



The Craig H. Nielsen Foundation’s mission encapsulates its purpose. The values provide a lens with which to make decisions and identify directions where the Foundation’s support could have the biggest impact. Picturing a time when individuals with spinal cord injuries, and those who care for them, live full and productive lives as active participants in their communities, fuels the passion in the Foundation’s day-to-day activity. This vision can be achieved through support of excellent science and services, a commitment to collaboration and willingness to identify imaginative solutions that allow us to break through barriers once thought to be impassible. The Foundation plays an important role in the SCI funding landscape and, to make our vision a reality, we must continue to push our grantees, our community partners and ourselves to do more.

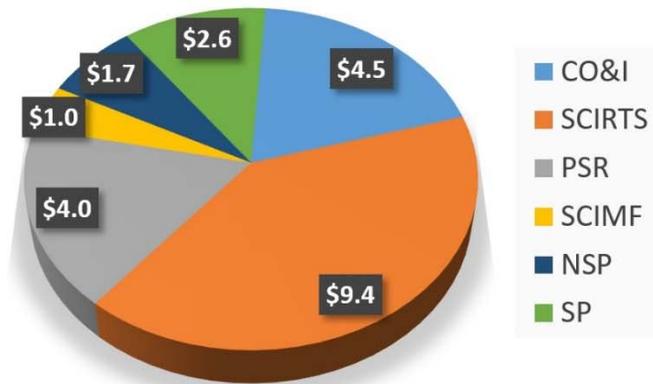
The Foundation’s robust programming and grantmaking processes continue to be thoughtfully implemented to ensure that the needs of the grantees are being met and align with the Foundation’s goals. This annual snapshot outlines the number of grants initiated and the financial commitments made by the Foundation, the trends emerging in each portfolio, and highlights selected grants that closed in 2018. This year our attention has been riveted on reports about: people experiencing unprecedented improvement in walking and cardiovascular function with epidural stimulation; huge numbers of connections being made between cellular grafts and damaged spinal cord pathways; new ways to motivate healthy lifestyle choices and exercise after SCI in both research and community settings; and an expanding number of doctors training to practice SCI medicine and sites offering the training.

Recognizing trends is also an important way to reveal topics with a potential for progress that are not receiving the attention they deserve. The Foundation can deploy resources to focus awareness and challenge the field to make needed progress. In addition, focusing on the outcomes of grants that have recently closed allows reflection on how the findings can impact future research and implementation to benefit people with SCI.

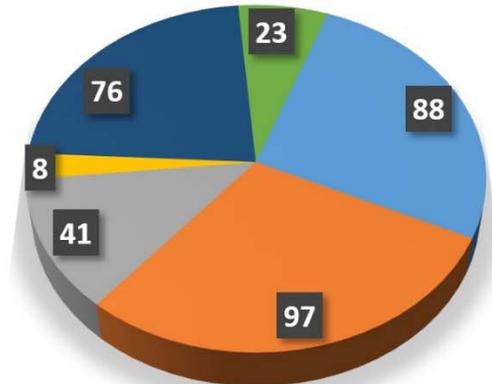
Current Grant Overview

At the end of 2018, there were 333 active grants across the Foundation’s portfolio, a slight increase from last year. Spending totaling \$23.2 million is shown by portfolio below, on a cash basis for 2018.

