

President's Report 2012 – 2013

This report covers the period from the last ESCIF Congress and Assembly of Delegates – May 2012 to the present – and outlines what has been done and achieved since the last meeting of ESCIF delegates.

Introduction

ESCIF has had yet another busy year! 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.

Not least, ESCIF's collaborations with other SCI organisations worldwide have continued to expand and the Global SCI Consumer Network has become a reality.

Assembly of Delegates 2012

Jani Trdina was re-elected to the position of Treasurer without contest.

Akson Ry from Finland was approved by the Assembly as a new member of ESCIF following a presentation by Annuka Koskela.

The Assembly also approved a number of changes to the Federation's statutes.

The provisional minutes from the Assembly of Delegates 2012 have been sent to all member organisations.

ESCIF Congress 2012

The ESCIF Congress and Assembly of Delegates 2012 was held in Italy, in the village of Lucignano in Tuscany. The theme of the congress was *The impact of the economic crisis on people living with SCI in Europe*.

The programme comprised a rather intense exchange of knowledge and experience, introduced by a study commissioned by ESCIF and FAIP and carried out by the research institute INSTUD.

In our discussions, we focused on the specific issues of rehabilitation, assistive devices and personal assistance, particularly in countries affected by the crisis (Spain, Netherlands, Czech Republic and Italy). Representatives from our member organisations in these countries gave presentations on the current situation and how people with SCI are being affected by the austerity measures introduced by national governments.

We also invited presentations from representatives of the European Disability Forum, of the Disabled People International and the European Network of Independent Living. This was a new departure for ESCIF as we have tended to focus upon input from SCI consumers and SCI professionals. This wider perspective provoked some interesting discussions and, among many in the audience, the acknowledgement that in these difficult economic times we should, perhaps, give more active support to general disability issues.

The final report based on the INSTUD report and the presentations and discussions from the Congress can be downloaded from www.escif.org.

ESCIF would like to extend its sincere thanks to both the organisers, speakers and sponsors of the Congress, and to Hollister Inc. who sponsored the report.

ESCIF Executive meetings

The Executive has held two meetings "in person" – both in Nottwil. A third meeting was, unfortunately, cancelled due to illness.

In addition, the Executive has held a number of telephone meetings – in November 2012, January 2013 and April 2013. Needless to say, the members of the Executive are in regular contact via email!

We would like to extend special thanks to Gabi Bucher who has joined the team to assist Urs Styger. Gabi's enthusiasm and willingness to "help out" have been much appreciated by all members of the Executive.

Preparation for the ESCIF Congress 2013

Preparations for the ESCIF Congress 2013 began after the summer last year and were discussed in detail in October when the Executive met in Nottwil. We were particularly pleased to have the opportunity to meet with Mirjam Brach from Swiss Paraplegic Research who came with some significant contributions to the programme.

We owe our biggest thanks to Urs and Gabi who have carried out most of the detailed planning and have dealt with all the practicalities involved in arranging this year's Congress. Many thanks too to Jani Trdina who took responsibility for setting up and developing the congress website.

Communication with members: ESCIF website and newsletter

As mentioned above, we have set up a new website www.escifcongress.org. This not only gives the possibility for online registrations but will also provide a source of information on future and past congresses.

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 Gunilla Åhrén at 1stexecutive@escif.org.

ISCoS 2012 in London 3 -5 September

The SCI consumer agenda: global perspectives was the title of the consumer workshop devised and led by ESCIF on the first day of the meeting. The workshop was the first independent consumer workshop to be included in the scientific programme of an ISCoS meeting.

The purpose of the workshop was to give SCI consumers from around the world the opportunity to present and discuss current, significant and pressing issues – as they define and identify them – and for SCI professionals to gain firsthand knowledge about the priorities of the community they serve. Although the SCI agenda differs in its priorities from world region to world region recent collaboration has indicated that, in fact, core issues are similar.

The workshop gave a unique insight into the issues that SCI consumers prioritise. It provided a platform where SCI consumers, professionals and policy makers could meet to exchange experience and ideas – with a view to future collaboration on how to resolve these issues. Around 90 people attended the workshop which was chaired by Jane Horseywell and co-chaired by the Executive Director of SIA UK, Paul Smith.

Pietro Vittorio Barbieri summarised the findings of the report – *The impact of the economic crisis on the lives of people with SCI in Europe* – and the conclusions of the discussions at the ESCIF congress in May 2012.

The final speaker of the workshop was Frans Penninx who, representing the ESCIF working group, presented the *ESCIF statement on quality in SCI rehabilitation and management* that was endorsed by the ESCIF Assembly of Delegates at the congress in Tuscany.

The other contributors came from India, Sri Lanka, Malaysia and US. All the presentations are posted on www.escif.org.

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.

Coloplast symposium on quality of life

ESCIF's Vice President, Winnifred de Moes, was invited to sit on the panel of the Coloplast satellite symposium at the ISCoS meeting. The topic of the panel debate was quality of life after SCI – with particular focus on the role of personal aids.

Official launch of the Global SCI Consumer Network

We were delighted to welcome both old friends and new to the launch of the Global SCI Consumer Network during the ISCoS meeting in London

ESCIF was well-represented by delegates from UK and Scotland, the Netherlands, Italy, France, Czech Republic, Norway, Sweden, Finland and Denmark; the ASCoN Consumer Network sent representatives from India, Sri Lanka and Malaysia, and was supported by our partners Livability Ireland.

The audience of around 60 people included SCI consumers and representatives of SCI consumer groups from the United States, Canada, Australia, Central America and South America.

The network now has “ambassadors” in Europe, Asia, US, Australia and Latin America, and has set up working groups to move the network forward in terms of organisation, funding and communication.

Frans Penninx attended the ASCoN meeting in Kuala Lumpur in November where he presented the background to and current situation of the initiative.

The network now has its own website www.globalsci.net.

ISCoS e-learning project

The e-learning resource www.elearnsoci.org was launched at the ISCoS meeting in London. As a member of the editorial board, Jane Horsewell was asked to attend the official launch and to make a short presentation on the relevance of the site from a consumer perspective.

International Perspectives on Spinal Cord Injury (IPSCI)

In last year's Presidential Report it was announced that the IPSCI report would be launched at the ISCoS meeting in London. Unfortunately, the launch was delayed for a second time! It seems now that the report will be made available at the ISCoS meeting in Istanbul later this year.

International Labour market Integration Assessment in persons with Spinal cord injury (ILIAS)

The study, which is a collaborative project between ESCIF and Swiss Paraplegic Research, has now been completed in Switzerland, the Netherlands, Denmark and Norway. A written summary of the preliminary results will be available at the Congress.

Marcel Post and Jan Reinhardt have submitted a workshop proposal to ISCoS 2013. If the abstract is accepted, Jane Horsewell will make a short presentation and Winnifred de Moes will participate in the panel discussion.

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 is nearing completion.

Gunilla Århén, the project leader, has been in contact with spinal cord units, clinics and departments throughout Europe asking them to complete an online questionnaire.

The results from the Nordic countries will be presented by Gunilla at the Nordic Spinal Cord Injury Society (NoSCoS) meeting in Helsinki in May. An abstract has also been submitted to the ISCoS meeting in Istanbul.

The final report will be posted on the website in the autumn of 2013.

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) will be presented by Antti at the NoSCoS meeting in Helsinki. An abstract has been submitted to the ISCoS meeting in Istanbul in October.

The final report will be posted on the ESCIF website in the autumn of 2013

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.