

Newsletter June 2013



Dear Colleagues

Summer is with us at last! For many this was heralded by the fantastic weather we enjoyed in Nottwil during the ESCIF Congress. While parts of central Europe were still suffering from extremely heavy rainfall and flooding, ESCIF delegates were basking in sunshine and temperatures of 30 degrees. Not that we actually had much opportunity to sit outside and enjoy it!

Our Swiss hosts had arranged an extremely interesting programme on the topic of Living with SCI: communication, information and learning that kept the delegates inside and attentive. If you were unable to participate, all the presentations are uploaded on the ESCIF website and there is a brief report in this Newsletter.

Two things from the meeting that you cannot experience via the website are the social programme and the atmosphere. Many thanks to Urs Styger and Gabi Bucher for arranging such super evenings – including the unforgettable optional event of Friday evening which was the sightseeing and dinner aboard the old steamer on the lake in Lüzern. The positive atmosphere of the Congress was, of course, created by the delegates and participants themselves; not just a meeting of SCI colleagues, but a meeting of old and new friends.

Many thanks to all who made the ESCIF Congress 2013 a great success.

On behalf of the ESCIF Executive

Jane

Jane Horsewell

ESCIF President

Email: president@escif.org

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Living with SCI: communication, information and learning



After a series of speeches welcoming the delegates followed by the “Get-together Dinner” on Wednesday 5 June, the Congress programme started on Thursday morning.

The first session of the Congress was led by Professor Fin Biering-Sørensen from Denmark who introduced the web-based learning resource developed by the International Spinal Cord Society (ISCoS). ESCIF’s President Jane Horsewell, who was a member of the editorial board of the project, considered the relevance of elearnsoci.org for SCI consumers and the possibilities to develop the resource further – specifically, with consumers in mind.

The next sessions were devoted to projects from Swiss Paraplegic Research: the development of an interactive website for people living with spinal cord injury Paraforum, which was followed by a workshop to discuss the ideas behind the development of the site; then the first results of the Swiss cohort study SwiSCI. ESCIF would like to thank Sara Rubinelli and Mirjam Brach (and colleagues) for their interesting contributions on Paraforum – we look forward to seeing and using the resource in future! Thanks too to Martin Brinkhof for giving insights into the highly ambitious SwiSCI project.

Two of ESCIF’s regular sponsors had been invited to make the next presentations. Kevin Schultes, a member of the Board of Trustees of the Manfred Sauer Foundation, introduced an online information service derQuerschnitt.de that had been launched by the Foundation earlier that week. Søren Bremer, from the Global Marketing department of Coloplast, presented two initiatives from the company; Innovationbyyou.com – a website where consumers can ask questions about and contribute ideas to the development of medical devices, including those for bladder

and bowel management – and the app Wheelmate which directs the user to the nearest disabled parking spaces and accessible toilets.

The final session of the day was a fascinating and optimistic presentation by Professor Dr Martin Schwab from Zürich on nerve fibre growth and regeneration in the injured spinal cord. Recent research has shown that it is possible to enhance nerve fibre growth by blocking certain proteins that inhibit that growth. We can only hope that the many experiments with first rats and then primates will result in similar positive results for humans with spinal cord injury.



After a long day ... a glass of wine and some crisps!



Despite the problems of accessibility, Winnifred goes for it!

Assembly of Delegates 2013

In addition to the “formalities” of approving last year’s report and accounts, the Assembly included the approval and acceptance of three new members.

From Denmark, Niels Balle introduced the organisation PTU (an organisation founded primarily for polio and traffic accident survivors) in his role as chairman of the SCI committee. He underlined the close collaboration between his organisation and the existing ESCIF member from Denmark, RYK. From the Czech Republic, David Ruzicka, told the Assembly about the activities of Czepa – an organisation for people living with spinal cord injuries based in the country’s capital Prague. Finally, from Spain, Esther Peris (who has previously represented the Spanish member

organisation ASPAYM at ESCIF meetings) and Natacha Leon provided an interesting insight into the activities of Fundación Lesionado Medular. Needless to say, these three new and active members were warmly welcomed by the delegates.

Finally, the Assembly turned its attention to the issue of “future activities”. It was decided to move ahead with the projects outlined by the Executive in the document that was sent out prior to the meeting. Jane Horsewell assured the members that the Executive would draw up a more detailed proposal of the two projects after the summer and that these would be sent to all member organisations.

The Executive would like to thank Daniel Joggi from the Swiss Paraplegic Foundation for acting as chairman throughout the Assembly.

Members' input

After lunch, on a hot Friday afternoon, ESCIF's Vice President, Winnifred de Moes, was the session chairman for the final part of the meeting. Fortunately, the presentations were so interesting that no-one in the audience fell asleep!

Mirjam Kanelec from the Slovenian organisation presented the results of a study into what it is like to live with a spinal cord injury in Slovenia. Perhaps the most surprising aspects of this study were, first, that they managed to reach 98% of the SCI population in their country and, second, that the questionnaire was not anonymous! This means that the organisation now has very specific, personal information and, thus, the possibility to assist individual members with the problems they confront in their everyday lives. The organisation has already taken action based on the results of the survey, for example, an architect has been visiting homes where people had responded that they had problems with accessibility.

