

## Newsletter February 2013



Dear Colleagues

Traditionally, this was the time to wish family, friends and colleagues "A happy and prosperous New Year".

Unfortunately, the present economic crisis casts doubt on the chances for "prosperity"! Most of ESCIF's member organisations are facing huge challenges in funding their activity levels and in striving to improve, or even retain, the standards of treatment, care and services for their

members.

We can all expect that 2013 will be a very busy year – let's hope that it will also be a very successful year! Please remember to share your ideas and experiences with your colleagues in ESCIF – I am sure that we can offer each other invaluable support.

The ESCIF Executive is busy planning various projects and activities for the coming year – not least, the Congress and Assembly of Delegates in June. You can read more about these in this Newsletter and on the website.

Our very best wishes to you all!

On behalf of the ESCIF Executive

Jane

Jane Horseywell  
ESCIF President  
Email: [president@escif.org](mailto:president@escif.org)

## Content

ESCIF Congress and Assembly of Delegates 2013

On-going ESCIF project:

*Information-gathering project on resistant bacteria in connection with SCI*

New ESCIF project:

*Comprehensive SCI management: the issue of lifelong care and follow-up*

ASCoN 2012 Conference, Kuala Lumpur, Malaysia

6th Coloplast SCI symposium

ISCoS 2013

ESCIF Congress and Assembly of Delegates 2014

## ESCIF Congress and Assembly of Delegates 2013

---



As mentioned in the last Newsletter, the theme, the dates and the venue for the ESCIF Congress 2013 have been decided!

We will be returning to Nottwil in Switzerland ... where ESCIF was founded in 2006. The theme for the Congress is *Living with SCI: communication, information and learning*. We will be looking at various communication and information sources that are available (or that soon will be available) to people in the SCI community. Delegates will have the opportunity to be shown around the Swiss Paraplegic Centre in Nottwil; an SCI treatment and rehabilitation centre that is widely regarded as being one of the leading centres in Europe.

The congress will start in the late afternoon of Wednesday 5 June 2013 and will finish at the same time on Friday 7 June 2013. Although restaurant prices and accommodation costs in Switzerland are relatively high, we have done our best to keep the costs for delegates' participation in line with previous years.

Congress Costs are:

€200 per delegate and per her/his personal assistant

€275 per participant of a member organizations and per her/his personal assistant

€275 per patron member and per her/his assistant

€350 for any other participant and his/per personal assistant.

Registrations received after 15 March 2013 will be subject to an additional administration fee of € 50 per person.



Visit the congress website [www.escifcongress.org](http://www.escifcongress.org) for further details – and to register.

### **Call for members input**

During the afternoon program on Friday, June 7, we invite members to give a presentation about a new project in their country that might be of interest or inspiration to other member organisations. The presentation should not exceed 10 minutes. The ESCIF Executive must be notified in advance.

If your organisation would like to give a presentation, please send your abstract to Winnifred de Moes, [vice-president@escif.org](mailto:vice-president@escif.org). Due to time pressure, all presentations must be given in English.

### **On-going ESCIF project: *Information-gathering project on resistant bacteria in connection with SCI***

---

The web-based survey on Meticillinresistent Staphylococcus aureus (MRSA) and bacteria, e.g. E.coli and Klebsiella, and bacteria in the bowel, e.g. E.coli and Klebsiella that produce extended spectrum betalactamases (ESBL) with resistance to third generations cefalosporins or those with carpanemases or other resistance genes causing carbapenem-resistant enterobacteriaceae (CRE, called ESBLcarba in the Nordic countries) in connection to SCI is now well underway. The e-mail with the log-in information has been sent out to the respondents, the SCI units in Europe. They now have until 28<sup>th</sup> February to answer the survey.

A report will be presented at the ESCIF congress in Nottwil. ESCIF also plans to present the Scandinavian part of the survey at the NoSCoS congress in Finland and the results of the whole survey at the ISCoS congress in Turkey.

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. If you think that your organisation or country isn't

represented in the survey please do not hesitate to contact Gunilla Åhrén at [1stexecutive@escif.org](mailto:1stexecutive@escif.org).

### **New ESCIF project:**

### ***Comprehensive SCI management: the issue of lifelong care and follow-up***

---

Since the endorsement of the ESCIF policy on the treatment, rehabilitation and lifelong care of people with SCI, ESCIF has elaborated the views and demands expressed in this policy; notably in the report on centralisation, released in 2010, and the statement on quality in SCI rehabilitation that was published and endorsed by the Assembly of Delegates last year.

All previous policy statements and reports have emphasised the importance – for SCI consumers in Europe – of lifelong care, follow-up and monitoring. ESCIF regards this as an essential part of the comprehensive management of spinal cord injury.

Lifelong care, follow-up and monitoring are not practised in all ESCIF member countries; problems of infrastructure and geography are frequently cited as reasons. In countries where lifelong care, follow-up and monitoring has been standard practice earlier, some ESCIF members fear that this is now being threatened by the effects of the economic crisis and cutbacks in healthcare.

The aims of the project are:

- To define/describe the purposes of lifelong follow-up of SCI
- To identify and describe the benefits of lifelong follow-up – from various vantage points – including the person living with SCI, SCI professionals, health service providers and social/welfare services
- To identify the minimum/ideal components of SCI follow-up and their frequency (in order to establish benchmarks), and where these should be carried out (GP, local hospital, specialised units etc.)

