2021 annual report



message

from the President & CEO

Since joining the Christopher & Dana Reeve Foundation in 2000, I have worked to ensure that people living with paralysis get the support they need for their lives. The Reeve Foundation has changed the narrative surrounding spinal cord injury research, bringing hope and, more importantly, progress to our community. It is my great honor to have been part of these efforts—and now to lead them.

In 2021, I became the Foundation's chief executive officer. In this new role, I carry with me memories from Reeve's extraordinary history: the scientists gathered at our symposiums, brimming with new energy and possibility; the community members determinedly racing across marathon finish lines on foot and by handcycle; and the Information Specialists in the early days of the National Paralysis Resource Center, fielding the deluge of letters and phone calls from families living with paralysis who finally had a place to seek answers.

These many years with the Foundation have taught me that our success stems from the strength of our community, those committed scientists, individuals and families who tirelessly support our mission. Going forward, collaboration will continue to guide our efforts in both care and cure. The more knowledge we share and the further we spread our message, the faster progress will arrive.

In 2021, the Reeve Foundation embarked on ambitious new partnerships with scientists and organizations dedicated to accelerating the pace of research, including the International Spinal Research Trust (ISRT), a United Kingdom-based non-profit funding worldwide efforts to develop effective treatments for paralysis. Working with ISRT will significantly expand our strategy to deliver meaningful clinical advances that reach families sooner rather than later.

As the pandemic continued to disrupt daily life, the Reeve Foundation's National Paralysis Resource Center worked to help community members overcome stress and feelings of isolation. The Peer & Family Support Program launched free, virtual support groups for people living with paralysis and caregivers. Our Quality-of-Life Grants Program awarded more than \$3.7 million to 172 programs in 43 states and Washington, D.C. The impact of these grants rippled through communities, providing accessible picnic tables at a South Bend, IN camp for children with paralysis; creating a new adaptive mountain biking program in Franconia, New Hampshire; and expanding accessible trail access at Glacier National Park.

The Reeve Foundation's work is deeply personal for everyone we serve—and for me. When I was 16 years old, I broke my C2 vertebrae. I recovered, but the experience fueled my determination to make a difference for people living with paralysis. For these individuals and their families, our work is vital— and so is your support. As ever, our strength lies in one another. Together we will continue the fight for tangible treatments and happy, healthy lives for people living with paralysis.



MAGGIE GOLDBERG

President and CEO

cultivatingcare

Dana Reeve's determination to support families affected by spinal cord injuries inspired her to create the National Paralysis Resource Center (NPRC) in 2002. Since then, more than 114,000 people have reached out to us from around the world, seeking the critical information and resources they need to build happy, healthy lives.

In 2021, the Administration for Community Living recognized the NPRC's impact and expertise by awarding its five-year grant to educate, inform and improve the lives of people living with paralysis. The Reeve Foundation, which applies for the grant in a competitive bidding process, is honored to oversee the only national program directly serving the 5.4 million Americans living with paralysis.

Whether building a robust network of peer mentors across the country or helping veterans navigate life after injuries, the NPRC is guided by the needs of community members. We launched the College Transition Program to support students with paralysis as they pursue higher education and prepare for future careers. The program provides free consultations with Accessible College, an organization that helps families navigate the transition, including securing accessible housing, understanding academic accommodations and hiring personal care attendants.

The Reeve Foundation continues to expand our outreach through a new partnership with Spinal Injuries Ireland (SII,) the country's only support and service agency for people who sustain spinal cord injuries. SII's comprehensive initiatives—including counseling, peer mentoring and activity programs—have already proven life-changing for many families.

Read about our <u>regional champions</u> on the Reeve blog page.

Nearly 1,500 new online advocates to

9,190 (as of January 2022)

and 57 Regional Champions (+14);

from 26 states.



