



CHRISTOPHER & DANA  
REEVE FOUNDATION

TODAY'S CARE. TOMORROW'S CURE.®

**2019**  
ANNUAL  
REPORT

# A Message

## FROM PETER AND JAY

More than 5.4 million people are living with paralysis in the United States. Close your eyes and picture your community. They are your friends, your family members, your neighbors. Like all of us, they are many different things. Teachers. Brothers. Baseball fans. **Paralysis doesn't define a life; it changes its shape.**

In 2019, the Christopher & Dana Reeve Foundation worked hard to support—and celebrate—the lives of people living with paralysis: our **See Us** social media campaign spotlighted the stories of thousands of wheelchair users across the country; our newly launched **Reeve Connect** forum became a virtual home base where community members shared experiences with others navigating the everyday challenges of paralysis; and our award-winning information specialists at the **Paralysis Resource Center** achieved an incredible milestone as they counted more than 100,000 individuals and families served with one-on-one assistance since the center was founded in 2002.

The Reeve Foundation believes independence and access are critical to the well-being of people living with paralysis. In 2019, we partnered with **Google Nest** to distribute 100,000 free digital assistants to improve home logistics for our community. We provided the beaches of Asbury Park, New Jersey, with **WaterWheels®**, adaptive chairs that allow wheelchair users to experience the joy of floating in the ocean. And we awarded a total of **\$4,074,152** in quality of life grants to 164 programs from California to Kansas to Vermont. Imagine the impact.

All that helps in the here and now, the Reeve Foundation is equally focused on the future. In 2019, we supported the best and brightest minds working to bring breakthrough treatments to people living with paralysis by investing more than **\$3.5 million** in research initiatives and labs across the country.

Behind the scenes this year, we also honored the efforts of one of our own, longtime Chairman of the Board, John "Jack" Hughes. Jack retired as chair after more than a decade of soft-spoken, dedicated leadership and service to the Foundation. His belief in data-driven analysis ensured the strength of our solutions and helped guide the Foundation; his achievements will long be felt by those we serve.

In the end, the work we do, the progress we make, is possible because of your support. When we close our eyes and picture our community, we see you. Family. Friends. Advocates. With your help, the Reeve Foundation will continue fighting together for today's care and tomorrow's cure.



Peter Wilderotter, *President & CEO*



Jay Shepard, *Chair, Board of Directors*

# Thinking Big FOR A BETTER FUTURE

Investing in people living with paralysis is at the heart of the Reeve Foundation's mission. We fight for victories that improve the day-to-day life of our community and fund efforts to discover treatments that will change their future.

In 2019, we granted \$2 million to the Kentucky Spinal Cord Injury Research Center at the University of Louisville in continued support of its groundbreaking epidural stimulation therapy program. This research, which has helped a dozen participants stand again and several to walk short distances, is critical to understanding how the therapy can improve bladder and bowel control, sexual function and temperature regulation; each incremental breakthrough expands knowledge within the field, helps target treatment efforts and moves patients closer to the day when vital functions once thought to be lost forever are restored. To date, 12 participants have had stimulators implanted in their lower backs as part of The Big Idea trial, with six more surgeries scheduled next year. The group ranges from 21 to 62-years old and includes 11 men and 4 women from across the country.

The Foundation also made significant investments in the labs of Dr. Murray Blackmore, an associate professor of biomedical sciences in the College of Health Sciences at Marquette University working to develop gene therapies to promote the regrowth of axons in the injured spinal cord and brain, and Dr. Chet Moritz, an associate professor in the Division of Physical Therapy, Department of Rehabilitation Medicine at the University of Washington, who is developing treatments for paralysis using brain-computer interfaces and neurotechnology.

Supporting the most promising research in spinal cord injuries is vital, but the Foundation is also committed to accelerating the development of treatments and therapies with comprehensive reach across our community.



