

# Progress in **RESEARCH**

Fall 2024

Forty years ago, the idea of restoring function after spinal cord injury (SCI) seemed unattainable. Today, our vision of a world where SCI doesn't result in paralysis, and paralysis does not result in diminished quality of life is closer than ever.

We're committed to supporting high risk/high reward clinical trials that push technology beyond conventional uses to ensure that the unmet needs of our SCI community are finally addressed. The quality-of-life issues that are a consequence of spinal cord injury are an important piece of our work to achieve Tomorrow's Cures. Extreme pain, bowel, bladder and blood pressure control, sexual function and the ability to sweat all contribute to the combined insult that encompasses SCI—which is why we are working with diverse partners to find cures and treatments to help people improve their quality of life.

We also recognize that scientific research is one piece of a complex puzzle designed to bring forward real cures. Another crucial aspect of our work is our ability to serve as a convener. We're an unbiased partner, with the capability to bring together key players across the health system — from regulatory bodies to medical professionals to the patient community and others. We ask questions like, "What's it going to cost? How do we get Congress to understand that this needs to be covered?"

No single organization can tackle these monumental challenges alone. We are excited to form new partnerships and engage with the SCI community to ensure that the next wave of discoveries is both meaningful and accessible—and we are accepting requests for applications for pre-clinical translational research in the areas of neuroprotection, regeneration, and plasticity.

As we look toward 2025, we aim to increase collaboration and direct input from those with lived experience to drive critical conversations with the FDA and others as we collectively work toward approved therapies that improve lives.



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By joining forces, we will create a successful strategy for SCI clinically-approved therapies. The work we're doing behind the scenes—engaging stakeholders in meaningful ways, and preparing for productive FDA discussions—is mission-critical, and we need your help.

Together, we can create a future where people with SCI can access the therapies they need, not in decades but in the here and now. We invite you to join us in making this vision a reality.

With gratitude and optimism,

**Dr. Marco Baptista**

Chief Scientific Officer

Christopher & Dana Reeve Foundation

## SECOND ANNUAL SPINAL CORD INJURY INVESTORS SYMPOSIUM

In June 2024, The Christopher & Dana Reeve Foundation and Lineage Therapeutics co-hosted the second annual Spinal Cord Injury Investors Symposium in San Diego, California. The first-in-its-class SCI conference brought together investors, scientists, patients, and caregivers to strategize and accelerate promising research and treatments for SCI.

“With this conference, we’re going beyond networking and sharing ideas to create a ‘working event’ where we use our cognitive diversity to come up with solutions to shared problems,” said Brian M. Culley, Chief Executive Officer of Lineage Cell Therapeutics Inc.

Throughout the Symposium, participants heard from the foremost experts in SCI, funders, and, importantly, from those with lived experience. In fact, the primary focus of these “mastermind sessions” was patient-focused drug development, or PFDD.

Two SCI patients, Jerod Nieder and Michaela Devins, and their caregivers, Hanna Nieder (who also serves as a Coordinator for the Reeve Foundation’s Peer & Family Support Program) and Kyle Devins, fielded questions from scientists and investors about what matters most to them. Moderated by Joseph Pantginis, PhD, Director of Research and Managing Director, Equity Research at H.C. Wainwright & Co., LLC, the discussion shined a light on a critical issue

in current SCI research: developing therapies that create meaningful change for people with SCI.

“Any improvement that adds more function, no matter how small, is relevant and meaningful to patients,” emphasized Jerod Nieder, a two-time panelist at the conference.

This crucial work doesn’t happen in silos. It happens when industry, patients, and investigators come together to address “shared pain points.” That’s what happens at the Symposium. Together, people who are invested in accelerating SCI research can pave a pathway toward promising discoveries.

In response to feedback from last year’s event, organizers expanded the conference, representing both preclinical and clinical companies. “It’s awe-inspiring to see competitors in the same room together working together toward a common goal,” says Marco Baptista, Ph.D., Chief Scientific Officer of the Christopher & Dana Reeve Foundation. “That’s the kind of collaboration we’ll need to guide the FDA to approve therapies that make a real difference in the lives of people living with SCI.” ◦



# SCI VENTURES LAUNCHES \$40M FUND FOR BREAKTHROUGH THERAPIES

In June, [SCI Ventures](#), a new venture philanthropy initiative conceived by the Reeve Foundation and co-founded with global partners, launched its first fund with \$30 million in commitments and a goal of raising \$40 million by year's end. Led by a team of thought leaders in venture capital, technology, and science, SCI Ventures aims to accelerate the funding and commercialization of innovative treatments for spinal cord injury.

