

Module 12 – SCI 101 for Researchers

Getting Started as an SCI Research Advocate

Since 2018 NASCIC has been facilitating community engagement in research by placing people with lived experience as advocates on partnered projects, including:

- **Consumer advisory boards**, which are teams of advisors with lived experience who provide feedback, guidance, and input.
- **Focus groups**, which are moderated and structured group discussions with a targeted group from the SCI community.
- **In-depth interviews**, which are highly structured one-on-one interviews with targeted key opinion leaders, including leaders in the SCI community.
- **Roundtable discussions** where a targeted team of people with lived experience participate in brainstorming or exploratory sessions.
- **Speaking engagements** that position the voice of advocacy in public platforms such as podium speaking positions, panel discussions, webinars/podcasts or other public forums.
- **Grant review**, which involves reviewing grant applications for funding bodies such as the U.S. Department of Defense or the Paralyzed Veterans of America Foundation.
- **Study surveys**, including designing, crafting and distributing SCI community surveys to gain quantitative results.

To get involved, the first step is to register with NASCIC's Project Engagement Database (or PED), which can be found on the NASCIC website under projects at <https://nasciconsortium.org/projects/>.

Burkhart – Now that you've completed this course, it's time to put that plan into action and making sure that you can share what you have learned. The best way to do that is to join the PED, project engagement database, within NASCIC, where we will help pair you with researchers that are looking for individuals with your specific injury criteria or maybe your specific research interest.

The PED asks you for information about yourself and your injury that is needed to match you with projects where your input will be most useful, and that best match your interests. For example, the PED asks for:

- Demographic information such as the region you live in, your age, your sex and gender identity.
- Information about your injury, such as the level of injury, and whether it is classified as complete or incomplete, as well as traumatic or non-traumatic.
- What kinds of projects or roles you are interested in, such as joining an advisory board or a focus group or designing and executing surveys, and
- Other information about you that could help you match with a research team, such as special skills or interests.

Your information will not be shared externally without your permission. It will only be used within NASCIC to match you to project opportunities.

When NASCIC undertakes a partnered research project, we email people who registered in the Project Engagement Database. The email gives a brief description of the project, who we're seeking to participate (for instance, levels of injury, level of experience, location, etc.), an explanation of the duties and responsibilities, the expected time commitment, and any other requirements for participation.

As you'll see in the next video, our staff and volunteers work closely with the research team to facilitate recruitment and outline an engagement plan.

NASCIC member organizations also have opportunities for research advocates. For instance, NASCIC principal members Unite 2 Fight Paralysis and the Paralyzed Veterans of America have programs that place individuals with spinal cord injury with an SCI research team.

Matthew Roderick – There are a lot of opportunities to become engaged, uh, in the process. There are opportunities to become involved in legislative efforts to fund science, or even beyond that to fund exercise programs and change policy around rehabilitation. There are opportunities to, uh, advocate, as we've talked about, directly into research science, it directly into labs, uh, reviewing proposals for federal agencies and nonprofit, organizations. I would implore you, encourage you, to get involved in whatever way fits you. What fits your skillset, what fits your interests, but everything from direct research science all the way up through high-level policy about how research happens, how healthcare is delivered, et cetera. So I would encourage you to look to explore all of those, and mine those, and see where you fit.

Attending SCI conferences and events is another way to get involved and learn more about SCI research and advocacy. Regional, national, and international SCI conferences and events are open to individuals living with SCI. Many, such as the annual Unite 2 Fight Paralysis Science & Advocacy Symposium (formerly Working to Walk) or the American Congress of Rehabilitation Medicine, have special rates or scholarships for individuals living with SCI.

Jake Chalfin – It's always good to start at a conference, like Working to Walk. At Working to Walk you meet other peers that are doing it, whether they're doing in-the-lab consulting, or

just doing advocacy work in general. You're meeting peers that are active in moving the field forward in any respect. You're seeing presentations that cover the entire gamut, and I think it provides a good baseline. You make some connections. I think it's helpful as a consultant to have a network and that way if you're in the lab and you have some questions that you might not be comfortable asking the lab, if you've got a network, you can ask somebody else and ask them and get some context. So I would say get a baseline, get out there, do some conferences, and it doesn't just have to be Working to Walk, but that's a good place to start, and then I think that'll help make you even more effective.

In addition to or instead of participating in research projects as a consultant or advisor, you can explore participating in a clinical trial as a research participant. You can find out about clinical trials that may be relevant to you on SCITrials.org. SCITrials.org is an online platform created and run by NASCIC, endParalysis, and the American & Canadian Spinal Research Organizations that enables individuals to:

- Search clinical trials by location, injury details, therapies, and outcomes
- Receive email updates on new trials of interest
- Read about the trial in everyday language
- Find answers for the most common questions about trials, and
- Quickly apply directly to the trials.

As you begin this journey as a research advocate you may come across opportunities on your own, such as with a local SCI organization or a local rehab hospital. When you take on the role of a research advocate, it is important to remember to evaluate whether the opportunity meaningfully engages the entire SCI community.

For review, there is more information on meaningful engagement and tokenism in Module 11: SCI 101 for Researchers, both in the supplemental materials and in the video lesson titled "An Engagement Framework: The IKT Guiding Principles."

Ian Burkhart The most important thing to remember is that you wanna highlight your lived experience as well as the lived experience of the community. So taking the findings that you have learned in this course so that you can understand that you're not just pushing your own views, but being a representative of the community as a whole.

The next video on Getting Started as an SCI Researcher also contains information on how NASCIC ensures that partnered research projects meaningfully engage the SCI community.