

Research is the Foundation for Successful Advocacy

Presented by: Cheryl Vines
& Lisa Elijah



Welcome & Webinar Process

- Today's webinar will be recorded and available for viewing on PVA.org
- Closed Captioning is available. Click the CC button in the meeting controls bar at the bottom of your screen to turn it on.
- If you have a question, please type it in the Q&A box. Questions will be answered at the end of the program.



Introductions

- Cheryl Vines— Director of Research and Education
- Lisa Elijah— Grassroots Advocacy Manager, Retired Air Force, PVA member

Research & Education

- Funds Research & Educational grants
- Creates Clinical Practice Guidelines
- Conducts a Healthcare Provider Summit
- Develops Resources and Support for SCI, MS, & ALS Care
- Support University Based Research in SCI, MS & ALS



Government Relations

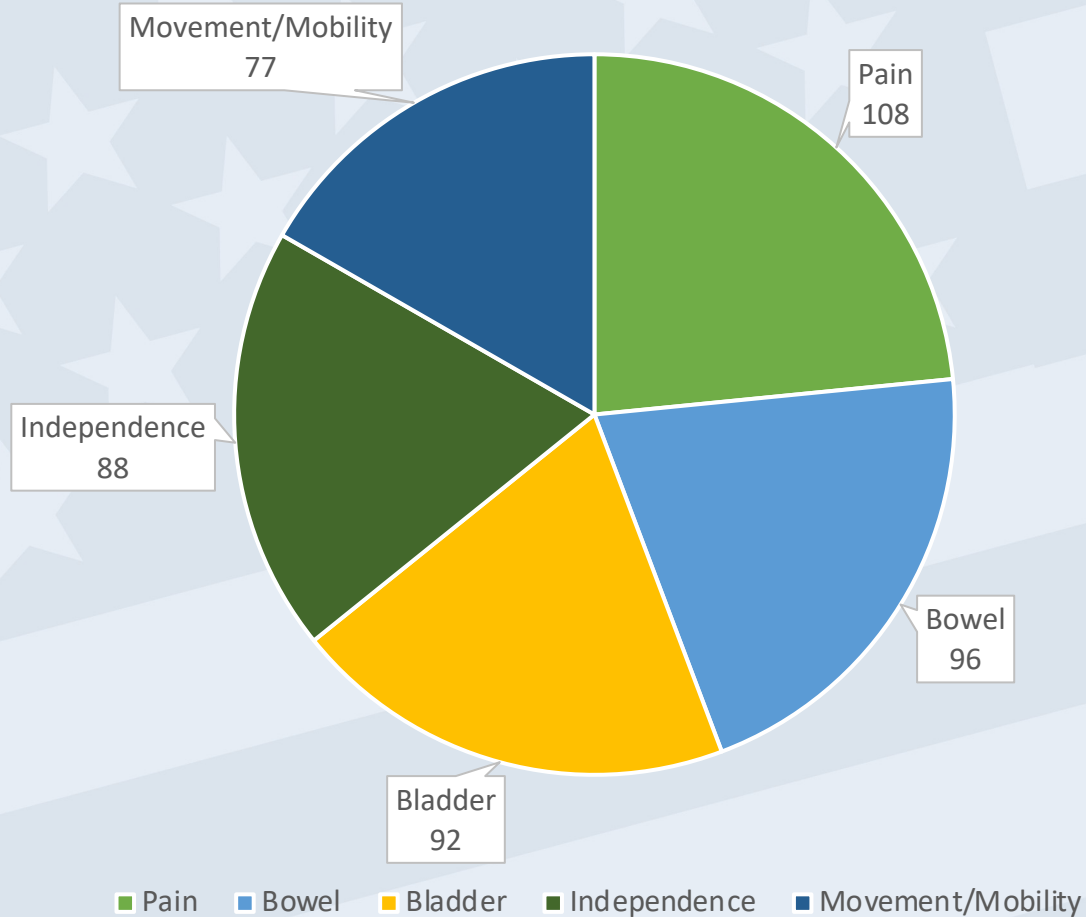
- Policy Priorities
- Yearly Legislative Summit
- Grassroots Advocacy
- Chapter Government Relations Support

Importance of Research



What is important to those who live with SCI/D?

What is your biggest daily challenge?



Over 30% of respondents wanted to be both more active in, and learn more about, research advocacy.

Why do we need research advocates?

In the past, research has often been done without input from the end user on the research question, process, or outcomes. This can result in the product or result from the research being abandoned, as it is not actually helpful to the person that it is targeting.

Other communities have had great success in using research advocates to move research forward in an inclusive manner, such as certain pediatric genetic disorders, cancer, and Parkinson's disease.

What is a research advocate?

- Research Advocates.....

- collaborate with researchers and research institutions to make research more useful for the SCI/D community.
- provide researchers with the perspective of the SCI/D community and help researchers to focus on the questions and issues that are most important to the community.
- ensure that quality of life for the community is kept at the forefront of research projects.

There are many ways to be involved in research as an advocate. A research advocate can work directly with the scientific community or be a bridge between researchers and those who live with SCI/D.

Research advocacy is not one size fits all.

Who can be an advocate?

Anyone with lived experience can be a research advocate.

You do not need to have a background in science or research to get involved as a research advocate.

You do not need to have a certain level of ability or disability to be a research advocate.

The level of involvement and commitment will vary, and can depend on many factors, including the type of research being done.

What does a research advocate do?

The overall goal of research advocacy is to improve the way research is designed, conducted and shared.

There are many roles that a research advocate can fulfill, such as being part of consumer advisory boards or focus groups, partnering with researchers directly, or doing community outreach to help others better understand SCI/D research.

Most importantly, a research advocate provides the perspective of the SCI community to researchers.



NASCIC RESEARCH ADVOCACY COURSE





How do I get started?

Remember, you *do not* need to be an expert on the science of SCI/D or the research process to get started as an advocate.

You *do* need an interest and commitment to providing a link between people who live with SCI and those who do the research about it.



NASCIC RESEARCH ADVOCACY COURSE



Resources

- NASCIC course <https://nascic.org/>
 - 12 modules
 - SCI focused
- National MS Society <https://www.nationalmssociety.org/Research/Participate-in-Research-Studies>
- ALS Association
<https://www.als.org/research/participate-als-research>
- PVA <https://pva.org/research-resources/research-foundation/>
- Spinal Cord Injury Clinical Trial Directory
<https://scitrials.org/>
- Local SCI clinic or VA
- Engage with researchers at conferences or events in your area



**Use the Things You are
going Through for a
Purpose**



Research Drives Legislation

Data and Research are critical for pushing change to and introducing new legislation

Use Your Story to Help Others

- You are the only person to live your life
- Your experiences make you a subject matter expert
- Researchers and Legislators both value your stories
- How you navigate life is critical for understanding what needs to be changed

In Closing

- You are an essential part of advocacy
- How you advocate can look like a lot of different things
- Do what makes you feel empowered and gives you purpose

Q&A

We are happy to answer any questions you may have.

This is just an overview of certain aspects of research advocacy.

Reach out to us any time at CherylV@PVA.org and LisaE@PVA.org.