

President's Report 2011 – 2012

This report covers the period from the last ESCIF Congress and Assembly of Delegates – May 2011 to the present – and outlines what has been done and achieved since the last meeting of ESCIF delegates. It also includes some plans for the coming year.

Introduction

ESCIF has had another busy and successful year! We have seen more cross-national collaborations between our member organisations and a greater involvement with projects initiated by ISCoS and other stakeholders in the field of SCI.

The members of ESCIF have always stated that they wish (or, perhaps, “demand” is a better word!) to be fully involved in setting the agenda for people with SCI. I think that we can say, quite honestly, that we are well on the way to achieving this goal.

Assembly of Delegates 2011

Winnifred de Moes was re-elected to the position of Vice President without contest.

LARS (The Norwegian Spinal Cord Injuries Association) was introduced by its Chairman, Leif Arild Fjellheim, and was approved by the Assembly as a new member of ESCIF.

Alarme from France, presented by Corinne Jeanmaire, was also accepted as a member.

The provisional minutes from the Assembly of Delegates 2011 have been sent to all member organisations.

ESCIF Congress 2011

The ESCIF Congress 2011 took place in De Rijp, the Netherlands, and was hosted by the Dutch organisation Dwarslaesie Organisatie Nederland. The Congress was held at the Hotel De Rijper Eilanden, north of Amsterdam, which provided an ideal and accessible setting for the meeting of around 90 participants. Once again, we would like to thank the organisers for their work – and for an interesting and successful meeting.

ESCIF was pleased to be able to welcome both old friends and new colleagues among the delegates, speakers and sponsors. The topic for the Congress was *“Proven” Quality in SCI Rehabilitation* and each speaker approached the topic of quality from his/her own perspective – as consumer, as healthcare provider, as SCI professional etc. To introduce the theme, Marius Buiting gave a fascinating talk which questioned our traditional concepts of what quality is and how we can achieve it. The final session of the Congress was a workshop discussion in three groups designed to elicit input for a policy statement on quality considerations in SCI rehabilitation.

A “quality working group” was established to elaborate the policy statement, comprising Jane Horsewell, Frans Penninx and Gunilla Århén. The proposed policy statement has been circulated for consideration and discussion together with other materials for the 2012 Congress and Assembly of Delegates.

ESCIF would like to extend its sincere thanks to both the speakers and to the sponsors of the Congress.

ESCIF Executive meetings

Since the Congress in De Rijp, the ESCIF Executive has held two meetings "in person": the first in Gothenberg in September 2010 (in connection with the NoSCoS conference) and the next in Copenhagen at the beginning of February 2012. The Executive will also meet immediately before the Congress in Tuscany.

The Executive has also held telephone conferences in October 2011, January 2012 and March 2012.

Preparation for the ESCIF Congress 2012

Preparations for the ESCIF Congress 2012 began in the autumn of last year, when the organising committee from the host organisation FAIP confirmed both the venue and the dates; in collaboration with the ESCIF Executive, the theme of the congress was decided upon – *The impact of the economic crisis on people living with SCI in Europe*.

The next priority was to define the objectives of the study to be carried out before the congress. A steering committee was established including representatives from ESCIF, FAIP and the research institute that has carried out the study.

The ESCIF Executive would like to thank the members of the organising committee from FAIP for their hospitality and hard work. Further, ESCIF would like to thank the companies and organisations who have supported this year's Congress.

Communication with members: ESCIF website and newsletter

In the past year, we have tried to post regular updates on the 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 etc. 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 Gunilla Århén at 1stexecutive@escif.org.

The Nordic Spinal Cord Society meeting 2011

This meeting was held in Gothenburg in September 2011. ESCIF had been asked by the conference organisers to arrange a "hearing" on the benefits and problems of the centralisation of SCI treatment, rehabilitation and lifelong care. Jane Horsewell chaired the session and Gunilla Århén presented the findings and recommendations contained in the ESCIF report on centralisation. Antii Dahlberg gave an account of the events leading up to the recent legislative changes in Finland and Fin Biering-Sørensen spoke on behalf of SCI professionals and ISCoS. Two SCI specialists from Sweden described the workings of the largely decentralised system in that country.

The hearing provoked a lively debate in the audience and a renewed determination among the Swedish SCI professionals present to work actively towards a more centralised system. The SCI research working group also submitted an abstract to the NoSCoS conference entitled *Regaining functionality following a spinal cord injury (SCI): unproven therapies v. clinical trials and regenerative research*. Presented by Corinne Jeanmaire on behalf of the group, an important aim of the paper was to publicise the information to be found on the ESCIF website and to encourage input to the site from both SCI professionals and consumers.

ESCIF's participation in NoSCoS was supported by Coloplast.