In 2019, the Reeve Foundation became an investor in GTX medical BV, a medical device company developing an implantable spinal cord stimulation system with real-time motion feedback and the potential to restore the function of the spinal cord and improve the rehabilitation of people living with spinal cord injuries. Ian Curtis, board member of the Reeve Foundation, will join its board of directors.

GTX's advanced technology builds on research gains from the last two decades—much of it fueled by Reeve Foundation support—and will help bridge the translational gap that exists between academia and industry and bring tangible results to those living with paralysis.

Also, at the end of 2019, 185 acutely injured patients were enrolled in the RISCIS trial of the Reeve Foundation North American Clinical Trial Network® (NACTN), an international clinical trial testing the effectiveness of Riluzole in spinal cord injury; 30 also were enrolled in NACTN's RISCIS substudy to determine the drug's pharmacology.



## *Racing* TOWARD VICTORY

The profound and life-altering effects of spinal cord injuries encompass entire families. Many people who volunteer for Team Reeve® raise their hands to help in honor of a loved one living with paralysis.

In 2019, 110 team members across the country, from San Diego to Little Rock to Louisville, raised \$584,813 for the Foundation. They ran marathons on foot and using handcycles, sprinted through 5K races and conquered a three-mile obstacle course in a TOUGH MUDDER competition. Nearly everyone carried a story to fuel their efforts.

Rachel Cole traveled from El Dorado, Arkansas, to Chicago to run the marathon in honor of her husband who was injured in a boating accident. In New York, Kaitlin Munnely raced the marathon, her third Team Reeve event, for her father, who was paralyzed in 2015. High school language arts teacher Joe Rooney teamed up with Mike Nichols, a former student who sustained a spinal cord injury

playing hockey; Rooney fought off an excruciating hamstring cramp at the 24th-mile marker to push Nichols across the finish line.

“So many of our runners are motivated by the realization that the discomfort and pain they feel as they train is temporary, but what their loved one is going through is constant,” says Team Reeve Manager Kelly Lamb. “They join Team Reeve because they understand what a privilege it is to run.”

Lamb hopes to expand participation in 2020, not only to increase the funds that help support spinal cord research and treatment but also to raise awareness of the challenges faced daily by those living with paralysis.

“The more we’re out there, in as many places as we can be, the more people are aware of the Reeve Foundation’s work supporting people living with paralysis.”

# Celebrating Community A MAGICAL EVENING

More than 500 people gathered at Cipriani South Street in New York City on November 14 for “A Magical Evening,” the Reeve Foundation’s annual gala. It was a night of old friends and new faces, brimming with moments of reflection and renewal. Though conscious, as always, of the work still to be done, the event provided a chance to recognize the dedication of the Foundation’s champions, whose unsurpassed outreach efforts make a difference in the lives of thousands of families across the United States every day.

John McConnell, Vice-Chair of the Reeve Foundation Board of Directors, was awarded the *Arnold H. Snider Visionary Leadership Award*, a testament to both his character and actions. For many, John is the enthusiastic runner, cheering on fellow Team Reeve members at races across the country. For others, he’s the forward-thinking board member eager to help the Foundation’s every effort, from development to brand strategy to governance.

John joined the Foundation in 2006, shortly after he sustained a spinal cord injury in a biking accident. Though he fully recovered, the experience

changed him. Within a year, John had run his first race for Team Reeve and made the Foundation’s work central to his life.

Presenting the award, Matthew Reeve praised John’s impact on the Foundation. “It is no exaggeration to say that, without question, we would not be where we are today without John’s involvement and dedication.”

The evening also paid tribute to the Brown family, whose extraordinary outreach and advocacy efforts through the Alan T Brown Foundation helped thousands of newly paralyzed individuals realize that life could and would happily roll on.



