

# 2022

## ANNUAL REPORT

# MESSAGE

from the President & CEO

The Christopher & Dana Reeve Foundation is dedicated to the belief that people living with paralysis deserve the chance to define themselves, to live and work independently, to pursue joy in whatever way they choose. For more than four decades, we have fought to redefine what is deemed possible in both care and cure — and we're not done yet.

In 2022, the Reeve Foundation celebrated its 40th anniversary with ambitious plans to expand community engagement and outreach. We hosted receptions across the country to spotlight the research gains emerging as a result of Reeve investments. We partnered with national non-profit organizations from Dallas to Detroit to better reach underserved communities. And we grew participation across key Foundation initiatives, raising a record-breaking \$725,000 in Team Reeve events, and increasing our volunteer network to more than 10,000 advocates who highlight access and policy issues at the legislative level.

The 20th anniversary of the National Paralysis Resource Center inspired an array of new programming and educational outreach in honor of its visionary founder, Dana Reeve. We increased webinars and resources on topics that matter deeply to community members, from caregiving to health equity, and added an Adaptive Sports and Recreation booklet and 13-part wheelchair comparison video series to our comprehensive library. Most critically, our Information Specialists provided the one-on-one assistance that defines Reeve to more than 7,800 people from around the world.

As we worked to support families in the day-to-day, we also focused on their future. In 2022, we invested more than \$2 million in labs across the country and launched the Reeve Foundation Spinal Cord Injury Advisory Board to help identify research and development opportunities that will yield the greatest gains for community members. Collaboration is critical for this new era of research— and the Reeve Foundation is helping lead the charge.

We thank you for supporting our vital work and look forward to celebrating the triumphs still to come. Together, we will build the vibrant future our community deserves.



Maggie Goldberg  
*President and CEO*

# Tackling a Caregiving Crisis

The Washington Post | LIVE

## The Caregiving Crisis

Thursday, Sept. 22 at 11:30 a.m.

Allen, Pagé, Pauly and Saujani discuss the state of caregiving, the impact of the pandemic and the effect on the economy.

To register to watch, visit: [wapo.st/caregivingsept2022](https://wapo.st/caregivingsept2022) or scan code below with a smartphone camera:

**Tim Allen**  
CEO, Care.com

**Reshma Saujani**  
Founder & CEO, Mindy Project for Moms & Frantic, Girls Who Code

**Brooke Pagé**  
Co-founder WHO of SCI

**Elena Pauly**  
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Content from the Christopher & Dana Reeve Foundation

**Regina Blye**  
Chief Program & Policy Officer, Christopher & Dana Reeve Foundation

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### The real cost of unpaid caregiving and impact of the pandemic

By Washington Post Live  
September 22, 2022 at 11:30 a.m. EDT

THE CAREGIVING CRISIS #POSTLIVE

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twp LIVE

Tim Allen, Brooke Pagé, Elena Pauly and Reshma Saujani join Washington Post Live on Thursday, Sept. 22. (Video: The Washington Post)

Caregivers provide critical support to millions of people living with paralysis across the U.S., helping with essential daily activities that foster health and independence. The National Paralysis Resource Center (NPRC) offers support to community members who serve as caregivers through our peer mentoring programs and free, year-round virtual support groups. But the challenges of caregiving also require urgent and widespread attention.

In 2022, the Reeve Foundation commissioned a national survey to assess the general public's familiarity with paralysis and caregiving. The survey of more than 1,000 Americans revealed that the majority (69%) underestimates the prevalence of those living with paralysis in the U.S., although one out of every three respondents reported knowing someone with paralysis. Nearly 80% believe that a family member providing long-term care for someone who is living with paralysis should receive

some form of compensation from the government. These findings will bolster the efforts of Reeve's advocacy team in Washington, D.C. as they educate policymakers about the inequities experienced by people with paralysis.

