can be effectively used to study human brain development.

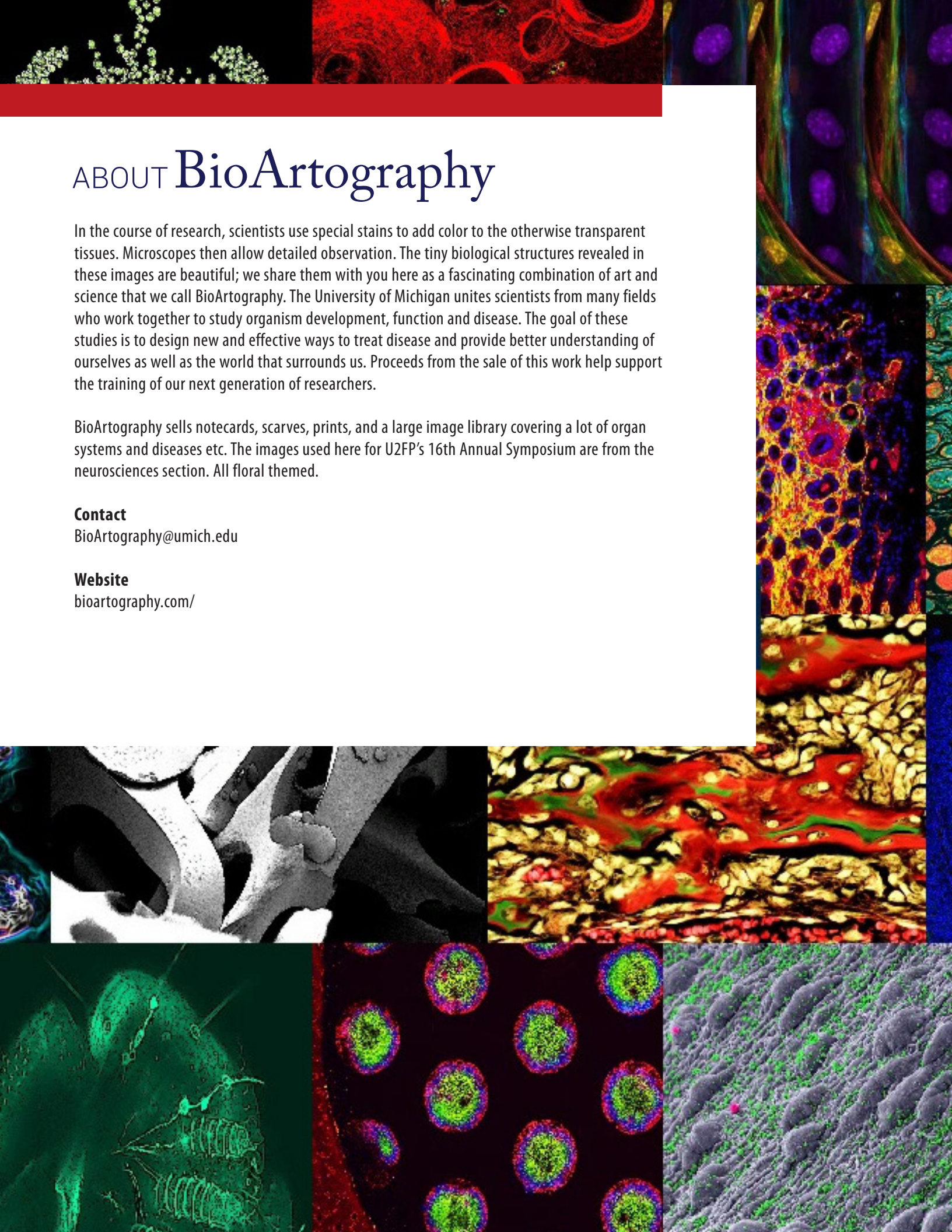
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SUNFLOWER

Maria Morrell, Ph.D., Postdoctoral Research Fellow, Department of Cell and Developmental Biology, University of Michigan Medical School

The goal of our research is study the potential of neural stem cells for repair after injury to the central nervous system. Certain regions of the adult brain contain neural stem cells that have the capability to form all types of neural cells: neurons (nerve cells), astrocytes (supporting cells) and oligodendrocytes (myelin forming cells). In this micrograph the spherical cluster of neural stem cells was stained to identify a protein typically found in astrocytes (red). The nuclei of the cells have been stained blue.

