



Discovering the Treasure of the Paralysis Resource Center

Sheila Fitzgibbon

Senior Director, Paralysis Resource Center



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



Paralysis Related Question

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

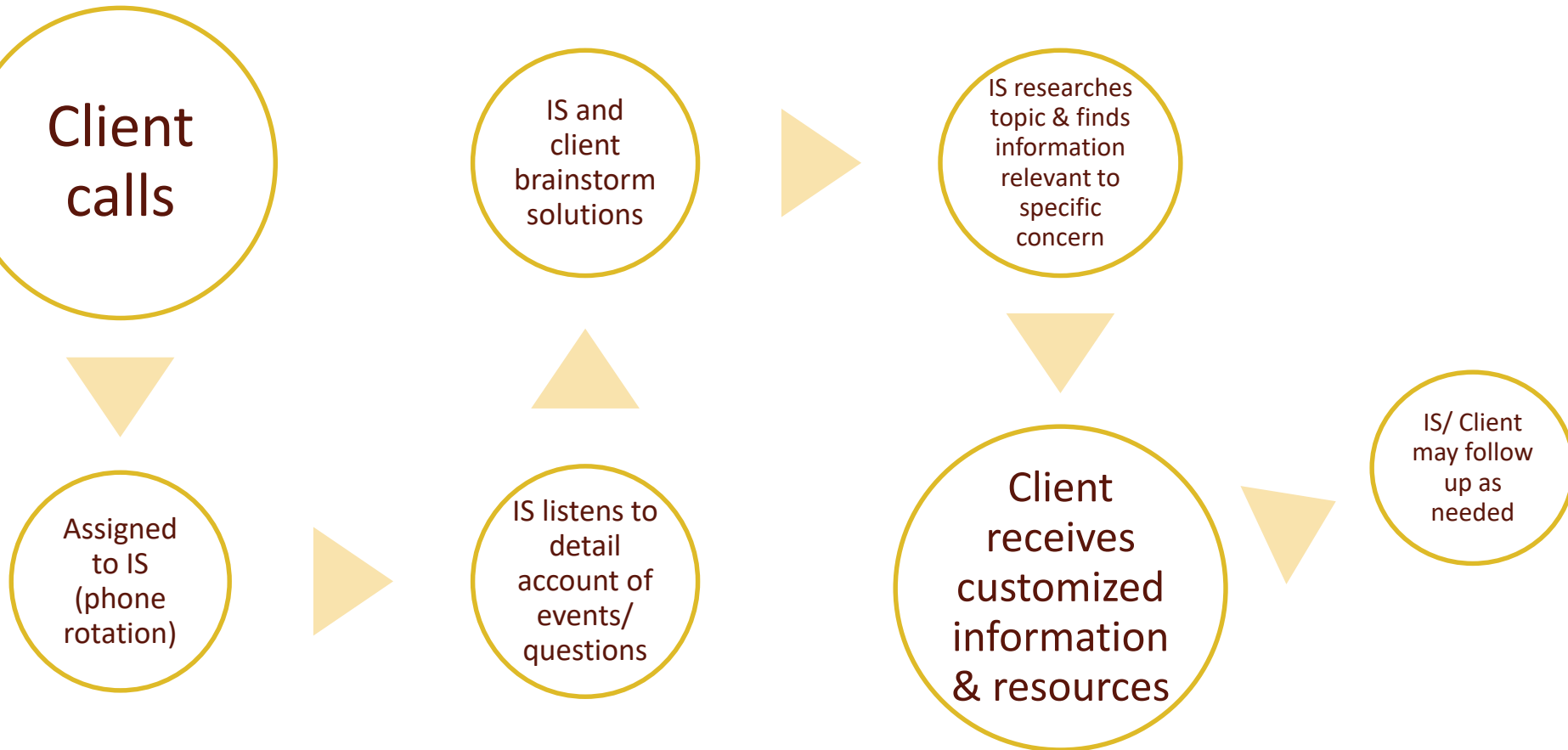
Today's Care: Information Services

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

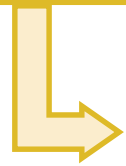
IS will research based on your concerns, location, available resources, language preference, etc.

You will receive a **customized** answer and resources.

Anatomy of a PRC Call



Clients experience changes in their paralysis



Life events create new situations

Newly Injured/
Diagnosed

Return home

College, moving, work changes

Health problems

Increase need for assistance

Aging

★ PRC offers throughout life span continuum of care resources.

Living with Paralysis

Get Support

Get Involved

Research

Events

Blog & Forum

About Us

Donate

Get Support

Ask us anything

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: *

-- please select your preferred language --

-- please select your preferred language --

- English
- Chinese
- French
- German
- Hindi
- Italian
- Japanese
- Korean
- Native American
- Portuguese
- Russian
- Spanish
- Tagalog
- Vietnamese
- Unspecified
- Other

Services in 150+ languages available

[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 \(Tagalog\)](#)

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

Yes

Preferred date of call (all times are EST):

Apr 26, 2017

8:00am - 8:30am

8:30am - 9:00am

9:00am - 9:30am

9:30am - 10:00am

10:00am - 10:30am

10:30am - 11:00am

11:00am - 11:30am

11:30am - 12:00pm

12:00pm - 12:30pm

12:30pm - 1:00pm

1:00pm - 1:30pm

1:30pm - 2:00pm

2:00pm - 2:30pm

2:30pm - 3:00pm

3:00pm - 3:30pm

3:30pm - 4:00pm

4:00pm - 4:30pm

4:30pm - 5:00pm

[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 \(Tagalog\)](#)

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 syndrome

Spina bifida

Stroke

Traumatic brain injury

Other

Type of paralysis:

Paraplegia (T1 and below)

Hemiplegia

Other

Quadriplegia (C8 and above)

Not sure

Is a ventilator required?

