

Module 11 – SCI 101 for Researchers

The Lane Lab: A Case Study on Collaboration

Here's an example of how insight into lived experience can shape research priorities, from Michael Lane, a Primary Investigator and Associate Professor at Drexel University whose lab conducts preclinical research on strategies for promoting plasticity to improve recovery after cervical spinal cord injury.

In 2020, Jacob Chalfin, an SCI research advocate who has a cervical spinal cord injury, joined the Lane Lab as a consultant. He participates in monthly lab meetings via Zoom.

Jake Chalfin – It's sort of a kind of a monthly roundup, everyone checks in, everyone gets on the same page, a little housekeeping, and then maybe one or two of the students will run through a presentation on the research that they're working on. And basically I listen, if I have any questions I can pipe up at any time.

Their conversations have opened up new avenues of research for the lab.

Michael Lane – After interacting with people through various foundations and especially after having our consultant work with us with lived experience, one of the things that's become very clear is why do we not do more interventions in chronic injury? Now the initial response from scientists' perspective was cost: We don't start there because it's more expensive. But obviously there is a very important need, and that drove my research team to seek funding. So now we have funding, luckily enough, to be able to start looking at using treatments to treat the chronically injured spinal cord, and we hope to see the same level of efficacy. So we've changed our mindset in that regard, we've taken something from the patient population to see what's important to them, what's crucial, to those living with spinal cord injury, and how we can better do our science to meet their needs.

Insights from this collaboration also changed the course of a specific line of inquiry the Lane Lab was planning related to sleep-disordered breathing in people with cervical injury.

Michael Lane – In some cases, people living with spinal cord injury, cervical injury, can have sleep disordered breathing. And so we still don't know much about that, and I remember speaking to our consultant Jake Chalfin, and saying does he notice any of these sorts of things. He corrected me very quickly, and said actually he doesn't know, because his sleep patterns are already disrupted. His regular sleep patterns have to be disrupted, so that he doesn't know if he has irregular sleep patterns normally.

Jake Chalfin – I have to wake up several times a night to cath, and so my sleep pattern's already shot. I'm not sleeping through the night whether I'm breathing well or I'm not breathing well.

Michael Lane – And so straight away, I thought OK, this is a completely different question to ask. So we began looking at that a little more, and that's become a new area of our research to see if we can better understand something that really Jake has taught me a little bit about just by interacting with him.

Conversations between the two also have led the lab to explore upper extremity function in addition to respiration.

Michael Lane – Whether it's motor or sensory function of the upper extremity, one new area of our research is to start looking at that because it's another area of dysfunction that affects so many people, And so if we can develop treatments that can improve either respiration or upper extremity function, we're now developing a treatment that's relevant to more people.

Jake Chalfin – When I first got hurt, the focus for me and probably most people was how to get back on your feet, But then over time, you realize that you sadly get used to a wheelchair, but things that are worse than that are your bladder and bowel management, fear of pressure sores, grip, dexterity, all of that other stuff, blood pressure, circulation. And so I'd really like to see research directed at things that will improve our daily lives. The ultimate goal is full cure, but potentially on the way to a full cure can we start, can the science start solving little problems that--along the way—that are still very relevant. Those sorts of things, I think, are the most important and really what I kind of try to impress upon the people in the lab.

Michael and Jake say that what drives this collaboration is a commitment to learning and communication, and a mutual respect for each other's roles and contributions.

Michael Lane – I think he and I agreed right up front that we didn't know how this collaboration would work. We both agreed that we were here to learn from each other, and it was a fairly fluid sort of relationship to start with because it had to be. We had no expectations except the fact that we wanted to learn from each other. And I think that's what's really driven our collaboration and ongoing relationship, and that is just communication. Asking questions. And I've always said to Jake there's never a bad question – I've said that to all my trainees – and they'll ask questions of Jake as well so we can, bidirectionally, we can learn as much as possible.

Jake Chalfin – I think it's my understanding and perspective of where they are in the process, along with their being welcoming to me and willing to listen to me, and proactive enough to invite me in, so I think we're both coming together with the right mindset.

Jake offered this advice to SCI researchers who want to engage people with lived experience:

Jake Chalfin – Ask a lot of questions. Be willing to consider designing your future work around feedback and recommendations of your person with lived experience. Whenever somebody with lived experience joins a lab, the lab is automatically going to be involved in the middle of

and working through research projects that have been designed and started already. There's not a lot of influence we can have in those currently active projects. But we can learn from those projects. And I think that that interaction, that relationship, will then lead to when these projects are wrapping up, and scientists are getting ready to study the next thing, and write grant proposals to get funding for the next couple years of research that they want their lab to do, that's where we consultants can really help steer those labs. So if you are a director of a lab, and you want to invite somebody in, lean on them to help you come up with what should be studied next.