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Raising awareness for spinal cord injury research

The last annual Wings for Life World Run, a charity event to increase public awareness for spinal cord injury research, was held on May 6, 2018. More than 100 000 people participated in 203 races that took place simultaneously in 66 countries. Participants “run for those who can’t”—hoping that one day, patients with spinal cord injury might be able to at least stand and walk.

In the USA alone, approximately 17 500 new cases of spinal cord injury occur each year, and the prevalence has been estimated to be between 245 000 and 345 000.¹

Recovering the capacity to walk remains a dream for most patients. Advances have taken place over the past decade, but the major challenge in spinal cord injury research is the translation of findings from basic science to the clinic.² This translation has been hindered by the compartmentalisation of research approaches (basic vs clinical research) and clinical care (acute vs chronic care), involving an array of disciplines ranging from trauma-surgery, neurosurgery, intensive care and anaesthesiology, neurology, and rehabilitative medicine. Translational research in spinal cord injury holds promise, but so far has not achieved any clinical success (ie, no treatment has been approved yet, other than rehabilitation), and needs to move forward in an area often perceived as being fraught with insurmountable hurdles. In this context, and given that the pharmaceutical industry does not consider this field profitable, foundations specifically focused on spinal cord injury have a fundamental

role in advancing the prospects of success. Some of these non-governmental organisations are the International Spinal Research Trust, the Craig H Neilsen Foundation, the International Foundation for Research in Paraplegia, the Christopher and Dana Reeve Foundation, the Rick Hansen Institute, and the Wings for Life Spinal Cord Research Foundation.

Translational spinal cord injury research requires tailored funding approaches for which collaborative partnerships between academic and industry are fundamental. Examples that illustrate such partnerships include ongoing clinical trials probing the blockade of myelin neurite outgrowth inhibitors^{3,4} (such as Nogo-Receptor Trap^{3,5} [AxeR 204]) or neutralising antibody approaches (ATI355, Nogo Inhibition in Spinal Cord Injury [NISC], which follows on a first in man trial [NCT00406016])^{3,6}. Encouraging findings from epidural stimulation⁷ in rodents and humans signal a need for investigating whether improvements in selected muscular function indeed translate into better activities of daily activity.

This investigation is among the aims of the STIMO trial (NCT02936453, Epidural Electrical Simulation [EES] with Robot-assisted Rehabilitation in Patients with Spinal Cord Injury). All three trials are supported by the “Accelerated Translational Program (ATP)” of the Wings for Life Spinal Cord Research Foundation. An independent observational follow-up study of prematurely terminated, industry-initiated stem-cell transplantation trials has also been integrated into the ATP portfolio (INSTrUCT-SCI, NCT03069404)⁸, thus adding to the clinical translation chain.

By supporting these cutting-edge studies, funders leave the comfort zone of orthodox project funding and take responsibility for a steeper learning curve of relevance for the international spinal cord injury research community. The Wings for Life World Run (figure) also raises awareness simultaneously across many countries, where healthy and individuals with spinal cord injury share a heartfelt desire for cure and publicly proclaim their support to go any extra miles for progress.

For more on the **Wings for Life World Run** see <http://www.wingsforlifeworldrun.com/us/en/>



Figure: Creating awareness and resources for relatively rare diseases such as spinal cord injury by modern crowd-based approaches, such as the Wings for Life World Run

Despite experimental spinal cord injury being reasonably funded as a basic science entity, sparse funding for translational research and early-phase clinical trials poses a rate-limiting hurdle. This bottleneck has been further narrowed by low financial incentives for pharmaceutical industry to become involved given a comparatively small market size. Wings for Life is an international non-governmental organisation that created the World Run as a novel and inclusive running-event, allowing recreational participants and professional athletes to join the same event all over the world.

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The Swiss Federation of Clinical Neuro-Societies and Young Clinical Neuroscientists Network

The Swiss Federation of Clinical Neuro-Societies (SFCNS) was founded in 2009 and currently unites 14 clinical neuroscience associations. Its primary goals are the promotion of clinical, scientific, and educational interdisciplinary collaboration, as well as to establish a united voice towards other organisations, policy makers, and society.¹ The SFCNS has received a mandate from the Swiss public health authorities to coordinate the implementation of highly specialised medicine in clinical neuroscience. Similar to the German *Neurowoche*,² the

SFCNS organises an interdisciplinary congress every 3 years (the next taking place in Lausanne, Switzerland, on Oct 23–25, 2019). This congress and our annual SFCNS Summer School promote education and discussion in clinical neuroscience. Last year, the SFCNS launched the journal *Clinical and Translational Neuroscience*, as successor of the *Swiss Archives of Neurology and Psychiatry*, founded by Constantin von Monakow about a century ago.³

In 2016, the SFCNS endorsed the creation of the Young Clinical Neuroscientists Network (YouClin). The need and advantages of encouraging and engaging junior minds are increasingly recognised.⁴ The mission of YouClin includes to represent the interests of junior clinicians with respect to current issues and future development of Swiss clinical neuroscience and the promotion of interdisciplinary training. These goals are enacted by a steering committee composed of 14 delegates at an intermediate career stage from across the country, reflecting the clinical neuroscience specialties represented within the SFCNS. Other aims are the integration of care providers and researchers from non-medical disciplines, and the rapprochement of neurology and psychiatry.⁵ YouClin will also elaborate on strategies for equal gender opportunities.

To the best of our knowledge, the SFCNS appears to be the only national association of professionals from different clinical neuroscience disciplines in Europe. Development of the SFCNS might have been favoured by the circumscribed Swiss clinical neuroscience landscape, where most colleagues know each other well, despite working in three different linguistic zones, but certainly also by a strong tradition of dialogue and consensus. This small world striving for excellence and its enthusiasm towards innovative biomedical research, regenerative cell therapy, genomics, and neurotechnology provide an ideal

environment for synergy and progress in clinical neuroscience.

At a global level, interdisciplinary cooperation has already become indispensable in the management of patients with stroke, CNS tumours, dementia, or sleep disorders.⁶ Functional restoration and neuroprosthetics represent imminent challenges for clinical neuroscience, requiring specific skills in translational research, neuroradiology, and intensive care. State-of-the-art clinical neuroscience will also depend on the implementation of integrative clinical pathways from the emergency room to neurorehabilitation, for patients of different ages. These challenges require united and determined action.

We declare no competing interests. CB served as founding and first president of the SFCNS from 2009 to 2013, AV was the second SFCNS president from 2013 to 2017, KS is the third and current SFCNS president and AAS serves as founding YouClin chair. We thank Renaud Du Pasquier and Philippe Ryvlin for valuable discussion. AAS reports fellowships from the Baasch-Medicus Foundation and the Leenaards Foundation.

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