Yes

Not sure

No

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

Specific background info

Assigned by language, availability & knowledge

Customize answer by topic expert



- Workspace
- Search the PRCDB
- Add a Queue Record
- Settings

Jane Doe

John Doe

Current Assignment:

Open

Current Queue Record: 81382

[ACTION >](#)

Current Follow-Up

PFSP Referral Requested

Client Information

[CONTACT DETAIL](#)

[EDIT](#)

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

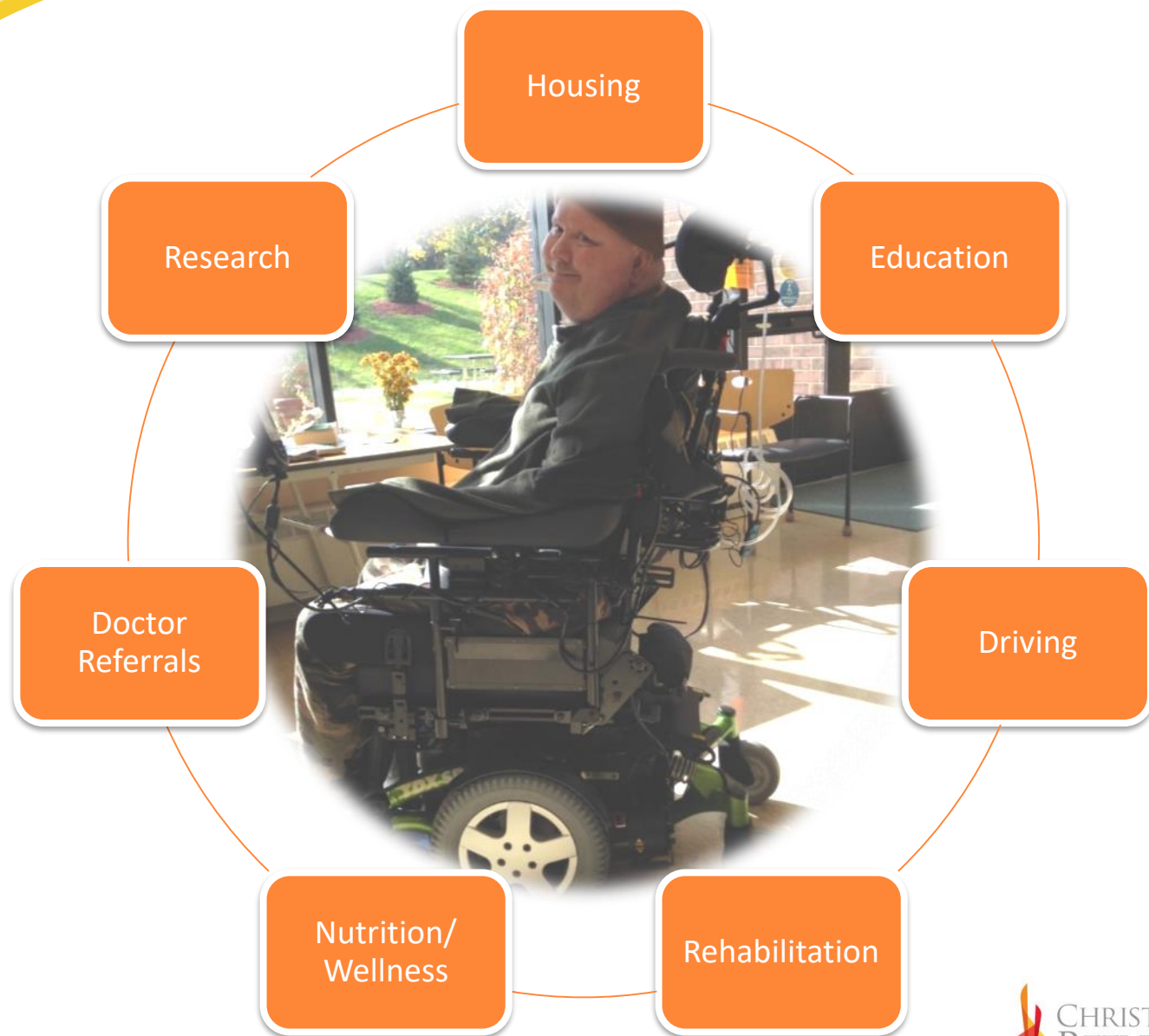
Armed Forces Information

Veteran Status: No
Services Branch: *Not Specified*
Info on VA: *Not Specified*

Action HistoryMar 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 auctor uma turpis dictum sem. Vestibulum nibh ex, varius quis nulla vitae, placerat gravida nisi.



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.

