Planning a holiday?

Gemma

If, like me, you have a spinal cord injury, or if you care for someone who has, you will know that going on holiday is not as easy as just booking the cheapest package deal you can find!

My name is Gemma and I was paralysed from the neck down in a car crash when I was 7. One year after the accident, my family and I travelled to County Mayo in Ireland. Organising the trip was a nightmare. Before the booking would be accepted, my dad had to travel to the airport with my wheelchair to see if it could be accommodated in the hold. Then, when we arrived at the airport, there was no ambi-lift arranged to get me on the aircraft. Luckily I was only eight and my dad could carry me, otherwise we would have had to cancel the trip. On arrival, the hotel we had booked had no way of accommodating us because they had no rooms on the ground floor and no lift.

The biggest single difficulty I have is cost. Whenever I travel on holiday, I have to take at least two carers and so everything costs three times as much as it would if I was able bodied. The other big problems are the amount of medical equipment I need to take with me and the toilet facilities. On a long flight I will often have to be carried through the cabin two or three times. Then it's a question of luck: some attendants and airlines see you as an inconvenience and make that fact totally obvious. Others can't do enough for you.

An improvement in my mobility, even small, would make travelling and everyday tasks – not just when I am on holiday – so much easier. I long for the day when I can pick up the phone and book a short break away just for myself without the need for carers, Customer Services, letters from the Doctor or Special Needs Departments! I honestly believe that we are now closer than ever to that day and that's why I support Spinal Research.

It may all sound negative but, believe it or not, travel is my favourite pastime and I will continue to travel for as long as I can!

Fundraising News

Saddle Up Raffle - your chance to win amazing equestrian prizes

The first prize is a WOW saddle worth over £1700.00, and other prizes include: a personalised portrait of the winner's horse by Kathy Lewis, one of five pairs of Ariat boots, and half a tonne of Bailey's horse feed. Raffle tickets will be priced at £10 for ten and proceeds will go towards our pioneering research.
To buy tickets please call Isabel on 01483 898786 or email saddle-up@spinal-research.org. We are also looking for any yards, tack shops or equestrian outlets to help sell the tickets. If you can help please get in touch today!

Thank you Peter! We were very sorry to say goodbye to our Director of Development Peter Banyard who, after 30 years at Spinal Research, is now retiring. Peter was instrumental in developing our research strategy over the years and was an excellent fundraiser too, securing many donations from high profile individuals. We will miss him very much, but he has promised to still help as a volunteer. We'll hold you to that Peter!

Everyone at Spinal Research is devastated at the tragic news about the Puttick family

Neil and Kazumi were very devoted parents of Sam, who was a very happy little boy despite having a very high spinal cord injury, which meant that he was paralysed from the neck down. They were very enthusiastic supporters of Spinal Research, and their deaths come as a terrible shock to all of us. This is a great tragedy, and our hearts go out to Neil and Kazumi's families at this very difficult time. We have set up a tribute page at www.samneilandkazumi.puttick.muchloved.com where you can leave your messages of condolences. If you wish to read more about Sam's short life please visit www.stuff4sam.wordpress.com

Would you like to help us cut costs and direct even more funds to research? You can opt in to receive our Research Digest by e-mail. Just send your details to anna@spinal-research.org to be added to our e-mailing list.

I want to turn research into a treatment for paralysis

Here is my donation of £

Name
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❑ Please send me an acknowledgment of my donation
❑ Please send me information on leaving a gift in my Will
❑ Please sign me up for e-news, my e-mail is:

If you Gift Aid your donation, Spinal Research will receive an additional 28p per £1 donated at no extra cost to you.

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Please return this form to Spinal Research, Bramley Business Centre, FREEPOST (NW5645) Guildford GU5 0AZ (no stamp necessary).

