



The National **Long-Term Care**  
**Ombudsman** Resource Center

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# **Technical Assistance (TA) Talk**

An Introduction to the National Paralysis Resource Center

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September 21, 2023

# Welcome

- ▶ TA Talks are **informal**, quarterly calls on **specific topics**
- ▶ Hosted on Zoom and **livestreamed on Facebook**
- ▶ Opportunity to **learn from your peers** and **receive technical assistance**
- ▶ Unmute yourself to ask questions via **audio**, or type your question in the **chat**
- ▶ This meeting is being **recorded** and the **PowerPoint** will be emailed all registrants and our listserv
- ▶ Please complete the **evaluation** questionnaire using the link provided in the chat and closing slide at the end of the meeting
- ▶ **Certificates of participation** will be provided to everyone attending on Zoom for at least 30 minutes
- ▶ Links to **resources** will be posted in the chat box and will be posted to the NORC website – [ltcombudsman.org](http://ltcombudsman.org).
- ▶ Ideas for topics? Email [ombudcenter@theconsumervoice.org](mailto:ombudcenter@theconsumervoice.org)

# Speakers



**Rebecca Sultzbaugh**  
**MANAGER**

Peer & Family Support Program,  
Christopher & Dana Reeve  
Foundation



**Emily Wolinsky**  
**DIRECTOR**

Outreach & Education at the  
Christopher & Dana Reeve  
Foundation

# Exploring the Supports of the National Paralysis Resource Center (NPRC)



# Speakers

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- **Rebecca Sultzbaugh** is the Manager of the National Paralysis Resource Center's Peer & Family Support Program, where she manages the training and certification of new mentors along with other aspects of the PFSP. She has been with the Reeve Foundation for 16 years.
- **Emily Wolinsky** is the Director of Outreach & Education for the National Paralysis Resource Center, where she plans and executes Reeve's participation in national events and builds connections within the paralysis community to enhance NPRC's virtual and live programming. She has been with the Reeve Foundation for 7 months.

# Objectives

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- Gain an understanding of how the supports of the National Paralysis Resource Center can benefit people living with paralysis, their families, and caregivers.
- Gain an understanding of how the National Paralysis Resource Center can support your role as an ombudsman.
- Identify beneficial resources for your clients/residents from the NPRC.
- Learn how to access the resources available through the NPRC.

# National Paralysis Resource Center

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In 2002, the National Paralysis Resource Center opened its doors to promote the health, independence and well-being of individuals living with paralysis by providing comprehensive resources, education and referral services.

## **Information Specialists**

Provide individualized support and guidance to people living with paralysis, as well as their family and caregivers.

## **Peer & Family Support Program**

Offers peer-to-peer support to help families impacted by paralysis navigate the short-term realities and long-term challenges.

## **Quality Of Life Grants Program**

Awards financial support to nonprofit organizations that mirror the Reeve Foundation's mission to improve quality of life.

## **Military & Veterans Program**

Supports the unique needs of service members regardless of when they served or what caused/causes their paralysis.

# Today's Care

## Information Specialists

**120,000+** families have received one-on-one assistance, which is available in **170 languages**



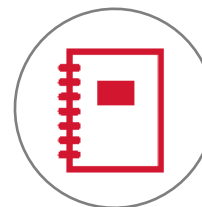
## Quality of Life Grants

**\$41 million+** awarded to over **3,700** non-profit programs in all **50 states**

## Reeve Summit:

### Where Care, Cure and Community Connect

Annual summit with a spectrum of care and cure topics designed for the community and professionals



## Paralysis Resource Guide

**225,000+** copies distributed to the Reeve Foundation's community

## Virtual Community

**3M+** users visit ChristopherReeve.org and social media channels annually



**1st** call made when loved one is diagnosed with paralysis



## Health-Related Materials

**250,000+** pageviews, video views and downloads of educational content annually

## Military and Veterans Program

Supports the unique needs of **service men and women** regardless of when they served or how they were injured



