

Report from ESCIF Congress and Assembly of Delegates 2008

The ESCIF Congress 2008 was held in Umag, Croatia from 24 – 26 April. The meeting was a very successful, interesting and lively event, thanks to the very active participation of the delegates and – not least – to the hard work and excellent planning of our hosts HUPT (The Croatian Paraplegic and Tetraplegic Association). ESCIF would like to thank Janko Ehrlich-Zdvořák and Manda Knežević, in particular, and other members and friends of HUPT for making our meeting in 2008 a truly memorable occasion.

The Congress was opened on the evening of 24 April with a welcoming address from Daniel Joggi, the President of ESCIF, and a speech from Manda Knežević, the President of HUPT. (Download 1)

On the following morning, the delegates gathered to consider the issues of spinal cord injury in the senior population and aging with SCI. The first speaker was Professor Zvonko Jejla from the University Hospital in Zagreb who offered what he called “a very personal view” of the question of aging with SCI. This was an extremely interesting lecture based on Professor Zvonko’s long experience of working with persons with SCI. (Download 2)

The next speaker could also claim a wide experience of the consequences of SCI. Dr Gabriele Kirchmair from Austria is not only a physician and researcher, but is also spinal cord injured. Her lecture prompted many questions and a lively discussion. (Download 3)

Finally, Dr Jan Reinhardt from Swiss Paraplegic Research rounded off the morning with a presentation of the literature relating to the social aspects of aging. His very succinct review provided delegates with many references for further reading on this subject. (Download 4)

The afternoon was spent in discussions of the draft of the ESCIF Policy Statement on the treatment, rehabilitation and long-term care of persons with SCI. The decision to formulate a policy statement on this topic emerged from discussions at the ESCIF Congress in 2007. The draft had been circulated earlier and some changes and additions had already been made – but feedback from the member organisations had raised some questions which deserved further consideration.

The first question was whether the policy should include direct references to relevant clauses in the UN Convention on the Rights of Persons with Disabilities. It was finally agreed that an introduction or preamble underlining these connections should be formulated.

A further issue concerned the question of information and advice. All member organisations receive requests for information concerning the value of certain new or experimental treatments for SCI. The policy statement also emphasises the importance of “information” to those who are newly-injured and to their families. How can we ensure that the information and advice we give is accurate and relevant? The general conclusion here was that a statement should be posted on the ESCIF website that could provide some guidelines concerning evidence-based information and advice. In terms of the policy statement, it was agreed that the question of experimental treatment was only one question among many that the

newly-injured confront. Practical, vocational and financial issues are also extremely pertinent and here, it was felt, the organisations were well-equipped to deal with questions or to refer to other who could.

A final and more general discussion hinged upon the scope of the policy statement. Some delegates suggested that the policy statement should include references to, for example, social rights or access to mobility aids and other assistive devices. The overall conclusion was that the present policy statement fulfils its intended purpose and defined scope; it is not comprehensive – and was never intended to be – so that, in the future, work on other policy statements relating to other relevant issues could well be on ESCIF's agenda. At present, however, four groups have been established; these will carry out further work on the policy statement.

On the 26 April the delegates met for the formal Assembly of Delegates which was conducted in accordance with the agenda that had been circulated prior to the meeting.

The ESCIF Policy Statement was accepted after agreement was reached on a few editorial adjustments.

One very important item was the election of a new Treasurer. Adrian O'Donnell, who was elected at the founding assembly of ESCIF, had tendered his resignation. Janez Trdina from Slovenia was elected. Daniel Joggi thanked Adrian for his work in the Executive over the past two years.

Organisations from three countries had applied for membership prior to the meeting; Romania, Montenegro and Bosnia-Herzegovina. Unfortunately, only Romania was able to send delegates to Umag and, because of this, it was decided that Romania should be accepted as a full member of ESCIF while Montenegro and Bosnia-Herzegovina should be offered provisional membership to be confirmed at next year's congress.

After the Assembly of Delegates, the final scheduled item for the 2008 Congress was an update on the collaborative project between Swiss Paraplegic Research and ESCIF *It takes two to tango revisited*. Dr Jan Reinhardt presented the preliminary results from the Swiss pilot study and the modifications to the research plans and methodology for the European study. The delegates accepted the proposed changes. (Download 5)

Jane Horseywell
Vice President
ESCIF