2018 Spending, in Millions¹



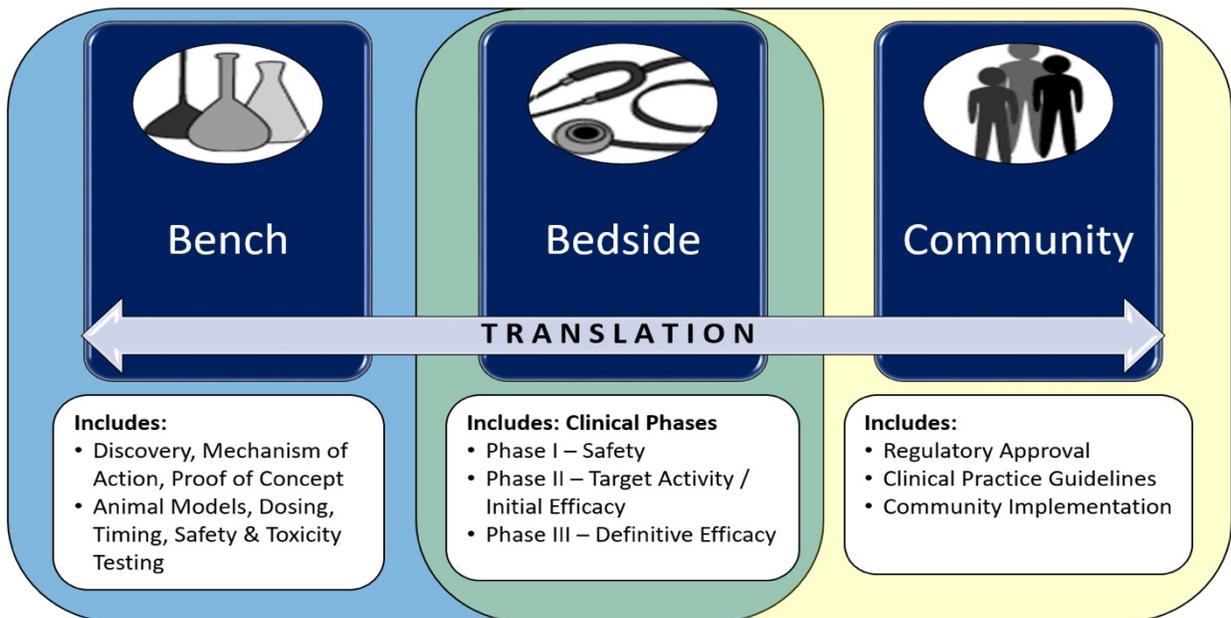
Active Grants, end of 2018



¹Does not include a one-time gift for the Craig H. Neilsen Rehabilitation Hospital.

Making it Real – Focusing on Translation

Translation is key to meeting the Foundation’s mission to improve peoples’ quality of life through funding of research and programmatic activities. Sometimes referred to as “bench to bedside,” the Foundation strives to go even further, bringing those benefits to people with SCI and their families. Translation of new knowledge gained through research is the first stage, followed by laboratory studies that use that knowledge to develop new and effective therapies. Human studies (clinical trials) are the next step, with early phases testing safety and determining whether treatments hit their target.



Ultimate translation moves proven treatments into real world, community use where improved clinical practice and access allow people with SCI to receive healthcare and engage fully in activities that add to their quality of life. Throughout this report, examples have been selected to show the progression of ideas and research findings into new efforts, some crossing from one Foundation portfolio into another.

SCI RESEARCH ON THE TRANSLATIONAL SPECTRUM (SCIRTS)

Summary of 2018 Grants

# Postdoctoral Fellowships	# Pilot Research Grants	# Senior Research Grants	# Awards / # Applications	Total Amount for 2018 Cycle
5	17	6	28 / 82 (235 LOIs)	\$9,090,204

