Discovering the Treasure of the Paralysis Resource Center

Sheila Fitzgibbon
Senior Director, Paralysis Resource Center
We created the Paralysis Resource Center to help people navigate the chaos of paralysis with reliable information, referral services, and a message of hope.”

- Dana Reeve
Contacting the PRC’s Information Specialists

- Call us at 1-800-539-7309
- Request a phone appt. online
- Ask a question online
- Visit our NJ office

Paralysis Related Question
Today’s Care: Information Services

Ask a question. IS will listen to your concerns and will gather pertinent information.

IS will research based on your concerns, location, available resources, language preference, etc.

You will receive a **customized** answer and resources.
Anatomy of a PRC Call

Client calls

Assigned to IS (phone rotation)

IS and client brainstorm solutions

IS listens to detail account of events/questions

IS researches topic & finds information relevant to specific concern

Client receives customized information & resources

IS/Client may follow up as needed
Clients experience changes in their paralysis

Life events create new situations

Return home

College, moving, work changes

Health problems

Increase need for assistance

Aging

PRC offers throughout life span continuum of care resources.
Ask us anything

Our team of information specialists is available to answer questions and provide individualized support. We’re on hand to help whether you’ve sustained an injury, or are getting in touch on behalf of someone else.

3 ways to contact the call center

**Give us a call**

Our information specialists are available Mon-Fri, 9am-5pm ET. You can also leave a message, if you are calling after hours.

1-800-539-7309

**Schedule a call**

Schedule a call with an information specialist at a convenient time.

--- please tell us who you are ---

Arrange a call

**Send a question**

Use our form. An information specialist will respond as soon as possible.

Individual living with paralysis

Submit a question

Over 80,000 people with paralysis, their families, or caregivers, have been assisted by PRC information specialists.
Send us your question

Have a question? Our team of information specialists are standing by to offer information and resources. Ask your question and leave your details. We’ll get back to you as soon as possible.

Your question and personal information

Your question: *

Your first name: *

Your last name: *

Your preferred language: *

Download the Reeve Foundation’s Paralysis Resource Guide

Languages

- English
- Español (Spanish)
- Français (French)
- 中文 (Chinese)
- हिंदी (Hindi)
- 日本語 (Japanese)
- 한국어 (Korean)
- Tiếng Việt (Vietnamese)
- Tagalog (Tagalog)

Services in 150+ languages available
Schedule a call

Schedule a call at a date and time that's convenient for you, and one of our information specialists will be in touch.

**Can we call you at anytime?**

- [ ] No
- [x] Yes

**Preferred date of call (all times are EST):**

- [ ] Apr 26, 2017

**Times Available:**

- 8:00am - 8:30am
- 9:00am - 9:30am
- 10:00am - 10:30am
- 11:00am - 11:30am
- 12:00pm - 12:30pm
- 1:00pm - 1:30pm
- 2:00pm - 2:30pm
- 3:00pm - 3:30pm
- 4:00pm - 4:30pm
- 8:30am - 9:00am
- 9:00am - 9:30am
- 10:00am - 10:30am
- 11:00am - 11:30am
- 12:00pm - 12:30pm
- 1:00pm - 1:30pm
- 2:00pm - 2:30pm
- 3:00pm - 3:30pm
- 4:00pm - 4:30pm

**Your question and personal information**

**Your question:**

**Your first name:**
## Paralysis information

### When did the paralysis start?
- 14 days or less
- Over one year
- 15 days to one year
- Not sure

### What caused the paralysis?
- Cerebral palsy
- Guillain-Barre syndrome
- Multiple sclerosis
- Neurofibromatosis
- Result of surgical or medical procedure
- Spinal cord injury
- Transverse myelitis
- Not sure
- Disease
- Lou Gehrig's disease / ALS
- Muscular dystrophy
- Post-polio dystrophy
- Spina bifida
- Stroke
- Traumatic brain injury
- Other

### Type of paralysis:
- Paraplegia (T1 and below)
- Hemiplegia
- Quadriplegia (C8 and above)
- Not sure

### Is a ventilator required?
- Yes
- No
- Not sure

## Personal information

### Are you interested in a peer mentor?
If so, please indicate who is requesting a peer mentor. Check all that apply.
- Individual with paralysis
- Family member and/or caregiver