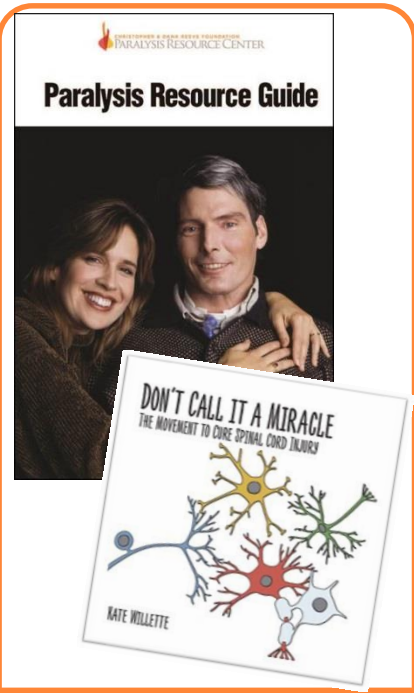
International resources >

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

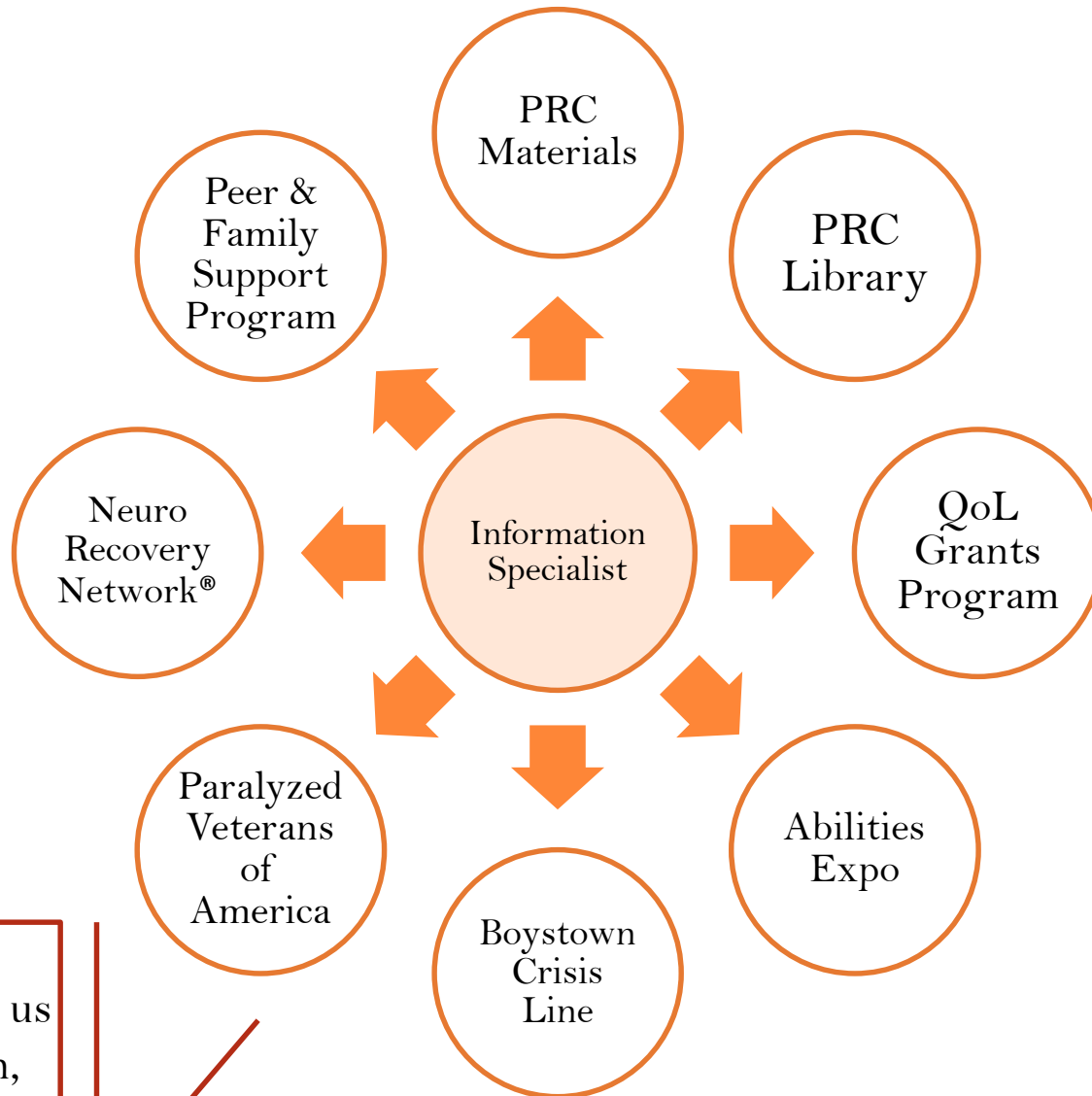


Fact Sheets



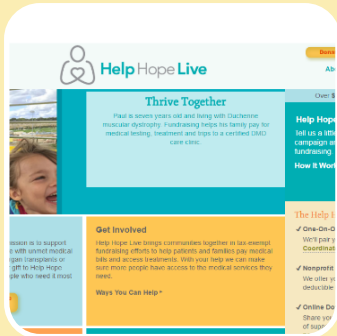
Publications





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

Top Referrals



FUNDING

- HelpHopeLive



DRIVING

- Association for Driver Rehabilitation Specialists



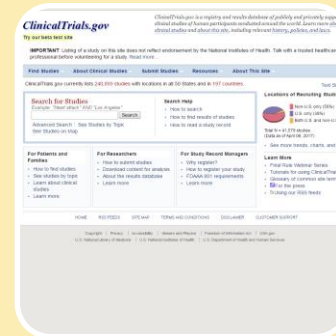
MILITARY & VETERAN

- US Department of Veterans Affairs



REHABILITATION

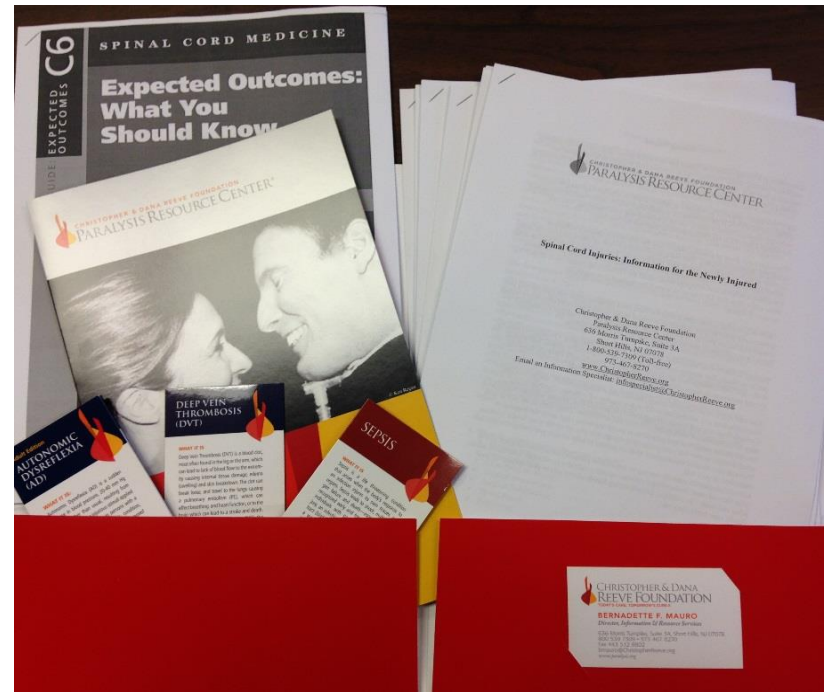
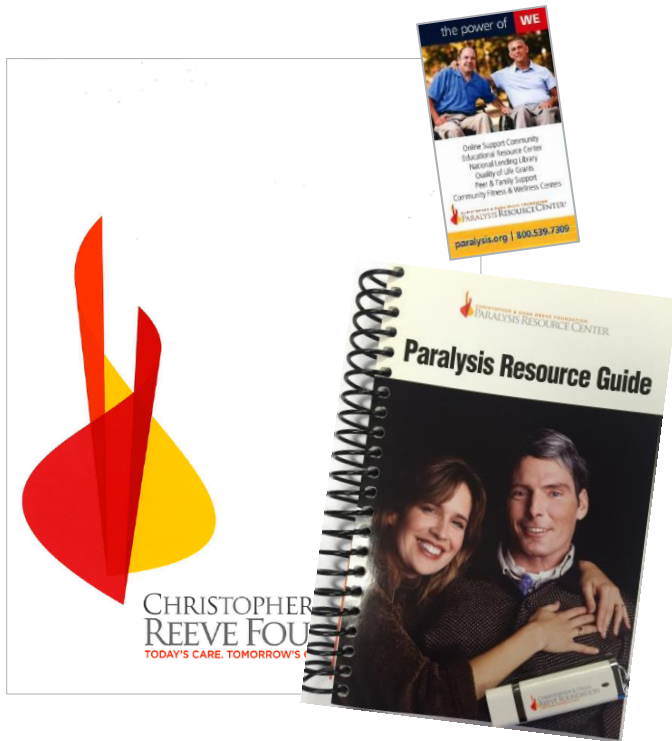
- Commission on Accreditation of Rehabilitation Facilities (CARF)




CLINICAL TRIALS

- ClinicalTrials.gov

Our clients receive...



Customized documents, resources & publications in print or electronic version

A photograph of Erin Cobb, a former U.S. Marine, smiling and sitting in a wheelchair. She is wearing a bright blue sleeveless top and a necklace. The background is a blurred outdoor setting with trees and a blue sky. A semi-transparent dark blue box is overlaid on the left side of the image, containing white text.

"[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*



Paralysis Resource
Center

Internal
Referrals

External
Referrals

Peer & Family
Support Program

- Workspace
- Search the PRCDB
- Add a Queue Record
- Settings

Jane Doe
John Doe

Open
Current Queue Record: 81382

Current Follow-Up

ent: ACTION >



- Client requests peer support
- IS provides information about PFSP

