

Charlotte's Story

- ❖ In August 2008 we were enjoying a family holiday on the beach on the IOW.
- ❖ Charlotte suffered a serious and life threatening brain haemorrhage. Totally out of the blue, she said “Mummy, I don't feel very well and I'm going to be sick”. Then she vomited many times, collapsed and went unconscious.
- ❖ We were helped on the beach by a GP who happened to be on holiday. I found out weeks later that it was Dr Rosemary Leonard from the BBC!
- ❖ I went in the ambulance with Charlotte and she was immediately given brain scans at St. Marys Hospital on the IOW. She was put on a life support machine.
- ❖ She was then air lifted by Coastguards helicopter to Southampton General Hospital to their specialist brain unit. There was no room for us in the helicopter as she had 6 medics with her.
- ❖ When we got to Southampton, we were taken to an empty room and told categorically that she would NOT survive.
- ❖ Charlotte apparently had a very rare brain condition; she had had a massive brain haemorrhage, caused by an Aneurysm and she also had something called an AVM (Arteriovenous Malformation).
- ❖ Neurologists had never seen this before in a child in the UK or in Europe.
- ❖ There were no guidelines written down anywhere about procedures and they telephoned their colleagues at Great Ormond Street and hospitals in Switzerland and Holland but no one knew what to do because it was a unique condition never come across ever before.
- ❖ Charlotte's brain was still swelling and they had to drill into her skull to stop the swelling.
- ❖ A drain was inserted into her brain to drain the blood from the haemorrhage. She remained in a coma and was on life support for 10 days.
- ❖ To seal the Aneurysm bleed, Charlotte needed pioneering surgery. A clip was apparently impossible due to the bleed being so deep in her brain. Metal coils which are usually used had also been ruled out by the surgeon because of the difficult roadmap in a young child. Therefore, the Aneurysm was sealed with something called ONYX, or superglue, which was a first in this country. So Charlotte received pioneering brain surgeon in Southampton.
- ❖ She came off the life support machine after 10 days but remained in a coma for a 5 further weeks

- ❖ When she eventually started to come out of the coma, both eyes were pointing in opposite directions. She could not SEE.
- ❖ She could not WALK, TALK, SWALLOW, she was INCONTINENT.
- ❖ She was mute for many weeks and could only BLINK for a 'Yes'.
- ❖ The Physiotherapists, SALT, OT very gradually managed to get her out of bed using a hoist and very supportive wheelchairs. Her speech slowly began to return.
- ❖ Basically, she had to learn how everything all over again, just like when she was a baby.
- ❖ She has had 5 brain operations in total.
- ❖ She has made a remarkable physical recovery and has astounded ALL the Neurologists.
- ❖ Eventually, we got her home. We did have some support from local services in the form of physiotherapy and OT but these were not specific to Charlotte's needs. She was referred to the Childrens Trust by Southampton General Hospital and was assessed at home by the Community Support Team in the September. They recommended that Charlotte attend a 4.5 day Interprofessional Assessment at TCT and an application for funding was made on 24th October 2009. After a long struggle to justify her needs, the PCT finally agreed funding some 2.5 months after the application was originally submitted!
- ❖ Charlotte came here in January 2009 for a comprehensive Interprofessional assessment delivered by the Community Support Team
- ❖ In the meantime Charlotte travelled up to Sheffield to receive Stereotactic Radio Surgery on her brain to treat the AVM. She was in this machine for 6 hours and although she has received this surgery, she still remains AT RISK for the next 2 years of having another brain haemorrhage.
- ❖ Following the recommendations of the Interprofessional Report produced after her assessment, Charlotte began a 3 month intensive re-hab programme here in May 2009.
- ❖ When she arrived, she was physically very well. She could walk, talk, eat and looked perfectly normal, yet she couldn't remember how to do everyday things; for example, getting washed and dressed, and has had to be re-taught.
- ❖ She made wonderful progress here and loved it. She usually came home at weekends but couldn't WAIT to get back on Sunday afternoons! She now functions as a 13 year old again and she has matured SO much.

- ❖ She has re gained her confidence and is now re-learning how to function in her every day life again.
- ❖ And here she is when she met up with Richard Hammond – you can see how well she looks now.
- ❖ Charlotte returned to school for 3 days a week and this year is going up to 4 days a week.

Thank you.