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ABOUT BioArtography

In the course of research, scientists use special stains to add color to the otherwise transparent tissues. Microscopes then allow detailed observation. The tiny biological structures revealed in these images are beautiful; we share them with you here as a fascinating combination of art and science that we call BioArtography. The University of Michigan unites scientists from many fields who work together to study organism development, function and disease. The goal of these studies is to design new and effective ways to treat disease and provide better understanding of ourselves as well as the world that surrounds us. Proceeds from the sale of this work help support the training of our next generation of researchers.

BioArtography sells notecards, scarves, prints, and a large image library covering a lot of organ systems and diseases etc. The images used here for U2FP's 16th Annual Symposium are from the neurosciences section. All floral themed.

Contact

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SciTrials.org

WHAT IS SCITRIALS.ORG?

Clinical trials are an essential part of the path to bring treatments to the Spinal Cord Injury community. Before SciTrials.org, users would have to search through hundreds of thousands of trials on ClinicalTrials.gov on every medical problem. It would be hard to find trials that were relevant to them, and have to do this on a regular basis. 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

WHO CREATED IT?

SciTrials.org was created by Niall El-Assaad, Corinne Jeanmaire (endParalysis), and members of the North American SCI Consortium (NASCI). This new tool has also been tested by members of the SCI community and endorsed by several SCI organizations.

WHO IS IT FOR?

The system is for people living with a SCI and their family members to find clinical trials that interest them with capabilities to apply for the trial. Additionally, it is for Investigators to help increase recruitment requests for their respective trials. It is also a source of reliable and easily accessible information for all clinicians in the field of SCI. The aim is to balance the needs of both communities. Resulting in more people participating in trials, and trials having more candidates to find better matches.

WHAT DOES IT DO?

The tool collects all available clinical trial data applicable to spinal cord injury on a global basis. It makes the trials easily accessible (through our basic and/or advanced selection tool)

depending on the user's situation (e.g. chronic or acute, high or low injury, complete or incomplete) and wishes (type of trial, goal). It also makes the information from the investigator much more understandable as it provides an "overview" which describes the key data about the trial in lay language. It makes it possible for the user to receive information about new trials automatically or to easily ask more information from the investigator for a given trial.

WHAT TRIALS ARE INCLUDED AND WHAT IS EXCLUDED?

In the current platform we are importing all SCI trials that are posted on ClinicalTrials.gov. We are currently working on developing support to add trials from other trial registries from around the world. Trials are excluded from the platform if:

- they are not about spinal cord injury;
- they are not taking place at a University, Hospital, or Research Institution;
- they are trials that are asking for money for the research procedures or treatment.

Due to feedback from the community, we are initially writing lay-language overviews for the trials that are involving an intervention of some sort.

HOW IS INFORMATION PROVIDED IN THE SIGN UP FORM SECURED?

All information is protected by Google Firebase, which is a development platform provided and secured by Google.

WHO IS LIABLE FOR INFORMATION ON THE SITE?

All the information comes from publically available information on ClinicalTrials.gov or is obtained from the trial investigators. The trial investigators are responsible for the information they provide relating to trials.

The platform itself is covered by indemnity insurance under the American Spinal Research Organization doing business as NASCI.

SciTrialsFinder.net

WHY USE SCITRIALSFINDER.NET?

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 (we call these curations or curated trials). We have started by curating trials looking for participants for studies of interventions targeting improvement of neurological and related functional outcomes, currently underway in North America, Europe and Australia. In addition to the curated trials, users can also read about all SCI related trials from clinicaltrials.gov.

KEEP IN MIND...

Clinical trials of spinal cord injury are conducted with the goal to advance knowledge of the injured nervous system and to generate ways to improve recovery and life after the injury. It is important to understand that trials are conducted because we don't know if an experimental method is or is not effective. Please keep this in mind as you review clinical trials that you may be eligible for.

Please help us improve our site by providing feedback at feedback@SciTrialsFinder.net





This data sheet is a quick reference on demographics and the use of services by people with spinal cord injury in the United States (U.S.). Much of the information reflects recent data collected since 2015. Historical information reflects data collected since the early 1970s.