★ PFSP Referral Requested



- Internal Referral
- Warm transfer during PFSP office hours

Client Information

CONTACT DETAIL EDIT

Client Basics
ID: 6713 [m]

Jane Doe
800-539-7309
636 Morris Turnpike
Short Hills, New Jersey 07078
United States
Preferred Language: **French**

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

Peer mentor relationship starts

Doe who has been use some support, 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.



- Peer mentor relationship starts

- Workspace
- Search the PRCDB
- Add a Queue Record
- Settings

- Open
- Current Queue Re
- Current Follo
- ★ PFSP Referral

Client Inform:

Client Basic
ID: 6713 [m]

Jane Doe
800-539-7309
636 Morris Turn
Short Hills, New
United States
Preferred Langu

Additional D
Source: Telepho
Created: Jan 23
Created by: Sup
Newsletter: Yes

Relationship
Caregiver family
Healthcare Posi

Peer Progra
Interest: Possib
program, send b
How Heard: Not

Attached Fil
None

Christopher & Dana Reeve Foundation - Google Chrome
Secure | https://feedback.paralysis.org/actions/add_refer/81382/6713/543278

Refer

Enter referral information below.

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

* Who to Refer Client PWP Both

* Referred To Peer Program

* Referrer's Name

Referrer's Phone

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

SAVE BACK

ACTION >

EDIT

on John Doe who has been
ld both use some support,
ds how it is to live with
as knowledge of how to
ng due to a lack of
e and Medicaid. Any
reciated, thank you.

