

## Newsletter June 2014



Dear ESCIF colleagues

It seems a very long time since we last met in person – usually we would have seen each other at the annual ESCIF Congress by now! Still, I am sure that we are all looking forward to the Congress in De Rijp at the end of August.

We have received registrations from most member countries ... as well as some guests from US and Australia! Our Dutch hosts have put together a very interesting programme with a good combination of expert speakers (both SCI professionals and consumers). I am sure that we will all learn something that we can use in our own lives – and in our organisations for the benefit of our members.

If you haven't registered yet but would like to take part, please visit ESCIF website [www.escif.org](http://www.escif.org) as soon as possible. Don't miss the final deadline for registration which is 15 July 2014.

Looking forward to seeing you all soon – in the meantime I wish you a pleasant and relaxing summer holiday.

On behalf of the Executive

Jane

Jane Horseywell  
ESCIF President  
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[www.escif.org](http://www.escif.org)

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## ESCIF Assembly 2014 in De Rijp



### Elections

As we wrote in the special "Congress Newsletter" that was sent to you earlier this year, three positions in the Executive are up for election; the President and two board members. We therefore call for nominations to the Executive from all member organisations of ESCIF. We would appreciate it if you could send a short presentation of the person(s) you wish to nominate.

The election for the position of President is held as a "separate" election; the two positions as board members will be awarded to the two candidates who receive the highest and next highest number of votes among the candidates who are nominated. When you send your nominations, please make sure that you state clearly whether your candidate is standing for the position of president or as a board member.

The presentations of your candidates (and those who are standing for re-election) will be sent out together with the notification of the Assembly that will be sent to all the delegates at least six weeks in advance of the Assembly. Please send the presentation to Urs Styger, [secretary@escif.org](mailto:secretary@escif.org).

Please remember that if you are unable to attend the meeting, the ESCIF Statutes, allow you to send a "Power of Attorney" to a delegate from another organisation who can then vote on your behalf.

*Art. 7*

*In case of inability to attend an assembly of delegates, a member country may authorise another delegate association to vote on their behalf. A member association however may represent only one other member association through such authorisation.*

## Members' input

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We are very pleased that we have received requests from four member organisations to present their projects/activities during this session. We look forward to hearing from the Netherlands, Croatia, UK and Spain!

## Registration

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**Registration for the congress closes 15 July!**

### Projects:

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

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During the Assembly of Delegates last year, the Executive proposed this project in the presentation of "Future activities". The funding for the project has just fallen into place. Coloplast has agreed to provide the majority of the financial support and ESCIF can supplement this.

Details of the project will be forwarded to all member organisations later this month. It is essential that you react promptly if you would like to be involved. Involvement in the project will not cost you or your organisation anything – except time and hard work!

## End Paralysis Foundation

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a few years ago. If you haven't met her, you will have the opportunity in De Rijp where she will make a presentation on the very first day!

Corinne has recently launched a new foundation dedicated to the promotion and funding of SCI regenerative research projects.

As the ESCIF Executive proposes that ESCIF is named as a partner to this new foundation – and delegates will be asked to vote on this during the Assembly – it would be good if you could look at the website [www.endparalysis.org](http://www.endparalysis.org)

Many of you will already have met Corinne Jeanmaire who has been the mainstay of the ESCIF research group since it was started

## Global SCI consumer survey on participation in clinical trials

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This survey was launched as a follow-up to a workshop held at the ISCoS meeting in Istanbul last year. The aim of the workshop was to identify and discuss the problems that researchers face when enlisting SCI consumers to take part in international research projects and clinical trials. Jane Horsewell gave a presentation that approached this problem from the perspective of the consumer.

It was decided to carry out two surveys – among SCI consumers and a second among SCI researchers. The deadline for the consumer survey is 31 July 2014. Please read the news item on [www.escif.org](http://www.escif.org) and complete the survey – and forward the information to others in your organisation. The short questionnaire can be accessed on this link [www.surveymonkey.com/s/sciclinicaltrialssurvey](http://www.surveymonkey.com/s/sciclinicaltrialssurvey).

Information was sent to ESCIF members earlier this year but the response has not been very good. This is the first time that we have attempted to carry out a worldwide survey among SCI consumers – please help us to make it a success.

To see more about the workshop last year see one of the following websites:

ISCRR webpage:

[www.iscrr.com.au/news/events/iscos-2013-annual-scientific-meeting.html](http://www.iscrr.com.au/news/events/iscos-2013-annual-scientific-meeting.html)

RHI webpage:

[www.rickhanseninstitute.org/sci-resource/publications-60/news-archive/433-iscos-workshop-international-collaborations-the-way-of-the-future](http://www.rickhanseninstitute.org/sci-resource/publications-60/news-archive/433-iscos-workshop-international-collaborations-the-way-of-the-future)

If you have any queries you are very welcome to contact Jane on

[president@escif.org](mailto:president@escif.org)

## **Dutch SCI Association appoints Professor in SCI Rehabilitation**

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DWARSLAESIE  
ORGANISATIE  
NEDERLAND

As of May 1st 2014, Dr. Marcel Post is appointed at the University of Groningen as special Professor of Rehabilitation Medicine, particularly rehabilitation of people with spinal cord injury, at the Department of Rehabilitation Medicine of the Faculty of Medical Sciences in the University Medical Center Groningen. Dwarslaesie Organisatie Nederland (the Dutch SCI Association) established this chair in collaboration with De Hoogstraat Rehabilitation Center.

SCI rehabilitation in the Netherlands is of high quality, but the SCI research deserves further impetus. Hence the Dutch SCI Association has taken the initiative to come to the appointment of a special professor, partly as a "spider in the web" of the SCI research in the Netherlands. The research area of this new professor involves the rehabilitation of people with SCI, their social functioning and quality of life. The research will focus in particular on the multidisciplinary treatment of physical / mental problems and the impact on partners and family members, the employment situation and wellbeing of people with SCI. The new professor will cooperate with the SCI rehabilitation professionals united in the Dutch Flemish Spinal Cord Society (part of ISCoS) and the research network Spinal Cord Injury Investigation Network

Netherlands, which has been operating for over ten years as a partnership of researchers, clinicians and people with SCI.

There are more countries in Europe where such professorships exist (a.o. in Denmark) but maybe more ESCIF members could try to follow this example. As it offers an additional impetus towards cooperation with the SCI professionals/researchers and increases the involvement in SCI research.

### Contact person e-mail address

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ESCIF has contact information to all members. We use this to send all kind of official information. We would like to get an e-mail address to a contact person that we can use to send out more informal and important information like membership fee and congress registration. This is to make sure that this information doesn't get lost among other mails that are being sent to an info-mail address.

Please, send in an e-mail address to your contact person to Urs Styger, [secretary@escif.org](mailto:secretary@escif.org).

### Future ESCIF Congresses

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The ESCIF congress 2015 will take place in Brno in the Czech Republic 20 – 22 May. Para CENTRUM Fenix is the host and the congress will be held at Maximus Resort Hotel Brno, [www.maximus-resort.cz](http://www.maximus-resort.cz).

FAIP - Federazione Associazioni Italiane Para-tetraplegic has just informed the Executive that they are interested in organising the ESCIF congress 2016. Other member organisations have previously expressed interest in hosting the Congress in 2016 - if they are still interested they should contact Urs Styger as soon as possible.

If your organisation are interested in organising any future congresses don't hesitate to contact the Executive by mailing to Urs Styger, [secretary@escif.org](mailto:secretary@escif.org).