

## Module 1 – Introduction to Research Advocacy

### What is a Research Advocate?

In this video, you will learn:

- What we mean by research advocacy.
- Why research advocacy is important to the SCI community.
- The responsibilities of a research advocate.
- Examples of roles for research advocates.

People with a spinal cord injury, or “SCI”, can advocate for themselves and for the community in many different ways. For example, if you have worked to direct your own care or to help someone else get the information and services they need, then you have worked as an advocate. Raising awareness of SCI, raising money for SCI, and promoting policies or laws that benefit people with SCI are other ways to advocate for the community.

“Research advocacy” means talking to and collaborating with researchers and research institutions to help make research more useful for the SCI community. Its goal is to improve the way that research is designed, conducted, and shared so that it is more useful for the community.

All of these types of advocacy are crucial to NASCIC’s mission to bring about unified achievements in research, care, cure, and policy.

This course focuses on research advocacy, because the SCI community needs to become more involved in the research that is intended to serve us. NASCIC’s Past President Kim Anderson-Erisman explains why:

**Kim Anderson-Erisman** – Too many times in the past, things have been created from research without the end-user being included. And the product ends up being left on the wayside because it doesn’t meet the needs of the user. So in order to try to ensure that SCI research is useful, people with spinal cord injury need to be part of the process.

We can learn from the example of research advocates with other health conditions, who have made remarkable strides to speed up research and make it more relevant to their communities.

For instance, a research advocate whose child has a rare genetic disease called Friedreich’s ataxia, or “FA,” helped a biotech company realize that a treatment they were already developing for something else might also work in FA. The company is now developing the drug with help from the FA community.

Research advocates living with Parkinson's disease helped a pharmaceutical company fix a clinical trial that couldn't be finished because it was too hard for patients to participate in it. A new trial designed using the patient advocates' advice finished in record time.

Advocates for cancer research even created a new process to speed up the development and approval of new drugs that have exceptional results early in the research process. The U.S. FDA adopted this process, now called Breakthrough Therapy Designation, and has used it to approve hundreds of drugs – and not just for cancer.

What all of these examples have in common is that advocates served as a crucial link between their communities and researchers. If people with SCI connect and communicate with researchers and research agencies, then SCI research can benefit in the same way.

An SCI research advocate does not have to be a scientific expert to help improve research. Instead, SCI research advocates provide researchers with the perspective of the collective SCI community. They help research focus on the questions that are most important to the community and they help create studies that will improve quality of life for people who have an SCI. Research advocates do this by using their own experiences and the experiences of other people with SCI.

Let's hear an example from John Gensel, an SCI researcher from the University of Kentucky:

**John Gensel** – We got asked to apply for a specific grant to receive money to study specific area of research focused around alcohol. And, you know, I thought that I had a brilliant idea about how we could think about alcohol consumption and how it relates to spinal cord injury experiences and lives. And through my discussions with this individual with spinal cord injury, I realized that my thought process about what was a really, really cool area of research almost had no relevance whatsoever in the SCI community. It was a great reflection for me that saved probably years of research that really had no promise to move forward. So, for me, having that perspective at the beginning of the process really was a great means to ensure that our research was effective and efficient, and gave confidence that the work that we're doing could potentially have a positive impact.

There are many different roles for a research advocate. Examples include:

- Serving on advisory boards or committees that guide research projects or approve research funding.
- Partnering with researchers to help develop clinical trials that are safe and meet the needs of people living with SCI.
- Participating in focus groups to help researchers design new treatments.
- Helping to teach people with SCI and their families about clinical trials and to recruit patients to clinical trials.

- Helping people with an SCI understand scientific information and research findings that may help them.

This course will help you become a more effective, empowered SCI research advocate by teaching you how the world of SCI research works and giving you tools and strategies to decide when and how to make your voice—and the voice of the SCI community—heard.

This concludes Module 1 of the Research Advocacy Course. Before you take the quiz, here is a summary of key takeaways:

- The goal of research advocacy is to improve the way that research is designed, conducted, and shared.
- Research advocates do not have to be scientific experts.
- An SCI research advocate provides researchers with the perspective of the collective SCI community.
- There are many different roles for SCI research advocates:
  - Serving on advisory committees to help guide research projects.
  - Teaching people with SCI and their families about SCI research.
  - Helping people with SCI choose the right treatments for themselves.
  - Helping researchers design new treatments.
  - Helping design clinical trials.
  - Providing the perspective of the SCI community to researchers.