-Select a type-

-Select a type-

Accessibility and home modification
 Advocacy and Rights
 Assistive technology
 Causes of paralysis
 Costs and insurance
 Education and training
 Fitness and active living
 For Caregivers
 For Kids
 For Parents
 For Women
 Health
 International
 Lifestyle
 Rehabilitation
 Secondary conditions
 Support
 Wheelchairs
 WRRN

Quality of Life Grantees ★

the mission of increasing employment opportunities for people with disabilities in

enefits

ce Center ★

The Florida Spinal Cord Injury Resource Center (FSCIRC), established in January 1994, serves as the statewide clearinghouse of SCI resource information for persons who have survived an SCI, their families and friends, healthcare professionals, support groups, the media, and the general public

2 Columbia Drive, Tampa, FL 33606
 Tel: (813) 844-4286 · Fax: (813) 844-4322
<http://www.flspinalcord.us>
 Education and training

Synapse House
 3.8 miles away
 Synapse House's mission is to connect persons with
330 W. Fern St., Tampa, FL 33604
 Tel: (877) 932-1120 · Fax:
<http://www.synapsehouse.org>
 For Caregivers, Rehabilitation

Lowry Park Zoological Society Of Tampa
 4.4 miles away
 Tampa's Lowry Park Zoo's mission "to connect peopl



FLORIDA DISABILITY RESOURCES

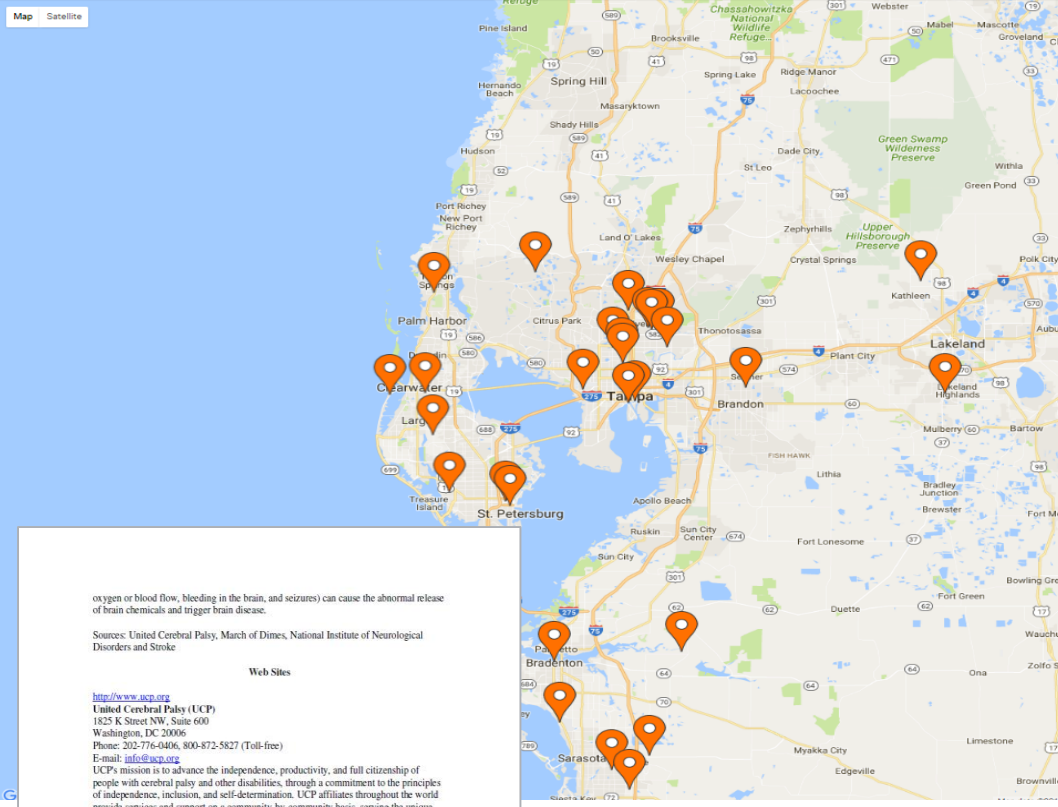
Affordable Care Act (ACA)

<http://www.the.sea.healthcare.gov/aca/aca.html>
 HHS.gov: 5 Years Later: How the Affordable Care Act is Working for Florida
 To get coverage under the ACA, go to <https://www.healthcare.gov> to find out more about the Health Insurance Marketplace and the options available in your state.
<https://www.healthcare.gov/what-is-the-marketplace-in-my-state/#state=florida>

Aging Resources

www.aging-top.org
Aging and Disability Resource Center Locator
 The Aging and Disability Resource Center Program (ADRC) is a collaborative effort of the U.S. Administration on Community Living (including [AOL](#) as of April 2012) and the Centers for Medicare & Medicaid Services (CMS). ADRCs serve as single points of entry into the long-term supports and services system for older adults and people with disabilities. Sometimes referred to as a "one-stop shops" or "no wrong door" systems, ADRCs address many of the frustrations consumers and their families experience when trying to find needed information, services, and supports. Through integration or coordination of existing aging and disability service systems, ADRC programs raise visibility about the full range of options that are available, provide objective information, advice, counseling and assistance, empower people to make informed decisions about their long term supports, and help people more easily access public and private long term supports and services programs. Click on your state to find state and local ADRCs.
 The core functions of an ADRC are 1) information, referral and awareness, 2) options counseling, advice and assistance, 3) streamlined eligibility determination for public programs, 4) person-centered transitions, 5) quality assurance and continuous improvement. ADRCs perform these functions by integrating, coordinating, and strengthening different pieces of the existing long term supports and services systems, including Area Agencies on Aging, Centers for Independent Living, state and local Medicaid offices, and other community-based organizations.

