

Newsletter December 2013

Dear Friends and Colleagues!



It seems just a short while ago that we met in Nottwil followed up by the Newsletter in June – and now Christmas is here! Where does the time go?

The ESCIF Executive held a meeting in Lobbach at the very end of August where we discussed the issues raised during the Congress and Assembly of Delegates.

The “big event” this autumn was the ISCoS scientific meeting in Istanbul – you can read more about this in the Newsletter. ESCIF was involved in a number of sessions – our presence was more visible than ever before! I was also fortunate enough to spend some time with our Turkish member organisation – TOFD – and I would like to send personal thanks to Ramazan Bas (President of TOFD) for the organisation’s hospitality and willingness to share their experience of working for people with SCI.

On 3 December I was invited to speak at the launch of *International Perspectives on Spinal Cord Injury* at the WHO headquarters in Geneva. As we have heard so much about the report during its preparation, it was exciting to see it published.

On behalf of the Executive, I would like to send personal greetings to all our ESCIF members and friends. Whether we say “Merry Christmas” or “Happy Holidays” or another timely greeting, doesn’t matter; we’ll be thinking of you all and looking forward to the next opportunity to meet. So – “Season’s Greetings”!

Jane

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There were approximately 600 participants from all around the world. The ESCIF delegation consisted of Jane Horsewell, Gunilla Åhrén and Winnifred de Moes.

ESCIF seemed to be all over the place at ISCoS! Jane Horsewell, President of ESCIF, both participated in and chaired several sessions on the scientific programme.

ESCIF SCI consumer workshop



The consumer workshop was held during the first day of the congress. The topic of the workshop was *Organisation of SCI treatment, rehabilitation and follow-up: are ideas and models developed in high-resource countries relevant to medium and low-resource countries?* The workshop was chaired by Jane Horsewell (President of ESCIF) and the panel members consisted of SCI consumers or representatives of SCI consumer groups from different parts of the world; Ramazan Bas (President of

TOFD in Turkey), Kim Anderson (US), Dr Daniel Rubio de Souza (Brasil) and Shivjeet Singh Raghav (India). Ramazan presented the current situation regarding the comprehensive management of SCI in Turkey and Jane turned to the topic of the panel debate by introducing the various policy statements and reports that ESCIF has prepared over the past five years. During the discussion it became clear that SCI consumers meet the same kind of challenges all over the world and that consumer organisations work with the same kind of issues. However the solution to the problems differs depending on local conditions, for example infrastructure.

Some members of the Turkish organization TOFD participated in the workshop audience; by using simultaneous interpretation all participants could participate in the discussion.

Posters

ESCIF participated with two posters from the two current on-going ESCIF projects; *Comprehensive spinal cord injury (SCI) management: the issue of lifelong care and monitoring* and *Information-gathering on resistant bacteria in connection to SCI*.

Visit www.escif.org to see the posters.

Global SCI Consumer Network meeting

At the ISCoS meeting in London in 2012 the Global SCI Consumer Network was officially launched. At this year's meeting Global Network ambassadors and other participants – about 25 people in total – from Asia, Australia, Europe, North America and Latin America were present.

Jane Horsewell (from Denmark and President of ESCIF) welcomed all participants and gave a short introduction to (the history of) the network. The presentation included information about the establishment of working groups, the “appointment” of ambassadors and other progress that has been made in the last year.

Then Shivjeet Singh Raghav (from India) gave an update about the activities of the ASCoN SCI consumer network in Asia including last year's meeting in Kuala Lumpur

and plans for the coming meeting in India. There have been a lot of developments regarding the national SCI consumer groups/organisations in the region. New groups/organisations have been established and the number of members per country is increasing rapidly. Concrete steps and actions are to be expected in the near future.

Next Bruno Landgraf das Neves (from Brasil) told us about building relationships between SCI consumer groups in Latin America. Bruno was supported during his presentation by Dr. Daniel Rubio de Souza from São Paulo. They explained the general situation relating to SCI in Latin America and described the current status of the inter-group contacts in Latin America. Much of the presentation was based on the information gathered by Federico Montero, the GN ambassador in Latin America. There are plans for future activities to consolidate and extend the contacts among SCI consumer groups in Latin America.

