

December 4th, 2018

Open letter to Dr. Lin Jakeman (N.I.H.) - email: lyn.jakeman@nih.gov

Copy for information: North America SCI Consortium (NASCI) - email: kxa304@case.edu (Kim Anderson) and info@nasciconsortium.org (NASCI contact)

Subject: Launching a Decade for Disruption in Spinal Cord Injury Research

Dear Dr. Jakeman,

I am extremely happy to learn of the NIH initiative to organize a meeting entitled "SCI 2020: Launching a Decade for Disruption in Spinal Cord Injury Research." As a paraplegic (since 2001), I am actively involved in various international projects to promote research into SCI recovery. Although I truly welcome the recognition for the need for Disruption, after reading the draft agenda, substantial doubts have plagued me.

1. **ACUTE injuries first on the Agenda? For us and with us?** On the research agenda the first day is solely dedicated to Acute and Sub-acute spinal cord injury. Even though the day includes a session whereby the SCI community will express their priorities, my opinion is that the prominent place given to Acute Research already sends a message. It neglects the fact that:

- All 2.5–3 million people affected by SCI worldwide are actually chronic. Unlike the complex and small Acute SCI population, Chronic SCI represents the only potentially attractive market for the Biotech Industry, as well as a multi-billion USD Healthcare/Welfare public saving opportunity
- Research on Acute Injury is less likely to lead to conclusive clinical trials and thus to actual therapies coming to market. As shown in a [2012 study](#), both high spontaneous recovery rate and complexity of enrolling patients after just hours after injury makes it scientifically very difficult (and quite questionable ethically!) to test a therapy at that early stage.

2. **CHRONIC SCI - E-stim and robotics: is this the best we can do?**

The second day Agenda implies that the 10-year-Disruption prospects for Chronic SCI are limited to, respectively, compensatory measures potentially improving quality of life and small functional improvement for a very small number of patients through robotics and E-stim.

Admittedly, E-stim has recently shown to enable a limited but so far unseen level of functional improvement for very few patients with incomplete injuries. For complete injuries, it has sometimes led to tiny but unexpected results.

Any progress is progress, but is this the breakthrough we are waiting for? Do we want to settle for that? Clearly, e-stim alone will never give the patients the kind of recovery they need, even though it will probably be part of the puzzle.

Disruption into recovery rather than just continue to make our paralysis more bearable.

We know that recovery from a Chronic SCI is likely to come in various gradual steps and will require combinations of various approaches. Surely then there is a need to seek answers/solutions for actual regeneration and/or bridging the chronically-lesioned cord?

Would it not be feasible and productive to discuss the facilitation of an environment; an eco-system and/or the setup of a flexible roadmap that will ease the development and testing of cutting-edge combination therapies (E-stim will probably be one of them) to gradually or partially bringing back various core functions to SCI patients?

I do not presume to have the answers; only these questions which are intended to be as constructive as possible.

As a European Citizen, I do welcome the tremendous role and support from the NIH with respect to SCI research. Spinal Cord Injury is a global condition and since the Draft Agenda is openly available on the internet, I have taken the liberty to raise these questions, and, hopefully, open the path to constructive discussion(s).

Thanking you for your attention and looking forward to your feedback.

With best regards.

Corinne Jeanmaire - SCI T10 since 2001

Founder and President of the [endParalysis foundation](#)

Member ("consumer" representative) of the [SciTrials.org](#) Expert Curation Committee

Member of the [ESCIF](#) (European SCI Federation) research group