

President's Report 2014 – 2015

This report covers the period from the last ESCIF Congress and Assembly of Delegates – August 2014 to the present – and outlines what has been done and achieved since the last meeting of ESCIF delegates.

Introduction

As the Congress in 2014 was held much later than usual, this report covers a shorter period than in earlier years. There are, however, a number of activities to report!

Assembly of Delegates 2014

Apart from the usual business of the Assembly (reports, accounts etc), there were two main highlights; elections to the ESCIF Executive and the decision concerning the Endparalysis foundation.

Jane Horsewell has served as the President of ESCIF since 2010 – and was willing to serve for another term of four years. In her presentation, Jane made it clear that if she were re-elected then it would be for four years ... and no longer. She emphasised the importance of continuity but also renewal ... ESCIF must identify “new” people to engage in the work of carrying ESCIF forward. Jane was re-elected and thanked the Assembly for their support!

Gunilla Åhrén, who was elected to the Executive board in 2010, also stood for re-election and was elected for a further four years. Gunilla has made a huge contribution to the work of ESCIF – not least, the project on multi-resistant bacteria published in 2013.

Pietro Barbieri had decided not to stand for re-election as a member of the Executive board. ESCIF had received a presentation from Nuutti Hiltunen from Finland that had been circulated to member organisations before the meeting. Nuutti was elected as the fifth member of the Executive.

Corinne Jeanmaire, from the ESCIF research group, set up a foundation in 2014 to support SCI research. Corinne presented the ideas behind the foundation during the first evening of the congress and, during the Assembly, it was decided that ESCIF should be named as an official partner of the new foundation. Please read more about the foundation – and the ongoing fund-raising efforts and activities – on the website www.endparalysis.org.

ESCIF Congress 2014 in De Rijp, Netherlands

Thanks to our hosts in the Netherlands, Dwarslaesie Organisatie Nederland, the ESCIF congress in De Rijp last year was a great success. DON arranged a very interesting – and very relevant – programme for the more than 90 people who took part in the meeting.

The theme for the congress was “Healthy ageing with SCI – what can be done?” DON had invited a number of medical specialists and SCI professionals to elucidate different aspects of healthy ageing in general and ageing with SCI in particular, ranging from issues such as health quality of life and self-management to nutrition and exercise. In addition, there were

a number of extremely interesting experienced-based presentations from some of our own members and their family members. This mix of professional input and contributions from people living with (or close to) spinal cord injury created a programme that was a perfect reflection of the ESCIF “spirit” – the close collaboration between professionals and consumers, and the recognition of the unique knowledge that we SCI consumers possess.

All presentations from the ESCIF Congress 2014 have been uploaded on www.escif.org

ESCIF Executive meetings

The Executive has held two meetings “in person” in the course of the year: the first in Nottwil at the end of September 2014, the second in Copenhagen in February 2015. 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 2015

Our current hosts, ParaCENTRUM Fenix, met with the ESCIF Executive in De Rijp in September last year to discuss the programme and practicalities of this year’s Congress. We already knew, at that time, that the theme of the Congress would hinge upon the project *Overcome Challenges*, but there were still a number of issues to be resolved; the detailed planning of the Congress continued by email exchange throughout the autumn and winter.

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 2014 in Maastricht, Netherlands

ESCIF was, as usual, very visible at the ISCoS meeting in the Netherlands which was held the week following the Congress.

Jane Horsewell was invited to be a keynote speaker at the meeting. This was “a first” for an SCI consumer without a medical background and can, perhaps, be seen as an indicator of how far ESCIF has come since its establishment in 2006!

The speech was entitled *Consumer initiatives in the comprehensive management of spinal cord injury: best practice and policy* and included a summary of some of the ESCIF projects carried out over the past few years. The main points of the speech are summarised below.

>The role of SCI consumers in all aspects of SCI management has become more visible and more influential over the past decade. In Europe this has been marked by the establishment, in 2006, of a pan-European SCI consumer umbrella organisation, the European Spinal Cord Injury Federation (ESCIF). Following its mission “to improve the quality of life of people living with spinal cord injury throughout Europe”, the federation has served to support the efforts of its member organisations to improve health and social service provisions for people living

with SCI in their countries, and to promote the collaboration between SCI consumers and SCI professionals throughout Europe.