Reeve advocates sent





33,121 messages

232 Tweets



107 Facebook Posts



ANNIE TULKIN, Founder and Director of Accessible College

treatments

Advancing scientific understanding of spinal cord injuries is crucial—yet not enough. Research must move beyond the labs and into clinical trials that develop tangible treatments available to everyone living with paralysis. The Reeve Foundation continues to urgently fight for scientific breakthroughs that will make a difference for community members. In 2021, we invested in promising initiatives and embarked on new collaborations with spinal cord injury organizations and medical companies to accelerate the pace of development.

The International Spinal Research Trust has long shared the Reeve Foundation's ambition to identify and deliver effective treatments for the millions of people living with paralysis. In 2021, we joined forces to lay the Foundation for a coordinated, global approach by uniting a network of experts from around the world under one umbrella. Together, we will support promising new technologies and therapies as they move from the preclinical stage through clinical trials and into medical practice.

The Reeve Foundation built new partnerships that can directly deliver treatments scientists believe will be necessary to improve functional loss caused by injuries, from mobility to cardiovascular and sexual health. With our investment in Onward, a Netherlands-based company developing breakthrough technology currently in global clinical trials that stimulates the spinal cord to restore movement and other functions. We also are supporting the efforts of Axonis, a U.S biotechnology company creating therapeutics to limit damage and foster regeneration after injury.





HARLEE SPEYER, Big Idea Participant at the University of Louisville's Kentucky Spinal Cord Injury Research Center

Finally, the Big Idea, a groundbreaking, Reeve-funded ed epidural stimulation trial at the University of Louisville's Kentucky Spinal Cord Injury Research Center, is nearing the finish line. By the end of 2021, 24 men and women from across the U.S implanted with simulators; the final dozen participants are scheduled to receive implants this year. Preliminary observations indicate the quality-of-life gains long sought by people living with injuries, including improved bowel and bladder function and blood pressure stability.

building community



WILL REEVEReeve Golf Classic

The Reeve Foundation's mission is inspired by the determined spirit of our community. In April 2021, hundreds of health professionals, advocates, community members and caregivers came together virtually for the 2nd annual Reeve Summit to brainstorm a future defined by access, inclusion, and innovation.

We celebrated speakers whose work is changing policy and transforming perceptions around what it means to live with paralysis, including legendary disability rights activist Judith Heumann, a former Special Advisor for International Disability Rights at the U.S. Department of State and Assistant Secretary for the Office of Special Education and Rehabilitative Services in the Department of Education; Dr. Oluwaferanmi Okanlami, Assistant Professor of Family Medicine and Director of Services for Students with Disabilities at the University of Michigan; and Wesley Hamilton, founder of Disabled But Not Really, and a recipient of the Craig H. Neilson Foundation Visionary Award; Ali Stroker, Tony Award Winner and Actor; and Will Reeve, ABC News correspondent. By the end of the conference, it was impossible not to feel recharged and ready to fight for the progress our community deserves.





ALAN BROWN, MAGGIE GOLDBERG, RON GOLD,
MARK MESSIER, SCOTT CHESNEY
Reeve Golf Classic

The 2021 Reeve Golf Classic, held at the historic Winged Foot Golf Club in Mamaroneck, New York, honored Gary Spitalnik, a long-time supporter of the Alan T. Brown Fund at the Christopher & Dana Reeve Foundation. In the autumn, salons in Denver and Chicago featured our latest research updates alongside cocktails, reuniting old friends and welcoming new faces.

Throughout the year, more than a thousand people participated in the marathons and community walks that make the Foundation's work possible, including Eric LeGrand's 11th Annual A Walk to Believe and the 2nd Annual Reeve Run & Roll. Running the New York City Marathon in November, Will Reeve set a goal of raising \$52,000 to honor his father who died at the age of 52—instead, he raised more than \$65,000.

donor spotlight: evelyn greenspan



For many families who support the Christopher & Dana Reeve Foundation, spinal cord injury research is personal. When they lace up sneakers for Team Reeve fundraisers or come together at A Magical Evening, it is in urgent pursuit

of treatments that will improve the lives of loved ones with injuries.

