

President's Report 2010 – 2011

This report covers the period from the last ESCIF Congress and Assembly of Delegates – May 2010 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.

Assembly of Delegates 2010

ESCIF's former President, Daniel Joggi (Switzerland), and Executive member Pekka Häätinen announced their decision not to stand for re-election.

Elections held during the Assembly led to the following result: Jane Horsewell (formerly Vice President) was elected as the new President and Winnifred de Moes was appointed Vice President of the federation. Two new members were elected to the Executive – Gunilla Åhrén from Sweden and Pietro Vittorio Barbieri from Italy.

The Assembly expressed their appreciation and thanks for the contributions made by Daniel and Pekka, and welcomed the two new members to the Executive.

We were also pleased to welcome the organisation from Turkey as a new member of ESCIF. The provisional minutes of the Assembly of Delegates 2010 have been sent to ESCIF member organisations and are also available on www.escif.org.

ESCIF Congress 2010

We were very pleased that we were able to hold the ESCIF Congress and Assembly 2010 at the Manfred Sauer Foundation in Lobbach, Germany. We would like to extend a special thanks to Manfred Sauer for allowing us to visit (again) and to Kevin Schultes and Veronika Geng for their enormous help with the logistics and practicalities.

The programme for the Congress was both interesting and inspiring: Many thanks to the invited speakers – Professor Fin Biering-Sørensen (Denmark), Prof. Dr José del R. Millán (Switzerland), and Per von Groote (Switzerland). The presentations from the invited speakers can be downloaded on www.escif.org.

The Congress also offered a thought-provoking session entitled *Hope or false hopes?*

The panel debate focused on the issue of SCI cure and experimental interventions. ESCIF would like to thank Daniel Joggi (Switzerland), Corinne Jeanmaire (France), Paolo Cipolla (Italy) and Martin Codyre (Ireland) for participating in the panel.

ESCIF Executive meetings

Since the Congress in Lobbach, the ESCIF Executive has held two meetings "in person": the first in De Rijp in September 2010 and the next in Berlin at the end of January 2011. The Executive will also meet immediately before the Congress in De Rijp.

From Friday 10 September to Sunday 12 September 2010 the Executive had the opportunity to introduce the two new members of the Executive to the ongoing work and activities involved, and to visit the Congress venue and discuss the programme with the ESCIF Congress 2011 organisers.

The second meeting was held from Friday 28 January – Sunday 30 January at the new Scandic Hotel in Berlin. Apart from the actual items to be discussed at the meeting, we were interested in appraising the hotel (which has 40 adapted rooms) with regard to future meetings in ESCIF.

The Executive has also held telephone conferences in November 2010, March 2011 and April 2011.

Preparation for the ESCIF Congress 2011

Preparations for the ESCIF Congress 2011 began in Lobbach last year and continued throughout the summer. By the end of September, the organising committee, working with the Executive, had agreed upon the programme, had contacted the speakers and had decided upon the venue. All relevant information was posted on the Congress website in October.

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

ESCIF website

It was decided to find a new company to implement the update of the ESCIF website. One of the important issues was to enable members of the Executive to add news and articles to the site. Jani Trdina has worked with a company in Slovenia on the design of the website and has been responsible for reorganising the information available on www.escif.org.

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 Jani at treasurer@escif.org.

ESCIF newsletter

It was also decided to give the ESCIF newsletter a "facelift" and to set regular dates for its publication. Newsletters have been sent out in October 2010, January 2011 and April 2011. 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 Åhrén at 1stexecutive@escif.org.

SCI research working group

Following the panel debate in Lobbach, we agreed to establish a working group to gather information on scientific research towards functional recovery following spinal cord injury, and to report on unproven therapies offered as "cures" for SCI. The aim was to provide objective information that is easily understandable for people without a medical background. This new section of the ESCIF website will "go live" on 11 May 2011 – one week before the Congress. Any questions, comments or input can be sent to the group at the email address given.

The Executive would like to thank all members of the working group – Corinne Jeanmaire, Harvey Sihota, Martin Codyre and Paolo Cipolla (who has now withdrawn from the group) for the tremendous amount of work they have put into this project.

ESCIF policy working groups

The report from the working group on the *Centralisation of treatment, rehabilitation and lifelong care of people with SCI* that was presented at last year's congress has been sent to a number of SCI professionals for review. The final report, which includes a few minor changes, will be available on the website before the Congress in De Rijp. We know that the report has stirred a great deal of interest and that it has, already, been used in various countries to guide and inform discussions on centralisation. (See also "Future activities") The group working on the establishment of spinal cord registries has decided to submit its report for publication in *Spinal Cord*. Until it is known whether or not the paper has been accepted, it is not possible to post it on the website. An executive summary is available on www.escif.org among the downloads from the Congress 2010.

Unfortunately, the group working on recommendations concerning peer-counselling and peer support initiatives has been seriously undermined by illness and, thus, the final report is not yet available.

ESCIF at ISCoS 2010

The 49th Annual Scientific Meeting of the International Spinal Cord Society was held in New Delhi at the end of October. At the meeting ESCIF's President, Jane Horseywell, chaired a workshop (sponsored by Coloplast) where the discussion centred upon the potential benefits of a global SCI consumer network. An account of the workshop and the presentations made by the members of the panel can be seen on the ESCIF website.

Further, Jane participated in a one-day closed workshop organised by WHO and the editors of *International Perspectives on Spinal Cord Injury*.

Finally, at a post-conference workshop on *Comprehensive SCI Management* at the Indian Spinal Injuries Centre in Delhi, Jane was invited to give a paper on *Community Inclusion following SCI*.

