



2020

annual report



Message

from the chair

The coronavirus reshaped the world with astonishing speed. Within a matter of days last spring, cities began locking down. Schools and businesses closed. Millions of people retreated to their homes. Life as we knew it suddenly seemed to halt.

But the vital work of the Christopher & Dana Reeve Foundation could not — and did not — stop. Pandemic or not, spinal cord injuries can't wait. For families needing urgent help navigating a child's spinal cord injury; people with limited resource's struggling to adapt a home around a new disability; or to finding rehabilitative care for a loved one, and secondary conditions complicating the lives of people with paralysis; our support was pressing if not more so, than ever.

In 2020, we invested \$3,074,574 in critical research projects and groundbreaking studies as part of our constant quest for cures. Additionally, our Information Specialists fielded more than 7,000 queries on topics ranging from finding fulfilling employment to accessing funding for wheelchairs. We awarded 138 Quality of Life grants totaling \$3,358,057 to organizations across the country, including a suicide prevention training program for veterans and an educational initiative designed to prepare medical students to better care for patients living with paralysis.

We also kept the community critically informed about the coronavirus, providing comprehensive information to help those facing heightened risks understand and safely navigate their everyday lives. More than one million new users visited our website in 2020, a tremendous increase with a clear message: the work we do matters.

We believe brighter days are on the horizon. No matter what the future brings, the Reeve Foundation will be here to provide the support that helps people living with paralysis build happy, healthy lives as we continue to seek **today's care and tomorrow's cure.**



Jay Shepard, *Chair, Board of Directors*

Providing Answers

in uncertain times



In 2020, the **Paralysis Resource Center (PRC)** provided the in-depth, day-to-day resources our community has long depended on while simultaneously mobilizing an urgent response to the ever-changing landscape created by the coronavirus.

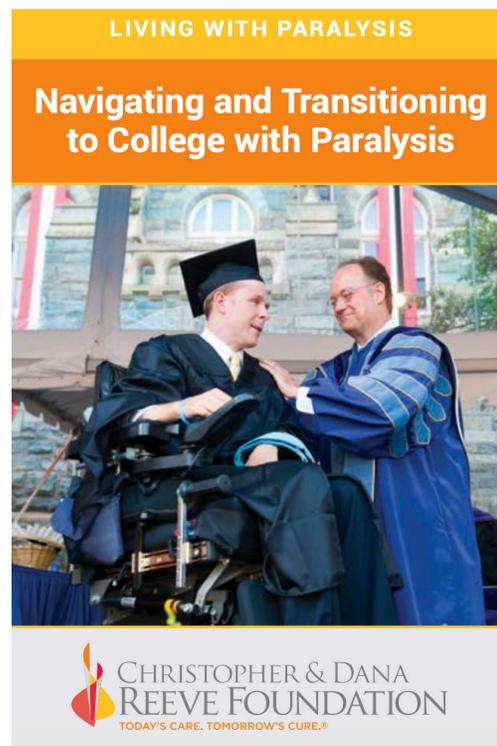
Throughout the year, monthly webinars and live-chats gave community members a place to ask questions and better understand how the virus and lockdown might specifically affect people living with paralysis. PRC staff worked tirelessly to raise awareness around pandemic issues, creating dozens of bilingual blogs that tackled topics ranging from managing doctor's visits and staying fit during quarantine to establishing safety precautions for caregivers. Stories from community members spotlighted the challenges faced by so many last year, whether transitioning to college with masks and hand sanitizer or filing for employment after being laid off.

For many individuals, the anxiety and emotional toll caused by the pandemic was devastating. In order to help maintain physical and mental health, the PRC's Quality of Life Grants Program, in partnership with the U.S. Department of Health and Human Services' Administration for Community Living, quickly created a COVID-19 grant program to target social isolation.

More than \$300,000 was awarded to 11 innovative programs helping people living with paralysis stay connected despite the pandemic. The grant supported outreach to a wide array of clients across the country: the Rocky Mountain MS Center offered online group workout sessions, counseling and peer-to-peer support to residents across Colorado; Paralyzed Veterans of America expanded access to virtual programs providing vital social connection and support by offering laptop loans in ten chapters; and Sistema Infantil Telaton USA created a virtual activities program incorporating art projects, karaoke and social meetups for children living with neurological and musculoskeletal disorders in Texas.

