

Newsletter June 2011

Dear Colleagues

It was really super to see so many of you at the ESCIF Congress in De Rijp last month. According to the “official” figures from the organisers, over 90 people attended the meeting.

Once again I can only praise our colleagues from the Netherlands for arranging an exciting and interesting programme – in somewhat unusual, but highly accessible, surroundings! Feedback from the delegates, the speakers and other guests was overwhelmingly positive. If you weren't able to join us, you can read more about the meeting and access the presentations on the ESCIF website.

Winnifred de Moes was uncontested in the election to the Executive, so we are very pleased to have Winnifred as our Vice President for a further four years.

As announced in De Rijp, next year's Congress will be hosted by the Italian organisation FAIP in Tuscany. We would like to thank Pietro Vittorio Barbieri from the ESCIF Executive for leading this initiative. Read more details in this newsletter.



By the way, I hope that you have all had a chance to look at the new section on the website that provides information about “unproven therapies” and about serious clinical trials in the area of regenerative research. This section has already stirred a great deal of interest in the SCI community and has received much praise from SCI consumers and professionals alike.

The Executive is already working on the activities and issues discussed in De Rijp but we are also looking forward to the summer holidays – as we know you are!

This newsletter contains a few requests for assistance (cries for help!) that we hope you will consider carefully and respond to as soon as possible.

We wish you all an enjoyable and relaxing summer.

On behalf of the ESCIF Executive

Regards

Jane

Jane Horsewell ESCIF President
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ESCIF Congress 2012

ESCIF Congress 2011 in de Rijp, the Netherlands

Welcome to the
2011 ESCIF Congress and
Assembly of Delegates
18 – 20 May
in The Netherlands.



A report from the Congress is available on www.escif.org and the speakers' presentations can be downloaded.

Further information about the Assembly of Delegates will be uploaded soon.

But the formal part of the annual ESCIF meeting is only one aspect of our yearly "get-togethers"! Another (perhaps just as important) aspect is the

chance to meet and update each other, to discuss and exchange ideas. We are rather good at this!



Many thanks to Igno van Heijst for the photos!

Nordic Spinal Cord Society (NoSCoS) meeting 2011



The Nordic Spinal Cord Society (NoSCoS) will hold their biannual meeting in Gothenburg this coming autumn. ESCIF will host a hearing on the benefits of

centralisation of SCI treatment and rehabilitation. Jane Horsewell will chair the hearing and Gunilla Åhrén will present the ESCIF policy on centralisation and the findings of the policy working group. Antti Dahlberg from Finland will describe the process that led up to the recent decision taken by the Finnish parliament to centralise care for SCI people in the country. Professor Fin Biering-Sørensen from Denmark and ISCoS, Axel Brattberg and from Sweden has been invited to join the panel discussion.

The abstract submitted by the SCI research working group has also been accepted by the conference organisers: *Regaining functionality following a spinal cord injury (SCI): unproven therapies v. clinical trials and regenerative research*. The paper will be presented by Corinne Jeanmaire in a plenary session.

For more information about the NoSCoS meeting go to www.noscoss2011.com.

International Spinal Cord Society (ISCoS) meeting 2011



As a further step towards promoting a global network of SCI consumers, Jane Horsewell and Frans Penninx (from the Dutch Association) attended the joint

meeting of The American Spinal Injury Association (ASIA) and the International Spinal Cord Injury Society (ISCoS) in Washington DC in June. Here they invited conference delegates to a meeting to discuss this ESCIF initiative in the hope that they could enlist the support and assistance of active SCI consumers from the US and Canada. The efforts seem to have been successful as many useful contacts were established.

The next hurdle is to raise funding and sponsorship for the project. Several contacts have already been made and Jane and Frans are optimistic that plans to launch the global network at the ISCoS meeting in London next year will go ahead.

Quality in SCI rehabilitation

We intend to formulate a policy statement on Quality in SCI rehabilitation based on our workshop discussions in De Rijp. The working group consists of Jane Horsewell, Gunilla Åhrén and Frans Penninx. The group is in the process of sifting through the notes and input from the workshops, and will draft the document after the summer. It will then be sent to ESCIF members for discussion and comment. We expect the final version to be endorsed by the Assembly of Delegates at next year's Congress.

Survey on social service systems

The organisation ParaCENTRUM Fenix, Brno has carried out a brief survey on the differences between social service systems in ESCIF countries as a link in its efforts to influence legislation in the Czech Republic.

At the Congress in De Rijp, the delegates from ParaCENTRUM Fenix presented the preliminary results of the survey and encouraged member organisations who had not responded to the questionnaire to do so.

Please contact Lia and Vojtech at vasicek@paracentrum-fenix.cz.

Changes to the ESCIF Statues

The Executive will address a revision and update of the federation's Statutes in order to bring these in line with the current situation. The main issues are eligibility for membership of ESCIF and voting rights.

We would, however, appreciate help from our member organisations. As we asked at the last Assembly, would you read the Statutes carefully and consider any other changes you feel could be relevant? The Statutes can be read on www.escif.org.

Please send your suggestions to Urs Styger at secretary@escif.org as soon as possible so that we can include them in our discussions at the next meeting of the Executive in September.

Information-gathering project on MRSA

We are gathering background information on MRSA from different experts in the area to be able to formulate a survey study. We will start contacting you in the autumn after the summer holidays.

ESCIF Congress 2012

Our host for the Congress and Assembly of Delegates 2012 is FAIP the Italian SCI umbrella organisation. The meeting will be held from 23rd to 25th May 2012 at the holiday centre I Girasoli di Lucignano which lies 40km from Siena in the heart of the Tuscan countryside.



You can view the venue at www.igirasoli.ar.it.