Lia Vasickova from ParaCENTRUM Fenix in the Czech Republic described an information project that the organisation began last year. As road traffic accidents constitute the major cause of traumatic SCI in the country, the project is designed to inform and warn older school pupils of the potential dangers of venturing forth in today's busy streets.

Frans Penninx told the audience about a recently-completed project in the Netherlands that was aimed at describing the optimal care pathways for people with SCI from the accident/onset, through treatment and rehabilitation, to lifelong care and follow up. As a member of the ESCIF working group on lifelong care, Frans pointed out that the final issue is awaiting further elaboration in the group's report that will be released this autumn!

Finally, Annuka Koskela and Anni Täckman from Finland showed us a magazine produced by Akson ry. Dealing with a range of different issues concerning fertility, pregnancy, and parenting with SCI, the organisation decided, after a very positive response in Finland, to translate the magazine into English for the benefit of other SCI colleagues in Scandinavia and Europe. It's a beautifully produced publication that should be brought to the attention of our members. Like the other presentations from the session, a pdf. file of the publication can be downloaded from the ESCIF website.

Congress participants

Unfortunately, there were a few mistakes in the participant list that was included in the Congress brochure. As promised, we attach a corrected list with this Newsletter.



It was great to see Colm from Ireland again!

In addition to our new members, it was also good to see those who were unable to join us in Italy last year.



Dougy from SIS couldn't make it last year ...



Onboard the steamer! Hannes and Monika from Austria joined us ...

Please check your membership details ...

In addition to the list of people who attended the ESCIF congress this year, we would ask you to take a couple of minutes to check the "ESCIF members 2013" file that is sent out with this Newsletter. Further, please look on the website to make sure that the information there is up-to-date.

Any corrections or changes should be emailed to secretary@escif.org with the subject heading "Correction to list of members from" with your country filled in the space!

New SCI prevention video ...

TOFD, our member in Turkey, has produced a video warning of the dangers of diving into shallow water. The organisation wishes to focus upon this problem that is widespread during the summer months and suggests that other ESCIF member organisations could upload the video to their national websites

ESCIF members will be able to download the video from this link within 14 days:

<https://www.wetransfer.com/downloads/7eb0309d6c3f8b881f17f49685fcafc20130624072304/8ae4700a5d939f1fec5c74c6e20d53e120130624072304/90d873>

The International Spinal Cord Society (ISCoS) is also planning a project involving the dissemination of "SCI prevention videos". If your organisation has recently produced an informational video or short TV spot on this issue and you would be willing to share the idea, please send a link to Jane Horsewell at president@escif.org. Thanks!

ILIAS project

Unfortunately, the promised report from the ILIAS team was not ready in time for the ESCIF congress and, due to other activities, it was not possible to produce an update for this Newsletter.

ESCIF has been assured by the project leaders that information on the results of the completed studies in Switzerland, Netherlands, Denmark and Norway will be made available to ESCIF members in the autumn.

Information-gathering project on resistant bacteria in connection with SCI

The on-going web-based survey on multiresistant bacteria in connection to SCI is well underway. The first preliminary results on the Nordic countries were presented at the NoSCoS congress in Helsinki in May 2013.

The preliminary results show that the level of awareness differs between the countries and that there are several issues that need to be addressed. Unfortunately we still lack responses from some of ESCIFs member organisations. Up to this date we have responses from; Austria, Belgium, Czech Republic, Denmark, Ireland, Finland, Lithuania, Netherlands, Norway, Scotland, Spain, Sweden, Switzerland and United Kingdom.

Country	Contacted	Answered	%
Austria	4	2	50
Belgium	7	2	29
Czech Republic	7	5	71
Denmark	2	2	100
Finland	4	3	75
Germany	1	0	0
Iceland	1	0	0
Ireland	1	1	100
Italy	16	5	31
Lithuania	3	3	100
Netherlands	7	1	14
Norway	3	1	33
Romania	1	0	0
Slovenia	1	0	0
Spain	13	4	31
Sweden	22	16	73
Switzerland	3	2	67
UK	10	1	10
Total	106	48	45

We will keep the survey open during the summer and autumn in order to increase the response rate. We will send the contact persons in a mail with details on which units in their country that haven't answered. The project has been accepted as a poster on the ISCoS 2013.

NoSCoS 2013



There was no theme for the 13th NoSCoS congress – instead the organisers had different topics; children, women, technical aids and ventilator support apart from the free papers.

The whole congress consisted of 10 minute presentations apart from the keynote lectures which were held by Marca E. Sipski, Outi Hovatta, Jürgen Pannek and Fin Biering-Soerensen.

The only news was that there were more presentations from consumers than before. ESCIF was represented with two oral presentations. Antii Dahlberg (Finland) talked about ESCIF's new project; *Comprehensive SCI management: the issue of lifelong care and follow-up* and Gunilla Åhrén (Sweden) talked about the project on *Information-gathering project on resistant bacteria in connection with SCI*.

ESCIF Congress 2014

The ESCIF Congress and Assembly of Delegates 2014 will be held in De Rijp in the Netherlands. The theme of the ESCIF Congress is *Healthy Ageing: what can be done?*

More information will be available on the ESCIF website and on the congress website in the autumn this year.

Next year's hosts are the Dutch Spinal Cord Injury Association. You may recognise some of the faces below – you can be sure that you will see them next year in De Rijp!



The Dutch contingent in Lüzern 201

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