## Peer & Family Support Program

**23,000+** people have received support from **500+** certified peer mentors who are also impacted by paralysis



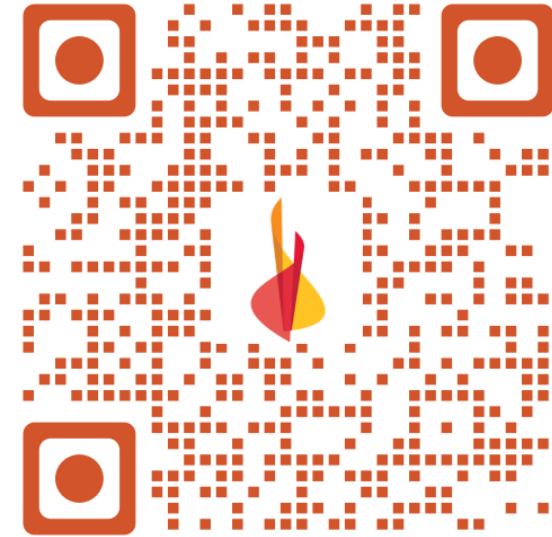
# Programs

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# Information Specialists

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- Our certified Information Specialists are trained to help anyone – from people living with paralysis to family members and caregivers – as they attempt to navigate their changing world and the services available to them.
- Call 1-800-539-7309 to be connected!
- Email [InfoSpecialist@ChristopherReeve.org](mailto:InfoSpecialist@ChristopherReeve.org)



ChristopherReeve.org/ask

# Resources for Caregivers

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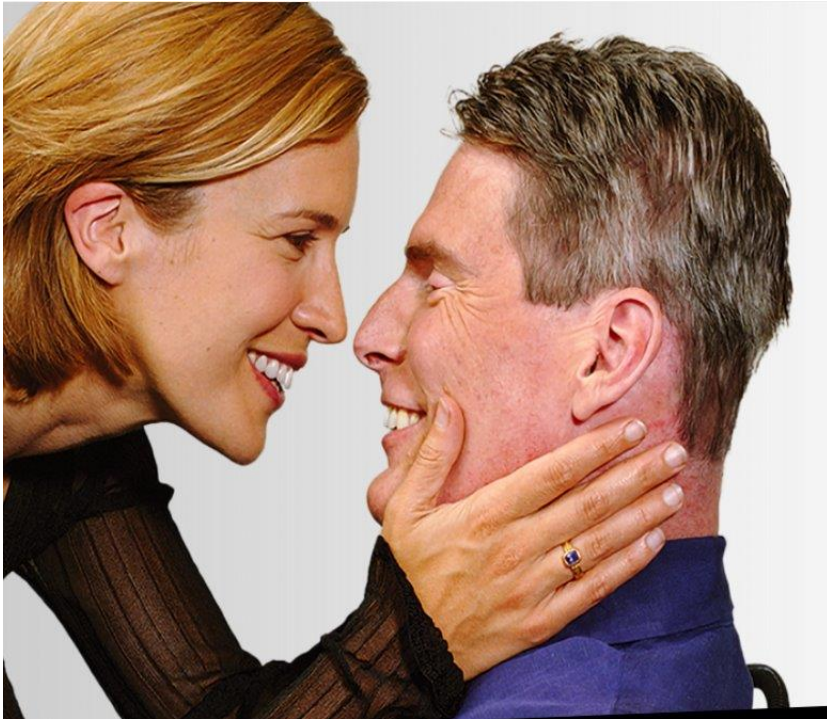


Image: A close-up photo of Dana Reeve with her hands on husband Christopher Reeve's face. They are looking into each other's eyes and smiling.

- Section of website devoted to caregivers, including tips and links to other helpful information.
- Blogs and other content by and for caregivers.
- Virtual support groups held twice a month for caregivers and family members, led by a mental health professional and a peer with lived experience.
- Peer mentoring program that extends to caregivers — those who apply will be matched with another caregiver for conversations and support.

