

## Grant funds spinal cord injury study in four countries

A recently awarded research grant will fund a study to assess the quality-of-life (QoL) perceptions among spinal cord injury (SCI) patients across four continents.

Funded by the Craig H. Neilsen Foundation, the project is being led by a Professor of Physical Medicine and Rehabilitation, Denise G. Tate, PhD, and brings together an international team of SCI researchers from the United States, Brazil, Australia, and the Netherlands. Collecting standardized QoL information from SCI patients can guide future therapeutic approaches. It can also help individual patients set recovery goals and expectations, said Tate, who has led international collaborations in the field for years.

"Hospitals around the world assess these injuries differently. Doctors ask different questions. We think there is value in asking the same questions across the board, regardless of country or culture," Tate said. "But if we're all using these same questions, does this ruler actually measure the same thing for patients in the United States as it does in Europe, Australia or Brazil?"

The "ruler" in question is a previously agreed upon universal data set that Tate helped create a few years ago with support from the International Spinal Cord Society. The Spinal Cord Injury Quality of Life Basic Data Set (SCI-QoLBDS) consists of three questions designed to measure patient satisfaction with life overall, satisfaction with physical health, and satisfaction with mental health. The Neilsen grant will fund a study to conduct a cross-cultural validation of the SCI-QoLBDS tool.

Spinal cord injuries, whether caused by disease like cancer or by traumatic injuries, impact up to half a million people each year, according to the World Health Organization. The injuries can be catastrophic, causing partial or complete paralysis; complicated, sometimes ushering in a myriad of related chronic illnesses; and costly, as patients endure extensive therapy and rehabilitation. And to what end?

"Quality of life – and the question of how our various medical advances and discoveries actually improve it – is very important to our patients and their clinical providers but it is also very subjective," Tate said. "One patient may prioritize walking again as their main life goal after SCI. Another may be more focused on restoring bladder or bowel control. If we want to compare results across the board for research purposes or for clinical trials, we should be focused on common elements that can guide us."

In search of these common elements for assessment, the International Spinal Cord Society (ISCoS) and the American Spinal Injury Association (ASIA) developed the International Spinal Cord Injury Standards and Datasets. These are now part of the NIH/NINDS initiative for development of common data elements to be used by NIH-funded researchers worldwide for a number of chronic conditions including SCI.

Tate's study will include a prospective international validation of the SCI-QoLBDS across five research sites: Michigan Medicine; Craig Hospital in Denver; Caulfield Hospital in Melbourne, Australia; University Medical Center Utrecht, in the Netherlands; and the Hospital das Clinicas at the University of Sao Paulo Medical School, Michigan Medicine's primary partner school in Brazil. The study will focus on 560 SCI subjects including outpatients and inpatients from these five hospitals. The study will also include qualitative interviews with a number of patients from each site to better understand their views on quality of life after SCI and lend context to their individual perspectives. To accomplish those aims, the Neilsen Foundation, which focuses its efforts on spinal cord injuries, awarded \$400,000 for this project for three years. The group meets monthly via video conferencing calls to discuss progress and priorities.

"Everyone on the team is delighted. This foundation doesn't fund a whole lot internationally, so we feel very fortunate that they decided our project was worthwhile," Tate said. "In the long run, we hope to ensure that most hospitals and clinics worldwide are using these QoL datasets. Better research means being able to provide clinical services to our patients that are most meaningful to them and which can improve their engagement in treatment and overall QoL."



Dr. Tate

