

A new path towards a cure



Institution of
Spinal Cord Injury





Auður Guðjónsdóttir

The Institution of Spinal Cord Injury, Iceland (ISCI) was founded December 2007 at the initiative of the Icelandic O.R. nurse **Auður Guðjónsdóttir**. The mother of a woman who sustained spinal cord injury (SCI) in her teens, Ms. Guðjónsdóttir has for years campaigned strongly for efforts to break the impasse in which SCI treatment has been for the past half-century. This includes cata-

lysing the Icelandic government's use of its international influence to promote progress in SCI research and treatment – one of the most challenging areas of modern medical science. Ms. Guðjónsdóttir's perseverance and vocal advocacy efforts have raised Icelandic awareness of the need to improve SCI research and treatment. The Icelandic government, businesses and individuals have now joined forces to launch the ISCI in order to realise her vision.

The ISCI's founders include the Icelandic Ministry of Health, the investment companies FL Group and Exista and the Municipality of Seltjarnarnes, in addition to Ms. Guðjónsdóttir herself and her daughter Hrafnhildur Thoroddsen.

The ISCI Board of Directors:

Auður Guðjónsdóttir,

Chairman of the Board

Hanna Katrín Fridriksson,

Special Adviser to the Minister for Health

Júlíus Thorfinnsson,

Head of Corporate Communications at FL Group

at FL Group

Sigurður Valtýsson,

CEO of Exista

Jónmundur Guðmarsson,

Mayor of Seltjarnarnes

The organisation's patron is former President of Iceland Ms. **Vigdís Finnbogadóttir**. The special adviser is Dr. **Harry S. Goldsmith**, Professor of Surgery and pioneer in procedures to treat SCI. The ISCI's Executive Director is **Berglind Skúladóttir Sigurz**.

The ISCI's mission is to be a leading advocate of advances in the treatment of SCI and to work towards cures of such injuries through every possible means.

The institution strives to further the principle established by the World Health Organisation (WHO) that all people have the right to the best possible health. In its search for cures to spinal cord injury, the ISCI places focus on:

- ❖ Raising global awareness of the gravity of SCI as a health problem and inviting ideas for improving SCI treatment.
- ❖ Raising funds internationally for medical, scientific and other activities demonstrably developing innovative SCI treatment.
- ❖ Developing and continually updating an international databank storing the most important information on innovations in SCI treatment in the world's main languages (www.sci.is).
- ❖ Holding meetings with innovators in function-restoring therapies and/or procedures and awarding recognition for pioneering excellence in the SCI field.

Background

2001 An international SCI conference was held in Iceland under the auspices of the Icelandic Ministry of Health and WHO. The key aim was to determine the current status of SCI treatments around the world. 25 pioneers in SCI therapies and/or procedures from various countries attended the event. After the conference, the then WHO Director-General, Gro Harlem Brundtland, asked the Icelandic Minister for Health to establish an SCI database in Iceland.

2002 Icelandic MPs proposed a concerted international effort to improve SCI therapies and procedures at a meeting of the Council of Europe.

2005 The film documentary **You Will Never Walk Again** was produced to raise global awareness of SCI. The film has been translated into numerous languages and broadcast by TV channels including the Icelandic National Broadcasting Service, Danmarks Radio (which broadcast the film in the Nordic countries), Deutsche Welle (Germany's international broadcaster, which showed the

film in German and English in a large number of countries), the Catholic Church's TV channel in Venezuela (which broadcast the film in Spanish to most countries in South and Central America) and the British channel Reality TV (which showed the film in 123 countries). In addition, the documentary was televised in Israel, Jamaica, Montenegro, Pakistan, Ecuador and Hong Kong, the last of which showed it in Chinese throughout Far Asia. The film has been broadcast under a range of names, including *Every Step you Make*, *The Miracle* and *Hope Never Dies*. The Icelandic Foreign Ministry, embassies and consuls assisted with the film's distribution.

The Icelandic Ministry of Health launched the **SCI Database** (www.sci.is and www.sci-therapies.info), an international informational resource for innovative SCI treatment. The Database provides information in English, Spanish, Arabic and Chinese, with translations into Russian in progress.

The database's Director is Dr. Laurance Johnston, PhD, MBA, whose responsibilities include compilation of all information entered into the database. The five translators of the contents are all doctors or scientists, and hail from Cuba, Mexico, Israel, China and Russia. The database has entered into an informal co-operation with Paralyzed Veterans of America (PVA), which is currently working on the publication of its contents in book form. Currently consisting of 220 pages, the database has been used by doctors, scientists and disabled people in 169 countries since its inception.

2006 Three members of Iceland's parliament together with Ambassador Hördur H. Bjarnason and Audur Gudjónsdóttir gave a presentation to the European Council on SCI issues and what Iceland has to offer in worldwide SCI advocacy efforts.

2007 Desember 11th the Institution of Spinal Cord Injury was founded.



Iceland as a leading advocate of progress in the SCI field

At the ISCI's opening ceremony, Iceland's Minister for Health, Gudlaugur Thór Thórdarson, remarked that by establishing the institution Iceland could be opening a path for other Western countries to champion specific health causes – by raising and channelling funds to defined research areas and information dissemination at an international level. On the same occasion, former President of Iceland Ms. Vigdís Finnbogadóttir said that a well educated and prosperous nation advancing the cause of SCI patients internationally and lobbying for progress in the field could benefit the global community enormously.