<http://doh.kermitics.state.fl.us/index.php>
 Department of Elder Affairs for state of Florida
 4040 Esplanade Way
 Tallahassee Florida 32399-7000
 Phone: 850-414-2000



oxygen or blood flow, bleeding in the brain, and seizures) can cause the abnormal release of brain chemicals and trigger brain disease.

Sources: United Cerebral Palsy, March of Dimes, National Institute of Neurological Disorders and Stroke

Web Sites

<http://www.ucp.org>
United Cerebral Palsy (UCP)
 1825 K Street NW, Suite 600
 Washington, DC 20006
 Phone: 202-776-0406, 800-872-5827 (Toll-free)
 E-mail: info@ucp.org
 UCP's mission is to advance the independence, productivity, and full citizenship of people with cerebral palsy and other disabilities, through a commitment to the principles of education, inclusion, and self-determination. UCP affiliates throughout the world provide services and support on a community-by-community basis, serving the unique needs of people with disabilities in their region.

<http://pait.audi.udel.edu/paitlab/cpGuide.html>
Alfred I. duPont Hospital for Children, Gait Analysis Laboratory: Cerebral Palsy Programs/Guide
 This guide contains an overview of cerebral palsy in infants and children, including causes, diagnosis, types, prognosis, treatment, and associated medical problems. It contains an overview of material discussed in much more depth in Bachrach Miller's book, *Cerebral Palsy: A Guide for Care*.

<http://www.aacpdm.org/>
The American Academy for Cerebral Palsy and Developmental Medicine (AACPDM)
 555 East Wells, Suite 1100
 Milwaukee, WI 53202
 Phone: 414-918-3014
 E-mail: info@AACPDM.org
 AACPDM is a multidisciplinary scientific society devoted to the study of cerebral palsy and other childhood onset disabilities, to promoting professional education for the treatment and management of these conditions, and to improving the quality of life for people with these disabilities. The scope of the Academy's interests has expanded from an initial focus on cerebral palsy into related areas of developmental medicine, including spina bifida, neuromuscular disease, traumatic brain injury and other acquired disabilities, genetic disorders, communications problems, and specific learning disabilities.

www.yousoop.org
Cerebral Palsy Foundation (CPF)



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: sfitzgibbon@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 sheets, 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):

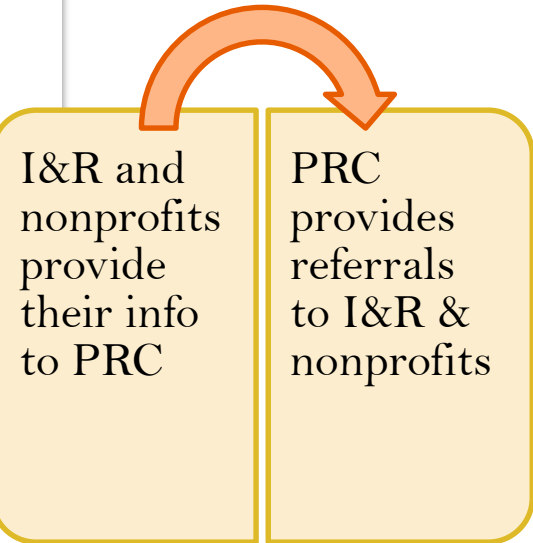
The below info should be filled out so we have a way to reach you but this info will not appear in the resource map or fact sheet.

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



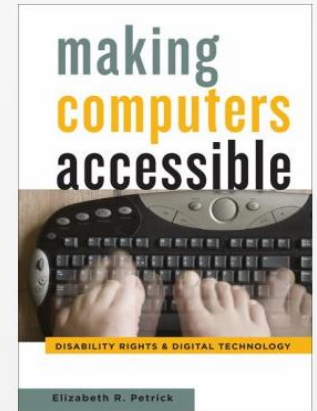
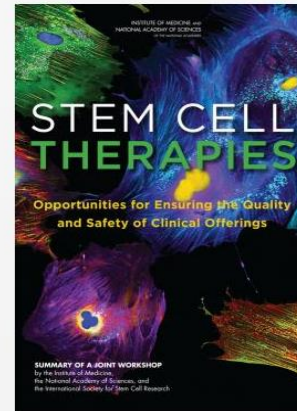
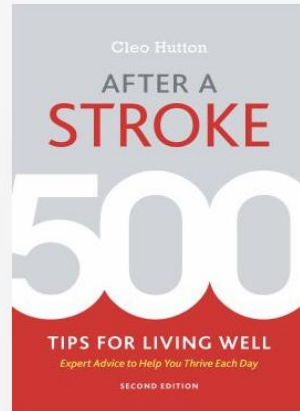
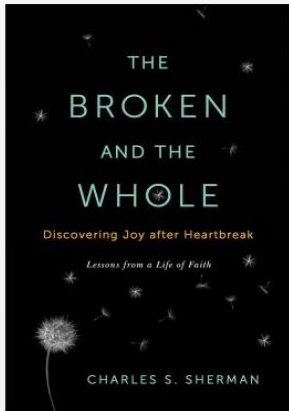
Online [catalog](#) and children's [catalog](#) @ ChristopherReeve.org/Library

Christopher & Dana Reeve Paralysis Resource Center

[Search](#)

[Advanced Search](#)