Reeve also sponsored **"The Caregiving Crisis,"** a *Washington Post* event discussing the challenges of unpaid caregiving. The moderated conversation, hosted by health and community experts, was live-streamed on the newspaper's homepage and across social media channels, helping raise awareness about this critical issue. The work of the Reeve Foundation was also promoted live onscreen throughout the program and in a sponsored video segment featuring NPRC Chief Program and Policy Officer Regina Blye.



# Fostering Inclusive Engagement

The Reeve Foundation is dedicated to advancing access and inclusion opportunities for people with paralysis in every aspect of life. In 2022, we launched an innovative partnership with Peloton to create the “Seated Adaptive Strength Program,” an 8-session exercise class designed specifically for wheelchair users. The groundbreaking program, created with input from Reeve Foundation community members, is now featured on the company’s popular home exercise bikes and mobile app. The collaboration also resulted in a new meditation class that includes breathing techniques meant to accommodate the needs of those living with quadriplegia and a curated collection of classes for caregivers focused on breathing, upper body stretches, lower body strength, healthy back yoga flows, and strength warm-ups. Fueled by positive community feedback, Reeve will continue to seek opportunities to embed adaptive options throughout public spaces.

## Expanding Community Outreach

Paralysis impacts families across the U.S., from Baltimore and Los Angeles to small towns in rural Arkansas. In 2022, the Reeve Foundation worked to strengthen outreach and engagement across diverse populations. **Jamil Paden**, Reeve’s new Racial & Health Equity Manager, developed innovative partnerships with Black, Indigenous, and People of Color-led non-profit organizations and Delaware State University, a historically Black college and university, to promote NPRC resources in underserved communities throughout the country. In addition, Paden increased webinars and workshops spotlighting issues around disability and racial equity and helped expand the scope of existing Reeve programs. In December, the Quality of Life Grants Program awarded more than \$142,000 in its first-ever round of Racial Equity Grants. Targeting remote and under-resourced communities, the grants helped seed peer support programs and expanded community access in Buffalo, Philadelphia, and Detroit.



# New Appointments

In 2022, the Reeve Foundation welcomed new colleagues whose expertise quickly improved efforts to advance research gains and create community connections.



**Chief Scientific Officer Marco Baptista, Ph.D.**, will oversee the Foundation's research portfolio and lead efforts to expand data sharing, increase participation in clinical trials, and generate results-driven scientific partnerships. Baptista, a neuroscientist with experience in both non-profit and pharmaceutical fields, most recently served as vice president of research programs at the Michael J. Fox Foundation for Parkinson's Research. His deep industry experience and knowledge will help drive Reeve's efforts to unite academics, scientists, and industry members in a new model of collaboration that will accelerate the discovery and development of promising treatments.



**Regina Blye joins the National Paralysis Resource Center as Chief Program and Policy Officer** with expansive plans to build new collaborations that spotlight Reeve's resources and comprehensive supports. She will develop new NPRC initiatives that not only respond to the evolving needs of community members, whether newly injured or aging with paralysis, but that spotlight the health and economic disparities that continue to affect people with paralysis. Blye, who was appointed to the United States Access Board by President Barack Obama, previously led the Independent Living Services program at the Administration for Community Living.



**New Chief Development Officer Colleen Coppla** will lead Reeve's fundraising initiatives that directly support efforts to advance scientific breakthroughs. In this role, she will oversee all development operations for the Reeve Foundation, including major gifts, corporate and foundation relations, Team Reeve, special events, and planned giving. Coppla brings more than 20 years of nonprofit management and fundraising experience to the Foundation; most recently she served as Vice President of Development at Montclair State University.

# Revamping **RESEARCH**

Transformative treatments for spinal cord injuries are finally within reach as decades of research gains converge with 21st century technological breakthroughs. But advancing progress at this critical moment will require a new model of collaboration.

