

[Inside Philanthropy: A Funder Focused on Spinal Cord Injury Brings a Trust-Driven Approach to Research Grantmaking](#)

By Paul Karon

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This spring, with COVID restrictions loosening, IP has been discussing whether philanthropy will return to business as usual in a post-pandemic era. But, as in society more generally, some of the adaptations funders made in response to the pandemic seem to be sticking around as the emergency eases—leading to important potential changes in grantmaking for the foreseeable future. Here’s one funder that’s reexamining longtime processes.

The Craig H. Neilsen Foundation, which supports research and other issues related to spinal cord injury, was one of many foundations that responded rapidly to the pandemic. The foundation’s community of concern, people with spinal cord injury (SCI) and paralysis, typically depend on daily or even round-the-clock assistance from caregivers. Social distancing was not an option, and their SCI put them at greater risk of serious illness if they did contract COVID-19.

In June of last year, the foundation announced \$10 million in crisis funding to researchers and the SCI community. Grantees included front-line workers who provide many of the basic services people with SCI need, and the foundation awarded money speedily and without all the usual restrictions and reporting requirements. As Neilsen Executive Director Kym Eisner [wrote recently](#): “We trusted that our colleagues with ‘boots on the ground’ knew how to best meet the immediate needs of their communities. To provide the resources they needed to respond, we built a funding process that was as simple and immediate as possible.”

In fact, when the pandemic hit, many funders sought to be more responsive to vulnerable populations by using a faster, more trust-driven approach to grantmaking. For Neilsen, the approach worked well. The partner organizations Neilsen funded were able to keep providing services to clients with SCI.

It’s one thing to ease the grant review process in an emergency to keep crucial front-line nonprofits and services functioning. It’s another to speed up the review process in the more arcane world of research, where scientists focus on technical distinctions in which non-specialists

may not be fluent. But, Eisner said, the pandemic also created risk of serious disruption for the research community, just as it did for providers of basic services. For example, many scientists were barred from entering their labs and worried that research staff might have to be laid off. Important progress could be lost or delayed.

So the Neilsen team decided they'd extend the same trust-driven grantmaking to their longtime research grantees, awarding grants in less than a week. It was a decision based on experience—in other words, the researchers they funded had earned their trust. “Early on in the pandemic,” Eisner said, “we offered supplemental support to researchers with open grants—both time and money.” Keeping their less-senior staff employed and their projects viable was a priority for the foundation. The foundation’s confidence in their research grantees was strengthened when they saw that researchers only requested additional funds for pandemic-related issues.

“Although scientific research requires a longer review process, the foundation believes that all of our work can embrace the principles of trust-based philanthropy,” Eisner said. “I don’t know exactly what it will mean a year or two or three down the line, but we’re trying to use some of those strategies across all of our portfolios, and I don’t think it would have happened if we were not thrust into this pandemic environment.”

The Neilsen foundation was established in 2002 by gaming industry businessman Craig Neilsen, who became a paraplegic in 1985 after a car accident. After rehab, he returned to work and evidently not much slowed by his paralysis, continued to expand his businesses. He died in 2006, and in 2011, the foundation was fully endowed with additional funds from his estate—assets in 2019 were \$448 million.

Their programs support scientific, charitable and educational organizations involved in SCI research, as well as training in spinal cord medicine and the provision of services to individuals and families affected by spinal cord injury.

During the pandemic, the Neilsen Foundation also launched the new Craig H. Neilsen Visionary Prize, with an unrestricted award of \$1 million to people who made important contributions to the SCI community. The first cohort of three prize winners was announced in September last year. Recipients included the founder of a nonprofit serving the SCI community, a pioneering nurse who uses a wheelchair, and a spinal cord researcher.

In addition, last year saw another milestone for Neilsen: the opening of the Craig H. Neilsen Rehabilitation Hospital at the University of Utah, enabled by the foundation's \$47.5 million grant. The 75-bed hospital is a state-of-the-art facility for SCI patients, and is designed to improve the quality of life for people with disabling conditions, and to accommodate family and caregivers.

The long-term effectiveness of a more trust-driven approach to research funding remains to be seen. But Eisner said it's an experiment worth trying: "If the Neilsen Foundation can take the risk and show that it's a risk worth taking, then others can follow."