The existence of the Foundation, which became part of the Reeve Foundation this year and is now known as the Alan T. Brown Fund, is a testament to a mother's fierce love. Fran Brown launched the Foundation in 1988, six months after her son Alan became paralyzed. What began as a family mission to pursue treatments for a cure expanded into a movement to improve the everyday lives of people living with paralysis.



To honor their tireless support of the community, the entire Brown family was awarded the *Christopher Reeve Spirit of Courage Award*, which recognizes individuals who, like Christopher, embrace wild dreams that create new frontiers.

Reeve Foundation CEO Peter Wilderotter praised the Browns and "their tremendous contributions to the cause."

"What we have done as separate organizations has been great," he said. "What we can do together will be spectacular."

## PRC HIGHLIGHTS



In 2019 we grew **36%**  
to **6183 online advocates**.  
(In January 2019, online  
advocates were 3,928)



**100,000+**

families have received individualized support,  
services and information, including specialized  
assistance for military families and veterans, in

**170 languages**

## *Behind* THE SCENES

Reeve Foundation board members dedicate countless hours to spotlighting the urgent need for tangible gains in spinal cord injury treatment. For incoming chairman Jay Shepard, the mission is personal.

In 2015, Jay's daughter Ellie was paralyzed in a diving accident. Within days of her injury, Mr. Shepard became one of the thousands of people who reach out to the Reeve Foundation each year as they navigate the immediate shock of spinal cord injuries.

"The same day I was told my daughter would probably never walk again, I put in a call to the foundation," he said. "That call turned the nose of the Titanic away from the iceberg before it hit it for us. It altered the course of the desperation and isolation of what we were dealing with and gave us real hope."

Mr. Shepard recently retired as CEO of Aravive, a clinical stage biopharmaceutical company, in order to devote himself to leading the Reeve board. Prior to his retirement from Aravive, he was president and CEO of Versartis until its merger with Aravive; executive partner at Sofinnova Ventures; president and CEO of NextWave Pharmaceuticals (acquired by Pfizer) and Ilypsa (acquired by Amgen); and interim president and CEO of Relypsa. Mr. Shepard, who is also chair of Aravive's board and a board member of Esperion Therapeutics, earned a B.S. in business administration from the University of Arizona.

As chairman, Mr. Shepard will focus on broadening the base of scientific and academic experts collaborating with the Foundation and each other in order to hasten advances in care and progress toward a cure for patients living with paralysis.

"The reason we have confidence is not because I'm a misty-eyed father and biotech CEO, but because we've already seen big breakthroughs," he said.



Joel Faden

"There are a lot of reasons to have hope."

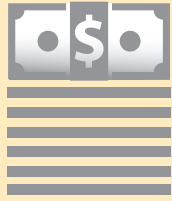
The New Year brings other changes to the board with the retirement of longtime Executive Committee Chairman and Treasurer, Joel Faden.

Mr. Faden was Christopher's business manager and a friend to both him and Dana. After joining the Reeve Foundation in 1999 as one of Christopher's original board members, he spent the next twenty years helping Christopher's vision of hope and possibility for people living with paralysis become a reality. Mr. Faden's passion for the cause was clear to anyone who met him, whether at one of his beloved golf fundraisers or chairing the finance committee.

His generous spirit helped the Foundation feel like extended family.

"Joel helped steer our ship during our darkest days – after the loss of Christopher and Dana," said Chief Operating Officer Maggie Goldberg. "He was steadfast by our side and made sure we were always on course. We celebrate and thank him for all the years of service he has given to this Foundation."

# PRC HIGHLIGHTS



**\$4,074,152**

awarded in 2019 by  
**Quality of Life  
Grants Program**

**14,000+** people  
have received support from  
**mentors** who are also  
living with paralysis



**80,000+**

followers on **social media**  
fostering real time  
community connections

## *Spotlight* DANTE PICCOLO

Dante Piccolo hates to run. But when his mother became paralyzed from the neck down, he realized he had to do something as she fought to recover. He began searching for charities that supported people living with spinal cord injuries and discovered the Reeve Foundation.

