Congress of the United States

Washington, DC 20515

March 24, 2023

The Honorable Robert Aderholt Chairman Subcommittee on Labor, Health and Human Services, Education Committee on Appropriations Washington, DC 20515 The Honorable Rosa DeLauro Ranking Member Subcommittee on Labor, Health and Human Services, Education Committee on Appropriations Washington, DC 20515

Dear Chairman Aderholt and Ranking Member DeLauro,

As Members of Congress who support the 5.4 million Americans living with paralysis, their families, and their caregivers, we write to thank you for your ongoing support for this community, and to respectfully request \$10,700,000 in FY 2024 for the National Paralysis Resource Center (PRC) within the Administration for Community Living (ACL) at the Department of Health and Human Services (HHS). The PRC was authorized to provide the newly paralyzed with grants, information, support, and advocacy.

The PRC was created in 2002 to help individuals living with paralysis achieve independent, high-quality lives while assisting those who care for them. Through targeted resources and programs, the PRC reinforces the development of services to support independent living within the disability community and helps address many of the problems that individuals and families living with paralysis face.

Among the critical programs that the PRC supports and operates are a network of Information Specialists, a national Military and Veterans program, a Peer and Family Support Program, and a substantial Quality of Life Grants Program that funds community-based organizations making a difference around the country. These programs—outlined further below—do not exist within any other federal entity, and insufficient federal funding for the PRC would jeopardize vital services and support for paralyzed Americans.

Information Specialists

Information Specialists are a core feature of the PRC. Trained specialists, some living with paralysis themselves, provide personalized support to help individuals and families navigate the vast amount of information and services available for those living with paralysis. Information Specialists, who are full-time PRC employees, are trained to answer any question related to paralysis, including Spanish language inquiries. Since its inception, the PRC's Information Specialists have provided direct, one-on-one counseling to more than 114,000 people and have helped hundreds of thousands more through the PRC's Paralysis Resource Guide, which is downloadable online and a staple in hospitals and rehabilitation facilities across the country. Because the PRC's Information Specialists work at a national level, they can connect individuals, families and caregivers to resources and caregivers across state lines.

Peer and Family Support Program

The Peer & Family Support Program is a national network that creates connections for people living with paralysis, their families, and caregivers. To date, certified peer mentors have provided support to approximately 19,600 people receiving mentoring through in-person meetings, telephone, e-mail, and videoconferencing. The program currently has more than 480 mentors in over 40 states. In recent years, and particularly as the nation

has grappled with the COVID-19 pandemic, the PRC increased its virtual training to increase and diversify its peer mentor pool and revise its training curriculum. Since its inception, the Peer Program has also mentored more than 1,500 caregivers, providing an important peer support network for individuals who are often underserved

Military and Veterans Program

The PRC helps service members navigate their military benefits and combine them with civilian programs to foster high levels of health, well-being, and independent living. The services are especially encouraged for those who, for a variety of reasons, never before sought support and thus provides help to individuals across a wide array of service eras and causes of injury. In addition, the Military and Veterans Program (MVP) Advisory Council works to better identify and define the needs of service members as well as leverage, develop, and maintain collaborative relationships with other national and local organizations that serve the military and veterans' community. The MVP Council is a group of trained volunteers who are retired service members, civilians, and caregivers with ties to the various branches of the Armed Services. Council members serve as a bridge to access the Veterans Administration and other military and veteran programs and services.

Ouality of Life Grants

The Quality of Life Grants Program strives to empower individuals with disabilities and their families by providing grants to nonprofit organizations that improve quality of life through inclusion, access, independence, opportunities for community engagement, and other life-enhancing endeavors. Since 1999, the PRC's Quality of Life Grants Program has directed over \$37 million to over 3,550 projects in all 50 states and territories.

The program continues to address the deleterious impact of social isolation during the COVID-19 pandemic through a grant program that aims to enhance connectedness of people living with paralysis and their caregivers to their communities and prevent adverse health outcomes.

We share these details with you to emphasize how vital the PRC is to individuals living with paralysis, as well as to their families and caregivers. To that end, we urge you to include \$10,700,000 for the PRC in the FY 2024 Labor, Health and Human Services, Education and Related Agencies appropriations bill.

Thank you for your consideration.

Sincerely,

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