

Newsletter October 2012



Dear Colleagues

At last, an update on the activities within ESCIF over the past few months! And there have been quite a few, as you can read in the following pages.

But first of all, many thanks to the organising committee from Federazione Associazioni Italiane Paraplegici (FAIP), who worked so hard to prepare an extremely interesting programme for the congress in May. Thanks too for giving the ESCIF delegates and other participants the opportunity to experience a wonderful few days in the Tuscan countryside!

ESCIF was very involved in the ISCoS meeting in London in September; in organising the first consumer workshop at the scientific meeting; in the launch of the Global SCI Consumer Network; in the panel of the Coloplast symposium and in the launch of elearnsci.org – a new educational initiative from ISCoS.

On behalf of the ESCIF Executive

Regards

Jane

Jane Horseywell ESCIF President

Email: president@escif.org

Content

ESCIF congress in Tuscany, 23 to 25 May 2012

The statement on Quality in SCI rehabilitation

SCI consumer workshop at ISCoS in London

Coloplast symposium on quality of life

Launch of the Global SCI Consumer Network

Information-gathering project on resistant bacteria
in connection with SCI

ESCIF invoices

ESCIF Congress and Assembly of Delegates 2013

ESCIF Congress in Tuscany, 23 to 25 May 2012

ESCIF Congress and
Assembly of Delegates
23 - 25 May 2012
in Italy.



The ESCIF Congress and Assembly of Delegates 2012 was held in Italy, in the village of Lucignano in Tuscany. The setting was beautiful but the theme of the congress *The impact of the economic crisis on people living with SCI in Europe* demanded the full attention of the delegates.

The programme comprised a rather intense exchange of knowledge and experience, introduced by a study commissioned by ESCIF and FAIP and carried out by the research institute INSTUD. The results of the study can be downloaded from the ESCIF website.

In our discussions, we focused on the specific issues of rehabilitation, assistive devices and personal assistance, particularly in countries affected by the crisis (Spain, Netherlands, Czech Republic and Italy). Representatives from our member organisations in these countries gave presentations on the current situation and how people with SCI are being affected by the austerity measures introduced by national governments.

We also invited presentations from representatives of the European Disability Forum, of the Disabled People International and the European Network of Independent Living. This was a new departure for ESCIF as, previously, we have tended to focus upon input from SCI consumers and SCI professionals. This wider perspective provoked some interesting discussions and, among many in the audience, the acknowledgement that in these difficult economic times we should, perhaps, give more active support to general disability issues.

The congress presentations and the report prepared by INSTUD can be downloaded from www.escif.org



Further to the INSTUD report, we are currently working on an ESCIF report that will include the results of the presentations, input and discussions during the congress.

The statement on Quality in SCI rehabilitation

The policy statement on Quality in SCI rehabilitation and management was sent out to members for discussion and comment prior to the meeting. As we had hoped, the final version was endorsed by the Assembly of Delegates on the last day of the congress. The statement is available on the ESCIF website. Please remember to draw the attention of the SCI professionals in your country to this latest ESCIF statement!

SCI consumer workshop at ISCoS in London

The SCI consumer agenda: global perspectives was the title of the consumer workshop devised and led by ESCIF on the first day of the meeting. The workshop was the first independent consumer workshop to be included in the scientific programme of an ISCoS meeting – and we hope that it will be the first of many at future conferences.

The purpose of the workshop was to give SCI consumers from around the world the opportunity to present and discuss current, significant and pressing issues – as they define and identify them – and for SCI professionals to gain firsthand knowledge



Chairing the SCI Consumer

about the priorities of the community they serve. Although the SCI agenda differs in its priorities from world region to world region recent collaboration has indicated that, in fact, core issues are similar.

The workshop gave a unique insight into the issues that SCI consumers prioritise. It



Bathma Krishnan from Malaysia

provided a platform where SCI consumers, professionals and policy makers could meet to exchange experience and ideas – with a view to future collaboration on how to resolve these issues.

Around 90 people attended the workshop which was chaired by ESCIF's President, Jane Horsewell, and co-chaired by the Executive Director of SIA UK, Paul Smith.

The workshop included two presentations from ESCIF. The first was a preliminary report from the 2012 ESCIF congress on the impact of the economic crisis on people living with SCI in Europe. Pietro Barbieri, who is a member of ESCIF's Executive and one of the hosts for the congress, made the presentation. Frans Penninx from our member organisation in the Netherlands and a member of the "quality working group" presented a summary of the ESCIF statement on quality in SCI rehabilitation.



Cyril Siriwardane from Sri Lanka

The presentations from the SCI consumer workshop can be downloaded from the ESCIF website; www.escif.org.

Photos by Leif Aril Fjellheim (LARS)

Coloplast symposium on quality of life

ESCIF's Vice President, Winnifred de Moes, was invited to sit on the panel for the Coloplast satellite symposium at the ISCoS meeting. The topic of the panel debate was quality of life after SCI – with particular focus on the role of such things as personal aids. Choice of catheters played, naturally, a significant role in the discussion and both health and safety factors, as well as design were considered. The urologist Jean-Jaques Wyndaele from Belgium (who is the President-elect of ISCoS and Editor of *Spinal Cord*) was the moderator for the session.

Launch of the Global SCI Consumer Network



We were delighted to welcome both old friends and new to the launch of the Global SCI Consumer Network during the ISCoS meeting in London. ESCIF was well-represented by delegates from UK and Scotland, the Netherlands, Italy, France, Czech Republic, Norway, Sweden, Finland and Denmark; the ASCoN Consumer Network sent representatives from India, Sri Lanka and Malaysia, and was supported by our partners Livability Ireland. The audience of around 60 people included SCI consumers and representatives of SCI consumer groups from the United States, Canada, Australia, Central America and South America. Go to www.globalsci.net to read more about our activities and plans.

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, in the bowel producing Beta-Lactamase with an extended spectrum like Extended Spectrum Beta-Lactamase (ESBL) in connection to SCI is starting this autumn. The members' task will be to identify the SCI units in their country and collect the contact information of the respondents to the survey. ESCIF's task is to collect and analyse the result of the survey. The intention is to present the result at the ESCIF congress in 2013.

In October all the ESCIF members will be contacted by mail. At the ESCIF Assembly in De Rijp 2011 a contact form was passed around. Organisations that were not present or that haven't responded to mails will be contacted at the official mail address. If you think that your organisation isn't represented in the survey please do not hesitate to contact Gunilla Åhrén at 1stexecutive@escif.org.

ESCIF Invoices

The invoice for the ESCIF membership fee is sent out by mail to the official mail address of the member organisations; often the info-mail. If you prefer to have the invoice sent to a different mail address, please let us know. Send a mail to secretary@escif.org with the right mail address.

ESCIF Congress and Assembly of Delegates 2013

In 2013 ESCIF will be returning to Nottwil in Switzerland ... the place where the Federation began in 2006.

The working title for the congress is *Living with SCI: communication, information and learning* – and, as the title suggests, we will be looking at various internet communication and information sources



that are available (will soon be available) for people within the SCI community.

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.

More information will follow later this autumn when we will be launching a congress website – in the meantime, please keep an eye on www.escif.org for updates.

Please save these dates: 5 – 7 June 2013!!