You can also donate online by credit card at
www.spinal-research.org

❑ If you no longer wish to be on our mailing list, please tick

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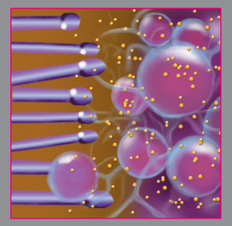
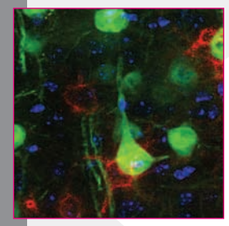
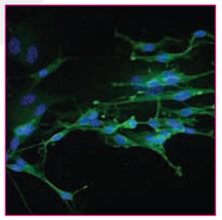






SPINAL RESEARCH
fighting paralysis... and winning

Progress makes scientists and patients ReJoyce

Spinal Research has recently funded the first clinical study of the ReJoyce System at the University of Alberta in Canada. Aimed at those with high-level cervical injuries, ReJoyce is unique in combining FES (functional electric stimulation) with in-home rehabilitation.

The system consists of a spring-loaded joined arm that presents users with manual tasks of varied difficulty. A wristlet, triggered by a wireless sensor put behind the ear that detects small tooth clicks, stimulates the paralysed hand muscles required to complete these tasks.

Professor Arthur Prochazka and the team behind ReJoyce were motivated by the particular needs of people with high level spinal cord injuries. "Restored hand function is at the top of the wish list of people with tetraplegia. Even small improvements in hand function can have huge implications, such as being able to work or live more independently" he said.

Rehab can be difficult to maintain when patients return home so the Rejoyce team have developed a telecom-link system to allow patients to use the ReJoyce in the comfort of their own home. All movements are measured with sensors and, using the internet and a webcam, they are remotely evaluated by a therapist.

Early results look promising, with subjects using the ReJoyce system outperforming in standard tests those using conventional rehabilitation regimes. Several other organisations are now planning studies – including Imperial College in London. Prochazka hopes to work with others, including teams in London and expects a commercial launch in Canada in mid-2009, with the US to follow and then the rest of the world.

For more information visit: www.ualberta.ca/~aprochaz/hpage.html and click on the link called 'In Home Telerehabilitation'.

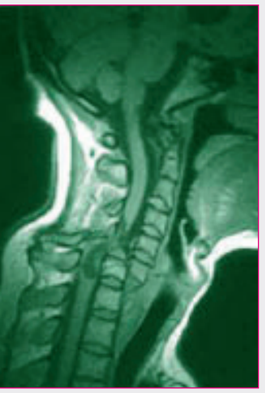
Translational Initiative Appeal - a thank you and an update

Thank you so much to everyone who has been donating to our Translational Initiative appeal. As you probably know by now, the Translational Initiative is the time when we aim to convert what has been proven to work in the laboratory into therapies that can be applied to patients.

The call for projects went out in March in a number of scientific publications, and applicants were asked to demonstrate they have mapped out the most effective ways to develop their treatments into ones that can be applied in people with spinal cord injury.

We have now received a number of applications, and our Scientific Committee will convene to discuss which of these are the most promising and should be invited to prepare detailed project plans and budgets. We will seek to work closely with applicants during this phase to ensure our expertise can be brought to bear on developing clinically relevant targets and milestones to monitor progress of funded projects.

We will be able to report back on their decision in the next few months so keep checking our website for news or, if you haven't already, sign up to our e-updates by visiting the website and clicking on 'Sign up for e-news' on the home page. Thank you again for your support!



Changes in trauma care - but will SCI patients benefit?

Trauma care in London is set to change, hopefully for the good. There is compelling evidence that a regional trauma care system (as adopted in the US, where mortality rates for the most severely injured patient are 40% lower than in the UK) improves patient outcomes. It is based on the principle that getting access to the most appropriate care rather than on getting to the nearest hospital as quickly as possible is the major factor influencing outcomes in major trauma.