The National Spinal Cord Injury Database is a prospective longitudinal multicenter study that currently captures data from an estimated 6% of new SCI cases in the United States. The database has demographic and condition status data through 2020 for 34,734 people with SCI.

National SCI Statistical Center
515 Spain Rehabilitation Center
1717 6th Avenue South
Birmingham, AL 35233-7330

For Statistics: 205-934-3342
For Business: 205-934-3320
TDD: 205-934-4642
FAX: 205-934-2709
E-mail: NSCISC@uab.edu
Website: uab.edu/NSCISC

Incidence

The 2020 population size in the United States was estimated to be about 331 million people. The most recent estimate of the annual incidence of spinal cord injury (SCI) is approximately 54 cases per one million people in the United States, which equals about 17,900 new SCI cases each year. New SCI cases do not include those who die at the location of the incident that caused the SCI.

- **Data Source:** Jain NB, Ayers GD, Peterson EN, et al. Traumatic spinal cord injury in the United States, 1993-2012. JAMA. 2015;313(22):2236-2243.

Prevalence

The estimated number of people with SCI living in the United States is approximately 296,000 persons, with a range from 252,000 to 373,000 persons.

- **Data Source:** Lasfargues JE, Custis D, Morrone F, Carswell J, Nguyen T. A model for estimating spinal cord injury prevalence in the United States. Paraplegia. 1995;33(2):62-68.

Age at Injury

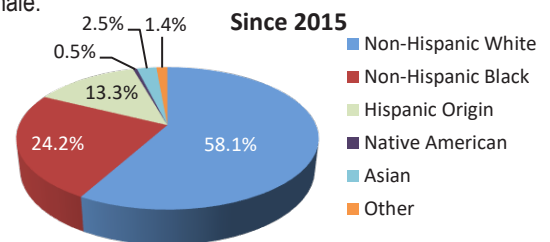
The average age at injury has increased from 29 years during the 1970s to 43 since 2015.

Sex

About 78% of new SCI cases since 2015 are male.

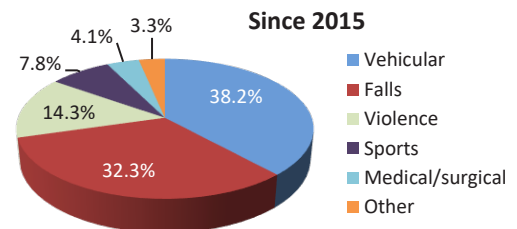
Race/Ethnicity

Recently, about 24% of injuries have occurred among non-Hispanic blacks, which is higher than the proportion of non-Hispanic blacks in the general population (13%).



Cause

Vehicle crashes are the most recent leading cause of injury, closely followed by falls. Acts of violence (primarily gunshot wounds) and sports/recreation activities are also relatively common causes. A customizable Leading Causes of SCI tool is at uab.edu/NSCISC.

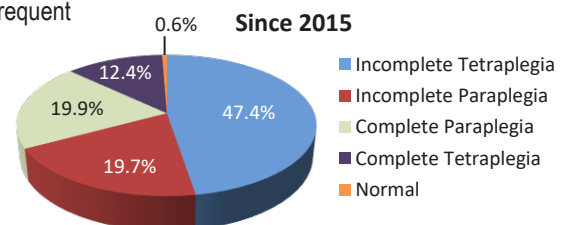


Lengths of Stay

Lengths of stay in the hospital acute care unit have declined from 24 days in the 1970s to 11 days recently. Rehabilitation lengths of stay have also declined from 98 days in the 1970s to 30 days recently.

Neurological Level and Extent of Lesion

Recently, incomplete tetraplegia is the most frequent neurological category. The frequency of incomplete and complete paraplegia is virtually the same. Less than 1% of persons experienced complete neurological recovery by the time of hospital discharge.



Education

Since 2015, about a quarter of persons with SCI have a college degree at the time of their injury, compared with 46% of people who survived 40 years of injury.