But sometimes generosity grows from afar—from a desire to help simply for the sake of helping.

Evelyn Greenspan lived a long, full life untouched by paralysis. Yet, when she died in 2019, just months shy of her 99th birthday, Greenspan bequeathed an extraordinary \$100,000 to the Reeve Foundation. The unexpected gift helped support research efforts across the country—and served as a powerful reminder that a stranger's selfless gesture can advance the hopes of thousands of families.

Greenspan's support for the Reeve Foundation stemmed from her admiration of Christopher Reeve and his relentless efforts to accelerate treatments for spinal cord injuries. Like Reeve, she believed in the potential for scientific progress, hoping that stem cell research, in particular, might yield effective and more widely available therapies for patients.

"She wanted to help the common man," said her son, Marius Greenspan. "She was a huge proponent of medicine, of good health for everyone."

Born and raised in Binghamton, New York, Greenspan's life was defined by a boundless curiosity about the wider world. She graduated from Cornell University in

1942 and moved to New Orleans, eventually hosting a radio show on a local station. The program, mixing talk and music formats, was a dream job for a person who chose to ride the bus not only to save money but for the chance to chat with strangers.

"She believed in learning something every day," Marius Greenspan said. "She was always asking questions. She had no agenda; she was just genuinely interested in people."

In 1955, she met her husband Earl, moved to Illinois, and raised two sons in a close-knit family that shaped the rest of her life. At the age of 69, Greenspan began studying for a law degree, but stopped after Earl was diagnosed with prostate cancer. After his death, she split her time between her son Gerald's home in Columbus, Ohio and in Fort Meyers, Florida, joining a community chorus, attending the local symphony, and traveling the world until she was in her mid-90s.

It was a happy life that left a mark, not only on Greenspan's family, but the beneficiaries of her quiet altruism. She donated to institutions ranging from Cornell University and the Southwest Florida Symphony to St. Jude Children's Research Hospital, funding charitable trusts and scientific research without the need or want of recognition.

But the work of the Reeve Foundation would not be possible without the support of families working tirelessly to accelerate treatments for loved ones living with paralysis—and individuals like Greenspan who choose to push for progress on behalf of strangers.

Such generosity, even when quietly given, deserves to be celebrated.

"My mother just believed in good causes," said Marius Greenspan. "She was a rare individual."

On giving

The Reeve Foundation's financial support helps scientists bridge the gap between their labs and the treatments that people living with paralysis urgently need. But these partnerships would not exist without the dedicated community members who believe in Reeve's mission.

There are many ways you can help. Remember the Foundation with gifts in your will and help sustain our work for years to come. Grab a friend or family member and join a Team Reeve event. Or simply give what you can. Every amount helps us continue the critical work of advancing innovative treatments for spinal cord injuries.

\$250,000 + Anonymous • Spine Extremity Tumor Research Endowment

\$100,000-249,999 Anonymous • Estate of Bonnie Ames • Jon & Helaine Ayers • Estate of Brooks Walker • Estate of Patricia Carlton • Estate of Dennis N Scoggins • F. M. Kirby Foundation • Thomas & Nancy Londres • Katherine Snider

\$50,000-99,999 Amerisure Charitable Foundation
• Kathleen Bridgman • Dana & Albert Broccoli
Charitable Foundation • Estate of Margaret Griswold
• James & Virginia Welch Foundation • Julie & Jon
Neustadt • Henry & Mary Stifel

\$25,000-49,999 Belote Family Trust • Cristina Carlino • Hollister Incorporated • Nadyne G. Edison Trust • The Ohr Hakotel Fund • The Roz & Marvin H. Weiner Family Foundation, Inc. • Jay & Pamela Shepard • Simmons Family Foundation • The Joyce C. Stern Foundation • Wakefern Food Corporation • Westmark Enterprises, FLP • Young Men's Philanthropic League Foundation, Inc.

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