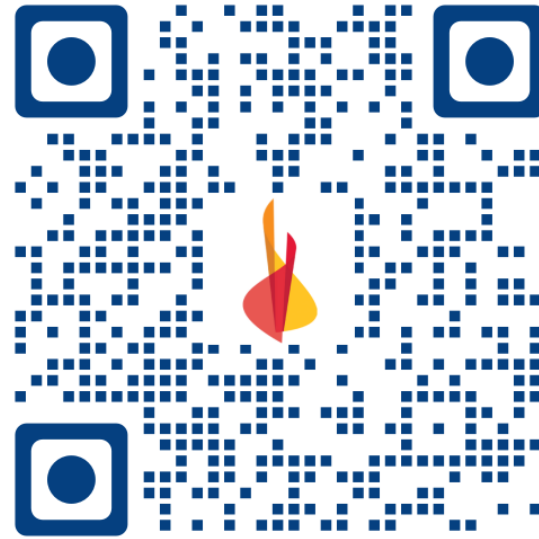
# Navigating Care

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- "Navigating the System" and "Caregiving" section in Paralysis Resource Guide
- Recorded webinars on the Christopher & Dana Reeve YouTube channel that cover topics related to caregiving

# Peer & Family Support Programs

- Support for people living with paralysis, family members, and caregivers
- Matched to people with similar levels of paralysis and experiences
- Mentors are trained and certified
- Mentors are plugged into local resources



[ChristopherReeve.org/Peer](https://ChristopherReeve.org/Peer)

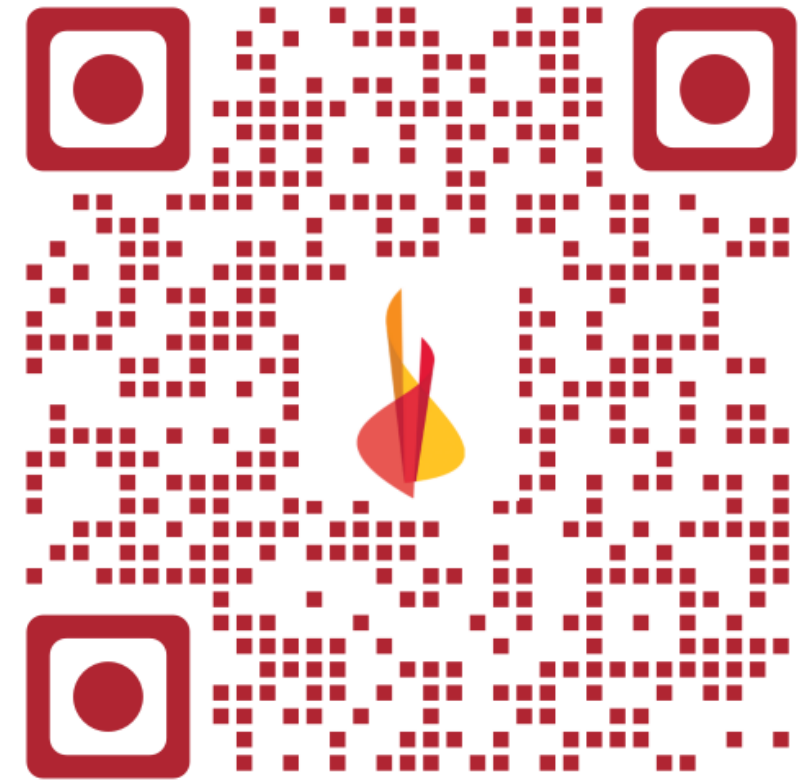


Image: Two women in manual wheelchairs sitting next to each other and smiling.