Subsequently Peter Perry (from Australia) presented information about Spinal Cord Injuries Australia and the consumer initiatives in Australia. The National Disability Strategy and the National Disability Insurance Scheme are of great importance to the national SCI strategy in Australia and could be an example to other countries. SIA Australia is in contact with the ASCoN Consumer Network.

Thereafter Frans Penninx (from the Netherlands) and Sara Rubinelli (from Switzerland) told about resources for online communication and the development of the GN website in possible collaboration with Paraforum (from Swiss Paraplegic Research). Finally Frans Penninx invited the audience to the meetings next year in the Netherlands, ESCIF congress and ISCoS.

After the presentations, Kim Anderson (from the US) chaired the discussion together with Frans Penninx and some conclusions were drawn.

A full report of the conclusions of the meeting can be found on www.globalsci.net (under the heading "Meetings"). The presentations from the meeting can also be downloaded here.

ISCoS Scientific Programme: workshops

The main topics of the ISCoS congress were

- Pathophysiology of Spinal Cord Injury (SCI)
 - Pathophysiologic pathways
 - Novel therapeutic approaches
- Natural disasters and SCI
- Acute care/management of SCI
- Spinal Surgery

The scientific programme consisted of many different interesting topics. The programme comprised many parallel sessions either held as plenary sessions with keynote speakers, or workshops or themed free paper sessions consisting of short scientific presentations. The quality of the sessions varied but most of them brought new and interesting angles to the challenges facing SCI.

On behalf the ISCoS Quality of Life (QoL) Special Interest Group, founded at the ISCoS meeting in 2012, Jane Horsewell arranged and chaired a workshop concerned with cross-cultural definitions of QoL among people living with SCI. Marcel Post (Netherlands), Denise Tate (US), Divya Parashar (India) and Szilvia Geyh (Switzerland) presented recent research in the field. They were joined by Kim Andersen (US), Anke Scheel (UK) and Lucy Robinson (UK) to discuss whether it is possible (or desirable) to work towards a common definition of Quality of Life.

During the ILIAS workshop concerning the first results of the study into labour market participation of persons with SCI, Marcel Post and Jan Reinhardt presented the results of the investigation in Switzerland, the Netherlands, Norway and Denmark. Jane Horsewell held a presentation explaining ESCIF's role in the study and on the role of paid work in the successful integration of people with SCI.

The workshop ended with a panel discussion chaired by Marcel Post. The panel consisted of Fin Biering-Sørensen (Denmark), Mirjam Brach (Switzerland) and Winnifred de Moes (ESCIF's Vice President, the Netherlands).

The two project leaders, Marcel Post and Jan Reinhardt, have agreed to write up a summary of the ILIAS results so far. The report will be uploaded on www.escif.org early in 2014.

On the last afternoon of the meeting, Jane was a keynote speaker at a session entitled *International Collaborations: The Way of the Future* which was chaired by Doug Brown (Australia) who is the current President of ISCoS. The purpose of the workshop was to identify barriers and enablers to setting up international research collaborations, international multi-centre clinical trials etc. Jane's presentation proposed that the involvement of SCI consumers in the research and trial design teams could help remove some of the barriers to participation.

Some information on the workshop can be found on the Rick Hansen Institute website, but the organisers of the workshop (from Australia and Canada) plan to upload the presentations and conclusions of the discussions on their websites – we will put a link on www.escif.org once this material is available.

The next step in this ongoing project is to carry out an online survey among SCI researchers into the barriers and facilitators to international research. Jane Horsewell and Kim Anderson (US) have been asked to devise a survey of SCI consumers on the subject of their participation in international clinical trials.

Project updates

Comprehensive spinal cord injury (SCI) management: the issue of lifelong care and monitoring

Unfortunately, the working group (Antti Dahlberg (Finland), Jane Horsewell, Colm Whooley (Ireland) and Frans Penninx (Netherlands) has suffered a number of health-related problems that have slowed down the progress of the work. Antti was named as the first author of the poster for the ISCoS meeting but was unable to be involved either in the preparation or the meeting itself. This was a great disappointment as Antti had presented the work at the NoSCoS meeting in May.

The final report from the group will, therefore, first be available early in 2014.

Information-gathering project on resistant bacteria in connection with SCI

The information-gathering part of the project is completed. We prolonged the study several times to try to improve the response rate and therefore didn't close the survey until late August.