The major driving conviction behind ESCIF is that SCI consumers possess a unique insight into living with SCI that gives them knowledge and experience that can complement and benefit that of SCI professionals. Further, ESCIF believes that SCI consumers have not only the right but **also the obligation** to contribute their expertise to the comprehensive management of SCI; an area that was earlier the sole preserve of SCI professionals.

ESCIF has carried out a number of fact-finding investigations and projects designed to identify and formulate standards of best practice in SCI management **from the perspective of SCI consumers**. The conclusions of these studies have been posted as reports on the federation's website, but also presented at international conferences – not least at earlier ISCoS meetings.

The ideas and practice of SCI consumer self-advocacy and empowerment is spreading throughout the world and, once again, this development is being driven and supported by contacts and co-operation within the SCI consumer community. The Global SCI Consumer Network was launched in 2012 and, although this network is still in its infancy, it has created and consolidated ties between consumer groups both within and between world regions.

The final "frontier" for SCI consumers is, perhaps, that of SCI research. Traditionally, the role of the consumer in SCI research has been that of "respondent" or "subject" ... In-keeping with the more active role of consumers in other areas of SCI management, SCI consumers are now demanding a role as active stakeholders who should be involved in prioritising research areas as well as the design of specific projects.

In conclusion, it may be enough to quote the (now) widespread slogan of the international disability community "*Nothing about us without us*". <

ESCIF consumer workshop at ISCoS 2014 "Consumer initiatives"

ESCIF had, once again, been asked to plan the consumer workshop for the ISCoS meeting. This year it was decided to spotlight various (and wide-ranging) initiatives taken by SCI consumers and consumer organisations to "fill in the gaps" left by the health systems and policy makers to provide the "comprehensive management of spinal cord injury".

ESCIF's president, Jane Horsewell, had arranged the workshop and was the chair of the 90-minute session. She had invited Anni Täckman from Finland to present Akson's activities on "parenthood and SCI" and Frans Penninx from the Dutch SCI Association to talk about their project that is based on "Back on Track" and is an online resource for people living with SCI and their caregivers.

The second part of the workshop turned its attention to SCI research. Here, Kim Anderson from the Miami Project (and one of the US ambassadors to the Global SCI Consumer Network) discussed the role of SCI consumers in the prioritisations made in SCI research. As the final contribution to the session, Corinne Jeanmaire introduced the work of the ESCIF research group and the new "endparalysis.org" foundation.

ESCIF would like to thank Hollister Inc. for the educational grant that made this possible.

ISCoS Quality of life workshop

Although Jane did not chair this session as she did last year – ESCIF's influence was clearly seen in the choice of speakers! The topic was “peer-counselling”, chaired by Lucy Tomlinson from Vitality UK , and it included presentations from Jos Dekkers (chairman of the Dutch SCI organisation), Kevin Schültes (from Manfred Sauer) and Jackie Boelens from Belgium who took part in the panel.

Global SCI Consumer Network meeting

It had been decided prior to the ISCoS conference to hold an “internal” meeting in the group in order to decide on future plans and to attempt to make a strategy for fundraising efforts.

Successful (re) integration of people with SCI

The ESCIF Executive proposed this project at the congress in 2013 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 first meeting of the working groups took place in Nottwil from 31 October – 2 November 2014. In all 24 people from 16 different ESCIF member organisations participated in the weekend seminar.

The aim of the seminar was to identify and define the main issues involved in the five themes of the project: employment and education, social and leisure activities, family roles, quality of life, mobility aids and assistive devices. The next step was to chart the work process for each group leading to the first milestone – the production of a preliminary report to be presented at the current congress.

A second meeting of the working groups is planned for early September 2015. The final report of the working groups will provide the basis for the theme of the ESCIF Congress in 2016.

An abstract of the project and planned activities was submitted to the ISCoS/ASIA meeting in Montreal (May 2015). This was accepted as an oral presentation. As no-one from the Executive was able to attend the meeting, it was decided that Niels Balle (leader of Working group 1) should present on ESCIF's behalf.

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 April 2015