

Update: regenerative research – September 2013

This is the first issue of a “newsletter” prepared by the members of the ESCIF SCI research group that was established in 2011 in order to share information about and to promote regenerative research.

*We hope that **Update: regenerative research** will provide useful information about regenerative research, inspire discussion of the issue – and not least – encourage active promotion of the opportunities offered by this field of research among the members of ESCIF organisations.*

Please feel free to forward this issue to others in your organization who you believe will find it of interest. If you would like to use the material in your members’ magazine, you are also very welcome to do so but please let us know by sending a short mail to research@escif.org.

SCI consumer involvement and regenerative research: embracing the new paradigms.

*Written by Corinne Jeanmaire, on behalf of the ESCIF SCI research group**

Consumer participation has become an increasingly accepted concept in the western healthcare world. When The European Spinal Cord Injury Federation (ESCIF) was founded in 2006, SCI professionals in some European countries asserted that SCI “patients” were not able to lead and run such an initiative. Despite the challenge from ESCIF “*Setting the SCI agenda in Europe*” at the 2009 ISCoS meeting, it took another two years for ISCoS to endorse the proposal that SCI consumers should have the right to organize sessions at their annual meetings.”

The question arises, should the involvement of SCI consumers be limited to sharing experiences, demands and needs to improve quality of life? Should SCI consumers restrict their focus to clinical research aimed at alleviating the health threats and practical difficulties of living with SCI? Although both of these are crucial, the answer must be a resounding “No”! In the same way that SCI organizations in Europe campaign for the prevention of SCI, we must also campaign for the research needed to improve functionality after SCI.

Some consumer organizations already contribute actively to the research that will, one day, enable progressive recovery after a spinal cord injury (SCI) and as SCI consumers we can only support their efforts and encourage them to do more. As consumers, and as the prime actors and determinants of our own lives, we need to make sure that a longer term, structural solution is sought. In other words, we need to express our demands clearly and take action in order to speed up towards a cure!

Efforts to improve the comprehensive management of SCI and, thus, to improve the quality of life for people living with a spinal cord injury is obviously still needed. In many parts of the world even surviving after paralysis is an absolute challenge. However, given current scientific advances, we cannot ignore that some level of functional recovery will also be an option in the future – provided the right priority is given to this target.

Looking at various medical conditions (e.g. ALS, Blindness, Cancer, AIDS...) one realizes that foundations/ patient organizations are becoming increasingly important drivers of biotechnology innovation. To expand the research being conducted for a given diagnosis, foundations are taking a very pro-active approach to funding R&D. In addition, some of them also provide a conduit to clinical expertise as well as potential access to patients and stakeholders, giving a research program a higher chance of translational success.

If we look at SCI, we do have some proactive forces among SCI organisations. We have chosen, within the ESCIF SCI Regenerative Research Group(*), to focus upon some of those organizations/projects that have gone beyond raising awareness and collecting funds. We will, in our coming updates, feature one organization or project – first in Europe and then in other regions in the world. Spinal cord injury is a global condition and we will need global, increasingly collaborative but also target-driven approaches to create better and faster results.

Further to the SCI-focused initiatives and organizations, we will also highlight some organizations (e.g. www.fastercure.org) that work as an enabler to speed up medical research progress in general or some initiatives/projects that are focused on other specific medical conditions (e.g. ALS or AIDS).

Indeed, joining forces and learning from each other is one crucial and prevailing element to ensure a better result; faster access to progressive functional recovery after SCI, and ultimately a cure.

** The ESCIF SCI Research Group was created in 2011 in order to share information about and support regenerative research. Its first activity was to set up a section on the ESCIF website dealing with research, clinical trials ... and unproven therapies. The group has presented its work at the Nordic Spinal Cord Society meeting in Sweden in 2011, and the Interdependence conference in Vancouver in 2012.*

If you have any questions or comments (or any ideas or input for future issues), please send a mail to research@escif.org.

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