

**Prepared Testimony of Alexandra Reeve Givens  
Board Member, The Christopher & Dana Reeve Foundation**

Before the House Committee on Appropriations Subcommittee on Labor, Health and Human  
Services, Education and Related Agencies,  
April 26, 2018

Thank you for this opportunity to submit testimony in support of an appropriation of \$8,700,000 for the Paralysis Resource Center (PRC) within the Administration for Community Living.

I am proud to speak on behalf of the 1 in 50 individuals living with paralysis in the United States, who rely on programs like the Paralysis Resource Center to live independent and empowered lives. The Reeve Foundation has operated the Paralysis Resource Center for 16 years, competing in a rigorous, competitive bidding process every three years for renewal of the contract. For fiscal year 2019, we request a funding level of \$8.7 million for the Paralysis Resource Center, which would restore the PRC to previous funding levels and is an increase of \$1 million over the FY18 omnibus.

Despite its tremendous success, the PRC has been recommended for elimination in the President's budget for the second year in a row. The proposed justification is that its initiatives "could be carried out with other existing funding streams to deliver services more efficiently." The PRC is the only program of its kind that directly serves individuals living with spinal cord injury, MS, ALS, stroke, spina bifida, cerebral palsy and other forms of paralysis. Attempting to replicate the PRC's already established and thriving programs would take years and result in greater costs—precisely the opposite of what the Administration's budget aims to do.

When my father, Christopher Reeve, was paralyzed from the neck down due to a spinal cord injury in 1995, we found ourselves in total darkness as to what to do next. There was no phone number to call for guidance or help. There were no experts reaching out to connect us to the right rehabilitation facilities, or discuss how we could support his return home and ongoing

well-being. There was certainly no promise that an individual living with that level spinal cord injury could lead a full and active life as a father and husband. But, instead of accepting that life with paralysis would be full of limitations, my father dreamed of a brighter future.

That was the genesis of the Christopher & Dana Reeve Foundation: my father's dream to elevate the needs and rights of the 5.4 million Americans living with paralysis. But my father was far from alone. The real drive behind the Paralysis Resource Center came from my stepmother, Dana. As a caregiver herself, she knew that paralyzed individuals and caregivers around the country need a centralized place to call for resources and expertise.

Since the PRC opened its doors in 2002, it has served as a free, comprehensive, national source of informational support for people living with paralysis and their caregivers. Our work is deeply aligned with ACL's mission to empower people living with disabilities and older adults to live independently and participate in their communities throughout their lives.

#### *A. The PRC's Core Programs*

(1) **Information Specialists.** One of the PRC's most essential functions is the team of certified, trained Information Specialists who provide personalized support on how to navigate the challenges of life with paralysis. This team of experts, many living with paralysis themselves, are often the first port of call for individuals who are newly injured or diagnosed.

When college football star Eric LeGrand – whom Chairman Cole was kind enough to meet last year – sustained a spinal cord injury that left him paralyzed from the neck down, his mother had no idea how to care for her son when he returned home. She leaned on the PRC's Information Specialists to map out a plan for Eric that helped him thrive as a student and now college graduate. Even seven years after his injury, Karen LeGrand credits the Information Specialists with being their go-to resource to keep Eric healthy and living an active life.

To date, our Information Specialists have provided direct counseling to 90,000 people. We have distributed 200,000 copies of our *Paralysis Resource Guide*, which is a staple in hospitals and rehabilitation facilities across the country.

(2) **Peer & Family Support Program.** A second pillar of the PRC is our Peer & Family Support Program. This program is born of the idea that the best source of knowledge is experience: and that peer-to-peer connections empower not only the newly-paralyzed individual, but also the mentor. Through the PRC, more than 280 peer mentors have been trained and certified in 43 states. These individuals have mentored 8,000 peers, including 1,500 caregivers.

(3) **Quality of Life Grants Program.** Our third pillar, the Quality of Life Grants Program, operates at the community level to fund nonprofit initiatives in all 50 states. Since 1999, the Quality of Life Grants Program has directed over \$23 million dollars to assist nearly 3,000 projects. This program has increased employment trainings and accessible transportation; established adaptive sports programs and camps for children; improved access to buildings, playgrounds and universities; helped individuals learn how to manage their financial well-being, and provided support services for veterans. Critically, these programs use the public attention that comes from receiving PRC funding – often fairly small grants – to raise additional funds in their community, creating a powerful return on investment.

(4) **Military & Veterans Program; Multicultural Outreach Program.** The PRC has a comprehensive Military and Veterans Program, which provides dedicated resources to help individuals navigate military and civilian benefits and programs as they reintegrate into their communities. The PRC also facilitates a Multicultural Outreach Program that is designed to engage and support underserved populations like ethnic minorities, older adults, low income earners, and LGBTQ individuals.

(6) **ChristopherReeve.org.** One of the most challenging aspects about living with paralysis is combating feelings of isolation and exclusion, especially for those who are unable to leave their homes due to physical and societal barriers. The Reeve Foundation’s website, ChristopherReeve.org, provides a vibrant online community and resource hub that attracts close to two million visitors per year.

***B. The Value of Integrated Services.***

There are many examples in which an individual living with paralysis has not only participated in one program of the PRC, but has benefitted from a suite of our free services. When Sterling Thomas, a college student from Oklahoma, sustained a spinal cord injury in 2012, his family was at a loss as to how to emotionally and physically support their son. They turned to the Reeve Foundation’s website to understand Sterling’s prognosis and prepare for his future needs. They referred to the *Paralysis Resource Guide* as a critical tool for managing his health, and connected with an Information Specialist who provided guidance to further improve Sterling’s quality of life. Once Sterling and his father felt confident in their path forward, they became certified peer mentors through the Peer and Family Support Program to help other families in the Oklahoma area navigate life after paralysis. And, I am excited to report that the Sterling Thomas “Push-Push-Pray Foundation” applied for a Quality of Life grant to host the *No Boundaries Expo*, an event that was in peril after its original host closed its chapter. Sterling’s is just one of many stories of how the PRC serves as a lifeline to help families from the moment of injury or diagnosis through the many chapters of living with paralysis—providing a continuum of care made possible by the depth and breadth of the PRC’s offerings.

### ***C. The Importance of Federal Funding.***

I would like to close my remarks by emphasizing why federal funding for this program is so important. Simply put: neither the Reeve Foundation, nor any organization competing to run the PRC, could provide this type of centralized resource alone. A resource center that is relied on by literally millions of Americans affected by paralysis needs consistent, regular funding. Because many individuals living with paralysis have to attend rehabilitation clinics and/or draw on other resources from out of state, nationwide expertise is required. To get the benefit of investing in a centralized hub of information, we need to promote and deliver these services at scale. Federal funds are essential for this valuable, life-changing resource to work.

Federal funding for the PRC is also a good investment. Our resources help people adapt their homes and gain the tools they need to return to their communities, and eventually to work. The programs funded by the PRC make people less dependent on healthcare providers, so they can reduce their medical costs—saving dollars for Medicaid and Medicare. Our Military and Veterans Programs provide an essential continuum of support for returning heroes as they transition out of the VA system. Our national model and household name allows us to leverage a small team to have maximum impact. The PRC is smart federal funding at work.

My father once said, “Hope is like a lighthouse”, helping individuals who are lost in the darkness find their way. But like a lighthouse, hope must be built on solid foundations. The resources, support and community created by the PRC are the foundation for hope for millions of individuals affected by paralysis around the country. I urge you to protect the Paralysis Resource Center and help individuals achieve greater quality of life, health and independence by supporting its vital work. Thank you.