

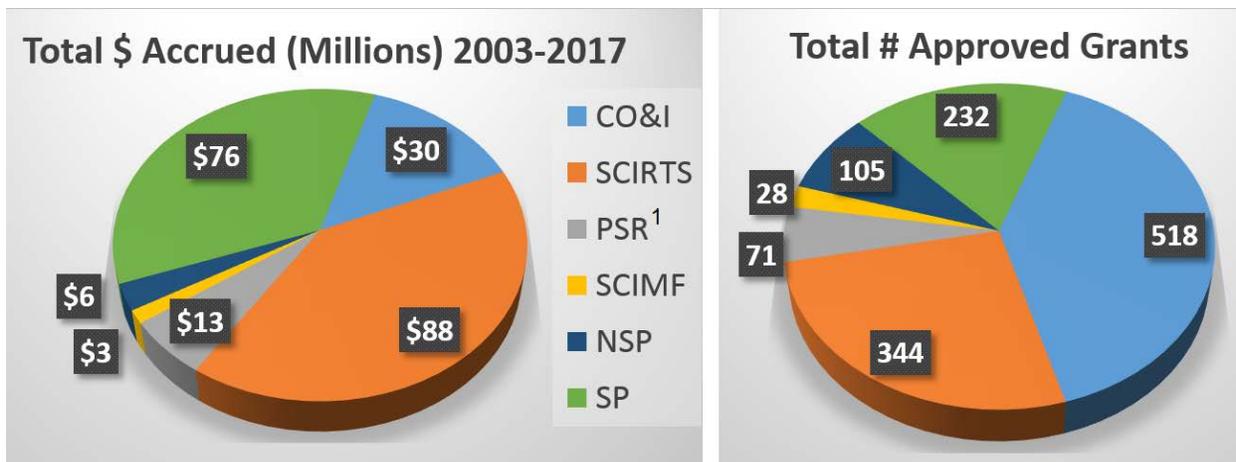


The Neilsen Foundation recently commenced a process to evaluate its impact by gathering information from multiple perspectives in order to assess how Foundation support stimulates progress in the field. The staff initiated a look back at the Foundation's overall funding history using a variety of analyses. For programmatic review, focus in each of the Foundation's portfolios was placed on the outcome of grants that were completed over four consecutive years (2014-2017), which were awarded during a period of rapid growth and maturation of funding priorities. Finally, interviews with external observers provided specific examples of successes and future opportunities but, perhaps more importantly, emphasized the Foundation's broader influence and sincere gratitude for our ongoing commitment to the field.

When asked about the Foundation's impact, Steven Kirshblum observed: "I see the Foundation as being both the bus (vehicle) for movement of the field forward, as well as at times also serving as the driver of that bus...The Foundation is open to being innovative with its thinking, taking chances by creating new paths for institutions and researchers to develop their ideas." His comments speak directly to our institutional values and provide an inspiring metaphor and encouragement to continue to be creative in working to meet such high expectations.

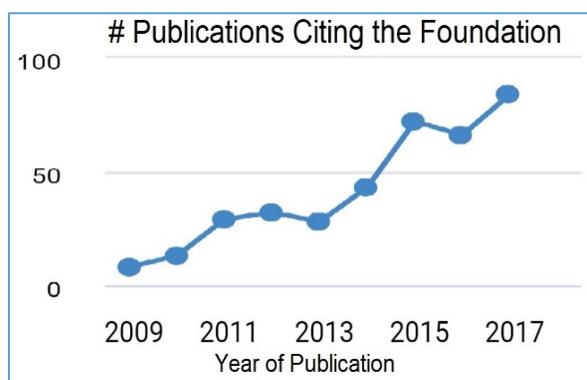
Determining what impact looks like is inherently difficult because, much like the idea of a "cure" for SCI, impact means different things to different people. The majority of the Foundation's grants fund pilot studies and training opportunities and are meant to launch larger future efforts. In addition, many grants have multi-year timelines for achieving their immediate aims and even longer horizons for their ultimate goal of improving quality of life. Because the Foundation is investing in both new ideas and the next generation of students and leaders, not all impact can be seen within a brief time period. This dilemma is shared by most funders and is compounded by the fact that many of the supported programs have multiple funding sources, all acknowledged for their contributions to different components of specific projects.

To assess the Foundation's performance, it is important to recall the extent and types of grants that have been made since its inception. As of December 31, 2017, the Craig H. Neilsen Foundation has awarded approximately 1,300 grants since 2003. These grants total approximately \$216 million accrued-to-date.



¹ Number of approved PSR grants (71) includes 2018 Cycle grants to be accrued in 2018.

A first step in assessing the result of research investments is using the grant database (Dimensions for Funders) that powers the Foundation’s website search. It indicates that over 380 publications cited the Foundation between 2004-2017. The associated graph shows the growing number of citations since 2009.



