We create opportunities for independence for people with disabilities through research, education, and consultation.
Christopher & Dana Reeve Foundation Paralysis Resource Center: Your Source for Information, Services and Support

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Evaluation Survey & Contact Information

Your feedback on this webinar is important to us. At the end of the presentation you will be asked to complete an evaluation. Please click on the link provided at that time and fill out the brief survey.

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What You Will Learn…

• The wide array of free resources, programs and services available to CILs and their consumers

• The general demographics of Americans living with paralysis and spinal cord injuries

• Resources especially useful for CILs in assisting consumers with community connection, exercising self-determination, health and well-being

• The benefits of the PRC’s national peer-to-peer mentoring program that provides information, resources, and support to people living with paralysis, their families and caregivers

• Grant opportunities from the Reeve Foundation available to CILs
Today’s Care. Tomorrow’s Cure.®

The Christopher & Dana Reeve Foundation is dedicated to curing spinal cord injury by funding innovative research, and improving the quality of life for people living with paralysis through grants, information and advocacy.
Paralysis Resource Center

The Paralysis Resource Center (PRC) is a comprehensive national source for free paralysis information, services and programs for individuals with paralysis, their families and caregivers.

The PRC improves the quality of life of people living with paralysis through its grants, programs and resources.
Definition of Paralysis

Reeve uses a functional definition of paralysis: “Inability or difficulty moving arms and/or legs.”
Over 5.5 million Americans are living with paralysis

- Spinal Cord Injury: 1,275,000 (23%)
- Multiple Sclerosis: 939,000 (17%)
- Stroke: 1,608,000 (29%)
- Unspecified Birth Defect: 110,000 (2%)
- Neurofibromatosis: 212,000 (4%)
- Traumatic Brain Injury: 242,000 (4%)
- Cerebral Palsy: 412,000 (7%)
- Post-Polio Syndrome: 272,000 (5%)
- Other: 526,000 (9%)
Over 1.2 million Americans are living with spinal cord injuries.

Unknown/No Response: 109,000 (9%)
Natural Disaster: 8,000 (1%)
Birth Defect: 34,000 (3%)
Victim of Violence: 57,000 (4%)
Sporting/Recreation Accident: 206,000 (16%)
Fall: 112,000 (9%)
Motor Vehicle Accident: 311,000 (24%)
Accident Working: 362,000 (28%)
The Information Specialists team provides support and responds to questions from individuals via telephone, email or in-person.

- Available for all stages of living with paralysis
- Multilingual services available
- Specialists can be reached at 800-539-7309
- 9 am – 5 pm Eastern, Monday-Friday
The Paralysis Resource Guide

- Available in hard copy in English and Spanish.
- Available online in English, Spanish and Chinese.
- www.paralysis.org – Click on “Paralysis Resource Guide.”
- Also available in audio format.
Online Community

• A free social networking platform dedicated to the paralysis community, family and friends, caregivers, and healthcare professionals.

• Join the discussion and reach out to experts like Dr. Dan and Nurse Linda

• The Life After Paralysis blog represents a variety of paralysis community members. It is a place for open conversation about the issues and the interests of people living with paralysis, their families, friends, caregivers, and the professionals that serve them.
Military & Veteran Program (MVP)

• Guides service members through the military and veterans healthcare systems

• Outreach to Military Treatment Facilities and VA Medical Centers

• Connects service men and women and their families with the Peer & Family Support Program, matching them to MVP Peer Mentors
Community Outreach Program

The Multicultural Outreach Program serves diverse communities across the United States and partners with organizations to improve the quality of life for people living with paralysis and their caregivers.
Our speakers present on a range of topics, including:

- How to thrive after trauma
- Dispelling myths about paralysis and disability
- Motivation and going forward
- Achieving the best results from your consumer
National Lending Library

- The Reeve library is a national clearinghouse of information on all subjects related to paralysis
- 5,000+ books & videos available for free loan
- Items can be mailed to a person’s home with return postage
- Interlibrary loans state-wide and nationally
Neuro Recovery Network

• The NRN is a clinical research network of rehabilitation centers and community health and wellness facilities.