“By the end of the week, I was signed up to become part of Team Reeve,” he said.

Mr. Piccolo, who raised \$34,000 for Team Reeve running the New York City Marathon, was one of 87 runners who trained and raced beneath the Foundation’s banner in road races in 2019.

For the 25-year-old banker living in New York, it was a way to stay connected with his mother as she worked to recover at the family’s home in Pittsburgh, nearly 400 miles away. They compared notes on their progress by phone every day; as spring turned to summer and Mr. Piccolo increased his miles, his mother worked hard in intensive physical therapy. After a few months, she was able to take a step; by the day of the race, she was able to walk short distances with help.

Piccolo said the training with Team Reeve in honor of his mother provided a lesson in perspective.

“You do it for those who wish they could, and you feel like you’re making a difference,” he said. “When you want to give so much to someone you love, nothing will stand in the way.”







Ginny and Jim Welch



Barbara & Dave Baldwin, Charlotte & Hank Stifel, Ginny & Jim Welch

## *In Memorium* JIM WELCH

While 2019 saw many gains for our community, it also brought personal loss. The Reeve Foundation mourns the death—but is grateful for the life—of James O. Welch, Jr., board member and longtime advocate for the spinal cord injury community.

Before Christopher Reeve helped change what the world thought possible for people living with paralysis, Mr. Welch was already a believer. He and his wife Ginny first joined the American Paralysis Association—later to become the Christopher & Dana Reeve Foundation—in its earliest days, when spinal cord research was still dismissed as a scientific dead end.

Mr. Welch served as a board member for more than 30 years, remaining steadfast in his efforts to expand funding and research for paralysis and related neurological disorders. Reeve Foundation vice chair Alexandra Reeve Givens said Jim’s tough questions, expansive thinking and booming voice would be long remembered in the boardroom.

“Jim will be sorely missed, but his kind heart and passionate leadership will not be forgotten,” she said.

# ON GIVING

Each dollar we raise is invested in programs that improve the quality of life for our community and advance innovative treatments for spinal cord injury. **There are many ways you can help.** Remember the Foundation with gifts in your will and help sustain our work for years to come; in 2019, bequests totaled \$3,328,631. Grab your sneakers and join a Team Reeve event; our NYC team of 70 marathoners raised \$424,000 in 2019. Or simply give what you can; more than 600 people made donations of less than \$25 to the Reeve Foundation in 2019, totaling \$9,015.74. Every amount helps.

**\$250,000 +** Anonymous • Jon & Helaine Ayers • Estate of Genoa Johnson • Estate of Margot Marx

**\$100,000 – \$249,999** Anonymous • Kathy Bridgman • Estate of Adam Douglas Cole • Estate of Delores M. Hyde • Estate of Evelyn Greenspan • Estate of Jill K. Nelson • Estate of Jackie Turnbow • F. M. Kirby Foundation • JC Kellogg Foundation Fund • The Jules L. Plangere Jr. Family Foundation • Jane Kirkeby • Katherine Snider • Travis Roy Foundation • The Walkabout Foundation

**\$50,000 – \$99,999** Amerisure Charitable Foundation • The Craig H. Neilsen Foundation • Fred & Barbara Fielder • John & Gail Hughes • James & Virginia Welch Foundation • Jon & Julie Neustadt • New Jersey Devils Care Foundation, Inc. • Henry & Mary Stifel

**\$25,000 – \$49,999** AirBNB Inc • Sean Hannity • Hollister Incorporated • Jay & Linda Grunin Foundation • The Roz & Marvin H. Weiner Family Foundation, Inc. • Scott Remington Family & Close Friends • Charlotte Stifel • Wakefern Food Corporation • Young Men's Philanthropic League Foundation, Inc.

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To view a the 2019 financials and our IRS Form 990, please visit our website at [ChristopherReeve.org](http://ChristopherReeve.org).



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