# Virtual Support Groups

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- *Living with Paralysis* support groups and *Caring for a Family Member with Paralysis* support group
- Each FREE group is led by a mental health professional and a peer with lived experience
- Separate *Living with Paralysis* support groups are held for people living with paraplegia and those with quadriplegia
- A chance to connect with others and gain insight, support, and guidance
- Each group meets twice a month



[ChristopherReeve.org/VirtualSupport](https://ChristopherReeve.org/VirtualSupport)



# Quality of Life Grants Program

Images: a collage of organizations and projects that have received Quality of Life grants



*Infinite Flow  
has allowed me  
to put the rhythm  
into my roll.*

Engracia

[InfiniteFlowDance.org](http://InfiniteFlowDance.org)



# Quality of Life Grants Program

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- Provides grants to nonprofit organizations whose projects and initiatives foster inclusion, involvement and community engagement, while promoting health and wellness for those affected by paralysis in all 50 states and U.S. territories.
- \$41 million to 3,700 organizations since 1999



# Advocacy

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Image: Reeve Foundation's Alan Brown in his wheelchair in front of grass and a pool, with trees and the U.S. Capitol Building in the background.

- Online advocacy program with over 10,000 advocates across the country – our goal is 12,000 by the end of the year
- Regional Champion Program – 72 grassroots advocates across 27 states, eventual goal of every state and congressional district being covered. Legislative "first responders"
- 2023 Federal Priorities: passage of the Air Carrier Access Amendments Act, funding caregiving solutions, funding SCI Model System centers, funding for paralysis research, funding for the NPRC

# Military & Veterans Program

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- Supports all military service members - no matter when they served
  - Injury doesn't need to be combat or service related.
  - Covers all types of paralysis under the NPRC. Also covers caregivers.
- Offers tailored information and referral services
- Helps individuals navigate military benefits *and* civilian programs
- Military and veteran peer mentors are available through our Peer and Family Support Program
- Fosters higher levels of health, wellbeing, and independent living

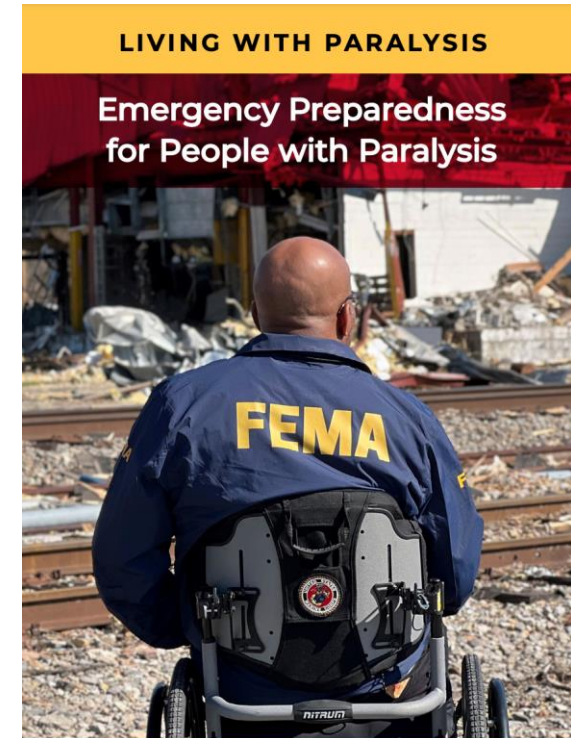
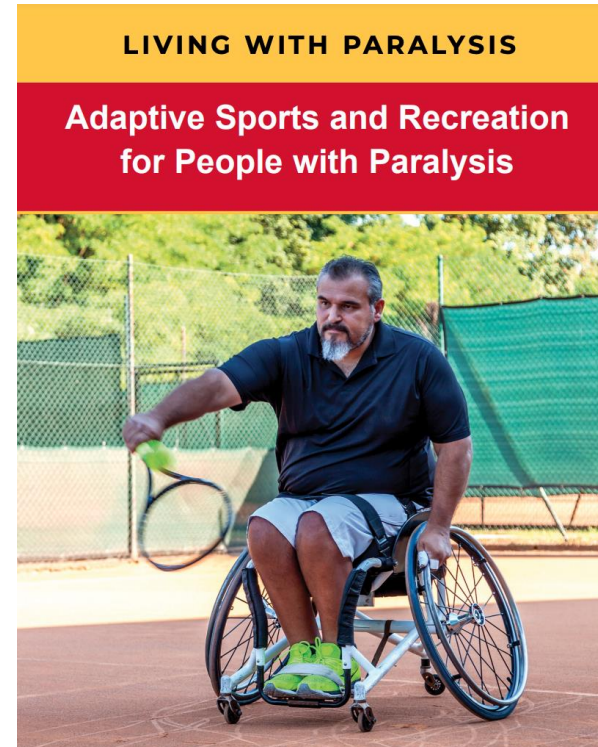
# What's new