### Would you like to receive our email newsletter and other Reeve updates?
- Yes

Submit information
Clients’ Inquiries ➔ PRC Database
Jane Doe
John Doe

Open
Current Queue Record: 81382

Current Follow-Up
PFSP Referral Requested

Client Information

Client Basics
ID: 6713 [m]
Jane Doe
800-539-7309
636 Morris Turnpike
Short Hills, New Jersey 07078
United States
Preferred Language: French

Comments/Question
I am mother and parent provider for my 36 yo son John Doe who has been paralyzed since a car accident in 2011. We could both use some support, especially from anyone near us who understands how it is to live with SCI. My son desperately needs a doctor that has knowledge of how to deal with his problems; his health is deteriorating due to a lack of appropriate care providers who accept Medicare and Medicaid. Any suggestions or advice would be helpful and appreciated, thank you.

Additional Data
Source: Telephone
Created: Jan 23, 2003 9:59am EST
Created by: Super Administrator
Newsletter: Yes

Relationship to PWP
Caregiver family member or friend
Healthcare Position: Not Specified

Peer Program
Interest: Possibly interested in peer program, send brochure
How Heard: Not Specified

Attached File(s)
None
PWP Basics
ID: 280876
John Doe
800-539-7309 - Home
New Jersey
United States
Preferred Language: English

Demographics
Date of Birth: May 5, 1982
Age Group: 30 to 39
Deceased: No
Gender: Male
Marital Status: Single
Ethnicity: Mixed Race
Hispanic: No

Paralysis Information
Date of Paralysis: Not Specified
How Long Since Paralysis: Over One Year
Created on: Mar 21, 2017
Cause of Paralysis: Spinal Cord Injury
Cause of Spinal Injury: Motor vehicle accident
Position: Not Specified
Paralysis Type: Not Specified
Inpatient: No
Ventilator Dependent: No
Insurance Type: Medicaid, Medicare
DME: Not Specified
Transportation: Not Specified

Attached File(s)
None

Action History
Mar 30, 2017 - 8:30 AM EDT - Sent Email Message (Information Specialist)
To:
Lorem ipsum dolor sit amet, consectetur adipiscing elit. Suspendisse aliquam, lacus nec interdum condimentum, ligula tortor aliquam purus, vel euctor urna turpis dictum sem. Vestibulum nibh ex, varius quis nulla vitae, placerat gravida nisi.

Contact Information
Veteran Status: No
Services Branch: Not Specified
Info on VA: Not Specified
Free services and downloads

Paralysis Resource Guide
Our free guide is an essential tool for everyone living with paralysis.

Wallet cards
Get handy wallet cards with vital information that could save your life. Available for both adults and kids.

Lending library
Our lending library has over 5,000 books, DVDs and magazines. Loans, including postage, are completely free.

SCI Research 101
Don't Call It A Miracle: The Movement To Cure Spinal Cord Injury by Kate Willette covers research basics.

Fact sheets A-Z
Our fact sheets are updated regularly to include information and services for top paralysis topics, as well as state and international resources. Review and download our hundreds of fact sheets for free.

Topic resources
Download free fact sheets listing topical disability resources.

State resources
Download free fact sheets listing disability resources for every state.

International resources
Download free fact sheets listing international disability resources.

Hojas de datos en español
Descargue hojas de datos que listan recursos para la discapacidad por temas gratuitamente.
Free Materials & Resources

Books

Wallet Cards

Fact Sheets

Publications
Our resources & partnerships allow us to provide in-depth, customized responses
Top Referrals

**FUNDING**
- HelpHopeLive

**DRIVING**
- Association for Driver Rehabilitation Specialists

**MILITARY & VETERAN**
- US Department of Veterans Affairs

**REHABILITATION**
- Commission on Accreditation of Rehabilitation Facilities (CARF)

**CLINICAL TRIALS**
- ClinicalTrials.gov
Our clients receive...

Customized documents, resources & publications in print or electronic version
“[The MVP] literally saved my life. The director gave us lots of resources, talked us through the processes and answered all our questions. To have her knowledge and authority to point us in the right direction was life changing.”