• These facilities develop and deploy standardized, evidence-based, activity-based therapies to promote functional recovery and improve health and quality of life for people living with paralysis.
Don’t Call It a Miracle by Kate Willette covers the basic biology of an injured spinal cord, the approaches scientists are taking to heal, mend or bypass the nervous system and what you, as a non-scientist, can do to speed things along.
Questions & Answers
Peer & Family Support Program

The Peer & Family Support Program (PFSP) is a national peer-to-peer mentoring program that provides support and information on local and national resources to people living with paralysis as well as their family members and caregivers.
Goals of the Peer & Family Support Program

• Increase the amount of mentoring occurring across the country
• Provide support and information to people living with paralysis, their family members and caregivers so that they can maintain independence and improve their quality of life
• Provide a standardized baseline of training to ensure a level of consistency across the country
• Connect our peer mentors and peers to the Paralysis Resource Center
Peer & Family Support Program Statistics

• Over 500 peer mentors in 39 states
• Over 3,500 peers
• 57 peer mentor trainings
• Over 7,000 encounters
Peer Mentor Trainings

Training and certification process

• Submit a brief online application
• Attend a training
• Agree to code of conduct and submit to a background check

Virtual trainings

• Virtual trainings are conducted using videoconferencing
• Allow participants to attend from their homes/offices or as part of a group at a host facility

Training curriculum

• Topics covered include effective peer mentoring, ethics in mentoring, and interpersonal communication skills along with an introduction to the Reeve Foundation and Paralysis Resource Center
Peer Recruitment and Referrals

Proactive approach to promoting peer mentoring
• Hospitals / Rehab centers
• Nonprofit organizations
• Peer Mentors
• Reeve Foundation outreach

Peer referrals
• Reeve Foundation Information Specialists team
• Self referrals
• Reeve Foundation social media
• Partners
• Community mentoring
• Non-partner referrals
Peer/Peer Mentor Relationship

• A peer-focused program
• The peer/peer mentor relationship is a private, confidential relationship
• Peers determine the topics of discussion, how often they meet with their mentor, and how they will communicate with their mentor (in person or by phone, email, text, or video chat)
• Peers can request a different mentor
Matching

The peer mentor/peer match is very important. Every effort is made to match a peer with a peer mentor that is the same:

- Level of injury
- Gender
- Approximate age
- Cause of paralysis
- Ethnicity/culture

Additional factors considered

- Hobbies and interests
- Program coordinator’s familiarity with some peer mentors

Remote mentoring
Questions & Answers
Quality of Life Grants Program – Who Can Apply?

Reeve Foundation funds:

- Nonprofit organizations
- Tribal Entities
- Municipalities
- NGOs outside the United States

Reeve Foundation can’t award grants directly to individuals. Individuals seeking financial assistance are referred to the Information Specialist team.
Eligibility Requirements

- Project or program will serve individuals with paralysis and their families
- Applying organization does not have to specialize in serving people with disabilities
- IRS501(c)(3) status confirmed (Fiscal Sponsors accepted) OR
- Government agency or department
- Tribal entity
- NGOs outside of U.S. are eligible
- Prior grantees must skip 3 grant cycles before reapplying
- Applicants not funded do not need to skip before reapplying
Application Process

- Online application process
- www.ChristopherReeve.org/QoL
- Click on **Apply Here** button
- Read everything on *Application and Guidelines* page, including
  - Quality of Life Guidelines
  - List of Application Questions
  - *People-First Language Guide*
  - *A Quick Guide to Establishing Evaluation Indicators*
- Technical Assistance webinar archived on website
Funding Priorities

• Programmatic costs much higher priority than operating costs
• Programs for people with paralysis and their families higher priority than general disabilities
• Independent living
• Inclusion
• Community integration
• Underserved communities
• Caregivers
Quality of Life Grants Program Timeline

Two grant cycles per year

• First Cycle
  – Online application opens 1st week of January
  – Deadline February 16th
  – Decisions announced end of May

• Second Cycle
  – Online application opens July 1st
  – Deadline August 15th
  – Decisions announced end of December
Final Questions & Answers and Evaluation

Any final questions?

Please click the link below to complete the evaluation survey:

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