Education (%)	At Injury	Year 1	Year 10	Year 20	Year 30	Year 40
High School Only	51.7	52.2	50.2	46.4	41.8	34.6
College or Higher	23.7	26.1	27.6	26.7	34.9	45.6

Occupational Status

Since 2015, 18% of persons with SCI are employed at year 1 post-injury. The employment rate increases over time to 32% at 30 or more years post injury.

Status (%)	At Injury	Year 1	Year 10	Year 20	Year 30	Year 40
Employed	68.3	18.2	24.8	30.0	31.9	32.3
Student	7.6	7.0	2.8	0.8	0.3	0.0

Marital Status

Since 2015, the percentage of people who are married is relatively consistent up to year 30 post-injury, with single/never married status slowly decreasing and divorce status slowly increasing.

Status (%)	At Injury	Year 1	Year 10	Year 20	Year 30	Year 40
Single	44.3	42.8	37.3	37.2	33.4	24.5
Married	37.8	37.0	34.2	34.5	35.4	44.3
Divorced	8.7	10.5	19.3	19.3	21.8	21.6

Re-Hospitalization

Since 2015, about 30% of persons with SCI are re-hospitalized one or more times during any given year following injury. Among those re-hospitalized, the length of hospital stay averages about 18 days. Diseases of the genitourinary system are the leading cause of re-hospitalization, followed by disease of the skin. Respiratory, digestive, circulatory, and musculoskeletal diseases are also common causes.

Historical Lifetime Costs

The average yearly expenses (health care costs and living expenses) and the estimated lifetime costs that are directly attributable to SCI vary greatly based on education, neurological impairment, and pre-injury employment history. The below estimates do not include any indirect costs such as losses in wages, fringe benefits, and productivity (indirect costs averaged \$78,633 per year in 2020 dollars).

Severity of Injury	Average Yearly Expenses (in 2020 dollars)		Estimated Lifetime Costs by Age at Injury (discounted at 2%)	
	First Year	Each Subsequent Year	25 years old	50 years old
High Tetraplegia (C1–C4) AIS ABC	\$1,163,425	\$202,032	\$5,162,152	\$2,837,031
Low Tetraplegia (C5–C8) AIS ABC	\$840,676	\$123,938	\$3,771,791	\$2,319,988
Paraplegia AIS ABC	\$567,011	\$75,112	\$2,524,270	\$1,656,602
Motor Functional at Any Level AIS D	\$379,698	\$46,119	\$1,724,594	\$1,217,266

Data Source: Economic Impact of SCI published in the journal *Topics in Spinal Cord Injury Rehabilitation*, Volume 16, Number 4, in 2011. ASIA Impairment Scale (AIS) is used to grade the severity of a person's neurological impairment following spinal cord injury.

Historical Life Expectancy

The average remaining years of life for persons with SCI have not improved since the 1980s and remain significantly below life expectancies of persons without SCI. Mortality rates are significantly higher during the first year after injury than during subsequent years, particularly for persons with the most severe neurological impairments. A customizable Life Expectancy Calculator tool is at uab.edu/NSCISC.

Age at Injury	Life Expectancy (years) for Post-Injury by Severity of Injury and Age at Injury										
	No SCI	For Persons Who Survive the First 24 Hours					For Persons Surviving at Least 1 Year Post-Injury				
		AIS D Motor Functional (Any Level)	AIS ABC Para	AIS ABC Low Tetra (C5–C8)	AIS ABC High Tetra (C1–C4)	Ventilator Dependent (Any Level)	AIS D Motor Functional (Any Level)	AIS ABC Para	AIS ABC Low Tetra (C5–C8)	AIS ABC High Tetra (C1–C4)	Ventilator Dependent (Any Level)
20	59.4	52.1	44.8	39.2	32.5	10.0	52.5	45.2	40.1	33.6	17.1
40	40.7	35.0	29.6	24.8	20.7	8.7	35.2	30.0	25.5	21.7	13.1
60	23.3	19.4	16.1	13.1	11.2	3.7	19.6	16.5	13.8	12.4	7.9

Historical Causes of Death

Persons enrolled in the National SCI Database have now been followed up to 47 years after injury. During that time, the causes of death that appear to have the greatest impact on reduced life expectancy for this population are pneumonia and septicemia. Mortality rates are declining for cancer, heart disease, stroke, arterial diseases, pulmonary embolus, urinary diseases, digestive diseases, and suicide. However, these gains are being offset by increasing mortality rates for endocrine, metabolic and nutritional diseases, accidents, nervous system diseases, musculoskeletal disorders, and mental disorders. There has been no change in the mortality rate for septicemia over the past 47 years, and there has only been a slight decrease in mortality due to respiratory diseases.