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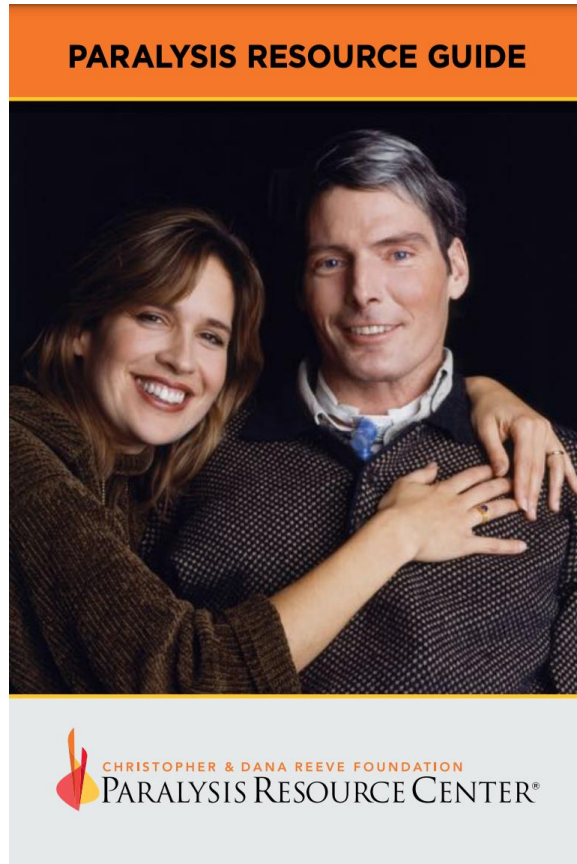
- Rural Quality of Life grant
  - Focus on promoting accessibility and participation for people living with paralysis in rural communities
  - Could include focuses of:
    - Transportation
    - Assistive Technology
    - Employment and Education
    - Peer and Family Support Groups
    - Health
    - Agriculture and access to healthy foods

# What's new

- New educational booklets
  - Sports and Recreation
  - FEMA Emergency Preparedness



# Paralysis Resource Guide and Wallet Cards



Free,  
comprehensive  
guide available as  
a PDF, e-book,  
audiobook, and  
hard copy.

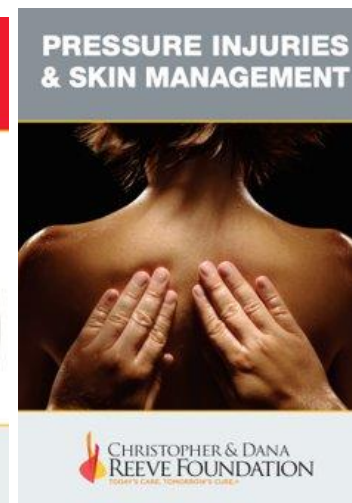


Free wallet cards  
on secondary  
conditions that  
can be used in a  
medical crisis.



# Fact Sheets and Education Booklets

- 170+ fact sheets on different disability-related topics
  - Emergency preparedness, employment, dating, fitness and exercise, housing and home modification, insurance, parenting, travel, etc.
- Patient education booklets
  - Pressure injuries and skin management, self-advocacy, pain management, adaptive sports, etc.