Throughout the pandemic, the PRC also continued to help families experiencing the daily challenges of living with paralysis. PRC Information Specialists fielded emails and calls from every state and as far as India and Brazil. An updated and expanded Paralysis Resource Guide was published alongside new booklets on subjects that included women's mental health, parenting with disabilities and the most frequently asked new injury questions.

The PRC also launched two new programs to directly support young students with paralysis and individuals seeking to return to work: free college preparation and transition support for students with physical disabilities; and pre-employment benefits analysis for help evaluating how to minimize loss of benefits such as Medicaid when transitioning back to work.



Building *the future today*

Christopher Reeve had faith in the future and fought for his belief that a cure for spinal cord injury was possible.

In 2020, the Reeve Foundation continued to support his pursuit of scientific progress with the launch of **The Rex Marco, M.D., Fund of the Christopher & Dana Reeve Foundation**. Created with a \$1.1 million gift from Dr. Marco's Spine Extremity Tumor Research Endowment, the Fund is helping expand investments in treatments and quality of life initiatives for those living with spinal cord injuries.

Dr. Marco was inspired to join forces with the Reeve Foundation after sustaining a spinal cord injury in 2019. A nationally renowned spinal surgeon and musculoskeletal oncologist, he'd spent decades building a life dedicated to making a difference. Suddenly, he was a spinal surgeon with a C4 spinal cord injury. Yet, as he lay in the intensive care unit at Houston's Memorial Hermann Orthopedic & Spine Hospital, Dr. Marco didn't grieve his changed body or the life he had lost. Instead, he thought about Christopher Reeve.

"I knew that I could be angry, but I didn't feel angry," Dr. Marco says. "I wanted to do what Christopher Reeve did, and help raise money for research and to find treatments for people with spinal cord injuries. I thought of him so much during that time. I knew that was part of the plan for my life."

Rex Marco, M.D. with family and friends



Despite decades of scientific gains, the pace of research and treatment for spinal cord injury remains frustratingly slow. In 2020, to hasten progress toward effective therapies, the Reeve Foundation invested more than 3 million in research initiatives across the country, including the groundbreaking **Big Idea** study at the University of Louisville's Kentucky Spinal Cord Injury Research Center.

Five new participants, ranging in age from 22 to 55, received epidural implants in 2020 as part of the multi-year epidural stimulation trial funded by the Reeve Foundation. To date, 18 people have been successfully implanted as part of the Big Idea, including Denna Laing, whose surgery was delayed for three months due to the pandemic lockdown.



Rex Marco, M.D. at a conference

Since receiving the implant in June, Laing has experienced improvements in cardiovascular function and blood pressure regulation. She recently began her next phase in the study, this time featuring a combination of cardiovascular and standing training. While the ongoing pandemic makes it incredibly challenging to be so far from family and friends in Boston, Laing understands how important these trials are to the millions of people living with paralysis around the country.

"I can see how it would benefit so many people," she says. "It's just the waiting. Everyone is sick of waiting. And that's why it's really important to get these sessions done and move this trial forward, so people don't have to wait anymore."



Denna Laing at the Big Idea study in Louisville

Moving Together

toward a cure

The Reeve Foundation's efforts to accelerate the pace and progress of spinal cord injury research depend on the generosity of our community. Our supporters rise at dawn to run marathons. They gather with family and friends for fundraising walks or 18 holes of golf in rain or shine. They show up, year after year, to support our mission with donations that seed research labs and clinical trials investigating treatments for spinal cord injuries.