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Data from the National SCI Database is from 29 federally funded SCI Model Systems since 1973. Presently, there are 14 systems and 5 Form II (follow up) centers sponsored by NIDILRR. For a complete list of current SCI Model Systems, go to www.msktc.org/sci/model-system-centers.

Document Citation: National Spinal Cord Injury Statistical Center, Facts and Figures at a Glance. Birmingham, AL: University of Alabama at Birmingham, 2021.



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MUSEO CAJAL
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MADRID

Image credit: PURKINJE NEURON, Santiago Ramón y Cajal

STEM CELL FACTS

ISSCR



INTERNATIONAL SOCIETY
FOR STEM CELL RESEARCH

The ISSCR is an independent, nonprofit organization providing a global forum for stem cell research and regenerative medicine.

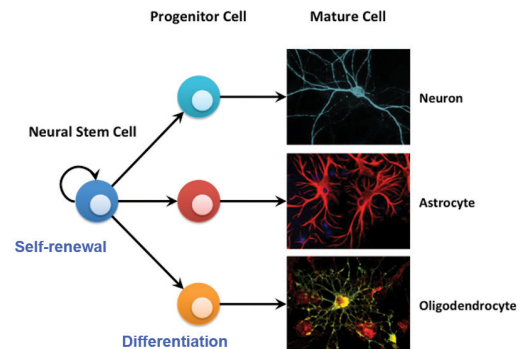
WHAT ARE STEM CELLS?

Stem cells are the foundation cells for every organ and tissue in our bodies. The highly specialized cells that make up these tissues originally came from an initial pool of stem cells formed shortly after fertilization. Throughout our lives, we continue to rely on stem cells to replace injured tissues and cells that are lost every day, such as those in our skin, hair, blood and the lining of our gut. Stem cells have two key properties: 1) the ability to **self-renew**, dividing in a way that makes copies of themselves, and 2) the ability to **differentiate**, giving rise to the mature types of cells that make up our organs and tissues.

TISSUE-SPECIFIC STEM CELLS

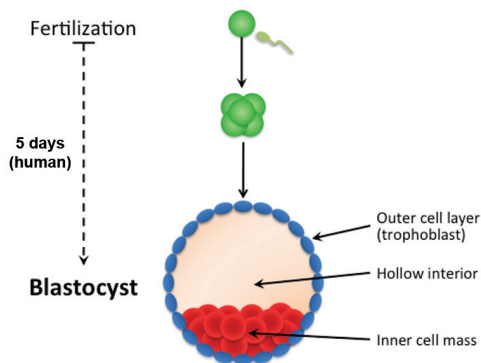
Tissue-specific stem cells, which are sometimes referred to as “**adult**” or “**somatic**” stem cells, are already somewhat specialized and can produce some or all of the mature cell types found within the particular tissue or organ in which they reside. Because of their ability to generate multiple, organ-specific, cell types, they are described as “**multipotent.**” For example, stem cells found within the adult brain are capable of making neurons and two types of glial cells, astrocytes and oligodendrocytes.

Tissue-specific stem cells have been found in several organs that need to continuously replenish themselves, such as the blood, skin and gut and have even been found in other, less regenerative, organs such as the brain. These types of stem cells represent a very small population and are often buried deep within a given tissue, making them difficult to identify, isolate and grow in a laboratory setting.



