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Institute of Spinal Cord Injury, Iceland

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His Excellency, Mr Ban Ki Moon United Nations Secretary-General UN Headquarters First Avenue at 46th Street New York, NY 10017 USA

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A year ago, I read an article that you had written in a newspaper in Iceland. In the article, you encouraged grassroots associations and others to come up with ideas as to what the 2015 Development Goals should be. This gave us at ISCI the idea to propose that finding treatments of nervous system injuries should be made a Development Goal.

Icelandic members of parliament subsequently submitted a proposal for a parliamentary resolution (see attachment 1) to the Althingi for actions toward the cure of spinal cord injury. The resolution was passed in May 2014 with 58 unanimous votes; 5 members were absent. The resolution (see attachment 2) provides for, among other things, the authorities in Iceland to seek the support of other nations in ensuring that one of the Development Goals set by the UN next year is directed at finding a cure for neurological diseases and injuries. As there has been considerable unrest in Icelandic politics recently and because the fact that bureaucracy is always rather slow, I am afraid that this proposal will not be discussed at the UN in time before the 2015 Development Goals are set, hence the reason for my letter.

I would like to ask you to please use your influence to ensure that "increased understanding of the workings of the nervous system" is made one of the Development Goals the UN sets next year. The reasons for my request are as follows: hundreds of millions in the world suffer with disabilities due to incurable diseases of or injuries to the nervous system, such as MS, MND, Alzheimer's, Parkinson's, ADHD, mental illness, epilepsy, cerebral palsy, Tourette syndrome, tumours in the nervous system and injuries such as spinal cord and brain damage, shoulder dystocia and more.

The reason why it is so hard to provide cures is that medical science does not have full understanding of the workings of the nervous system. This is why the nations of the world need to launch a campaign for better understanding of the way the nervous system does work and thereby help the international neurological sciences community that desperately needs the attention and help of the international community. The UN is the spokesperson for the world's nations, and this is why I believe that the UN is ideal for launching the campaign, The campaign would benefit all mankind. First, we need to understand, and then we can start curing.

The nervous system is one of the most difficult fields in medicine and the system where we have achieved the least success. It was therefore a distinct pleasure when the Nobel Prize for medicine in 2014 was awarded for a neurology-related discovery. The Nobel Committee thereby drew attention to the nervous system and the necessity of achieving progress in this field. It would, therefore, be an extremely welcome move if the UN would take over from where the Nobel Committee left off and carry the matter forward within the UN.

I am an O.R. nurse, a married mother of three and a grandmother. Twenty-five years ago, my daughter was in a car accident and suffered multiple injuries, including spinal cord injury. She was paralysed from the waist down. Since then, I have been closely monitoring the manner in which medical science is progressing at finding a cure for spinal cord injury as well as other injuries and illnesses involving the nervous system.

In 2007, I established the grassroots association the Institute of Spinal Cord Injury, Iceland www.isci.is. The Institute works on actively involving the Icelandic authorities on behalf of finding cures and improving treatment of injuries to the nervous system and is wholly based on the selfless and voluntary work of numerous people. Since ISCI was established, the following has been achieved:

In 2011, the Government of Iceland agreed to take on spinal cord injury as a side project to the UN Decade of Action for Road Safety, as nearly half of those who suffer injuries to the spinal cord and become paralysed do so in traffic accidents. Greta Gunnarsdóttir, Iceland's ambassador at the UN, subsequently announced the Government's decision at a meeting at the UN. That same year, Ólafur Ragnar Grímsson, the President of Iceland, presented the decision to Jean Todt, the President of FIA, and Berglind Ásgeirsdóttir, Iceland's Ambassador in France presented the matter to Gerard Saillant, the Vice-President of FIA.

Due to the excellent decision of the Icelandic authorities in taking on spinal cord injury as a side project to the Decade of Action, the Icelandic Althingi (parliament) submitted a proposal on spinal cord injury at the meeting of the Nordic Council in 2011, and in 2013, the Ministerial Committee of the Nordic Council agreed to make the search for the cure of spinal cord injury one of its priorities. This work has already begun under the leadership of the St. Olav Hospital in Norway.

In 2014, the Icelandic Ministry of Health held a conference with specialists in spinal cord injury from all the Nordic countries, the UK and the US as well as representatives from FIA. The meeting was chaired by Kristjan Tomas Ragnarsson, professor and Head Physician at Mount Sinai Hospital in New York. The role of the experts was to plan, on behalf of the Ministerial Committee of the Nordic Council, the manner in which the Nordic countries could best achieve better results in the treatment and cure of spinal cord injury.

Mr Ban Ki Moon

All that I have discussed above as regards the collaboration between the grassroots association ISCI and the Icelandic authorities can be traced to the UN's launch of the UN Decade of Action for Road Safety. A long and successful journey is often the result of a single, small step forward. We have seen how many changes for the better have resulted in making illiteracy, gender equality and more into Development Goals. This is why I am humbly asking you to give the nervous system issues the same chance.

With respect and friendship, Audur Gudjónsdóttir (sign)

Chairman of the Board of ISCI

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Attachments:

- 1. Proposal for a Parliamentary Resolution at the Legislative Session, 2013-2014.
- 2. Parliamentary Resolution Passed by the Althingi on 16 May 2014.

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