

Newsletter October 2010

Dear Colleagues

Since the congress in Lobbach in May, the members of the Executive have been busy with plans for the coming year. The congress in 2011 has been arranged and the speakers invited; the ESCIF website is undergoing a major "face-lift" and will include some new features intended to improve our internal communication; the new working group on research and information has already sifted through a great deal of information on "unproven therapies" that will go online as soon at the new website is ready.

The Executive held a meeting in September in De Rijp in the Netherlands. This is the venue for next year's congress and I can assure you that our Dutch colleagues have chosen avery accessible and friendly meeting place.

The congress organization team has put together a very exciting programme – so I am sure that we are going to have a fantastic few days there next May!



At the meeting, it was decided that Winnifred de Moes (ESCIF Vice President) should attend the annual meeting in the European Disability Forum later this autumn. ESCIF became a member of EDF almost a year ago but, as yet, we have not participated in any of the EDF meetings or events. Winnifred has promised to write a short report for the ESCIF website.

I am busily preparing for the International Spinal Cord Society meeting in New Delhi at the end of October. Coloplast has sponsored a workshop on "consumer organizations" and has asked me to chair the workshop. In addition to this, the *International Perspectives on Spinal Cord Injury* group is holding an invited workshop to discuss the first draft of the report. Following the conference there is a two-day workshop for SCI healthcare professionals in the Asian region and I have been invited to give a paper on *"Community inclusion".* I am, of course, delighted and honoured to participate – and I will certainly report back to you all.

In the meantime, keep an eye on the website and remember to send us any news of activities in your organizations.

On behalf of the ESCIF Executive Regards to you all Jane

Jane Horsewell, ESCIF President email: president@escif.org



Contents

New Website

ESCIF Congress 2011 in de Rijp, The Netherlands

Members' questionnaires

Identify key people

Call for ideas and happenings

Confirmation of receipt of the ESCIF newsletter

Release dates for ESCIF newsletter



New Website

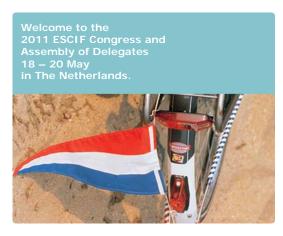
A new ESCIF website will soon be launched. The new website will look slightly different from the old one and will contain more interactive functions. The idea is to create a more accessible website which is easy to navigate.

One of the new functions will be a website modification system which enables members of the Executive to change the information on the website more easily. We hope to get a more "lively" website which keeps up to date with all the latest news.

Later we hope to add a forum for all ESCIF members. This will improve our opportunity to communicate good ideas, interesting topics of concern to all, SCI related problems etc. between ESCIF member countries and with the Executive.

Stay tuned-in at <u>www.escif.org</u> for the latest updates!

ESCIF Congress 2011 in de Rijp, the Netherlands



The 6th ESCIF Congress will take place 18 – 20 May 2011 in de Rijp in the Netherlands. This little town is located 30 km north of Amsterdam. It is the first time that the ESCIF Congress will visit the Netherlands.

The theme of the Congress is "(Proven) Quality of SCI Rehabilitation". The programme consists of many interesting aspects of quality issues with regard to SCI. It

will also give room for interactive workshops to enable ESCIF to set a new agenda for increasing the quality of life for people living with SCI by considering our demands to quality in rehabilitation.

Please visit the ESCIF Congress 2011 website for further information and registration, <u>www.ESCIFcongress2011.nl</u>



Members' questionnaires

Over the past couple of years, ESCIF has been trying to gather and update information about its member organizations. We have sent out a questionnaire with the ESCIF newsletters and also direct to the contact person listed in the register of members.

It is important for ESCIF to know its members. The information will help us to direct our efforts and to make sure that the members gain the most from their membership of ESCIF. It is also important that we can give an accurate picture of how SCI consumers are organized within Europe to those people and organizations we wish to work with and to influence - in different areas of concern for people living with SCI.

We still lack questionnaires from some members. We therefore urge you to send in your questionnaire to ESCIF's secretary Urs Styger at <u>secretary@escif.org</u>. If you are unsure of whether you have sent in your questionnaire or if you need a new questionnaire, please don't hesitate to contact Urs.

Identify key people

ESCIF is becoming more and more recognized as an organization that many consumers and professionals listen to. But we do not want to rest at that. We want more people within and outside of Europe to know about us and listen to us. It is important in our quest to "set the SCI agenda in Europe".

We therefore urge you all to send us the names and contact information of key people in your country, in Europe and the rest of the world who you think might benefit from information from and about ESCIF, or that ESCIF and your own organization might benefit from. These could be people in NGO's, in national Parliaments, the EU Parliament, EDF and other European organizations, SCI health professionals and so on.

Please send in your list of key people to ESCIF's secretary Urs Styger at <u>secretary@escif.org</u>. The contact details should be as accurate as possible and, most importantly, should include the person's email address.



Call for ideas and happenings

The ESCIF statutes state that we shall work towards

- the formation of closer relationships between the individual national SCI parent organisations
- the exchange of information

On the ESCIF website it says that:

The vision of the federation is to improve the quality of life of people in all parts of Europe who are living with a spinal cord injury.

This will be achieved through:

• The exchange of information, experience and knowledge The pan-European network will facilitate this exchange and will work to ensure that information is available to all those living with a spinal cord injury, irrespective of country.

To achieve this goal we need the help from every member organization. Please send in any ideas and projects your organization is working on or information on activities or happenings in your country. The information can be posted on the ESCIF website and/or in the ESCIF Newsletter.

Confirmation of receipt

It has come to our knowledge that not all members receive this Newsletter. It might be because we have the wrong contact person in your organization or that we have an incorrect email address. Since it is very important that your organization gets the latest updates from ESCIF, we would ask you to send an email confirming that you have received this Newsletter to ESCIF's secretary Urs Styger at secretary@escif.org. We will make an effort to contact all the member organizations that we do not hear from to ensure that they get information in the future.



Release dates for ESCIF newsletter

In future we plan to send out ESCIF Newsletters on a more regular basis - in January, April and June. Please remember to send in ideas and announcements and/or reports of happenings and activities in good time so that we can be sure to include these in the Newsletter. Send the information by email to <u>secretary@escif.org</u> and include "Newsletter input" or similar in the subject line.

Thank-you!

Regards ESCIF Executive

If you need to contact the ESCIF executive or speak to ESCIF secretary, Urs Styger, you will find the contact details on the website.