# State Resources - ChristopherReeve.org/state

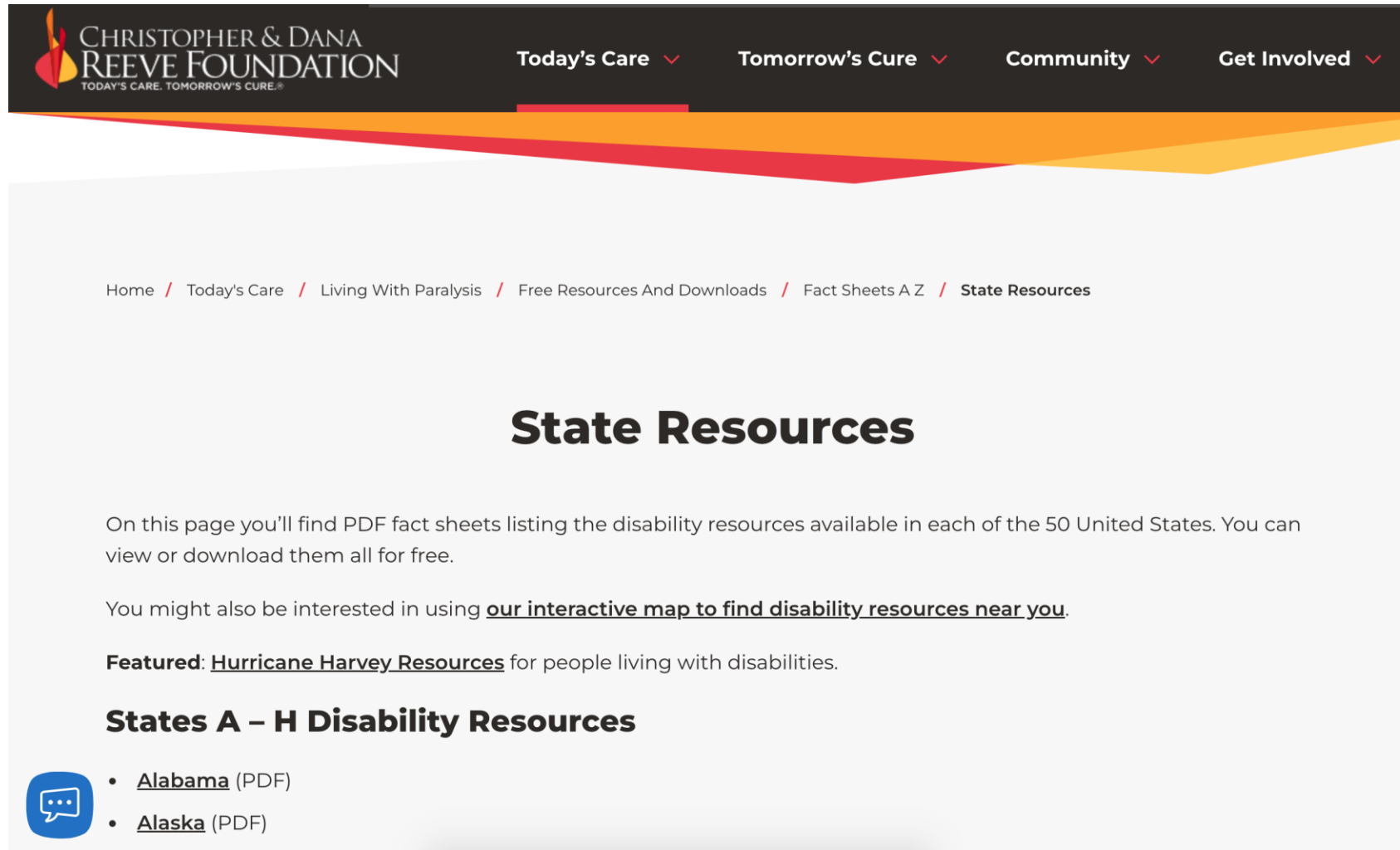


Image: A screenshot of the State Resources webpage on the Reeve Foundation's website.