New Releases



Nonfiction

Fiction

Memoirs

Reference

Educational Videos

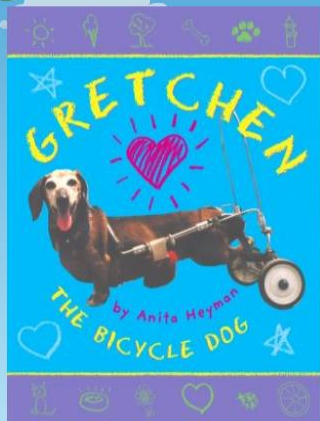
Documentaries

Type here to search

Search

14 Results for Dogs

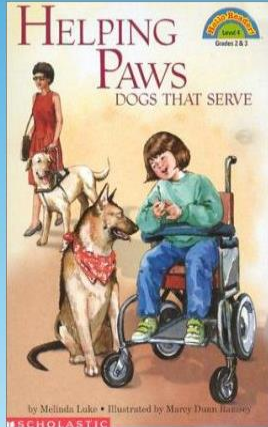
in



Non-reference

SF 426.5 .H49 2003

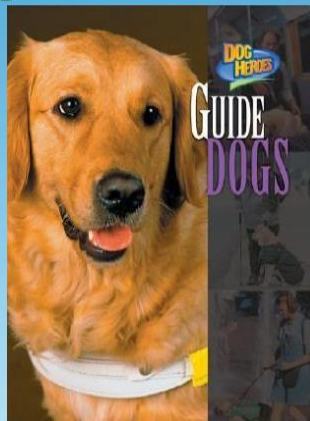
in



Non-reference

SF 428.2 .L85 2001

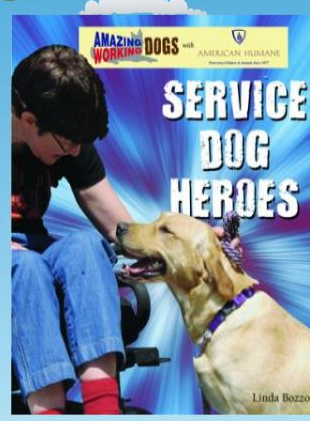
in



Non-reference

HV 1780 .M337 2005

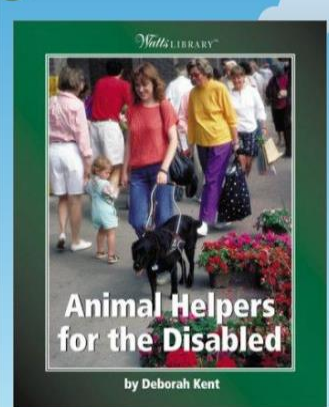
in



Non-reference

HV 1569.6 .B69 2011

in



Non-reference

HV 1569.6 .K46 2003



Explore Categories



Series & Chapter Books



Christopher & Dana Reeve Paralysis Resource Center

English (Change Language)

Multilingual options available

Peer & Family Support Program

National Peer Mentoring Program



Support for people living with paralysis,
families & caregivers

Matched to people with similar
experiences

Mentors are trained & experts in local
resources

Local ambassador program @ Level I
Trauma Centers

Quality of Life Grants Program

Funds nonprofit initiatives that support people living w/ paralysis

QoL

Impact

Over \$21 million awarded through QoL Grants

Military & Veteran Program



Injury doesn't
need to
be combat-
related

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

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



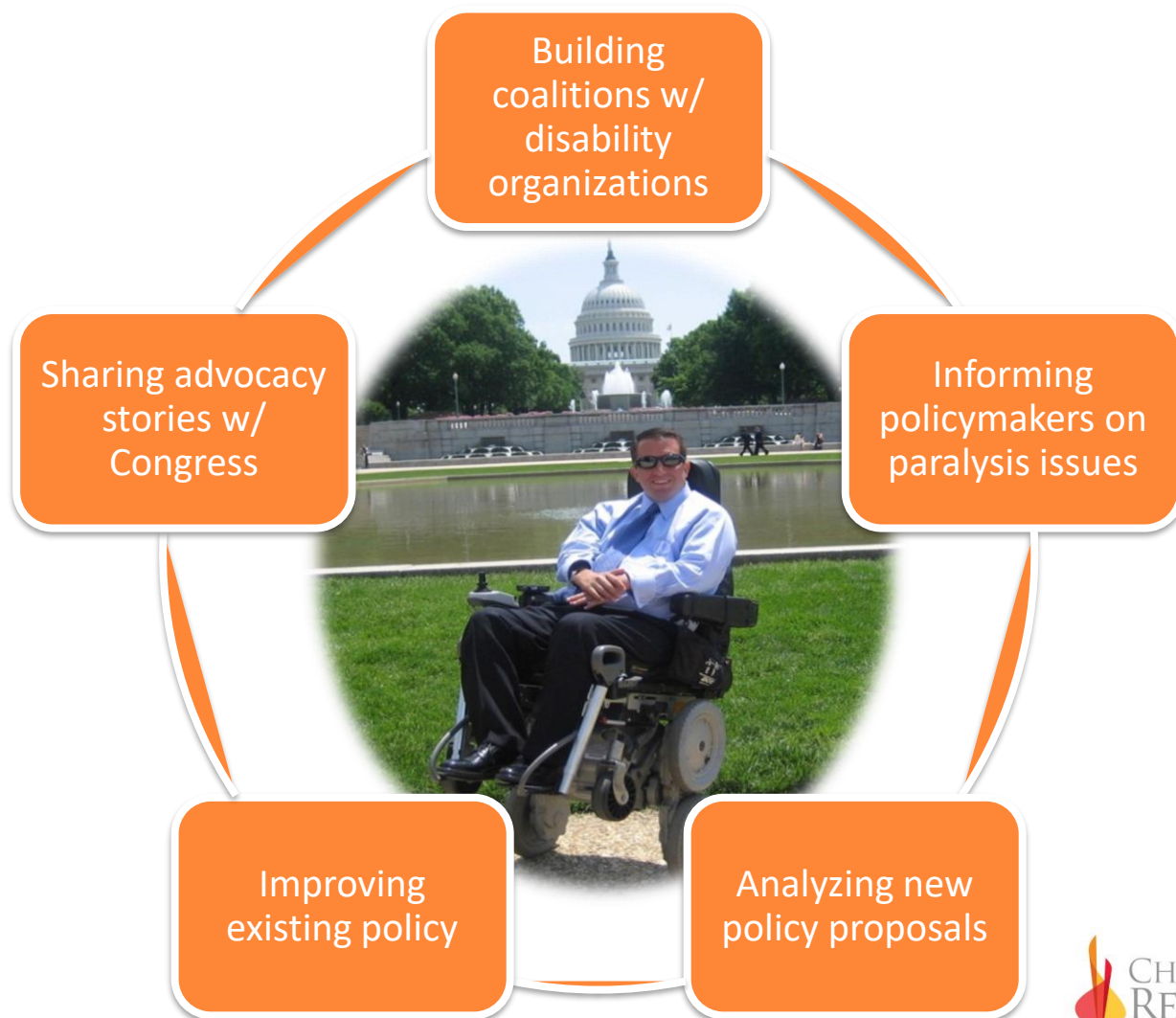
Upcoming events:

