EDITOR'S PAGE

Spinal Cord is 50 years young in 2012

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Dear *Spinal Cord* reader,

I am happy to introduce the first issue of the 50th *Spinal Cord* year. To celebrate this 'Golden' event, I have included a list of highly valuable manuscripts. I looked at the 25th 'Silver' jubilee issue and found that topics studied then are still mostly the same as today. If you look at the contents page you will find several of the major topics in Spinal Cord Medicine highlighted as well as interesting new information. We are confident that also in her 50th year *Spinal Cord* will receive many submissions that help to increase our knowledge and guide us towards an ever improving comprehensive care system.

I invited F Biering-Sorensen to write a contribution to this page on a process in which he has been very instrumental: establishing International Spinal Cord Injury (SCI) Data Sets.

This started at a meeting prior to the 2002 congress of ISCoS and ASIA in Vancouver. Collecting SCI Data Sets will facilitate comparisons regarding injuries, treatments, and outcomes between patients, centers and countries. The International SCI Core Data Set was developed to standardize the collection and reporting of a minimal amount of information necessary to evaluate and compare results of published studies, for example, including information on gender and age of the study population at the time of injury, the current age of the study population, the length of elapsed time after injury when data are being collected, the causes of spinal cord lesion, and the neurologic status of the study population. Data from the Core Data Set are recommended, as a descriptive table in most publications including individuals with SCI. International SCI Basic Data Sets are the minimal number of data elements, which should be collected in daily clinical practice for a particular topic, to be the initial checklist for the clinician. Therefore the various Basic Data Sets can be the basis for a structured record in centers worldwide caring for individuals with SCI. In addition these Basic SCI Data Set elements should be included in future SCI research for the relevant topics. International SCI Basic Data Sets are available or in development within the following areas: Spinal Column Injury; Non-traumatic Spinal Cord Lesions; Lower Urinary Tract Function; Urinary Tract Infection; Urodynamics, Urinary tract imaging; Bowel Function; Female Sexual and Reproductive Function; Male Sexual Function; Cardiovascular Function; Pulmonary Function; Endocrine and Metabolic Function; Skin and Thermoregulation Function; Musculoskeletal Function; Pain; Activity and Participation; and Quality of Life. All finished data sets are available at ISCoS web site (www.iscos.org.uk). For each data set a syllabus including definitions, data collection form, and instructions on how to collect each data item are developed.

International SCI Extended Data Sets are more detailed data sets, which may be used as optional for a topic, but may be recommended for specific research studies within the particular area.

All International SCI Data Sets are through an approval process including review by the Executive Committee of the International SCI Standards and Data Sets, ISCoS Scientific Committee, ASIA Board, relevant and interested (International) Organizations and Societies and persons. In addition the data sets are on the web sites of ISCoS and ASIA for review at least one month. Furthermore, all International SCI Data Sets are scrutinised by the National Institute of Neurological Disorders and Stroke (NINDS), the National Institutes of Health (NIH), the Common Data Element (CDE) and the project working group to create variable names for each data element in the data sets and make a suggested database structure for each data set. The database structure allows data to be stored in a uniform way in databases to promote sharing data from different studies (www.iscos.org.uk). Finally have recommendations for translation and reliability testing of International SCI Data Sets been developed.

It is logical that the more the data sets will be used the bigger and more complete the overall picture will become.