

# Brachial Plexus Injury Newsletter

## In this edition...

Welcome to the Winter 2012 edition of Brachial Plexus News. There's lots of interest in this edition.

We have...

- Study Day
- Living With Brachial Plexus Injuries
- Announcements

The Scottish National Brachial Plexus Injury Service held a study day in April this year which was open to professionals from across Scotland.

16 delegates attended from the following professional groups: medical, nursing, physiotherapist, orthotics and came from Glasgow hospitals and community centres, Tayside, Renfrew and 2 Universities along with a visitor from Sweden.

It is our aim to educate and inform those professionals as to the service we provide and to increase their knowledge on all things to do with brachial plexus injury management and the roles of the team members.

Presentations were given by team members and some patients were also invited to participate in the study day. Many thanks to those who helped us out on the day (Denis and Stuart). On evaluation by the delegates who attended, they reported the lectures as being applicable to their needs. Further comments noted:

- "Patient sessions especially useful / more varied patient case studies would be useful
- Relevant... helpful...informative...linked to clinical practice...useful treatment options
- Good range...good quality lectures
- Excellent material on line...good resource
- Gained greater knowledge of BPI and service"

Our educational events for professional continue regularly and we are grateful to any patients who assist us in this important opportunity to share knowledge and experience with others.

*BW*

Report compiled by Beverley Wellington on 23/04/2012

## Living With Brachial Plexus Injuries: Nobody Said It Was Easy, BUT You Can Manage!

Just over 13 months ago, I crashed my scooter on the wet, oily roads of Beijing, China. The doctors at the international hospital gave me not a lot more than 0% chance of survival.

I had suffered massive head trauma, fracturing my skull in at least 3 places (thankfully I was wearing a helmet!) and had to be transferred to a local hospital to be placed into a coma. My partner was told that if I woke up there was a very good chance I would not remember anything or be able to do anything. I teach

Physical Education at an International School and while I was in the coma, my employers were meeting with the embassy about flying my dead body home.

I remember being in the coma and I can confirm, at least in my case, that there is indeed a light at the end of the tunnel. In fact I was in Venice during my coma, swimming in the canals, with people in their gondolas telling me to swim towards one of the small bridges where the light was shining. My Grandfather, who passed away 5 years ago, appeared and told me to go away I was too young to go there, I was 29 at the time.

I guess I took his advice, because 13 months on I am writing this article in the hope that it helps other brachial plexus sufferers to see a different kind of light at the end of the tunnel, and to live a full and healthy life.

The journey was a very long and difficult one. I



was told that my head injuries were too severe for me to fly. I stayed in China, where I was misdiagnosed with a spinal stroke and given so many mixed messages that I really had no idea what the future held for me. I had paralysis of the left side of my face and my left arm. I was told one hour that I would make a full recovery and then the next that there was no hope for me. At one point, a young doctor told me that I had cancer- just because I had blood in my urine sample! I desperately

wanted to return to work and be 'normal' ASAP and so I persevered with the ups and downs of China life and made it through thanks to the family and friends around me.

After 6 weeks of being in and out of hospitals in Beijing, I decided that enough was enough and I made the long journey back to Scotland. Finally, my luck started to change!

My local GP thought I had a clear brachial plexus injury, he sent me to another doctor who agreed and by luck they discovered the AMAZING brachial plexus injury unit at the New Victoria Hospital in Glasgow. Mr Hems was contacted and he asked to see me ASAP. Within a couple of weeks I had had the nerve conduction testing done and just a few weeks later I went under the knife to have the brachial plexus surgery.

Three nerves were severely damaged. There was no way of confirming that the nerves had not

*continued over...*

been ripped out of the central nervous system until they opened me up and located the nerves. I went into surgery knowing that when I woke up there was a possibility that they could tell me: sorry there was nothing they could do as the nerves had been separated from the central nervous system. I remember thinking, I just hope that when I wake up there will be a bandage on my leg and then I will know that there is hope!

