



August 27, 2018

Dr. Robert Finkelstein
Executive Secretary, NANS Council
finkelsr@ninds.nih.gov

Dear Dr. Finkelstein,

In a time in which patient engagement and consumer perspectives are becoming more prevalent in the regulatory process and commercialization pathway, an outstanding and unmet need is for these perspectives to be included and reflected throughout the scientific and discovery pipeline. The purpose of this letter is to invoke awareness among members of the NINDS and NANS Council regarding the lack of such translation with the spinal cord injury (SCI) community. Our organization, representing people living with SCI across North America, can only hope that you will share our plea with the entire NANS Council at the upcoming meeting on September 13, 2018.

The global incidence of traumatic SCI is estimated to be 23 cases per million or 179,312 new cases per year (Fitzharris et al., 2014) and, in the United States (US), the incidence is 54 cases per million or 17,700 new cases per year (NSCISC, 2018). The prevalence of people living with chronic paralysis, in the US, due to SCI ranges from 288,000 (NSCISC, 2018) to 1,462,220 (Armour et al., 2016). The reason for pointing out epidemiology is to highlight the fact that acute injuries only represent 1.2-6.1% of the SCI population in the US. It is critical to note that ALL acute injuries become chronic injuries at some ill-defined moment. *Accordingly, as our organization represents the North American population living with chronic SCI, we feel that it is only appropriate that funding for SCI be proportionally representative of the population.*

Funding for SCI research has not increased but has remained relatively steady over the last 12 years at approximately \$80M annually. Despite this investment, access to SCI care has decreased, economic burden has increased, and life expectancy has not improved. Total afforded days for both acute and rehabilitation care for SCI have decreased from 122 in the 1970s to 46 in 2017 (>60%). Concomitantly, lifetime cost of care has nearly doubled from \$2.9M in 2006 to \$4.7M in 2016 for a person living with high tetraplegia, for example. Moreover, the primary cause of death following SCI has not changed; it remains as pneumonia and septicemia. *Recognizing that SCI is a small proportion of the NIH orphan/rare/neglected disease portfolio, we believe that it is vital that funds are invested toward outcomes that can be translated widely to improve care, lower costs, and impact the quality of lives.*

While we recognize that the NINDS leadership and NANS Council do not have the ability to seek increases in the appropriation of dollars dedicated to SCI, we do ask that you recognize the need to allocate funding toward translational research. We are a small disease population that represent a large economic burden to federal and state budgets to keep us alive, healthy, and to retain a meaningful place in society. Translating and advancing emerging innovations in treatment for chronic injuries will have a significant impact towards reducing that economic burden.

We encourage the NINDS leadership and NANS Council to recognize the compelling request of the SCI population to provide suggestions for re-directing research funding within the guise of the NIH/NINDS mission. We further suggest engagement of the SCI community, including consumers and healthcare providers, throughout the entire research process. Recommended areas of greater emphasis include:

- Translational science,
- Consumer centricity and preference research,



- Implementation science,
- Cost-effectiveness research.

To impact the availability of breakthrough treatments, therapies, and care, it is important to include SCI community engagement throughout the translational pipeline as well as increase the weight of engagement as a funding criterion.

We beseech you to consider these points to redirect the annual \$80M appropriated to spinal cord injury research to make a meaningful impact in these key areas affecting the lives of people living with chronic spinal cord injury. Potential means to enact the aforementioned areas of greater emphasis could be when issuing funding opportunity announcements, in reviews of grant proposals, and recommendations for funding. These suggestions are in the spirit of improving the lives of people living with SCI within the communities that are served by the NIH mission.

Respectfully,

North American Spinal Cord Injury Consortium (NASCIC) Executive Council

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References

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Fitzharris M, Cripps RA, Lee BB. 2014. Estimating the global incidence of traumatic spinal cord injury. *Spinal Cord*. 52:117-122.

National Spinal Cord Injury Statistical Center, Facts and Figures at a Glance. Birmingham, AL: University of Alabama at Birmingham, 2018.

NIH-wide funding for SCI research (Dollars in Millions)

2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
\$80	\$80	\$87	\$78	\$79	\$94	\$80	\$82	\$71	\$77	\$81	\$76