

President's Report 2013 – 2014

This report covers the period from the last ESCIF Congress and Assembly of Delegates – June 2013 to the present – and outlines what has been done and achieved since the last meeting of ESCIF delegates.

Introduction

Despite the fact that the Executive board has been plagued by injury this past year (between us the five SCI members of the board have managed to break a leg, fracture a wrist, and dislocate and fracture a hip!), ESCIF has still been very active! In addition to our own ESCIF-initiated projects, we have been very involved in projects initiated by ISCoS and other stakeholders in the field of SCI.

Assembly of Delegates 2013

We were delighted to welcome three new members to ESCIF. From Denmark, Niels Balle introduced the organisation PTU (an organisation primarily for polio and traffic accident survivors) in his role as chairman of the SCI committee. From the Czech Republic, David Ruzicka, told the Assembly about the activities of Czepa – an organisation for people living with spinal cord injuries based in the country's capital Prague. Finally, from Spain, Esther Peris (who has previously represented the Spanish member organisation ASPAYM) and Natacha Leon provided an interesting insight into the activities of Fundación Lesionado Medular.

ESCIF Congress 2013 in Nottwil, Switzerland

The theme of the Congress this year was *Living with SCI: communication, information and learning* and the programme included presentations and workshop discussions on a range of research projects and online resources focussing on SCI.

The first session of the Congress was led by Professor Fin Biering-Sørensen from Denmark who introduced the web-based learning resource developed by the International Spinal Cord Society (ISCoS). ESCIF's President, Jane Horsewell, considered the relevance of elearnsoci.org for SCI consumers and the possibilities to develop the resource further – specifically with consumers in mind.

The next sessions were devoted to projects from Swiss Paraplegic Research: the development of an interactive website for people living with spinal cord injury *Paraforum*, which was followed by a workshop to discuss the ideas behind the development of the site; then the first results of the Swiss cohort study *SwiSCI*. ESCIF would like to thank Sara Rubinelli and Mirjam Brach (and colleagues) for their interesting contributions on *Paraforum*. Thanks too to Martin Brinkhof for giving insights into the ambitious *SwiSCI* cohort study.

Two of ESCIF's regular sponsors had been invited to make the next presentations. Kevin Schultes, a member of the Board of Trustees of the Manfred Sauer Foundation, introduced an online information service *derQuerschnitt.de* that had been launched by the Foundation earlier that week. Søren Bremer, from the Global Marketing department of Coloplast, presented two initiatives from the company; *Innovationbyyou.com* – a website

where consumers can ask questions about and contribute ideas to the development of medical devices, including those for bladder and bowel management – and the app *Wheelmate* which directs the user to the nearest disabled parking spaces and accessible toilets.

The final session of the day was a fascinating and optimistic presentation by Professor Dr Martin Schwab from Zürich on nerve fibre growth and regeneration in the injured spinal cord.

ESCIF would like to thank our Swiss hosts for their hospitality. Special thanks should go to Urs Styger and Gabriela Bucher for all their hard work in arranging this very successful event!

ESCIF Executive meetings

The Executive has held two meetings “in person” in the course of the year: the first at Manfred Sauer Foundation in Lobbach in September, the second in Paris at the end of March. As usual, a meeting has been held in the days running up to the present Congress. In addition, the Executive has held a number of telephone meetings throughout the year and is in regular contact via email.

Preparation for the ESCIF Congress 2014

Once the Congress theme for this year was decided upon, Winnifred de Moes (ESCIF Vice President) took on the role of co-ordinator between the Executive and the organising committee in the host organisation the Dutch SCI association. As Dwarslaesie Organisatie Nederland hosted the Congress in 2011 – the organising committee has been very self-sufficient, drawing on its experience from the last time! However “professional” the hosts may be, we are all aware of the huge amount of work that goes into the arrangement of this annual event. The Executive is extremely grateful that Winnifred and our hosts in the Netherlands were willing to take on the task for a second time.

Communication with members: ESCIF website and newsletter

Once again this year we have tried to post regular updates on the ESCIF website but we still lack input from member organisations. The Executive would like to encourage all member organisations to use the website to announce and report on events and initiatives in their country, to find collaborators for projects and activities, and to post updates on ongoing projects. Please send your information to secretary@escif.org or to president@escif.org.

The newsletter has also been circulated regularly. Again we would be very pleased to receive input from ESCIF members and other “colleagues”. If you would like an item to be included in the newsletter, please send it to secretary@escif.org or to president@escif.org.

ISCoS 2013 in Istanbul 28 – 30 October 2013

ESCIF and its work were, once again, well-represented at the ISCoS meeting. Our two projects on multi-resistant bacteria and SCI, and on lifelong care and monitoring of SCI were both presented as posters.

Following on from the success of the workshop at the 2012 meeting in London, we were also asked to arrange a consumer workshop as part of the scientific programme of the 2013 meeting. Using the earlier ESCIF work on policy and best practice issues as a starting point, the workshop was entitled *Organisation of SCI treatment, rehabilitation and follow-up: are ideas and models developed in high-resource countries relevant to medium and low-resource countries?*

In addition to presentations from Ramazan Bas, President of the Turkish SCI organisation, and from ESCIF, Jane Horsewell also moderated a panel discussion with representatives from Turkey, India, US and Brazil.