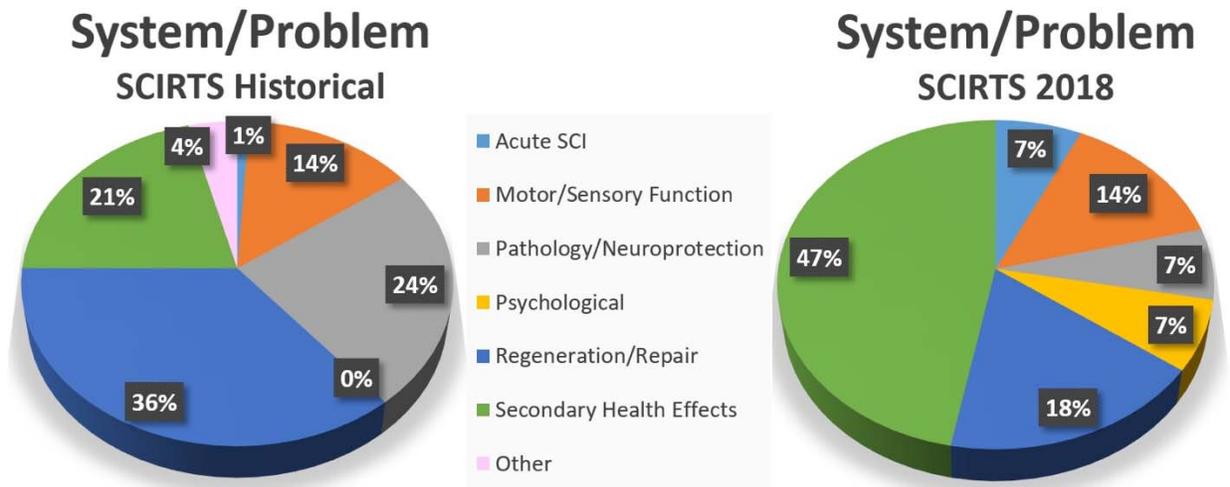
Investigators are under great pressure to win grants to support their research and laboratory staff, so many submit research proposals with similar aims to multiple funders, trying to assure funding. The Foundation routinely works with grantees as well as representatives of the other funders to ensure there is no budgetary overlap when grants are awarded.

Portfolio Trends

The SCIRTS portfolio supports research covering a broad range of topics, which vary year by year. Proposals received in this cycle indicate growing interest in devices and genetic models. Electrical stimulation is being tested to promote functional recovery, possibly guiding regenerating cells or causing surviving nerves to develop new connections. The hope is that these connections will carry information along new pathways past damaged areas of the spinal cord. Animals, genetically altered to turn on or off specific genes, can help teach the field what causes cells to either stop or start growing/functioning after injury. This knowledge guides development of new therapies. In addition, this portfolio receives many studies combining several promising types of treatment as a way to increase the overall benefit of a therapeutic strategy.

The 2018 SCIRTS cycle saw a greater emphasis on a variety of functional issues, with proportionally fewer grants focusing narrowly on cellular processes such as regeneration. As shown in the following pie charts, nearly half of the new grants fall into the category of secondary health effects such as pain, bowel, bladder, and sexual functions, as well as issues relating to bedsores/pressure ulcers, swallowing and cardiovascular health. Some laboratories are also beginning to use animal models of depression and related psychological issues after SCI. These grants are appropriate for the SCIRTS portfolio because they characterize the basic cellular actions that accompany or may underlie these secondary health conditions. The findings are being

used to establish the basis for design of future treatment approaches. Overall, the proportion of grants addressing these secondary issues more than doubled, and represents almost half of all funded grants in the 2018 SCIRTS cycle.



Final Reporting

In covering a translational spectrum, the SCIRTS portfolio supports grants that generate new knowledge and bring promising therapies into early-phase clinical testing. Eight grants completed in 2018 addressed common health issues experienced after SCI, including cardiovascular, bone, bowel and bladder problems. Regeneration and other changes in the wiring of the spinal cord accounted for eight grants ending this year, four grants explored basic SCI issues including motor/sensory function and seven grants focused on use of technologies, such as spinal stimulation, exoskeletons and other devices. These devices are being used either to measure brain activity or to generate movement by stimulating the brain or nerves throughout the body.

SCIRTS research projects completed in 2018 included a clinical trial repurposing a drug approved by the FDA for postmenopausal osteoporosis to reduce bone loss after SCI (ClinicalTrials.gov identifier: NCT01983475), and one testing a topical anesthetic to prevent a sudden rise in blood pressure (autonomic dysreflexia) that can be triggered by bowel routines (ClinicalTrials.gov identifier: NCT01567605). Alarming, it was discovered that the anesthetic actually *increased* AD episodes and should not be further tested. These results are being shared with both researchers and SCI consumers. This SCIRTS grant shows what can be learned from negative as well as positive results.