It is somewhat easier to evaluate the outcomes of workshops underwritten by Foundation support. In 2017, the result of many such efforts began to surface. A paper reviewing Upper Extremity Outcome Measures was published in the journal *Spinal Cord* reflecting the dialogue at the 2015 workshop. Also in 2017, “A Road Map to Clinical Translation” was developed following the Intermittent Hypoxia workshop held in July 2016. In addition, for the first time, the Foundation used its leadership position in the field to spotlight a specific issue facing people with SCI, bowel and bladder management. The Foundation convened this meeting because this issue is consistently ranked among the most difficult challenges faced by those living with SCI, but limited progress has been made in addressing these issues.

2014-2017 Portfolio Impact Analyses

Staff conducted a targeted examination of progress based on grants that closed in 2014 through 2017. The questions underlying the analysis were: 1) how many grants closed in that period; 2) how many reached their stated aims; and 3) what publications and/or additional funding have resulted? Given the diversity of the portfolios, a variety of different approaches were taken in the analyses that follow. The findings are presented under three major headings: Research, Program and Education.

RESEARCH PORTFOLIOS

SCIRTS: To assess this large portfolio, a questionnaire was sent to 105 grantees who completed their research grants, 71 of whom responded in time for inclusion in this report. The Foundation funded approximately \$18 million in grants to the 71 investigators that responded to the survey. They reported securing over \$70 million in subsequent funding from a variety of sources, building on these SCIRTS awards.

This funding included the following:

- 42% of these grants were funded by federal agencies
- 21% by state or local funders
- 36% by nonprofit organizations
- 1% by industry

Junior as well as senior researchers were successful in obtaining subsequent funding, including several postdoctoral fellows that have gone on to independent careers. In addition, these 71 grantees reported a total of 197 publications since 2014. Qualitatively, survey respondents indicated that SCIRTS funding has had a tremendous impact on the SCI research community. In one of the external impact assessment interviews, MJ Mulcahey noted that the Foundation, “has enabled the bringing together of the greatest minds in diverse perspectives” in basic research, outcome measures and collaborative translational efforts. She added that, “the work by and through these entities is not possible without CHNF funding, and it has transformed the way in which research and best practice is thought about and executed across the globe.”

PSR: The study of how people’s lives are changed by SCI and by new therapeutic options is at a very early stage. The Foundation’s first PSR grants were issued in 2014 with a goal of nurturing a relatively under-developed area of investigation. In all, 16 grants were completed between 2015-2017, half of those ending in 2017.

In another external interview, Chuck Bombardier, a PSR Review Board member and grantee, cautioned: “It is premature to expect visible impact on the field...It would take 10-15 years before mid-term outcomes would be expected.” Nevertheless, the progress of individual projects can be observed when new studies build upon prior funding. Of note, two initial Pilot grants funded in 2014 both succeeded in meeting their proposed aims to develop tools or experience that would facilitate future studies. To date, a total of 51 publications were reported by the 16 funded investigators and new grants totaling approximately \$5 million have been obtained, leveraging the Foundation’s initial investment.

PROGRAM PORTFOLIO

CO&I: The grant strategies and structures used in this portfolio have undergone significant refinement and experimentation in an effort to ensure CO&I was meeting its goals. Although information on additional funding received by grantee organizations has not been systematically tracked, the expectation that grantees develop sustainable funding is explicit in CO&I guidelines. Grantee reports have provided anecdotal evidence that the Foundation's funding has been instrumental in helping newly formed nonprofit and grassroots organizations secure funding at local, regional and national levels

Impact in CO&I is represented in various ways, for example, leveraging future funding, documenting numbers of people with SCI served, or by launching new initiatives. In addition, 15 organizations were funded that had been selected for invitation as Sustainable Impact Projects to build on prior Project or Network Grants.

EDUCATION PORTFOLIOS

SCIMF: The preliminary goal for the SCIMF portfolio was to augment the number of physicians entering and remaining in the field of SCI. Since the portfolio's inception, there are over 30 SCIMF alumni. The group of Fellows who started their training in 2017 will increase this number by 10. The number of sites approved and fellows trained has seen sustained growth and new programs have come on-line. There are now 21 accredited sites that offer the SCI subspecialty. The Foundation has been told anecdotally that its support has contributed to growing institutional investment and interest in SCI medicine training.

NSP: While Neilsen scholarships are not needs-tested, students with SCI often have limited financial resources. To date, 89 students have received Neilsen Scholarships. This group includes 70 undergraduate students and 19 graduate students. Of these, 27 students have graduated and 57 scholarships are still active. Five scholarships, unfortunately, were terminated when students left school and/or became ineligible (usually due to medical issues). Of the graduates, two continued their education by moving from two-year to four-year schools and three enrolled in graduate programs.

A common thread throughout feedback from the funded institutions is the heightened awareness of the needs of students with disabilities on their campuses. The program also fosters a relationship and exchange of ideas between the institutions that receive NSP support that will be strategically nurtured in the coming years.