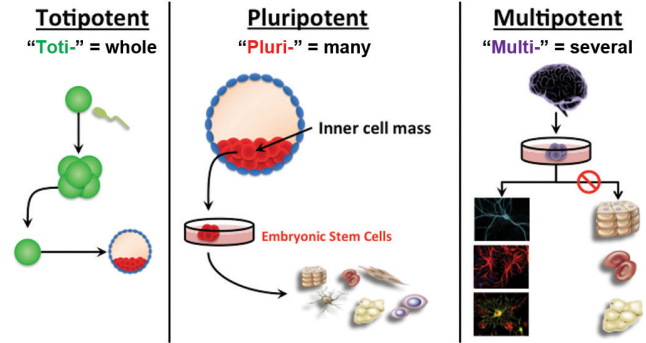
Neuron – Dr. Gerry Shaw, EnCor Biotechnology Inc.
Astrocyte – Abcam Inc.
Oligodendrocyte – Dhaunchak and Nave (2007).
Proc Natl Acad Sci USA 104:17813-8

EMBRYONIC STEM CELLS



Embryonic stem cells have been derived from a variety of species, including humans, and are described as “**pluripotent,**” meaning that they can generate all the different types of cells in the body. Embryonic stem cells can be obtained from the **blastocyst**, a very early stage of development that consists of a mostly hollow ball of approximately 150-200 cells and is barely visible to the naked eye. At this stage, there are no organs, not even blood, just an “inner cell mass” from which embryonic stem cells can be obtained. Human embryonic stem cells are derived primarily from blastocysts that were created by **in vitro fertilization (IVF)** for assisted reproduction but were no longer needed.

The fertilized egg and the cells that immediately arise in the first few divisions are **“totipotent.”** This means that, under the right conditions, they can generate a viable embryo (including support tissues such as the placenta). Within a matter of days, however, these cells transition to become pluripotent. None of the currently studied embryonic stem **cell lines** are alone capable of generating a viable embryo (i.e., they are pluripotent, not totipotent).



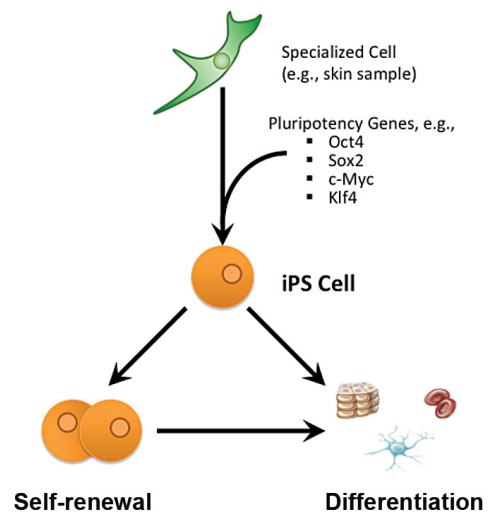
WHY ARE EMBRYONIC STEM CELLS SO VALUABLE?

Unlike tissue-specific (adult) stem cells, embryonic stem cells have the potential to generate every cell type found in the body. Just as importantly, these cells can, under the right conditions, be grown and expanded indefinitely in this unspecialized or “undifferentiated” state. These cells help researchers learn about early human developmental processes that are otherwise inaccessible, study diseases and establish strategies that could ultimately lead to therapies designed to replace or restore damaged tissues.

INDUCED PLURIPOTENT STEM CELLS

One of the hottest topics in stem cell research today is the study of induced pluripotent stem cells (iPS cells). These are adult cells (e.g., skin cells) that are engineered, or “reprogrammed,” to become pluripotent, i.e., behave like an embryonic stem cell. While these iPS cells share many of the same characteristics of embryonic stem cells, including the ability to give rise to all the cell types in the body, it is important to understand that they are not identical.

The original iPS cells were produced by using viruses to insert extra copies of three to four genes known to be important in embryonic stem cells into the specialized cell. It is not yet completely understood how these three to four “reprogramming” genes are able to induce pluripotency; this question is the focus of ongoing research. In addition, recent studies have focused on alternative ways of reprogramming cells using methods that are safer for use in clinical settings.



DISEASE-OR PATIENT-SPECIFIC PLURIPOTENT STEM CELLS

One of the major advantages of iPS cells, and one of the reasons that researchers are very interested in studying them, is that they are a very good way to make pluripotent stem cell lines that are specific to a disease or even to an individual patient. Disease-specific stem cells are powerful tools for studying the cause of a particular disease and then for testing drugs or discovering other approaches to treat or cure that disease. The development of patient-specific stem cells is also very attractive for cell therapy, as these cell lines are from the patient themselves and may minimize some of the serious complications of rejection and immunosuppression that can occur following

MOVING STEM CELLS INTO THE CLINIC

Clinical translation is the process used to turn scientific knowledge into real world medical treatments. Researchers take what they have learned about how a tissue usually works and what goes wrong in a particular disease or injury and use this information to develop new ways to diagnose, stop or fix what goes wrong. Before being marketed or adopted as standard of care, most treatments are tested through clinical trials. Sometimes, in attempting new surgical techniques or where the disease or condition is rare and does not have a large enough group of people to form a clinical trial, certain treatments might be tried on one or two people, a form of testing sometimes referred to as **innovative medicine**.