The Christopher & Dana Reeve Foundation pioneered the venture philanthropy model with initial investments in the technology company ONWARD® Medical and AXONIS Therapeutics. But this is the first time that five leading SCI-focused foundations have come together in support of a shared investment vehicle. In addition to the Christopher & Dana Reeve Foundation, partners include Wings for Life, The International Spinal Research Trust ("Spinal Research"), the Promobilia Foundation, and Shepherd Center.

"We're providing financial incentives and operational support to attract more capital to the SCI space," said Marco Baptista, Chief Scientific Officer of the Christopher & Dana Reeve Foundation. "By joining together, we're lowering the risk of investment while fast-tracking the path from bench to bedside." But the real beauty of this model is SCI Ventures' commitment to redeploying 100% of its investment gains into promising research efforts aimed at finding cures for paralysis.

SCI Ventures, an independently managed fund that shares the 501(c)(3) tax-exempt registration of the Reeve Foundation, focuses on seed and Series A investments and plans to support up to 20 companies. Its growing portfolio already includes:



- **ONWARD® Medical:** Using spinal cord stimulation, alone or in combination with brain-computer interface (BCI) technology, ONWARD Medical aims to restore movement and function.
- **AXONIS Therapeutics:** AXONIS is advancing drug discoveries designed to activate and modulate neurons to improve neural function.
- **Sania Therapeutics:** As a gene therapy company, Sania Therapeutics aims to selectively target dysfunctional neural circuits, beginning with spasticity
- **AUGMENTAL:** AUGMENTAL is the developer of MouthPad^, an in-mouth interface for hands-free human-computer interaction.

"With this fund, we're breaking down barriers and working together to accelerate the development of cure-oriented therapies for people living with SCI," Baptista said. And since paralysis shares commonalities with other conditions, such as stroke and neurodegenerative disorders, SCI Ventures expects technologies backed by the fund to have far-reaching impacts. ◦

The Reeve Foundation and Spinal Research have partnered to fund pre-clinical research applications on paralysis caused by traumatic spinal cord injury. Go to [christopherreeve.org](http://christopherreeve.org) to find out more about the application process.

## BOB YANT MAKES STRIDES WITH STRIVE

For more than 40 years, [Bob Yant](#) has been on a relentless mission to find a cure for SCI, providing critical support for the Christopher & Dana Reeve Foundation and helping drive our patient-driven research efforts.

Yant had recently earned his pilot's license and was pursuing a successful career in real estate when he sustained an SCI in a driving accident in 1981. But instead of letting the injury define him, Yant dedicated his life to raising money for research that would change the lives of people living with SCI.

What started as a goal to raise \$25,000 for pioneering research quickly became so much more. Yant dove deep into the science, teaching himself to decode medical journals, and staying in touch with investigators for updates. His passion and drive led him to join the American Paralysis Association's Scientific Advisory Board in 1982—years before it became the Christopher & Dana Reeve Foundation—where he served until 2011.

“Bob's tireless efforts have helped fuel Reeve's research and provide essential resources for

families across the country affected by SCI,” said the Reeve Foundation's Chief Scientific Officer Marco Baptista.

Last year, after attending the Foundation's first annual SCI Investors Symposium (co-hosted by Lineage Cell Therapeutics Inc.), Yant returned home and donated \$100,000 to the Reeve Foundation to support the development of Standardized Testing Research InVivo Endeavor ([STRIVE](#)), a more agile model for testing potential therapeutics and missing puzzle piece that for years has contributed to a gap in early-stage SCI research.

“Bob's lifelong dedication to solving problems for the SCI community is inspirational,” Baptista said. “His efforts have made a tremendous impact on what's possible for people living with spinal cord injury.”