# Resources by topic - ChristopherReeve.org/topic

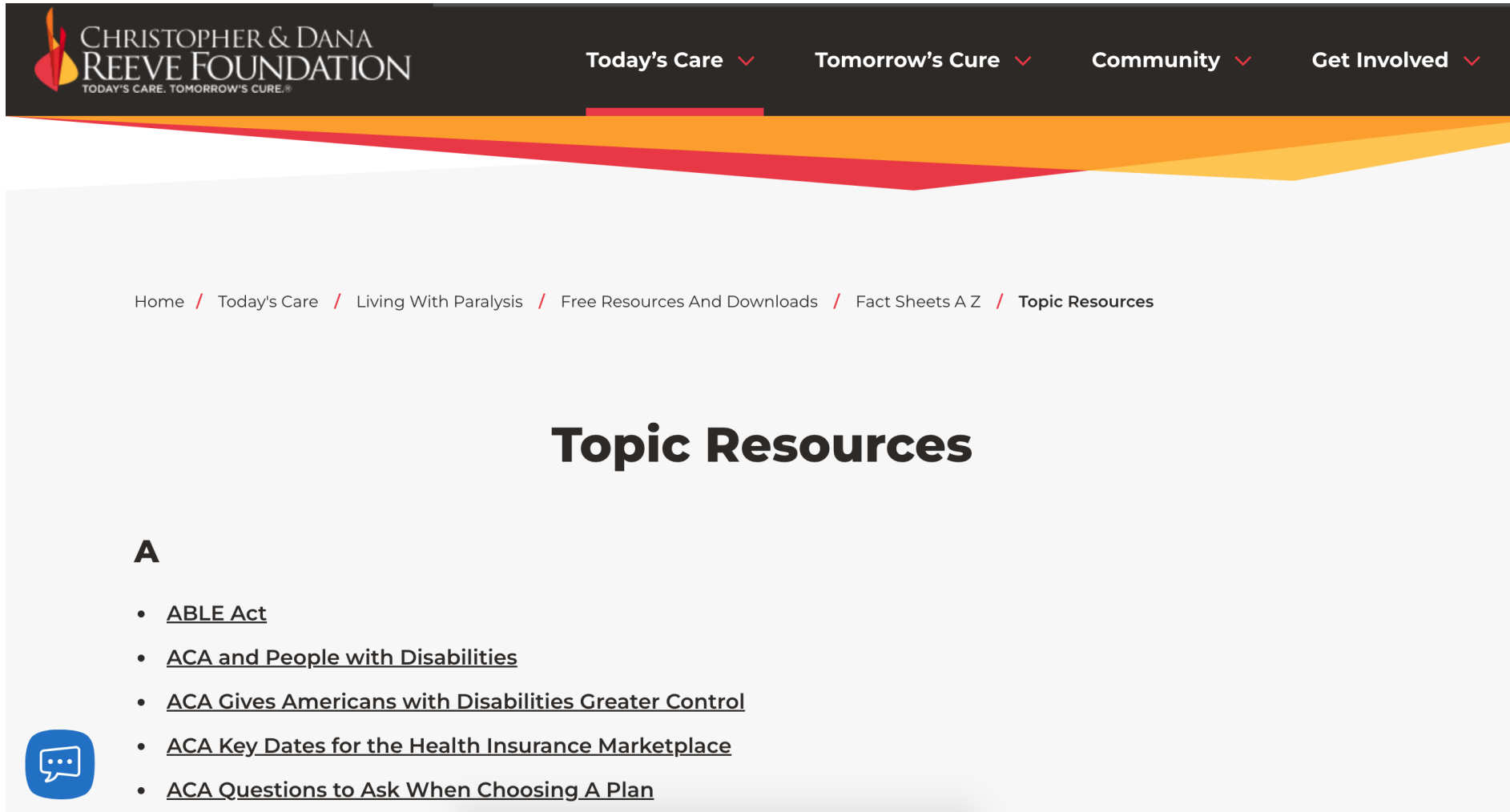


Image: A screenshot of the Topic Resources webpage on the Reeve Foundation's website.