In 2022, the Reeve Foundation forged new partnerships that will accelerate discovery and development, create a more robust clinical trial pipeline, and remove the barriers limiting ambitious engagement and investments throughout the field.

We worked with the **North American Clinical Trials Network** to increase testing sites and expand infrastructure at neurosurgery departments and university-affiliated medical centers, allowing more companies to conduct a greater number of trials. We launched the **Christopher & Dana Reeve Foundation Scientific Advisory Board**, comprised of senior and junior investigators from across the globe and in numerous scientific sectors, to help identify research and development opportunities that will rapidly increase the number of treatments moving from bench to bedside. We developed **Reeve Foundation Symposiums** to spotlight innovative research and bridge the gap between scientists, pharmaceutical companies, investors and community members. And we advocated for increased transparency and engagement through an **Open Data Platform** where shared lab gains, failures and ideas will help elevate the entire field.

## **ADVANCING BREAKTHROUGHS**

The Reeve Foundation partnered with **International Spinal Research Trust** to fund more than \$1.1 million in grants designed to fast-track spinal cord injury treatments. Grantees, chosen in a rigorous selection process by a committee of international experts and individuals living with SCI, include Karim Fouad, PhD, a professor at the University of Alberta, working to extend the rehabilitative period after injury in which significant functional gains typically occur; Molly Shoichet, PhD, a biomedical engineer at the University of Toronto, studying treatments that can penetrate the scar that forms around the injury and foster regeneration; and Chris West, PhD, an associate professor at the University of British Columbia, investigating the potential of hypoxia (exposure to short, repeated periods of low oxygen) to improve low blood pressure.

# OUTREACH and EVENTS

The Reeve Foundation has long served as a bridge for community members, connecting them not only with resources to support independent and fulfilling lives, but with one another. In 2022, the **3rd Annual Reeve Summit: Where Care, Cure, and Community Connect** drew individuals and families to Washington D.C from across the U.S. The event featured a keynote address from Leon Ford, co-founder of The Hear Foundation, and breakout sessions on topics such as caregiving, pregnancy, and the challenges of air travel for people with disabilities. Research updates from Reeve Foundation Chief Scientific Officer Marco Baptista provided an overview of recent advances in treatment and device development, leaving participants with a sense of hope and, more importantly, progress.



Reeve Foundation Staff



Regina Blye, Leon Ford, Maggie Goldberg, Justin Graves.



Julie Neustadt, Kelsey Grammer, Maggie Goldberg and Eric LeGrand

The Reeve Foundation celebrated 40 years of extraordinary progress in spinal cord injury research at the long-awaited return of **A Magical Evening**. We honored Julie Neustadt and Eric LeGrand, who exemplify the spirit of Reeve in both their pursuit of full lives and commitment to hastening scientific gains that benefit the entire community.



**Team LeGrand's 12th Annual A Walk to Believe** at Rutgers University kicked off our summer celebrations for East Coast community members and raised \$130,000. The **Reeve Golf Classic** at the Winged Foot Golf Club in Mamaroneck, N.Y. raised more than \$600,000 for research. Further south, friends old and new gathered for a cocktail fundraiser for Reeve hosted by renowned artist Peter Tunney. The event, held at Wynwood Walls, Miami's famed street art museum, raised more than \$125,000 and received local news coverage that spread awareness about our work.



Maggie Goldberg, Eric LeGrand, Marco Baptista PH.D.



Rutgers Scarlet Knight Mascot at A Walk to Believe Start Line.



Simmons Family and Friends



Will Reeve, Karrie Webb, Mark Messier.

# Donor Spotlight:

## Lorraine DiPaolo

On a recent trip to Lebanon, **Lorraine DiPaolo** could be found singing the praises of the Reeve Foundation, pointing a new friend to its website and work. Her passionate long-distance advocacy for people with spinal cord injuries is no surprise to those who have forever watched the fierce Brooklynite ignore expectations and seize a happy life.