- To define the often cited “problems” – lack of infrastructure, geography, financial constraints etc.
- To address the problems by
  - presenting selected case studies of current systems
  - considering alternative systems involving e.g. use of new technology/internet, “telemedicine”
- To draw up a policy statement that takes account of the above and that can be used in ESCIF member countries as leverage in order to
  - sustain the present system
  - improve the present system
  - introduce and organise a system of lifelong care, follow-up and monitoring where this does not exist.

The members of the working group are Antti Dahlberg (Finland), Colm Whooley (Ireland), Frans Penninx (Netherlands) and Jane Horsewell. The group would greatly appreciate input/information from ESCIF members in other countries. Please contact Jane Horsewell on [president@escif.org](mailto:president@escif.org).

The group will present its preliminary findings in Nottwil.

## ASCoN 2012 Conference, Kuala Lumpur, Malaysia

---



Asian Spinal Cord Network

The 11th annual Asian Spinal Cord Network (ASCoN) Conference was held November

29th – December 2nd, 2012 in Kuala Lumpur in Malaysia and was a great success. This conference brought together around 400 SCI professionals and 40 people living with SCI from Asia, Australia and the rest of the world. Frans Penninx attended the conference on behalf of the Global SCI Consumer Network.

The conference focused on the professional development of healthcare personnel involved with SCI care, the development of appropriate services for people with SCI and updates on current advancement in SCI care and prevention. During all four conference days there were dedicated sessions for people living with SCI. There were consumer workshops for three days and one day was dedicated to an active rehab camp and wheelchair games at a special venue. Sometimes the rooms where the consumer workshops was held was too small because quite a few SCI professionals also attended these workshops on 'Psychosocial Adjustment to SCI', 'Sexuality and Fertility after SCI', 'Consumer Networks', 'Peer training for Family Caregivers' and 'Experimental Treatments for SCI, What you should know'.

The workshop 'Consumer Networks' provided the opportunity for the ASCoN Consumer Network and other SCI consumer representatives from Australia and Europe to meet and progress the objectives of the Global SCI Consumer Network. People with SCI from Bangladesh, India, Malaysia, Nepal, Thailand, Sri Lanka, Australia, the Netherlands and Poland shared their national information and experiences. Sharing information regionally and globally was viewed as being a key to maintaining communication between organisations for people with SCI and providing updates on – for example – medical developments, travel information, advocacy, UNCRPD, insurance and employment issues. Identifying the right people to represent SCI consumers was considered an essential step in maintaining open communication between SCI organisations which will form the Global Network. It was suggested that a group of ambassadors be nominated who would maintain information flow between Network members and stimulate conversations and motivate developments in the SCI sector.

Key issues which members felt the Network should focus on:

- Implementation of UNCRPD – despite ratification at country level the evidence of impact on daily living of consumers particularly in low resource countries is negative. Survival of SCI consumers who are extremely poor is highly unlikely. The question was asked on how to get the support of national governments in

order to support activities and legislative changes that have real impact on the health and wellbeing of consumers.

- Body of evidence – as a network it is important to build a body of evidence of fulfilment and denial of rights. Each country should be responsible for providing information for the database where actions have been taken. Examples were put forward from Malaysia where developments have taken place on insurance issues.
- Fundraising – how to improve this at a national, regional and international level.

It was agreed that the most effective use of members' time and commitment would be to have a concrete set of actions to complete before the ASCoN conference next year in Vietnam. Members were asked to put forward suggestions to Shivjeet Raghaw before leaving the conference and these would then be collated and agreed upon.

## 6th Coloplast SCI symposium

---

The 6th Coloplast symposium was held in Barcelona on 18 and 19 January 2013. The theme this year was *Current topics on prevention of SCI and its complications*. More than 450 invited guests attended the event, together with representatives from Coloplast, from all over Europe – and as far away as China. The international composition of the audience was matched by that of the faculty; speakers from Europe, USA, Canada and Australia contributed to the scientific programme.

The meeting in Barcelona also witnessed the launch of Coloplast's newest product. Lars Rasmussen, the CEO of Coloplast, presented the Speedicath Compact Set; a compact (i.e. telescopic) catheter with an integrated and sterile bag. The set is available in both female and male versions.

For further details of the symposium, please visit [www.escif.org](http://www.escif.org)



## ISCoS 2013

---

The annual scientific meeting of ISCoS will take place in Istanbul on 27 – 30 October.

Once again ESCIF has been asked to arrange the SCI consumer workshop that will form part of the scientific programme of the meeting.

In collaboration with ESCIF's member organisation in Turkey, TOFD, we have developed a proposal for a workshop that includes both presentations and a panel discussion on the following topic: *Organisation of SCI treatment, rehabilitation and follow-up: are ideas and models developed in high-resource countries relevant to medium and low-resource countries?*

The session will be chaired by Jane Horsewell and Ramazan Bas (the president of TOFD).

## ESCIF Congress and Assembly of Delegates 2014

---

The dates for the congress in 2014 in the Netherlands will be 27 - 29 August 2014. The reason that the Congress has been moved to August is because the ISCoS 2014 congress will be in the Netherlands and takes place on 2 - 4 September 2014.

The organisations that organise the two congresses are cooperating and by matching the dates of both congresses we hope that more people will be able to attend both congresses.

**Please save these dates: 5 – 7 June 2013  
and 27 – 29 August 2014!!**

Remember to visit [www.escif.org](http://www.escif.org) or scan the QR-code for the latest up-date!