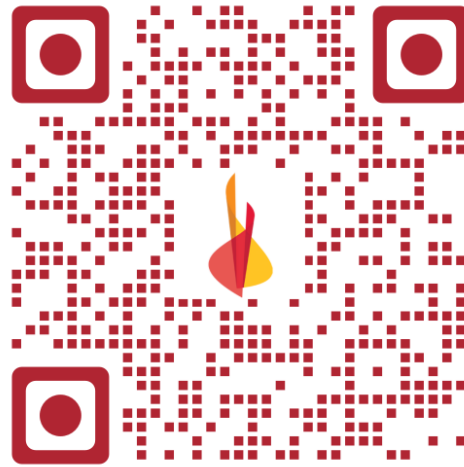
# Learn more

## Peer & Family Support



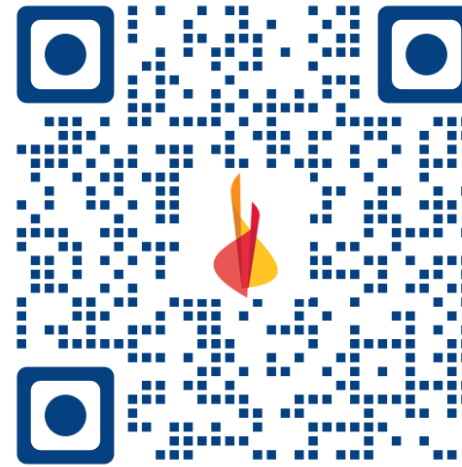
[ChristopherReeve.org/peer](https://ChristopherReeve.org/peer)

## Military & Veterans



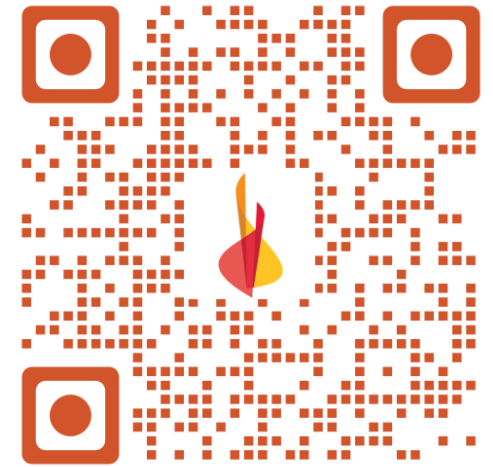
[ChristopherReeve.org/military](https://ChristopherReeve.org/military)

## Quality of Life Grants



[ChristopherReeve.org/QOL](https://ChristopherReeve.org/QOL)

## Information Specialists



[ChristopherReeve.org/ask](https://ChristopherReeve.org/ask)

For Additional Information Contact

**Christopher & Dana Reeve  
Foundation**

**National Paralysis Resource Center**

973-467-8270

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Emily Wolinsky, Director, Outreach & Education

[Ewolinsky@ChristopherReeve.org](mailto:Ewolinsky@ChristopherReeve.org)



ChristopherReeve.org/todays-care

# Review Objectives

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*Questions?*



# Discussion

# Key Resources

- Individuals with Disabilities - <https://ltcombudsman.org/issues/disabilities>

## Disabilities

### Individuals with Disabilities

A disability is an impairment that may be cognitive, developmental, intellectual, mental, physical, sensory, or some combination of these. It substantially affects a person's life activities and may be present from birth or occur during a person's lifetime. Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives.

- [Paralysis Resources](#)
- [Assistive Technology](#)
- [Additional Resources](#)
- [Ombudsman Program Examples](#)

# Join NORC's Email List

Join NORC's email list to receive **training opportunities, resources, and more!**

Visit [ltcombudsman.org/sign-up](https://ltcombudsman.org/sign-up).



# ▶ We Want to Hear from YOU!



<https://www.surveymonkey.com/r/XCNZYJJ>



The National **Long-Term Care**  
**Ombudsman** Resource Center

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# Connect with us!

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 [ltcombudsman.org](https://ltcombudsman.org)

 [ombudcenter@theconsumervoice.org](mailto:ombudcenter@theconsumervoice.org)

 The National LTC Ombudsman Resource Center

 @LTCombudcenter



Get our app! Search for "LTC Ombudsman Resource Center" in the Apple Store or Google Play

*This project was supported, in part, by grant number 900MRC0002-01-00, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.*