ESCIF was also involved in a number of collaborative workshops at the ISCoS meeting. On behalf the ISCoS Quality of Life (QoL) Special Interest Group, founded at the ISCoS meeting in 2012, Jane arranged and chaired a workshop concerned with cross-cultural definitions of QoL among people living with SCI. Marcel Post (Netherlands), Denise Tate (US), Divya Parashar (India) and Szilvia Geyh (Switzerland) presented recent research in the field. They were joined by Kim Andersen (US), Anke Scheel (UK) and Lucy Robinson (UK) to discuss whether it is possible (or desirable) to work towards a common definition of Quality of Life.

During the ILIAS workshop on the first results of the study into labour market participation of persons with SCI, Marcel Post and Jan Reinhardt presented the results of the investigation in Switzerland, the Netherlands, Norway and Denmark. Jane held a presentation explaining ESCIFs role in the study and, more generally, on the role of paid work in the successful integration of people with SCI.

The workshop ended with a panel discussion chaired by Marcel Post. The panel consisted of Fin Biering-Sørensen (Denmark), Mirjam Brach (Switzerland) and Winnifred de Moes (ESCIF's Vice President, the Netherlands).

On the last afternoon of the meeting, Jane was an invited speaker at a session entitled *International Collaborations: The Way of the Future* which was chaired by Doug Brown (Australia) who is the current President of ISCoS. The purpose of the workshop was to identify barriers and enablers to setting up international research collaborations, international multi-centre clinical trials etc. Jane's presentation proposed that the involvement of SCI consumers in the research and trial design teams could help remove some of the barriers to participation. This workshop formed the starting point for a survey into SCI consumer attitudes towards participation in clinical trials. Led by Kim Andersen, a researcher working at the Miami Project who has a spinal cord injury, the project has been launched worldwide via contacts in the Global SCI Consumer network. If you haven't already responded to the questionnaire, you can do so until 31 July via the ESCIF homepage.

We are grateful to both Coloplast and to Hollister Inc. whose support made it possible for us to attend the meeting and present our projects.

Global SCI Consumer Network meeting

Once again, this was held as an "off-programme" meeting where Global Network ambassadors and others – from Asia, Australia, Europe, North America and Latin America – met to give updates on progress in their region and to discuss plans for the future.

Shivjeet Singh Raghav from India told us about the new groups and organisations that have been established under the umbrella of the ASCoN Consumer Network in Asia, while Bruno Landgraf das Neves from Brazil told us of the efforts of Federico Montero, the GN ambassador from Costa Rica, to establish a network of SCI consumers in Latin America (Federico was unable to attend himself). There are plans for future activities to consolidate and extend the contacts among SCI consumer groups in Latin America.

Peter Perry (from Australia) presented information about Spinal Cord Injuries Australia and SCI consumer initiatives in Australia. The National Disability Strategy and the National Disability Insurance Scheme are of great importance to the national SCI strategy in Australia

and could be an example to other countries. SIA Australia is in close contact with the ASCoN Consumer Network.

After the presentations, Kim Anderson (from the US) chaired the discussion together with Frans Penninx (Netherlands). More details can be found on www.globalsci.net.

International Perspectives on Spinal Cord Injury (IPSCI)

Although the long-awaited report was discussed in a workshop at the ISCoS conference, the official launch did not take place until early December. Jane was invited to speak at the launch – as was Jean-Jacques Wyndaele, President Elect of ISCoS. The launch took place at the World Health Organisation headquarters in Geneva.

Swiss Paraplegic Research kindly forwarded copies of the report to all ESCIF member organisations earlier this year. The report can be downloaded from the ESCIF website.

Information gathering on MRSA

The project on practices used to address MRSA (Methicillin-resistant Staphylococcus aureus) and multi-resistant bacteria in the bowel among people with spinal cord injury was completed this spring – following some delays caused by extensions of the response deadline.

In addition to presenting the preliminary results of the survey at NoSCoS in 2013 and as a poster at the ISCoS meeting, Gunilla Århén, the project leader, has written a full report of the final results.

The report was circulated to all member organisations in June this year and can also be read on the ESCIF website.

Project on lifelong care, monitoring and management of SCI

The working group, consisting of Antti Dahlberg (Finland), Frans Penninx (Netherlands), Colm Whooley (Ireland) and Jane Horsewell, has concentrated upon the significance of regular follow-up for health and the report will include a list of recommendations on the structure, content and frequency of follow-up consultations.

Preliminary conclusions (focusing particularly upon the situation in Finland that is currently working to establish standardised follow-up) were presented by Antti at the NoSCoS meeting in Helsinki last year. The work was also presented as a poster at ISCoS 2013.

The publication of the final report has been seriously delayed by Jane's injury but the results will be presented by Colm Whooley at the present ESCIF Congress. The final report will be published on the website as soon as possible

Successful (re) integration of people with SCI

The ESCIF Executive proposed this project at last year's congress but it took some time to raise the necessary funding. This finally fell into place in June 2014 with Coloplast agreeing to provide the majority of the necessary funds. Invitations to join the various working groups and a detailed project description were mailed to all member organisations at the beginning of July. The information (including the registration form that can be downloaded) can be found on the ESCIF website. The deadline for registration is the end of July 2014.

Fundraising and sponsorship

None of ESCIF's activities – past or planned – would be possible without the financial and/or practical support of our sponsors. You can read about our regular sponsors under *Special Thanks* on the ESCIF website.

Jane Horsewell, ESCIF President, Copenhagen July 2014