DiPaolo's support for the Reeve Foundation began more than two decades ago, when she and her husband Gordon became dedicated annual donors. At the time, spinal cord injury research was too often dismissed as an academic dead-end. The DiPaolos' donation to Reeve — then and each year since — mattered, helping reinvigorate the field. It was a statement of belief in the future of those with injuries; the DiPaolos, more than most, knew well what was possible.

In 1960, Gordon DiPaolo sustained a C5-C6 injury in a swimming accident at the beach. The couple had just gotten engaged after a romantic courtship born in an Arthur Murray dance studio where both were instructors — a meet-cute fit for the silver screen.

“He walked out — a tall, smiling, handsome guy,” DiPaolo says. “And I fell in love.”

After the accident, they navigated Gordon's two-year recovery and rehabilitation together with determination and steady resolve; there was no internet, no National Paralysis Resource Center, no easy way to find answers, but Lorraine never doubted their future.

“I was determined to remain by his side through all of it,” she says.

And she did, building a career as a stockbroker and investment advisor while Gordon returned to school, earned his Ph.D. and launched what became a 50-year



career as a beloved finance professor at the College of Staten Island. They travelled the world, from Puerto Rico to Provence, threw exuberant parties for friends at the River Café, and were happy.

When Gordon died in 2020, DiPaolo's support for spinal cord injury-related organizations amplified: she connected with the Wounded Warrior Project and spoke with veterans who are injured; she is brainstorming ideas to help recruit veterans with spinal cord injuries to the College of Staten Island; and she recently designated the Reeve Foundation as a beneficiary of her estate, an act of generosity that will accelerate the scientific progress that she and Gordon first helped make possible.

DiPaolo's increased support and advocacy is not rooted in grief, but joy: in helping others, she aims to honor the extraordinary life the couple shared.

“We really did it all,” she says. “If I can give even one person a better chance at navigating paralysis, it's like I'm giving a gift to Gordon.”



# Donor Spotlight:

## David Carmel

On the cusp of his 50th birthday, **David Carmel** decided to conquer a longtime bucket-list challenge: the New York City Marathon.

He got straight into a rigorous training schedule, circling Central Park on his handcycle after work and tackling steep Adirondack roads on the weekends. He recruited his close friend Mike Green to join him and added a special twist to the quest: not only would they finish the race but raise more than \$100,000 for Team Reeve.

The choice to support the Christopher & Dana Reeve Foundation was personal. After Carmel sustained a C6 spinal cord injury in a diving accident in 1999, he listened to a recording of Christopher Reeve's memoir *Still Me* during his recovery at Kessler Institute for Rehabilitation; Reeve's words acted as a powerful motivator.

"As you're trying to process something so sudden and so transformative, to have somebody describing what they were feeling was really, really helpful," he says.

Carmel later earned his MBA at Stanford and worked to pass the California Stem Cell Research and Cures Initiative. For two decades, he helped steer the efforts of biopharmaceutical companies developing therapies for life-threatening diseases and now serves as Chief Growth and Innovation Officer for the Foundation at the National Institutes of Health.



"My goal is to bring more treatments to patients and really advance biomedical research," he says. "I understand the science and have the lived experience of knowing what it's like to live minute-to-minute and day-to-day. I'm bringing both of those perspectives into the field and creating a sense of urgency."

The marathon provided another chance to raise awareness and critical funds for research. When the race arrived, Carmel's determination helped him overcome an array of unexpected hurdles, including a torn muscle in his shoulder, a cycle stuck in high gear, and one of the hottest race days on record.

"I'm a stubborn person and in this situation it's helpful," he says.

In the end, Carmel not only crossed the finish line, but raised nearly \$140,000 with Green's help to become Team Reeve's highest fundraisers.

"It was really special to do it for Reeve," Carmel says. "That team aspect was so important, and being able to celebrate with everybody afterward was just amazing."





# 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.

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