Support of tool development, including new ways to accurately measure symptoms and inform treatments or diagnoses, is a gap area, particularly in validation of new measures. With Foundation support, a team of experts was formed to critically evaluate, adapt and

validate measures for use with children with SCI. The new recommendations have been published and are now freely available online. Further dissemination is being supported as part of a Sustainable Impact Project grant in the Creating Opportunity & Independence portfolio to develop user manuals, scoring report forms, computer-based testing, as well as training materials and workshops to instruct users of the pediatric measure and a SCI-Functional Index scale.

PSYCHOSOCIAL RESEARCH (PSR)

Summary of 2018 Grants

# Postdoctoral Fellowships	# Pilot Research Grants	# Studies & Demonstration Projects	# Awards / # Applications	Total for Grants in 2018 Cycle
3	8	7	18 / 32 (60 LOIs)	\$4,812,403

Portfolio Trends

The Foundation has placed an increased emphasis on activities that move research out of the halls of academia into the hands of people and organizations who can put it to practical use. In addition to evaluating the strength and soundness of the research design, the question “so, what’s next?” is being asked about proposed projects during the review process. The Foundation’s priorities include how funded research addresses translating, disseminating and applying study data for real-world use. Many recently recommended PSR grants are focused on Independence and Self-Care, two of the portfolio’s areas of emphasis. Such research is key to developing evidence-based programs, policies and practices that enable active community participation.

Final Reporting

Several recently completed grants focused on the psychosocial traits that enable a person to be flexible while adjusting to life after SCI, which can involve the need to overcome challenges such as loneliness and social isolation. The interventions studied include counseling by therapists and/or peers, multifamily support for people with SCI and their caregivers, and use of tele-rehabilitation. In addition, practical solutions were sought for specific issues including shoulder pain, barriers to travel, exercise and weight management. PSR studies also highlight different aspects of the incredibly challenging transition back into the community after acute care and inpatient rehabilitation.

Studies show that employment, recreation activities, social networks and geographic location all play important roles in building a sense of belonging. These findings are being disseminated to key SCI rehabilitation and community agencies to help prioritize strategies. Programs that effectively address community isolation included training and

peer-counseling to overcome barriers to fitness and motivate people to engage in health-related activities.

Full integration also involves cultural and environmental factors that can block or build a more inclusive and equitable community. Living independently and fully participating in the community involves being able to travel for work, school and leisure. A study to identify barriers and facilitators for travel by people with SCI has transitioned to working with the travel industry to enhance their perception of the disability community as a valuable segment of their customer base. This has led to CO&I grants supporting a collaboration with hotels and online resources for accessible travel, Travel 360, with an interactive image of a hotel room so travelers can identify potential issues in advance.

CREATING OPPORTUNITY & INDEPENDENCE (CO&I)

Summary of 2018 Grants

Project Grants # Awards / # Applications	Sustainable Impact Projects # Awards/# Applications	Total for Grants in 2018 Cycle
55 / 81 (140 LOIs)	3 / 5	\$4,289,494

Portfolio Trends

Due to reduced lengths of stay following acute care, the onus placed on clinicians to complete the most basic SCI education (e.g., transfers, bowel and bladder care, etc.) has become even more burdensome. Frank discussions about sexuality and women’s health issues are important topics that often do not receive the attention they deserve. Addressing these important issues was a theme that emerged in several CO&I grants. The demand for improved access to primary care physicians knowledgeable in needs of female patients with SCI will be addressed by three 2018 Sustainable Impact Projects developing a variety of new educational resources.

Final Reporting

Over 2,500 people with SCI/D received services due to Foundation support of 37 CO&I Project Grants that were completed this year. It is notable that in the Employment and Education categories, two traditionally under-represented areas, eight funded grants served 864 individuals with SCI/D during the grant period, 70% of all participants.