Coloplast symposium on *Current topics on SCI*

Held at the Coloplast head office in Humlebæk, Denmark, in November 2011, this was the 5th annual meeting on SCI sponsored by the company for SCI professionals. Jane Horsewell and Gunilla Århén were invited to participate in a panel debate on *Value-based healthcare delivery in SCI*.

Interdependence 2012

Arranged by the Rick Hansen Institute, the conference is to be held in Vancouver 15 – 18 May 2012. The abstract submitted by the ESCIF SCI working group, *Regaining functionality following a spinal cord injury (SCI): central issues for SCI consumers*, was accepted as a poster presentation. Corinne Jeanmaire is the presenter of the poster. Corinne's participation was made possible by financial support from Hollister Inc.

Promoting a global SCI consumer network

Jane Horsewell and Frans Penninx attended the ASIA/ISCoS meeting in Washington in June 2011. ESCIF arranged a meeting during the conference to discuss the network with SCI consumer groups in (primarily) US and Canada.

In the autumn of 2011, Jane and Frans were invited to attend the Asian Spinal Cord Network (ASCoN) meeting in Colombo, Sri Lanka. In addition to arranging and running a workshop for SCI consumers where both Frans and Jane made presentations, Jane was asked to give two other talks – one on community inclusion and the other on SCI self-advocacy groups.

Although the Global SCI consumer network will not be launched officially until the ISCoS meeting in London in September, the network's website will go live before the ESCIF Congress this year. More information will follow at the 2012 Congress and in the next ESCIF newsletter.

Jane and Frans have initiated fundraising efforts, independent of ESCIF fundraising, to support the future activities of a global SCI consumer network.

ISCoS e-learning project

Since this project was mentioned by Professor Fin Biering-Sørensen at last year's congress, ESCIF representatives have been involved in developing this distance learning tool. Jane Horsewell was invited to attend a meeting in New Delhi in April this year to discuss and review the final project.

Airlines and passengers with disabilities

Following a discussion about the allegedly discriminatory practices of the carrier "Norwegian", the Executive asked Winnifred de Moes, ESCIF's Vice President, to look into the practices of European airlines.

The report will be available on www.escif.org before the Congress in May.

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.

Future activities in ESCIF

The following activities and projects are those already planned and set in motion by the Executive. Other proposals will be discussed at the Congress in the session "Future activities". Please remember that the Executive is always pleased to hear of new initiatives from member organisations, particularly if these could benefit from a collaborative effort with other member organisations. Any ideas and proposals should be sent to president@escif.org.

ILIAS project

The investigation into the return to work after SCI was further delayed while the research group worked to ensure uniformity with the Swiss Paraplegic Research cohort study SwiSCI. The study is to be launched in Switzerland, Netherlands, Norway and Denmark in May 2012, and will be extended to other ESCIF member countries in 2013.

IPSCI

The final report will be launched at the ISCoS meeting in September in London later this year. The ESCIF Executive would like to thank all ESCIF members who have contributed to this joint WHO/ISCoS publication.

Information gathering on MRSA

The project on practices used to confront MRSA (Methicillin-resistant *Staphylococcus aureus*), *E.coli* and *Klebsiella* is underway and the questionnaire will be ready after the summer. The member organisations who agreed to take part in the study will be contacted by Gunilla Århén who is leading the project.

The SCI consumer workshop at ISCoS 2012

ESCIF has arranged the first independent SCI consumer workshop to be held at the ISCoS meeting in London in September. The workshop, entitled *The SCI consumer agenda: global perspectives*, will be chaired by Jane Horseywell and will include presentations by Frans Penninx on the conclusions of ESCIF's deliberations on "quality in SCI rehabilitation" and by Pietro Barbieri on the preliminary results of the investigation into the impact of the economic crisis. Other speakers are colleagues from India, Sri Lanka, Malaysia and US.

Launching the Global SCI consumer network

In addition to the consumer workshop, the official launch of the Global SCI consumer network will take place at the ISCoS meeting. We hope to attract an international audience and to extend our network of contacts with SCI consumers and their organisations worldwide.

ESCIF Congress and Assembly of Delegates 2013

After discussions with our colleagues in Turkey, TOFD, it has been decided to postpone Turkey's hosting of the ESCIF Congress. The problem was one which most countries will recognise – a lack of accessible accommodation! We had hoped to hold the congress in Istanbul where TOFD has been actively involved in projects to make the many historical monuments in the city accessible to wheelchair-users. Negotiations between TOFD and, for example, the Ministry of Tourism will continue. We look forward to the opportunity to visit Istanbul in the future.

Further items for discussion during the “Future activities” session

An extension of the study into the impact of the economic crisis

A project focusing upon the successful reintegration of people with SCI

A project on the consumer’s view of “quality of life”

Jane Horsewell, ESCIF President, Copenhagen, 3 April 2012