The Icelandic government's 2007 policy statement identifies human rights and development co-operation as among the new key areas of the country's foreign policy. The Icelandic health authorities' decision to promote progress in the SCI field globally marks the first recognition by a sovereign country of discrimination against those suffering from illnesses and disabilities whose

cure the free market does not profit from developing. The decision is also in conformity with the Icelandic government's policy statement on human rights and the UN Conventions on the rights of persons with disabilities and of other minorities.

In addition, the Icelandic health authorities have thus taken the initiative to form a new type of development co-operation in which affluent nations use their influence to solve global health problems left unaddressed although progress has been made in other areas of medical care.

SCI facts

An estimated 3.5 to 4.5 million people have sustained SCI in accidents worldwide. In Iceland there are about 100 spinal-cord injured people.

According to conservative estimates, people with SCI number approximately:
 250,000–300,000 in the United States
 400,000–450,000 in Europe
 500,000–550,000 in China

- Approximately 44–47% of SCI cases are incurred in traffic accidents
- SCI is also sustained in sports, wars and criminal activities as well as owing to illness and occupational accidents
- Young men comprise 80% of those incurring SCI in accidents
- The average age of those sustaining SCI is about 20 years

As a result of advances in medical science, an ever-increasing percentage of those injured in major accidents survive, which means that an ever-growing number of people live with SCI. It is also worth noting that the average

life expectancy of SCI patients is nearly as long as that of the general population.

Sustaining a spine fracture that leads to SCI not only confines the person in question to a wheelchair. The region of the body below the injury is paralysed or its functions are seriously impaired, e.g. the limbs, the inner organs, such as the bladder and colon, and the reproductive organs. Respiratory function diminishes or stops altogether in people with severe paralysis, and sensory function – the body's warning system – is lost. Therefore, SCI is one of the most devastating types of injuries a person can sustain, inflicting as yet incurable damage.

Key reasons for slow progress in the search for cures to SCI:

- Restoring function of the central nervous system is challenging
- Lack of funding
- Language barriers and prejudice between geographic regions

SCI therapy research

In many countries, the past decade has seen increased awareness of experimental research into function-restoring therapies for people with chronic SCI, i.e. who have had SCI for years. Most of these therapies deliver some, but never sufficient, benefits. Nevertheless, the research has been very informative for scientists.

Currently, there are 25 research projects in progress exploring avenues of using cells for SCI treatment. The three most-used types of cells in such research are olfactory cells, stem cells and Schwann cells. In other research, peripheral nerves are used to bypass the SCI injury site, and in some cases highly vascularised tissue (Omentum) from the abdominal area is surgically transposed to the injury site. In addition, pharmaceutical, oxygen, electrolysis, laser and cooling treatment are applied to chronic and new onset of SCI, to name a few examples.

Dr. Harry Goldsmith, the American surgeon and pioneer in procedures to treat SCI, has over the past few years published articles in eminent medical journals, in which he encourages changes in SCI treatment. In his view, SCI requires emergency treatment and a surgeon should be called immediately after the onset of SCI in order to alleviate pressure on the spinal cord. The removal of bones from the vertebra to assuage such pressure has been applied for decades to treat SCI immediately after onset. Dr. Goldsmith finds this procedure insufficient and that an incision of the dura mater, the protective membrane covering the spinal cord and brain, is needed to alleviate all pressure on the spinal cord and so that direct treatment of the spinal cord is possible.

Expert panels and priority projects

The ISCI is committed to forging partnerships with experts in as many countries as possible, including surgeons, neurologists, physiatrists and basic scientists.

The assessment of grant applications to the ISCI will be based on the expert opinion of the most eminent specialists in each field. Dr. Laurance Johnston, who is Director of the SCI Database, will head the panel of experts in question, while the ISCI Board makes the final decision on all grants awards.

Doctors, scientists and others with the most feasible ideas for research into SCI treatment will be given priority upon approval by the ethics committees of the respective institutions where the research is to take place.

Change of policy

Notwithstanding impressive advances in various fields of medical science in the past half-century, SCI treatments have seen little progress. The demand for rehabilitation techniques for the large number of injured soldiers returning from World War II led to the rehabilitative approach still current – to train people with disabilities towards improved function and self-reliance in a wheelchair. This rehabilitative philosophy has done much good and increased the independence of people with disabilities – but it is not a cure.

A major obstacle to progress in the SCI field is that businesses have seen little profit potential in developing cures of spinal cord injuries – unlike in many other medical fields. This results in insufficient investment in SCI research and experimental treatments for adequate progress to be made. Clearly, new ways of delivering real results are needed.

Why Iceland

Now the people of Iceland have decided to extend special attention to the matters of spinal cord injury with focus on change in treatment and the potential of cure.

Iceland is excellently equipped to contribute to and promote international efforts in the SCI field. The country boasts one of the world's most advanced health care systems as well as high levels of education and technology adoption. It is an independent and affluent country with the capabilities to effectively promote participation in SCI-related activities by other nations and international organisations.