In 2020, the coronavirus forced the cancellation of in-person events — from the New York City Marathon to our annual gala, *A Magical Evening* — that help make our work possible. But the Foundation quickly pivoted to virtual events, uniting and expanding our base of supporters despite the pandemic. In June, more than 1,500 participants from every state in the nation helped Eric LeGrand celebrate his 10th annual **A Walk to Believe**, raising a record-breaking \$189,000 — nearly double its 2019 total. Later that

month, Will Reeve hosted **A Magical Experience with Billy Porter**, a wide-ranging conversation with the Broadway actor and singer that touched on the power of performance, and the importance of inclusion and accessibility in public spaces; the intimate event drew 30 participants and raised more than \$3,000. In July, we hosted the **Reeve Golf Classic** at Ridgewood Country Club. It was a much smaller event than in years past due to the pandemic restrictions, but we still raised over \$100,000 and had a nice afternoon outside on the links. We also launched **Cards For A Cure**, a virtual poker series which raised more than \$20,000. And in October, the first-ever **Reeve Run & Roll 5K** raised \$315,000 with help from 861 supporters from as far as Singapore and Australia. The virtual aspect garnered immense enthusiasm from the community and helped gain new supporters: for 92% of participants, it was their first Team Reeve event.

"I'm so thrilled with the way the community rallied and grew this year," says Team Reeve Manager Kelly Lamb. "That was a tremendous victory."

Erica Bazerkanian added her own twist to the Run & Roll by turning the 5K into a self-made marathon in Simi Valley, CA. Bazerkanian, who has raised \$83,000 since joining Team Reeve in 2017, first discovered the Foundation after her father Jeffrey Stone was paralyzed by a spinal stroke. Before his death in 2016, she promised him she would celebrate his lifelong optimism by running for Team Reeve in his honor.

When her 2020 plans to run the St. George Marathon in Utah became impossible, Bazerkanian invited family and friends to support her solo challenge instead: "Paralysis doesn't take a break for COVID and neither will we."

On October 18, Bazerkanian set off at 7 a.m., joined along the way by fellow runners, friends and strangers alike: By day's end, she'd raised \$7,000 and recruited a dozen new Team Reeve members for the 2021 New York City Marathon.

"This keeps my dad's memory alive," she says. "It's really special to be able to turn what he went through into being able to do good for others."

There are many ways to support the Foundation's work. Sign up for upcoming Team Reeve events or simply donate in honor of a loved one who inspires you. And stay tuned for events still to come. Our strength lies in community, and we look forward to joining together in-person again.

Live Virtual Event with Billy Porter

Hosted by Will Reeve



A Magical Evening with Will Reeve and Broadway theater performer, singer, and actor, Billy Porter. Reeve and Porter joined the Reeve Foundation for a live virtual event discussing inclusion, advocacy, and more



Erica Bazerkanian and family participating in the inaugural Reeve Run & Roll

"I'm so thrilled with the way the community rallied and grew this year."

Team Reeve Manager Kelly Lamb



Damiere Shaw participating in the first virtual A Walk to Believe



Alan Brown participating in the inaugural Reeve Run & Roll



Joe Schiano participating in A Walk to Believe



Eric LeGrand of Team LeGrand, at Power Yoga over Paralysis



Denna Laing with friends and family participating in the inaugural Reeve Run & Roll

Connecting *community*

The Reeve Foundation serves as a bridge for community — connecting newly injured families with resources, funding science that hastens life-changing treatments, and spotlighting stories of determination that illustrate all that is possible after injury.

In February 2020, the first annual Reeve Summit, **Where Care, Cure and Community Connect**, brought advocates, researchers and community members to Washington, D.C. for three days of comprehensive conversation about living with paralysis.

The event, held just a month before the pandemic lockdown began, 270 participants from 37 states and nine countries and covered quality of life concerns and research initiatives that promise hope for the future. Speeches from keynote speakers, including Good Morning America anchor Robin Roberts, former U.S. Senator Tom Harkin, and disability activist Emily Ladau, inspired our audience, while smaller workshops focusing on health and lifestyle topics provided community members with practical advice and insight to carry home.



Cody Unser, Maggie Goldberg, Anjali Forber-Pratt, Shannon Unser



Julie Hocker, Commissioner of the Administration on Disabilities, ACL



Robin Roberts, co-anchor of ABC's "Good Morning America"



Breakout session—The State of Spinal Cord Injury Research

MILESTONE MOMENTS:

Celebrating 25 years of Christopher Reeve's legacy

On May 17, 1995, an equestrian accident left actor Christopher Reeve paralyzed from the neck down. Along with his wife, he created the Christopher & Dana Reeve Foundation to help all individuals living with paralysis reach their potential. As their legacy continues 25 years later, we celebrate key moments in the Foundation's history.