For more information on how science becomes medicine, please visit www.closerlookatstemcells.org.

CURRENT THERAPIES

Blood stem cells are currently the most frequently used stem cells for therapy. For more than 50 years, doctors have been using bone marrow transplants to transfer blood stem cells to patients, and more advanced techniques for collecting blood stem cells are now being used to treat leukemia, lymphoma and several inherited blood disorders. Umbilical cord blood, like bone marrow, is often collected as a source of blood stem cells and in certain cases is being used as an alternative to bone marrow transplantation.

Additionally, some bone, skin and corneal diseases or injuries can be treated by grafting tissues that are derived from or maintained by stem cells. These therapies have also been shown to be safe and effective.

POTENTIAL THERAPIES

Other stem cell treatments, while promising, are still at very early experimental stages. For example, the **mesenchymal stem cell**, found throughout the body including in the bone marrow, can be directed to become bone, cartilage, fat and possibly even muscle. In certain experimental models, these cells also have some ability to modify immune functions. These abilities have created considerable interest in developing ways of using mesenchymal stem cells to treat a range of musculoskeletal abnormalities, cardiac disease and some immune abnormalities such as graft-versus-host disease following bone marrow transplant.

REMAINING CHALLENGES

Despite the successes we have seen so far, there are several major challenges that must be addressed before stem cells can be used as cell therapies to treat a wider range of diseases.

First, we need to identify an abundant source of stem cells. Identifying, isolating and growing the right kind of stem cell, particularly in the case of rare adult stem cells, are painstaking and difficult processes. Pluripotent stem cells, such as embryonic stem cells, can be grown indefinitely in the lab and have the advantage of having the potential to become any cell in the body, but these processes are again very complex and must be tightly controlled. iPS cells, while promising, are also limited by these concerns. In both cases, considerable work remains to be done to ensure that these cells can be isolated and used safely and routinely.

Second, as with organ transplants, it is very important to have a close match between the donor tissue and the recipient; the more closely the tissue matches the recipient, the lower the risk of rejection. Being able to avoid the life-long use of immunosuppressants would also be preferable. The discovery of iPS cells has opened the door to developing patient-specific pluripotent stem **cell lines** that can later be developed into a needed cell type without the problems of rejection and immunosuppression that occur from transplants from unrelated donors.

Third, a system for delivering the cells to the right part of the body must be developed. Once in the right location, the new cells must then be encouraged to integrate and function together with the body's other cells.

GLOSSARY

Blastocyst

A very early embryo that has the shape of a ball and consists of approximately 150-200 cells. It contains the inner cell mass, from which embryonic stem cells are derived, and an outer layer of cells called the trophoblast that forms the placenta.

Cell line

Cells that can be maintained and grown in a dish outside of the body.

Clinical translation

The process of using scientific knowledge to design, develop and apply new ways to diagnose, stop or fix what goes wrong in a particular disease or injury.

Differentiation

The process of development with an increase in the level of organization or complexity of a cell or tissue, accompanied by a more specialized function.

Embryo

The early developing organism; this term denotes the period of development between the fertilized egg and the fetal stage.

Embryonic stem cell

Cells derived from very early in development, usually the inner cell mass of a developing blastocyst. These cells are self-renewing (can replicate themselves) and pluripotent (can form all cell types found in the body).

Induced pluripotent stem (iPS) cell

Induced pluripotent cells (iPS cells) are stem cells that were engineered ("induced") from non-pluripotent cells to become pluripotent. In other words, a cell with a specialized function (for example, a skin cell) that has been "reprogrammed" to an unspecialized state similar to that of an embryonic stem cell.