Already, the project has resulted in the development of a thoracic SCI model with different severities for studying locomotor changes, fine motor skills, gait analysis, bladder function and neuronal damage. ◦

## TEAM REEVE®

In early October, Team Reeve conquered the Bank of America Chicago Marathon, successfully raising more than \$200,000, and in early November we took on the TCS NYC Marathon with more than \$600,000 raised so far. Our Team Reeve athletes and supporters are the lifeblood of our Foundation, and we're proud to announce that we'll expand to the Boston Marathon in 2025, marking the 20th anniversary of our venerable endurance athlete fundraising team.

Your generous donations contribute directly to our mission and facilitate transformative effects on countless lives. Each dollar given is channeled toward groundbreaking research, diverse grant possibilities, and invaluable care resources for all



those affected. Your donation isn't merely a gift—it's a potent instrument of change. Please consider joining Team Reeve or lend your [support](#). ◦

## DONOR SPOTLIGHT: HEATHER & MARK SEGAL

By the time Mark and Heather Segal pedaled into North Dakota, they hoped the biggest challenge of their carefully planned 3,900-mile bike ride across the U.S already lay several states behind them.

On the third day of the trip, the couple discovered that wildfires had closed the critical road meant to carry them across Washington state. And so, they'd blown up their map, embracing an unexpected three-day detour and riding more than 200 extra miles to get back on track.

Easy? No. Satisfying? Yes.

But then came the headwinds of North Dakota. This was a problem that could not be solved, only endured.

After three straight days of riding against the wind, Mark raised the cuff of his jacket to reveal a white Team Reeve bracelet around his wrist. He'd worn it every day since 2021 when he and Heather had first set off on what would become an annual and epic fundraising ride across the country to raise money for SCI research.

On this day, he needed to see the bracelet, to remind himself of the friends he rode in honor of, and their ongoing determination to reclaim lives reshaped by injuries.

"When I pulled it out, that was my motivation," he says. "I imagined my friends rolling alongside me. I thought about the progress they've made and the obstacles they have to face to keep going. And I knew I had to keep going too."

On September 25, 68 days after they set off, the Segals rode the final miles of their journey back home to Larchmont, NY. Arriving on what would've been Christopher Reeve's 72nd birthday, the couple had much to celebrate.

Since 2021, they have ridden from one corner of the country to another for Team Reeve, pedaling close to 12,000 miles and raising



nearly \$128,000 to fund treatments and cures for SCI. They've survived countless challenges, including severe dehydration in Yuma, Arizona, a precarious ride across a bridge in Alabama during a storm with wind gusts of 40+ mph, and multiple days of bone-chilling rain on the coast of Oregon. They've sampled milkshakes and donuts in cities and small towns from Texas to Maine and stood in the shallow headwaters of the Mississippi River in Minnesota.

And, wearing their neon Team Reeve T-shirts every day, the Segals have introduced the work of the Christopher & Dana Reeve Foundation to hundreds of people along the way.

"Their impact has been remarkable," says Team Reeve Manager Kelly Lamb. "They are not only prolific fundraisers who push their goals higher every year, but ambassadors who are spreading the word of Reeve's mission mile by mile across the country."

The idea to ride for Team Reeve came to the Segals after a close friend of the family sustained a SCI. The accident occurred during the young man's first week of college in Miami when a strong wave tossed him upside down into a

sandbar, breaking his C6 vertebra. The Segals, who had watched him grow up alongside their own children, were heartbroken.

“It was overwhelming,” Mark says. “You see the randomness of it. That could be any of us. Your heart aches for the family. You just want to do something to help.”

SCI was already on their minds. A few years before, an old camp friend of Mark’s had become paralyzed as a result of medical complications. As they thought more and more about the injuries, the Segals realized their cycling could serve a greater purpose.

Their first ride started off in San Diego, California and stretched all the way to St. Augustine, Florida; it lasted 46 days, but the couple was hooked. Over the next four years, the annual rides became central to their lives. Though the days were not easy, the rewards were many, and especially found in the kindness of strangers.

There was the Chick-Fil-A staff who let Mark battle dehydration with a 2-hour nap at a dining room table. There was the truck driver who pulled his 18-wheeler over to share water with the couple on a scorching day. And there was the woman who, upon learning that the couple was riding for SCI research, peeled \$20 from her wallet’s emergency cash fund for an on-the-spot donation.

“We have seen the beauty of the country and the beauty of so many people,” Mark says.