CURE

- 2004 Launch of the NeuroRecovery Network (NRN) and the North American Clinical Trials Network (NACTN)
- 2011 First documented effect of epidural stimulation on voluntary movement – standing and assisted stepping after motor complete paraplegia. Led to the Big Idea protocol development
- 2012 *Journal of Neurosurgery* publishes 10 NACTN papers on spinal cord injury at the cutting-edge of clinical translation; *Archives of Physical Medicine & Rehabilitation* publishes 11 NRN papers demonstrating innovative rehabilitation treatments improve quality of life
- 2014 NACTN publishes the results of its Phase I clinical trial of the neuroprotective drug riluzole in acute spinal cord injury; joins RISCIS, an international Phase II/III clinical trials the following year
- 2016 NRN welcomes its first international Affiliate site, Neurokinex in the UK
- 2017 FDA approves The Big Idea protocol, with first participant implanted in 2018
- 2020 The Big Idea's 16th participant is implanted with an epidural stimulator



CARE

- 1999 Dana Reeve launches Quality of Life Grants Programs, which has provided \$30M in financial support to over 3,000 nonprofits nationwide
- 2002 The Paralysis Resource Center (PRC) opens; by 2020, more than 100,000 families have received one-on-one assistance
- 2003 First edition of the Paralysis Resource Guide is published; to date, more than 220,000+ copies distributed globally
- 2009 PRC produces a paralysis prevalence report that finds one in 50 Americans live with paralysis
- 2011 Peer & Family Support Program begins; today, has 400+ peer mentors
- 2020 Inaugural paralysis conference, Reeve Summit: Where Care, Cure and Community Connect

To learn more about the Reeve Foundation, visit www.ChristopherReeve.org



RAISING



awareness

Christopher Reeve changed the way people thought about spinal cord injury and helped blaze a new path for SCI research and all impacted by paralysis.

To mark the 25th anniversary of Christopher's injury, the Reeve Foundation launched **Hope Happens Here: 25 Stories**, a multimedia campaign celebrating individuals whose passion and perseverance has left an indelible mark on our community. Among these stories, readers discovered Hank Stifel, the New Jersey businessman who ignored skeptics after his son's spinal cord injury and dedicated the rest of his life to the pursuit of a cure; Scott Remington, a longtime Reeve Foundation supporter whose annual fundraiser in the Adirondacks has raised more than \$750,000 for research efforts and increased awareness about living with paralysis; and Jennifer Longdon, a member of the Arizona House of Representatives fighting for the rights of disabled and marginalized communities. Their stories, like Christopher's, remind us of the difference one person can make in the lives of many.

An infographic highlighting the Reeve Foundation's milestones since Christopher's injury further helped spread our message to new audiences across the country. The graphic was picked up by digital sites and national newspapers, including the *Los Angeles Times*, the *Chicago Tribune* and the *New York Daily News*, reaching more than 211,000,000 people.

Actors Meryl Streep and Ali Stroker also added heartfelt contributions to the campaign with videos honoring Christopher and the importance of the Foundation's work. By generously sharing personal memories of Christopher's legacy— "There are certain stars that we count on, never to dim, never to be extinguished, no matter how murky the sky or thick the cloud cover in November. We count on them to shine through, to give us inspiration from far, far, far away," Ms. Streep said – they provided a powerful and poignant introduction of the Foundation's work to countless new supporters.

on GIVING

Each dollar we raise is invested in research that improves our community's quality of life and advances 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 2020, bequests totaled \$609,452. Grab your sneakers and join a Team Reeve event. With 861 participants in all 50 states and eight other countries, we raised over \$330,000 with our first virtual Team Reeve event, Reeve Run & Roll. Or simply give what you can; more than 6000 people made donations of less than \$25 to the Reeve Foundation in 2020, totaling \$111,825.83. Every amount helps.

\$250,000 + Spine Extremity Tumor Research Endowment

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