

Newsletter December 2014



Dear ESCIF colleagues

The autumn of 2014 has been a very busy time for ESCIF. At the end of August we held the ESCIF Congress and Assembly of Delegates in the Netherlands, followed by participation in the ISCoS annual scientific meeting the following week. The first weekend of November was marked by the meeting of the five working groups involved in the Successful integration project. You can read more about these activities in this Newsletter.

But the year is drawing to a close and over the past month the Executive has been working with the hosts of the ESCIF Congress 2015 – ParaCENTRUM Fenix – preparing the programme and practicalities of the meeting in Brno in May 2015. As always, we look forward to meeting with the delegates from our member organisations at the Congress.

In the meantime, the members of the ESCIF Executive would like to send you all “Season’s greetings” and to wish all our member organisations, their members and our friends and supporters worldwide a very happy and healthy 2015 – with success in all their endeavours.

On behalf of Winnifred, Jani, Gunilla and Nuuti

Best regards

Jane

Jane Horseywell

ESCIF President

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ESCIF Congress 2014



Thanks to our hosts in the Netherlands, Dwarslaesie Organisatie Nederland, the ESCIF congress in De Rijp was a great success. They arranged a very interesting – and very relevant – programme for the 90+ participants which is the largest number of attendees at an ESCIF congress ever!

ESCIF is very grateful to Frans Penninx, Johan Elsinga and Jos Dekkers from DON for all their hard work in putting together the programme and finding sponsors to support the meeting. But we must also remember to thank Winnifred de Moes (ESCIF's Vice president) who had agreed to act as "coordinator" between the organisers and the ESCIF Executive – but ended up as the key logistics expert.

Without Winnifred's efforts we would have all been stuck at Schipol airport ... with no accommodation or food in De Rijp!

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.

Assembly of Delegates



Apart from the usual business of the Assembly (reports, accounts etc), there were also 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 last year.

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

Corinne Jeanmaire, from the ESCIF research group, has set up a foundation endparalysis.org. 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 current fund-raising effort – on the website www.endparalysis.org.



The Assembly also considered future projects in ESCIF. The *Successful integration* project that was described at the meeting in 2013 has now been started – thanks to support from Coloplast. The Executive still plans to move forward with the project *Growing your organisation* in so far as funding can be raised for this. Further, the idea of establishing a “strategy group” was discussed at the Executive meeting immediately prior to the congress. As this idea ties in with the need for “continuity and renewal” mentioned earlier, ESCIF will work to set up this group in 2015.

ISCoS 2014

The ESCIF Newsletter has received the following overview from Winnifred de Moes.

Around 1000 people (most of them professionals but also many consumers) from 87 countries attended the congress. Jane Horsewell and Winnifred de Moes represented ESCIF at the ISCoS scientific meeting 2014.

The main conference topics were:

1. Physical capacity and fitness

Physical capacity is the combined ability of the cardiovascular, respiratory and neuro-musculoskeletal systems to attain a certain level of physical activity. Following SCI, physical capacity is an important aspect of functioning and interacts, for example, with well-being and complications.

2. Consumer rights

Freedom of choice in the selection of treatment (e.g. stem cells, exoskeletons, euthanasia) or equipment (e.g. wheelchair) is very important for every individual.

3. Ageing

With today's specialised medical care, the life expectancy of persons with a SCI has improved considerably. However, not much is known about the effect of ageing with a SCI on body functions, activities or societal participation.

4. Orthotics

To increase the functionality of people with SCI orthotics are of utmost importance. Orthotics can range from neck collars to ankle-foot orthosis to wheelchairs.

5. Sexuality

Since SCI affects virtually every system of the human body, many people who sustain SCI have serious concerns about how their injuries have affected their ability to participate in and enjoy a sexual relationship. What is the state of the art regarding sexuality and SCI?

If you would like to read more about the meeting you can download the abstracts

<http://www.iscosmeetings.org/2014/wp-content/uploads/2014/08/ABSTRACT-BOOK.pdf>.

Keynote speech at ISCoS 2014: Jane Horsewell, President ESCIF

Consumer initiatives in the comprehensive management of spinal cord injury: best practice and policy

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. who supported the participation of Anni Täckman and Corinne Jeanmaire.