The ISCoS meeting has also given rise to two other exciting prospects; first that ESCIF has entered into an informal agreement with the Asian Spinal Cord Network based on information and experience sharing; second, the Executive officers of ISCoS decided, at a meeting in January 2011, to include a consumer-led session at all future annual meetings.

Airlines and passengers with disabilities

Last autumn organisations in Norway called for a boycott of the airline "Norwegian" on the grounds that the carrier insisted that people with a disability should be accompanied by another full-fare paying passenger.

The Executive asked Winnifred de Moes, ESCIF's Vice President, to look into the practices of other European airlines. We discussed the findings at the meeting in Berlin and decided to raise the matter with the European Disability Forum. A report will be posted on the ESCIF website.

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.

Quality in SCI rehabilitation

We intend to formulate a policy statement based on our discussions in De Rijp. Plans of how to do this will be discussed at the Congress.

ILIAS project

The investigation into the return to work after SCI, which was announced last year, has been delayed. However, the final version of the questionnaire has now been agreed upon by the group responsible for the project. The next step is to identify which ESCIF member organisations are willing to participate. Jan Reinhardt and Albert Marti will attend the Congress and will be pleased to answer any queries about the project.

Information gathering on MRSA

The original idea for this project came from one of our members in the Netherlands. Having looked into the problem and having discussed it with experts in this field, we have decided to broaden the study to include not only MRSA (Methicillin-resistant *Staphylococcus aureus*) but also *E.coli* and *Klebsiella* since they are seen as representing an even greater risk to the SCI population. We hope that all member organisations will support us in this project.

The Nordic Spinal Cord Society meeting 2011

This meeting will be held in Gothenburg in September 2011. ESCIF has 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. At this stage, the detailed planning of the session is not finished but it has been decided that Jane will chair the session and Gunilla will present the findings and recommendations contained in the ESCIF report on centralisation. We have invited Antii Dahlberg to present the events leading up to the recent legislative changes in Finland and Fin Biering-Sørensen to speak on behalf of SCI professionals and ISCoS.

The SCI research working group has 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*. An important aim of the paper (if accepted) will be to publicise the information to be found on the ESCIF website and to encourage input to the site from both SCI professionals and consumers.

The Executive is planning to hold its autumn meeting in conjunction with the conference. ESCIF's participation in NoSCoS has been supported by Coloplast.

Promoting a global SCI consumer network

The response to the workshop in New Delhi last year was so positive that the Executive agreed that ESCIF should work actively to promote the establishment of a global network. We have already forged links with ASCoN, and Jane and Frans Penninx will attend the ASIA/ISCoS meeting in Washington in June. ESCIF is arranging a meeting during the conference to discuss the network with SCI consumer groups in (primarily) US and Canada. Jane and Frans have initiated fundraising efforts, independent of ESCIF fundraising, to support the future activities of a global SCI consumer network.

European Disability Forum

It was announced last year that ESCIF intended to participate in the EDF annual meeting. Unfortunately this was cancelled. The Executive has agreed that our current Vice President, Winnifred de Moes, should represent ESCIF at the forthcoming meeting.

Amendments to ESCIF statutes

The Executive has become increasingly aware that some items of the Statutes are no longer tenable; they simply do not reflect the real situation in many European countries today. The immediate problem is, for example, that many countries have more than one "major" SCI organisation (sometimes representing different areas of activity) or that they have an overarching disability organisation (that is already an ESCIF member) but also an active organisation that is dedicated to SCI – in some countries these have been formed since ESCIF was founded. Obviously we do not wish to exclude organisations that have been active members for several years – but neither do we want to exclude other organisations that would benefit from ESCIF membership (or where ESCIF would benefit from their participation).

The Executive plans to address these issues in the coming months and to prepare a draft proposal on how to overcome them. This will be sent to all member organisations for discussion and comment. A final proposal will be presented to the Assembly next year. In the meantime, if you have any specific ideas, or if there are other amendments you feel are desirable, please send your suggestions to ESCIF's secretary, Urs Styger, at secretary@escif.org.

ESCIF Congress and Assembly of Delegates 2012

Our host for the Congress and Assembly of Delegates 2012 is FAIP the Italian SCI umbrella organisation. The meeting will be held in May 2012 at the holiday centre I Girasoli di Lucignano which lies 40km from Siena in the heart of the Tuscan countryside. The exact dates of the Congress will be announced at the 2011 Congress and, shortly afterwards, on www.escif.org.

The Executive would like to thank Pietro Vittorio Barbieri for taking the initiative and FAIP for agreeing to act as our hosts next year. We are already looking forward to it!

Further items for discussion during the "Future activities" session

- Future plans in the SCI research working group. Corinne Jeanmaire will present the group's proposals.
- Our member organisation in the Ukraine seeks input and collaboration regarding their current and future agenda. Please read and consider the "Ukraine Agenda" sent out with this report. Olena Pysarska will attend the Congress.
- Our member organisation in Turkey is working with the Ministry of Culture on a project to improve the accessibility of their historical buildings. Other members who have experience in this field are requested to offer their advice. Ramazan Bas will attend the Congress.
- The organisation ParaCENTRUM Fenix, Brno, has carried out a brief survey on the differences between social service systems in ESCIF countries as a link in its efforts to influence legislation in the Czech Republic. A wider study on reimbursement practices for personal and other aids could, perhaps, be useful.

Jane Horsewell, ESCIF President Copenhagen, 5 May 2011