Thankfully the nerves were not as bad as they could have been and they were able to branch two other nerves and take sensory nerves from my left leg to connect and strengthen the existing nerves.

I remember seeing Mr Hems in the recovery room and asking him to tell me how it went. He told me that I would not remember the conversation but that it went well and he would provide details the next day. I promised him I would and that he could even give me a quiz! The nurse misunderstood and told him I said that I would give him a kiss! How awkward, he was obviously frightened as he was off work the next day!

And so the recovery process began again. This time with a proper diagnosis, correct treatment and an incredible team of experts behind me.

I spent 6 weeks in the underclothing sling and then after seeing the team in Glasgow, I returned to work. I am sure they all thought that I was crazy, I mean I do teach Physical Education and coach football AND rugby!

I guess for me, by this point it had been 5 incredibly long months. I needed to see for myself that I could still be ME. The truth is I felt useless. I felt so far removed from the person I used to be.

That PE teacher that can take on half the high school rugby team at a time and still come out with the ball!

The good cook that liked to throw nice dinner parties, the Aunty that could throw the nephew up in the air and amaze him with the size and strength of muscles that he described as being stronger than any superhero!

I returned to work to a welcome home superhero sign and post it notes of messages all over my office. At this point I just wanted to cry, I felt like I was at the opposite end of the spectrum from superhero. There were times when I wish that I had never woken up from the coma. It must be the hardest words for a mother to hear, when her daughter (several thousand miles away) says Mum, I wish I had not survived. It didn't feel like I was me, I didn't feel like I was capable of living my life, at least the one I wanted to live.

I did the typically Scottish thing- grin and bear it! I put a fake smile on my face between the hours of 8 and 5.30, one so amazing that an American cheerleader would have been proud of it! I then spent the hours until bedtime angry, frustrated and depressed.

This went on for about two months and then I decided it really is do or die. I needed to take charge of my life, to beat this injury. I was doing lots of arm exercises and working hard, but I just needed more. I needed a goal. The team told me about a sling I could have made from the USA. I decided that was it- maybe I could take up running. I wanted to help other people less fortunate than me and so I decided to run the Berlin marathon and use it as a means to raising money for charity. I needed to show myself that you really can do anything you set your mind to and that I could still be me!

The training was tough, the arm was sore in the sling. I had to run more slowly than I thought I could, I was always a sprinter anyway I had to keep telling myself. Two weeks ago we completed the full Berlin marathon and raised

1,500 pounds for the brachial plexus unit, 3500 pounds for Whizz Kidz and 1500 pounds for the intellectually disabled children's groups my school in Beijing work with.

*I finally feel like me again!*

Don't get me wrong, I am not telling you all to go and run a marathon—but I am saying that when you are depressed and feeling like you just can't do things, you need to be the one that thinks about what is important to you and what will make you feel better and give you a purpose.

I feel so lucky that I am physically strong from all of my sports; it has allowed me to swing my left arm above my head just 8 months after surgery. I can now rotate my elbow at about 60% range. I can throw and catch a tennis ball with my left hand. In fact, I can even do the same with a rugby ball now.

Now, part of this is down to the amazing surgeons and the wonders they work! However, the rehab is down to you to follow the advice from Beverley, Lyndsay and Claire and work hard in your own time to exercise that arm and get it doing as much as possible, as often as possible. Trust me, the more exercises I do- the faster the arm responds and I get more and more arm function. On top of that, seeing the small changes and being able to do more for myself, makes me feel like I am in charge of this injury, not the injury ruling my life.

As I said in the title, nobody said it was easy BUT you can manage!



*Amy*

## TEAM CONTACTS

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## Projects ongoing

The new updated patient information booklet is due in print shortly and will be available on the website:

[www.brachialplexus.scot.nhs.uk](http://www.brachialplexus.scot.nhs.uk).

Next year Beverley, Claire & Lyndsay will be introducing a patient therapies focused clinic to be run quarterly...more details to follow.