-Erin Cobb
Former U.S. Marine
1. Client requests peer support
   - IS provides information about PFSP

2. Internal Referral
   - Warm transfer during PFSP office hours

3. Peer mentor relationship starts
Refer

Enter referral information below:

Referred by: Jane Doe on Mar 30, 2017 at 09:01 AM EDT.

* Who to Refer
  - Client
  - PWP
  - Both

* Referred To
  - Peer Program

* Referrer's Name: Jane Doe

* Referrer's Phone: 800-539-7309

* Referrer's Email: 

* Referrer's Relationship
  - Individual living with paralysis
  - Caregiver family member or friend
  - Non-caregiver family member or friend
  - Healthcare professional
  - Other: 

* Comments: Client requested a visit from peer mentor. Need help finding social activities in his area.

SAVE  BACK
Referrals to other I&Rs & organizations to provide targeted resources.
Resource Map or Fact Sheet Addition Template

If you would like for your non-profit organization to be considered for addition to our Resource Map (www.ChristopherReeve.org/resources) or one of our Fact Sheets (www.ChristopherReeve.org/FactSheets), or both, please fill out the following template and return it via email to: info@ChristopherReeve.org. It will be reviewed by staff and if it is approved, your organization will be added. This process can take a few weeks depending on staff availability. Thanks for your patience. Please check the applicable choices below.

__ I wish to update my organization's contact information on the Resource Map.

__ I wish to update my organization's contact information on the fact sheet(s). Please tell us which one(s):____

__ My organization is not currently on the Resource Map, I wish for it to be added.

__ My organization is not currently on the fact sheet(s), I wish for it to be added.

Name of Organization:
Street Address:
Town:
State:
Zip Code:
Phone:
URL/Website Address:
Mission Statement or a description of what services your organization provides for people with paralysis (Limit 100 characters):
The below info should be filled out so we have a way to reach you but this info will not appear in the resource map or fact sheet.
Name of a Person to Contact:
Email:
Phone:

Thanks for your interest!
Other services provided by the PRC
National Lending Library

- 5000+ books and videos available on paralysis-related subjects
- Free book/video loan with free mailing and returned postage
- Interlibrary loans state-wide and nationally
- Online catalog and children’s catalog @ ChristopherReeve.org/Library
Multilingual options available
# Peer & Family Support Program

<table>
<thead>
<tr>
<th>National Peer Mentoring Program</th>
<th>Support for people living with paralysis, families &amp; caregivers</th>
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<tbody>
<tr>
<td></td>
<td>Matched to people with similar experiences</td>
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<tr>
<td></td>
<td>Mentors are trained &amp; experts in local resources</td>
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<tr>
<td></td>
<td>Local ambassador program @ Level I Trauma Centers</td>
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</table>
Funds nonprofit initiatives that support people living with paralysis

Over $21 million awarded through QoL Grants

Impact

QoL
Military & Veteran Program

Supports all military services members—no matter what era they served in.

Injury doesn’t need to be combat-related.

Information & referral services tailored for Military and Veteran population.

MVP
Online Community

- On-demand videos
- Paralysis-related blogs and webcasts
- Facebook, Twitter, and online forums
- Monthly web chats

Free social networking platform dedicated to the paralysis community
Community Outreach Program

Targets gap areas and underserved communities

Partners with local organizations

Provides services in 150+ languages
Reeve Community Education Program

Educational training
Seminars
Web-based learning opportunities

Upcoming events:
www.ChristopherReeve.org/Newsletter
www.ChristopherReeve.org/Events
Advocacy and Education

- Building coalitions with disability organizations
- Informing policymakers on paralysis issues
- Analyzing new policy proposals
- Improving existing policy
- Sharing advocacy stories with Congress
Conference Outreach

- Attending
- Exhibiting
- Presenting
- Outreach about PRC services and products
Nothing of any consequence happens unless people get behind an idea. It begins with an individual and they share the idea with more individuals... and eventually, it becomes a movement."

-Christopher Reeve
Contact Us!

Sheila Fitzgibbon
Senior Director, Paralysis Resource Center
SFitztgibbon@ChristopherReeve.org

Paralysis Resource Center
Information Specialist Line
800-539-7309/ 973-467-8270
www.ChristopherReeve.org/Living-with-Paralysis