www.ChristopherReeve.org/Newsletter

www.ChristopherReeve.org/Events

-  Educational training
-  Seminars
-  Web-based learning opportunities

Advocacy and Education



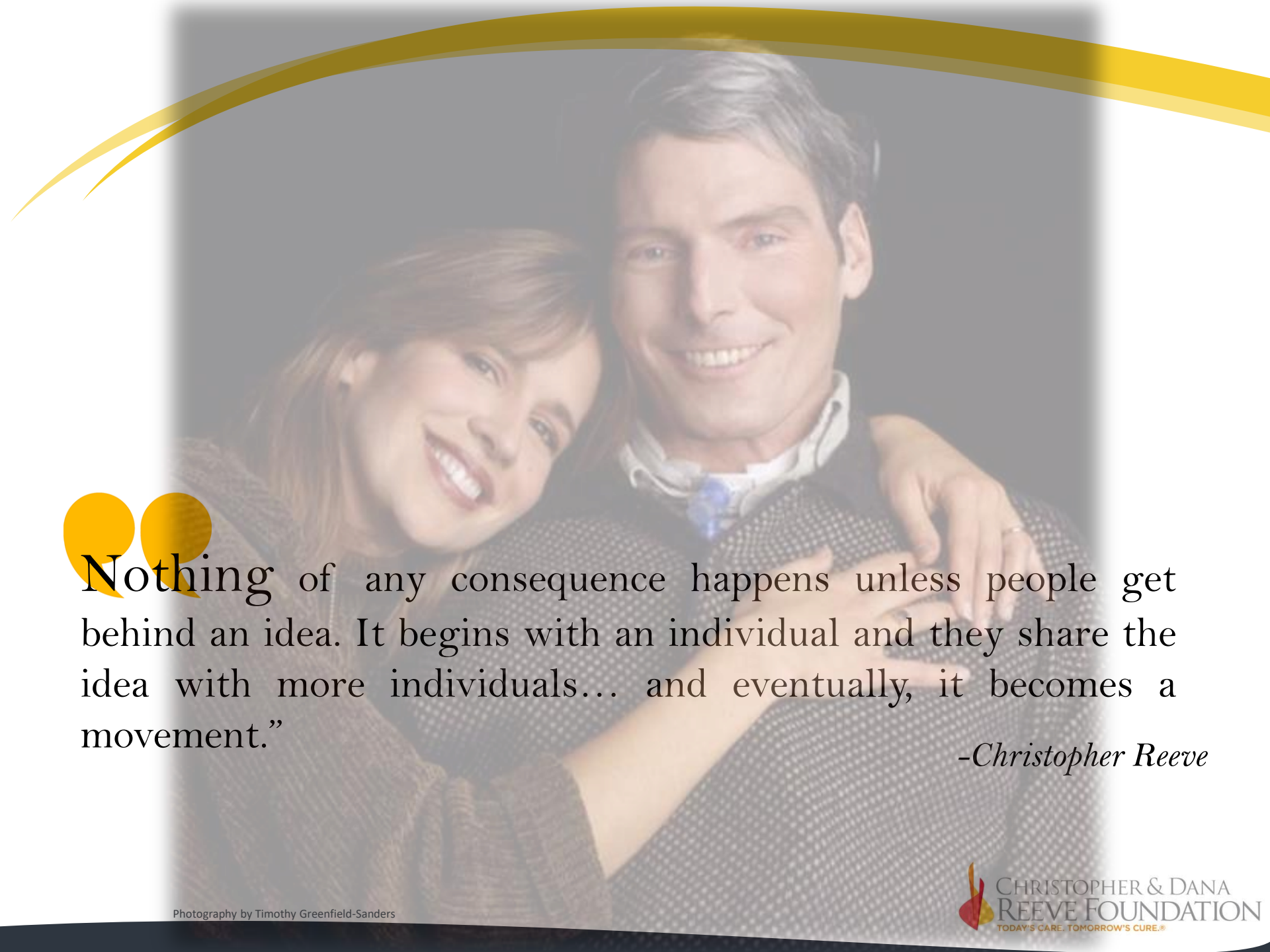
Conference Outreach

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

SFitzgibbon@ChristopherReeve.org

Paralysis Resource Center

Information Specialist Line

800-539-7309/ 973-467-8270

www.ChristopherReeve.org/Living-with-Paralysis