One moment from this summer that neither will soon forget came along the Snoqualmie Valley Trail in Washington when they encountered a cyclist on an adaptive mountain bike. As Mark began to talk about their ride for Team Reeve, the cyclist stopped him; he knew of the Foundation through its Quality of Life grants that supported local adaptive sports organizations, including the one that made his own ride possible.

“It was a very powerful moment,” Heather says. “Many associate Reeve with scientific advances, but there is also an emphasis on the here and now. The National Paralysis Resource Center and the grants program are all about care. And here we are, out on the trail, seeing the direct impact. It felt really good.”

After more than two months on the road, the couple is grateful for the many miles they’ve traveled.

Mark and I feel very blessed to be able to do this,” Heather says. “We are in good health. Our family is in good health. We don’t take any of it for granted. And we are proud and honored to be doing what we’re doing for Reeve.”

Donate [here](#) to support the Segals’ epic ride. Learn more about Team Reeve at [ChristopherReeve.org/TeamReeve](https://ChristopherReeve.org/TeamReeve).

## REEVE GOLF CLASSIC

Thank you to everyone who joined our Reeve Golf Classic at Winged Foot Golf Club to honor our dear friend Jon Weiner, whose generous support has helped sustain that crucial work in both care and cure efforts, serving millions of people with paralysis across the country.

We were touched by everyone’s overwhelming support of our mission to provide critical resources, information, and fund cures for the paralysis community. This year we proudly raised \$800,000. We graciously invite you to further our cause by demonstrating your [support](#).



## SUPER/MAN HITS THEATERS

“Super/Man: The Christopher Reeve Story” hit movie theaters across the nation on October 11, bringing Christopher Reeve’s incredible story—and the realities of SCI—to a new generation 20 years after his untimely passing. The film features never-before-seen footage of Christopher and Dana Reeve, shared for the first time by Matthew, Alexandra, and Will Reeve, who continue their family legacy as board members of the Reeve Foundation.

Directed by Ian Bonhôte and Peter Ettedgui, this inspiring documentary takes viewers through Reeve’s meteoric rise to fame, from his iconic role as Superman to the near-fatal horse-riding accident in 1995 that left him paralyzed. It also shines a spotlight on SCI, a condition that strikes an estimated 18,000 Americans each year with new injuries.

After his injury, Reeve became a passionate advocate for disability rights and a relentless champion in the quest to find a cure for SCI—all while continuing his career and embracing the most important role of his life: devoted family man.

Premiering to tears and a standing ovation at the 40th edition of the Sundance Film Festival in Park City, Utah, “Super/Man” features footage narrated in Reeve’s own words, taken from his memoirs, to tell a story of courage, resilience, and hope.

“I hope this extraordinary film provides an opportunity to ensure that spinal cord injury is visible on a world stage—prominence that is too rarely afforded to those living with disabilities,” said Maggie Goldberg, President & CEO of the Reeve Foundation, at Sundance.



“To hear Christopher’s voice again, reading from his memoirs and reminding the world of life lessons that come from strength in uncertainty, it is clear that, once again, he is speaking directly to us to ignite the world to action.”

As we commemorate the 20th anniversary of Reeve’s death from complications of SCI, the film serves as a moving reminder that strength



*Matthew Reeve, Alexandra Reeve Givens, Will Reeve at the NYC Premiere of Super/Man*

often rises out of life's greatest challenges—and is a testament to the Reeve Foundation's unwavering commitment to finding a cure for spinal cord injuries. ◦



*Lizzie Gillett, Robert Ford, Alexandra Reeve Givens, Maggie Goldberg, Will Reeve, Peter Ettedgui, Matthew Reeve, Henry Stifel, Ian Bonhôte at the Benefit Screening of Super/Man in NYC*



*Mary and Henry Stifel*

## TEAM LEGRAND'S A WALK TO BELIEVE

With your help, Team LeGrand raised \$120,000 at this year's A Walk to Believe celebration with Eric LeGrand and over 1,000 participants parading down The Rutgers Boardwalk in celebration on Saturday, September 7. [Click here to watch the recap video of the parade.](#)

Sponsored by GGL Law Firm and Prudential, this year's "A Walk to Believe" took place from April to September. Participants were encouraged to run, walk, skate, or roll to a 5K at their own time and pace to raise funds. Participants were also treated to tickets to the Rutgers Scarlet Knights football game and tailgate. Stay tuned for the Walk to Believe at Rutgers in 2025.