

Newsletter January 2011

Dear Colleagues

First of all, the ESCIF Executive – Winnifred, Jani, Gunilla, Pietro, Urs and I – would like to wish you all “Happy New Year” and a very healthy and successful 2011! The Christmas holidays in many parts of Europe and Scandinavia presented huge challenges for those who had to travel long distances to be with their families and friends – I hope that you all managed to battle through the snow and ice to enjoy the holidays with your loved ones.

I hope too that you have taken the opportunity to visit the ESCIF website. Although the work of updating and upgrading the site is not completely finished, significant improvements have already been made. Not least, the website provides a link to the ESCIF Congress 2011 website where you can read about the programme and speakers, and where you are able register online. Please note that you and your organisation can save money by registering early!



Please remember that your organisation is welcome to publicise events and activities on the ESCIF website. Even if the events are not “open” to participants from other countries, we can always learn from and be inspired by reports of national initiatives.

I feel confident that my participation in the International Spinal Cord Society meeting in October served to raise the profile of ESCIF among both SCI healthcare professionals and consumers. The “consumer workshop” sponsored by Coloplast, where we discussed the potential benefits of a global SCI consumer network, attracted a large audience and provoked a positive discussion. At a meeting following the workshop, an informal collaboration was forged between ESCIF and the Asia Spinal Cord Network (ASCoN). We intend to follow up this initiative in the coming year. You can read a report on the workshop and see the presentations of the panel members on www.escif.org.

Since our meeting in De Rijp in September, the Executive has been in regular contact by telephone and email. Later this month we are holding a real – as opposed to virtual – meeting to discuss the status of current activities and future plans.

On behalf of the ESCIF Executive

Regards to you all

Jane

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

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ESCIF Congress 2011 in de Rijp, the Netherlands

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



The 6th ESCIF Congress will take place during 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 areas in regards 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.

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

Publication of IPSCI delayed

On the third day of the ISCoS meeting in New Delhi, the editors of *International Perspectives on Spinal Cord Injury*, Jerome Bickenbach and Per von Groote, held a closed workshop to discuss the first full draft of the IPSCI report. Around 20 SCI professionals and SCI consumers who had contributed to the report spent the day discussing and making proposals for revisions, changes and additions to the content of the draft.

Alana Officer from the World Health Organisation announced that the publication of IPSCI would have to wait until the WHO *World Report on Disability* had been released. The publication date for WRD has now been set for 9 June 2011 – so tentative plans are being made to publish IPSCI in late autumn.

Despite this setback, Per von Groote will still speak at the ESCIF Congress in May.

Progress in Finland on centralisation issue

The Minister of Health and Social Services in Finland, Paula Risikko, has confirmed that the future treatment, rehabilitation and follow-up care of people with SCI will be centralised in three units.

The chairman of the Finnish SCI consumer organisation, Jukka Kumpuvuori, commented that the new organisation will, at first, only apply to persons with traumatic spinal cord injuries but added "still ... a huge step forward".

Read the Minister's email to ESCIF's President on www.escif.org.

Excellency Diploma Awarded in Romania

In 2010 the Romanian Society for Neurorehabilitation (a member of the World Federation for Neurorehabilitation) and the Romanian Spinal Cord Society, both co-founded and headed by Professor Gelu Onose, were awarded the Excellency Diploma by the Romanian Medical Association (RMA). The RMA integrates the majority of Romanian medical scientific and professional societies.

The Excellency Diploma was awarded to both organisations in recognition of their work and achievements in rehabilitation. Some of the achievements include the co-organisation of two National Conferences in Neurosurgery and Neurorehabilitation with international participation, the 6th Congress of the Academy for Multidisciplinary Traumatology, 3rd International Conference on Biomaterials and Medical Devices, and the provision of professional support for a national health programme providing four free catheters per day for intermittent catheterisation to all neurogenic bladder patients in Romania.

5th International Smiling Child Festival

The Spinal Cord Paralytics Society of Turkey have been organising International Smiling Child Festival since 2006.

They are looking for participants for the 5th International Smiling Child Festival. If you are interested in attending this festival, please contact them by e-mail, havvedasolak@gmail.com or basramazan@hotmail.com.

For further information about the Spinal Cord Paralytics Society of Turkey and International Smiling Child Festival please visit: www.smilingchild.com.

Information-gathering project on MRSA

ESCIF intends to launch an information-gathering project on MRSA (Meticillinresistant Staphylococcus aureus). The reason is that MRSA is fast becoming a problem for the health care system in Europe and all over the world. People living with SCI have an increased risk of getting MRSA. It is important for ESCIF, as a consumer organisation, to know how the different countries in Europe address this problem and how they treat people with SCI.

International Spinal Cord Society (ISCoS) meeting 2010

The International Spinal Cord Society (ISCoS) annual meeting was held in New Dehli. Coloplast sponsored a consumer workshop that was chaired by the president of ESCIF, Jane Horsewell. The workshop was attended by a great number of people and was very well received. Read the full story on www.escif.org.

EDF News

ESCIF is a member of European Disability Forum (EDF). As members we receive a lot of important news regarding disability. Not all of the news items are of direct interest to people living with SCI. ESCIF will select, post and comment on the news interesting to our members on the website. Please visit www.escif.org for further information.

Reminder of Members' questionnaires

In ESCIF Newsletter October 2010 we urged you to send in the members' questionnaire. Unfortunately few of you answered our call for this information. We therefore urge you once more to send in the questionnaire.

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.

Send in your questionnaire to ESCIF's secretary Urs Styger at secretary@escif.org. 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.

Reminder to Identify key people

In ESCIF Newsletter October 2010 we asked you to send us names and contact information of key people in your country. So far we have received very few. We therefore urge you once more to send us the names and contact information of key people in your country, in Europe and the rest of the world that you think might benefit from getting information from ESCIF, or that ESCIF and your own organisation might benefit from. They can be people in NGO's, in National Parliaments, EU Parliament, EDF and other European organisations, health professionals and so on.

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

Confirmation of correspondence

In ESCIF Newsletter October 2010 we asked you to send an e-mail to ESCIF to confirm that you receive this Newsletter so as to ensure that your organisation gets the latest update from ESCIF. We have received very few confirmations unfortunately. We will therefore make an effort now to contact all the member organisations that we didn't receive a confirmation from to ensure that they get information in the future.

Release dates for ESCIF newsletter

The coming ESCIF Newsletters are planned to be sent out in April and June. Remember to send in good ideas and happenings in advance to make sure that you will get these in the Newsletter.