Innovative medicine

Treatments that are performed on a small number of people and are designed to test a novel technique or treat a rare disease. These are done outside of a typical clinical trial framework.

In vitro fertilization

A procedure in which an egg cell and sperm cells are brought together in a dish to fertilize the egg. The fertilized egg will start dividing and, after several divisions, forms the embryo that can be implanted into the womb of a woman and give rise to pregnancy.

Mesenchymal stem cells

Mesenchymal stem cells were originally discovered in the bone marrow, but have since been found throughout the body and can give rise to a large number of connective tissue types such as bone, cartilage and fat.

Multipotent stem cells

Stem cells that can give rise to several different types of specialized cells, but in contrast to a pluripotent stem cell, are restricted to a certain organ or tissue types. For example, blood stem cells are multipotent cells that can produce all the different cell types that make up the blood but not the cells of other organs such as the liver or brain.

Pluripotent stem cells

Stem cells that can become all the cell types that are found in an implanted embryo, fetus or developed organism. Embryonic stem cells are pluripotent stem cells.

Self-renewal

The process by which a cell divides to generate another cell that has the same potential.

Stem cells

Cells that have both the capacity to self-renew (make more stem cells by cell division) and to differentiate into mature, specialized cells.

Tissue-specific stem cells

(also known as adult or somatic stem cells)

Stem cells found in different tissues of the body that can give rise to some or all of the mature cell types found within the particular tissue or organ from which they came, i.e., blood stem cells can give rise to all the cells that make up the blood, but not the cells of organs such as the liver or brain.

Totipotent stem cells

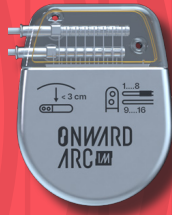
Stem cells that, under the right conditions, are wholly capable of generating a viable embryo (including the placenta) and, for humans, exist until about four days after fertilization, prior to the blastocyst stage from which embryonic stem cells are derived.

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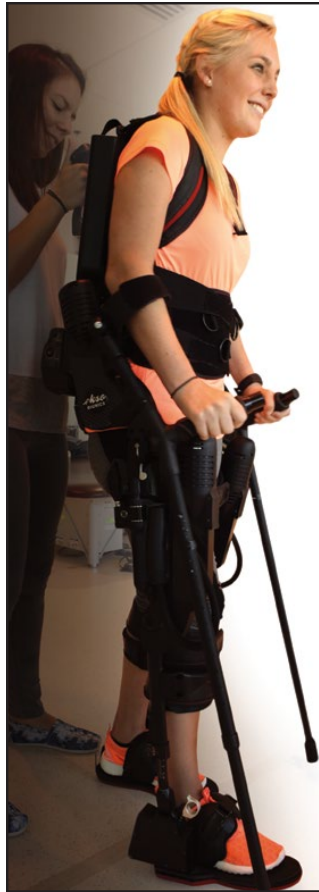
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U2FP's Annual Science & Advocacy Symposium

Our conference is a collaborative gathering that prioritizes the voice of the Spinal Cord Injury (SCI) Community. We bring together research scientists, clinicians, and community advocates, along with investors and industry leaders to exchange information and strategies for achieving recovery from SCI.

RACE FOR CURATIVE INTERVENTIONS

Team U2FP

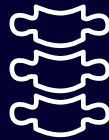
When you join Team U2FP you're helping us accelerate cures for the Spinal Cord Injury (SCI) Community! Your fundraising efforts help fuel all of our initiatives, pushing us closer to our goal: to achieve functional recovery for those living with an SCI.

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With almost \$12M in legislative funding passed by CAN Activists from the SCI Community - the tide is turning. We're making our voices heard. We've passed Spinal Cord Injury Research Bills in Pennsylvania, Minnesota, Ohio and Washington states with new initiatives started in Wisconsin, Texas and Colorado.

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Interested Researchers & SCI Individuals should complete the interest form. U2FP will then work to connect SCI Individuals with a research lab, and researchers with an SCI consultant.

U2FP's Annual Symposium

ORGANIZING **COMMITTEE**

Sam Maddox, Ryan Romine, Lucia Webb, Matthew Rodreick - Co-chairs
Jessica Frye - Graphic Design
Event Technology Services - Audio/Visual + Virtual Livestream Providers



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