A SIP grant completed in 2018, “Operation Outreach: Advancing SCI in Rural Communities,” was a state-wide initiative by the Arkansas Spinal Cord Foundation to create full and equal access to healthcare services for individuals with SCI, about 85%

of whom reside in rural areas. This project provided individuals with SCI and their families or caregivers with educational services by training rural clinicians who consulted directly with SCI specialists and utilized multimedia resource materials to increase their knowledge of SCI. While benefitting 350 individuals with SCI, limited internet access for both the practitioners and SCI families in the state is one of the barriers identified that must be overcome before this model can be replicated in other rural areas.

One-year Project Grants can have lasting outcomes. Examples of grants completed in 2018 that will continue to benefit the SCI community well beyond the funded grants are:

- The Triumph Foundation’s “SCI Return to the Community” Project Grant helped 800 people through Return to Work micro-grants that supported entrepreneurial activities, benefits counseling and peer mentoring for newly injured individuals.
- The Open Doors project serves a group of urban men who sustained SCI from gunshot wounds, connecting them with the resources to improve their lives and tell their stories. This project supported the launch of a writer’s workshop where participants develop their creative voice and career opportunities through music and poetry.

SCI MEDICINE FELLOWSHIPS (SCIMF)

Summary of 2018 Grants

For the 2018-2019 academic year, 11 new Neilsen Fellowships were supported and the 10 Neilsen Fellows supported in the 2017-2018 academic year completed their training.

# Fellowships / # Institutions	Total for Grants in 2018 Cycle (2018-2019 Academic Year)
11 / 8	\$1,049,148

Portfolio Trends

The number of programs accredited in SCI medicine by the ACGME and the number of sites funded by the Foundation have increased progressively since the inception of the portfolio. With the 11 Neilsen Fellowships supported for the 2018-2019 academic year, a total of 52 physicians have been trained since the Foundation funded its first SCI medicine fellowship in 2006. Recruitment began at the end of the year for 15 Neilsen Fellowship positions at the following 12 sites for the 2019-2020 academic year: Craig Hospital, Icahn School of Medicine (Mt. Sinai), Kessler Rehabilitation, MetroHealth Medical Center (Cleveland), McGuire Rehabilitation (Virginia Commonwealth), Shirley Ryan AbilityLab, University of Pittsburgh Medical Center, University of Texas (Houston),

University of Washington (Seattle) and three first-time participants, Pennsylvania State University, University of Michigan (Ann Arbor) and University of Utah.

Nationally, the Foundation funds just over half (i.e., 11 out of 21) of all such fellowship positions available annually. All other SCI medicine fellowship slots recruited this year were within the Veterans Administration (VA) system. The Foundation works with some VA-funded sites (e.g., University of Washington, McGuire Rehabilitation), providing co-funding that enables well-rounded training in both VA and civilian practice settings.

To promote early-career interest in SCI medicine, the Foundation also supports the Association of Academic Physiatrists' (AAP) medical externship program. This funding allowed 11 medical students to participate in SCI-specific clinical and research training mentorships during the summer of 2018. In addition, the AAP expanded this effort by providing all students participating in the clinical program exposure to SCI patient care.

NEILSEN SCHOLARSHIP PROGRAM (NSP)

Summary of 2018 Grants

NSP participation has increased from eight to 11 institutions with support starting with the 2018-2019 academic year. Recent restructuring of NSP grants standardized allowable tuition and fees (scholarships) as well as the supplemental support categories so that they can be awarded together in annual increments. Overall, 42 students were supported, the most in any cohort to date.

# Schools / # Students	Scholarship Amount	Supplemental Support Amount	Total for Grants in 2018 Cycle
11 / 42	\$1,772,096	\$1,228,992	\$3,001,088

Portfolio Trends

2018 saw the reach of the Neilsen Scholarship Program grow geographically and the number of participating institutions expand. The caliber of the students recommended by the schools was impressive and, this year, more of the students receiving support are pursuing advanced degrees.