With this in mind, London's primary care trusts (PCTs) have agreed to develop a similar model for the capital - a move that is likely to herald change across the country. But will it benefit spinal cord injury (SCI) patients? Those responsible for developing the proposal, Healthcare for London, have so far recognised that stroke or burns patients need particular consideration within any trauma network and plans have been developed for these. It is disappointing to see that no such attention has been given to those who have suffered spinal cord injuries. With such major changes being proposed there may never be a better time to establish the best care model for SCI and Spinal Research has responded to the consultation by outlining the strong case for regionalising SCI trauma care.

We recommend that ideally only one of the four proposed new trauma networks should receive SCI patients, making that centre automatically responsible for their care. Spinal cord injuries are relatively rare and also very complicated injuries, leading to clinical mismanagement amongst general trauma units and A&E departments who see so few. Thus, reducing the number of centres responsible for their care will ensure high patient volumes and concentration of appropriate level of specialist care and expertise not otherwise possible when spread too thinly.

Further information can be found on www.healthcareforlondon.nhs.uk.

Projects build on previous success

Prof J Fawcett

Prof S McMahon

Prof K Hunt

Dr H Van Hedel

Prof B Conway

Dr D Allan

Our Scientific Committee has recently approved funding for two very promising projects, which build on previous findings you might have read about in other issues of the Digest:

Combining rehab with chondroitinase for best results

Many people with SCI do go on to recover some limited function over time. Regeneration of damaged spinal cord tissue may account for some of this but it is now clear that the majority is due to the response of uninjured tissue attempting to make new connections. Treatments which encourage uninjured tissues to form new connections - known as plasticity - lead to functional recovery in experimental models but crucially the quality of improvement is enhanced when plasticity is fine-tuned by rehabilitation. One of the most promising treatments for promoting plasticity is chondroitinase, a bacterial protein that breaks down the network of material found in SCI scar tissue. Professors James Fawcett (University of Cambridge) and Steve McMahon (King's College London) - leading experts in the field - won funding to examine how chondroitinase affects the electrical connections of the spinal cord and why rehabilitation is far more effective after this treatment. Understanding why may be the key to optimising treatments and greater functional recovery in the future.

Technology gives the nervous system a helping hand

In a truly collaborative project, Professor Ken Hunt from the University of Glasgow aims to reduce the impact of many of the debilitating symptoms of SCI by combining rehabilitative robotic-assisted walking technology with electrical stimulation and feedback to reinforce patients' own desire to move. As with the project above, the approach exploits the central nervous system's capacity to adapt to change and injury, only this time giving it a high-tech helping hand. The project brings together a unique group of experts* from the National Spinal Injury Unit in Scotland and the newly-established Scottish Centre for Innovation in Spinal Cord Injury, academic departments from both the University of Glasgow and the University of Strathclyde as well as international collaboration from Balgrist University Hospital, Zurich, home of the European Multicenter Study for Human Spinal Cord Injury. The project will lead to a clinical study with SCI volunteers.

*Prof K. Hunt, Dr H. Van Hedel, Prof B. Conway and Dr D. Allan

International Campaign for Cures for Spinal Cord Injury Paralysis - update

The publication of the ICCP's (International Campaign for Cures for spinal cord injury Paralysis) Clinical Trials Guidelines was a great success - the lay summary document, titled 'Experimental Treatments of Spinal Cord Injuries: What you should know if you are considering participation in a clinical trial', was downloaded over a million times!* These guidelines are now referred to by regulatory authorities such as the powerful US Federal Drug Agency when considering applications for clinical trials of new treatments for SCI.

Now ICCP members (whose founder members include Spinal Research) have been discussing the next priority area to focus on. The new guidelines will this time consider practise standards for basic research with the aim of increasing the efficiency of translation of research findings into treatments. This fits in with Spinal Research's own Translational Initiative – where we will be concentrating on projects with the specific aim of 'translating' treatments from the laboratory into therapies that can be tested on patients, and therefore we welcome this development.

**Further information can be found at www.campaignforcure.org. To download the document, click on 'Experimental Treatments'.*