The conclusions from the findings are

- The level of awareness of MRSA and ESBL/CRE is generally high and guidelines exist in all the participating countries, the knowledge of and compliance to these guidelines differs between the SCIUs within the same countries. This calls for serious discussions on this subject between the SCIUs. An important consideration should be the use of dedicated personnel in the care of these patients.
- The screening process for both MRSA and ESBL/CRE needs attention. Even though well-documented procedures exist for screening, not all SCIUs comply with these, especially when it comes to other patients in the unit and staff members.
- Only half the SCIUs that have SCI specific registries report MRSA findings; if this were done consistently, it would provide a useful tool in monitoring and combating the problem.
- In those SCIUs where the care and rehabilitation possibilities for MRSA-positive patients are currently restricted, special attention should be given to the ways in which other SCIUs tackle the problem – to ensure that no SCI patient lacks relevant care and rehabilitation.

The full report will be available later on www.escif.org. The report will also be sent to all the participating SCIUs.

IPSCI

As you may already have seen on the ESCIF website, on 3 December 2013 the report *International Perspectives on Spinal Cord Injury* was launched at the WHO headquarters in Geneva. The report is the result of a collaboration between WHO and ISCoS with financial and practical support from Swiss Paraplegic Research.

In addition to presentations from the Director of the WHO department responsible, Dr Etienne Krug, and the project leader, Alana Officer, UN ambassadors from Australia, Ecuador and Mozambique had been invited to give their reactions to the report. Representing the SCI community, Jean-Jacques Wyndaele (President Elect of ISCoS), Shivjeet Singh Raghaw (Chairman of the ASCoN Consumer Committee) and Jane Horsewell had been invited to speak.



Dr Etienne Krug introduces the launch



*Shivjeet Singh Raghaw chats to Mirjam Brach from Swiss
Paraplegic Research*

So – what was the general consensus? ESCIF members are already aware that the compilation of the report has taken much longer than originally planned and, as such, one could be concerned that some of the information is already a little out of date. However, as Jane Horsewell pointed out, although the ideas presented in the report may not be new or surprising to those who are actively involved in the SCI community, the simple fact of having this amount of information and expert testimony in one document provides us with a very useful tool that we can use in our lobbying efforts. The report is written in a clear and easy-to-follow style – and comes in a short summarised version for those who do not have time to read the whole thing! This could be very useful in dealing with policy-makers!



Jane Horsewell, Jean-Jacques Wyndaele and Peter Woolcot from Australia

All ESCIF member organisations will receive a copy of the report in “book form” in January - thanks to Swiss Paraplegic Research. So please check that the address on the ESCIF website is correct!

The report can also be downloaded by following the link on www.escif.org

Paraforum

Paraforum was launched on December 2, 2013. This is an interactive online platform dedicated to SCI and could become an essential tool in the global communication between the members of the network that will consist of consumers, researchers and health professionals – as well as a source of information about the network to other stakeholders in the global SCI community. Paraforum is an initiative of Swiss Paraplegic Foundation led by Swiss Paraplegic Research supported by Swiss Paraplegic Association and Swiss Paraplegic Centre.

Paraform will start in German, French, Italian (languages used in Switzerland) and English. Paraform will be monitored every day and important questions / answers / information will be translated i.e. available in these four languages. There is a tentative plan to add Spanish as the fifth language.

Visit www.paraforum.org for more information

Problems in transit?

ESCIF has received a letter from a member of our Norwegian organisation LARS in which he described the difficulties he has encountered during journeys involving a change of flights. At Copenhagen airport he was forced to sit for several hours in a wheelchair provided by the airport as his own chair had been forwarded to his next flight with the rest of the luggage from the hold. In Frankfurt he was separated from the rest of his party and made to wait alone in the area for disabled passengers. The Chairman of LARS, Leif Arild Fjellheim, has suggested that ESCIF should investigate this matter.

I am sure that we have all had some “bad” experiences while travelling and can tell many anecdotes about these! I am particularly interested in hearing about any problems you have encountered in European airports while changing from one flight to another. Please send me a mail: president@escif.org

ESCIF Congress 2014

ESCIF Congress and Assembly of Delegates 27 – 29 August 2014 in De Rijp, The Netherlands

Programme «Healthy Ageing: what can be done?»

The latest information is on the congress website: <http://www.escifcongress.org/>

Remember to visit www.escif.org or scan the QR-code for the latest up-date!