Quality of life workshop

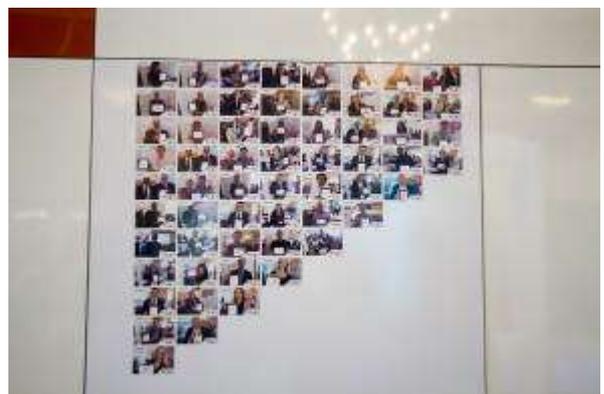
Although Jane did not chair this session as she did last year – ESCIF’s influence was clearly seen in the choice of speakers! The topic was “peer-counselling”, chaired by Lucy Tomlinson from Vitality UK , and it included presentations from Jos Dekkers (chairman of the Dutch SCI organisation), Kevin Schültes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

Medtronic "event" and fundraising at ISCoS



Medtronic, a company best-known in SCI circles for the development and distribution of Baclofen pumps to combat spasticity, held an event at their stand at the ISCoS meeting to draw attention to the “I can” campaign. The idea behind the campaign was to draw attention to the benefits of a life without spasticity. We all know that for some people with SCI, spasticity can be actively exploited – if it is predictable and can be controlled. For many, however, spasticity creates huge problems in carrying out everyday activities and the discomfort (pain) that arises leads to other issues – insomnia, fatigue etc.

The company invited the conference participants to draw an example of what “I can” do (or my patient can do) if I/he/she no longer suffers from the adverse effects of spasticity. The iPad drawings were displayed on a board behind the stand – and for each drawing submitted Medtronic promised a small donation to ESCIF! This



resulted in a total donation of \$4000!!

Naturally, we were thrilled to receive this unexpected “windfall” and we would like to thank Medtronic for their creative (and rewarding!) idea.

ESCIF Congress 2015



The ESCIF Congress and Assembly of Delegates 2015 will take place in Brno, the second largest city in the Czech Republic, from 20 May – 22 May 2015. The congress venue is the Hotel Maximus Resort – see

<http://www.maximus-resort-hotel-brno.com/>

Our hosts, paraCENTRUM Fenix, have been leaders of a trans-national project entitled Overcome Challenges. This project will inform the congress theme: *Employment after spinal cord injury*. Further information about the ESCIF congress 2015 – programme, registration, optional excursions etc – will be available soon on the ESCIF website www.escif.org and on the congress website www.escifcongress.org.

Projects

Successful (re-)integration of people living with a spinal cord injury



The project on the Successful (re-)integration of people living with a spinal cord injury started with great enthusiasm during a two-day workshop in a beautiful and sunny Nottwil in Switzerland. More than 25 people from 13 different countries met up Friday, 31 October – Sunday, 2 November to set off the project.

This project focuses on what the ESCIF member organisations can do to facilitate the successful (re-)integration of people with spinal cord injury in the community. Over almost two years, five working groups will explore and elaborate five different focus areas; Education and employment, Social and leisure, Family roles, Quality of life and Mobility aids and assistive devices.

The purpose of the workshop was to discuss and draw up the outlines of the overall project and sub-projects, identify focus areas and topics and finally to coordinate the working groups to ensure efficiency; to avoid double work but also to make sure that

all areas will be covered. After some sessions in plenum most of the work was done in the working groups to discuss what they want to explore, how they plan to do the work, when and how they will communicate and finally different deadlines. The working groups presented their results in plenum so that the different groups could draw from the experiences and ideas of the other groups. Now the working groups will continue working and their first progress report is due in April 2015. There will, of course, be some information presented at the Congress in Brno.

All the participants seemed pleased with the weekend and were prepared to follow up all the work after the workshop. Apart from the interesting topics and discussions, the workshop also offered good companions, lovely food, great weather and friendly hospitality of the Swiss.

Eucomed report and the Stop rEUse Campaign

Eucomed, which represents the medical technology industry in Europe, recently issued a report in connection to the EU Commission's proposal for the revision of the EU Medical Devices Directives (MDD). This proposal consists of numerous changes including the idea of classifying single-use medical devices as re-usable. The reasons include environmental and financial considerations. This proposal means that, for example, single-use catheters could potentially be classified as re-usable. The European Committee would make a decision on 9th – 11th of December 2014.

Due to this proposal Wellspect Healthcare launched a Stop reUse Campaign to lobby for the exclusion of catheters. They contacted both ESCIF but also many of the member organisations urging them to join the campaign, that can be found on www.change.org/p/stop-forced-re-use-of-catheters.

ESCIF has written a letter to the European Committee expressing that we understand and accept much of the underlying rationale for the proposal and that we support the report prepared by Eucomed but that there was one issue to which we wanted to

draw their attention. We were, and are, concerned for the negative effects on people living with Spinal Cord Injury if single-use urinary catheters would be classified as reusable. Especially stressing the increased risk of infection and premature death.

The letter will soon be uploaded on the website.