The schools selected in the 2018 process include five new institutions along with six that have previously participated in NSP. Returning schools are: two community colleges (Hinds and Portland) and the Universities of Alabama (Tuscaloosa), Arizona, Illinois (Urbana-Champaign) and Utah. First-time participants are: Georgia Institute of Technology, Pennsylvania State University, University of California (Los Angeles), University of Michigan, and University of Nevada (Las Vegas). These new institutions

have fully embraced the Foundation's intent, following rigorous guidelines. The schools that had prior NSP experience have adapted to the restructured guidelines and become mentors for the new institutions.

Progress and Final Reporting

Fourteen students graduated during the past year in programs that covered a wide variety of degree levels and topics. The annual progress reports submitted to the Foundation contain student letters that reflect a sense of independence and strength and highlight the impact the program has on participants. Such stories reveal the heart of the scholarship program. Scholarship students have turned challenges into opportunities by inventing adaptive devices to meet their needs, coaching and rehabilitation counselling, and excelling in athletics including marathon and Paralympic competitions.

This program relies on a successful partnership between the Foundation and the schools that receive the funding. Each grantee institution is a steward of the scholarship and supplemental support funds, working with students to eliminate barriers and enable them to thrive. In its first year, the University of Michigan has quickly become a model partner, propelling its students with SCI toward success, working with one medical student to create a new model for medical training that is workable for people with a range of disabilities. A longstanding partner, the University of Alabama, has shown unwavering support for its students with SCI, augmenting its adaptive athletics programs as well as other resources for students with disabilities on campus. The University of Arizona's adaptive athletics program supported the dreams of one Neilsen Foundation scholarship recipient who now has a Bachelor's degree as well as four Paralympic medals.

SPECIAL PROJECTS

Summary of 2018 Grants

Special Projects are developed around ideas that speak directly to our mission but do not present a good fit within the Foundation's standing portfolios. Applications to the standing portfolios come through a standardized process, with little or no input from Foundation staff as the concepts are being developed. Special Projects, however, are targeted efforts on which the Foundation works hands-on with organizations to brainstorm ideas and approaches that meet particular needs. They provide funding flexibility and acknowledge that some initiatives present unique opportunities that need to be evaluated through a different lens.

Although developing and initiating the core projects remain the responsibility of the grantee, leveraging the Foundation's institutional knowledge encourages these

promising, but sometimes novice organizations to identify milestones that speak to their organizational needs. This also allows the Foundation to undertake reasonable risk, monitor progress and protect its investment.

Progress and Final Reporting

One of the Foundation's first peer-reviewed Special Projects was to the Christopher and Dana Reeve Foundation, awarded in 2013 to support epidural stimulation research at the University of Louisville to restore cardiovascular benefits to study participants with chronic SCI. The investigators published an impressive group of papers in top clinical journals, reporting both immediate and long-lasting improvements in blood pressure control due to spinal stimulation. Related results were reported by investigators at the Mayo Clinic who were funded by a 2014 Foundation operating grant that initiated their epidural stimulation studies. In combination, these studies have provoked extensive discussion throughout the field and inspired many other laboratories to develop research programs in this area.

In response to hurricanes that devastated communities in Texas, along the Gulf Coast and Puerto Rico, the Foundation made a 2017 grant to United Spinal Association for relief targeted to help people with SCI/D. United Spinal developed a program to provide hundreds of micro-grants to assist with immediate needs through its local chapters and disability networks in the affected areas.

Excitement generated by the 2017 Bowel and Bladder workshop remains unwavering. This year, a paper summarizing the discussion and the priorities reached was published in *Experimental Neurology*. Working groups on Neuromodulation/Neurostimulation and Rehabilitation/ Activity/Exercise continue their efforts, both developing publications to inform the community of research in these areas.