

Community Matters: www.HelpTobyWalk.Com

Toby Cox is 5 years old, lives in Bradley Stoke and attends Holy Trinity Primary School. He has cerebral palsy and cannot walk unaided. Toby has just been offered a fantastic opportunity ... an operation in the USA that could enable him to walk, even run and play football with his friends! The cost for this chance to be able to play like his friends at school is £36,000 and the operation is set for June this year. We are only too delighted to help publicise Toby's story and the fund raising effort to **Help Toby Walk**. Toby's mum Donna tells us more:..

"Toby was born 10 weeks early by emergency c section as he had stopped moving in my tummy. We found out he had cerebral palsy when he was 5 months old which was devastating. Our gorgeous little boy now had the most huge mountains to overcome and was never going to be able to keep up with his peers, and play like other children. The future seemed so dark and bleak.

"He has had regular physio ever since to enable his muscles to stretch and is seen by a whole host of medical personnel. He uses a wheelchair when tired or poorly, and uses a walker to mobilise elsewhere. He is just learning to use sticks, but this is only inside and he cannot walk outside with them - that will always be out of the question, without the treatment offered in the USA.

"Watching Toby just trying to get comfy on the floor so he can play on his play station is heartbreaking, his little legs are so tight, he rocks around and fidgets, even this is so difficult for him. He will not be able to write with a pencil at school, so his work is conducted on a laptop, the spasticity in his legs overrides any hand fine motor control he might have, and makes pencil control virtually impossible.

"Toby never complains, he is such an intelligent little boy, who is always smiling, cheeky, and always seems to be a few steps ahead of us. He knows he is different, he longs to play football without his walker, he longs for a normal bike, he desperately wants Heeleys or a skateboard. This year he has decided that Santa might realise he has fixed legs and send him one of these toys!

"We saw a news article on the local news of a little boy travelling to St Louis for treatment for his cerebral palsy. We started looking into it and found out what an amazing revolutionary treatment it was. We had never been told that there was a permanent treatment for his spasticity (a secondary effect of cerebral palsy) - we were astounded. We started asking questions, but the information in the uk is very sketchy and most professionals have outdated and antiquated opinions about Selective Dorsal Rhizotomy.

"We found a centre in the UK that "performs" SDR, in Oswestry, but this is not at all comparable. The operation

does not go to the same levels as in the USA, it is not routinely performed, the outcomes are

poor and not as dramatic, the recovery period is double the time in the USA, Dr Park in the USA has performed over 1900 operations, Dr Roberts in the UK has performed 27. For his and other reason we decided that the USA was the way forward for Toby, the experience and professionalism of the team was more reassuring.

"We had to send all of Toby's medical information to St Louis so that Dr Park and his team could investigate and examine the data. We heard back very quickly that he was a perfect candidate! Nobody had ever given us this hope at what Toby might do. We now know, from other parents of children that Dr Park has operated on, that he is "pretty spot on" with his predictions. We were elated, Toby suddenly had a different future ahead of him - long term, different job opportunities - it was amazing!!!!!!

"The only sticking block was the cost, but that is not going to stop us. £36,000!! Two wonderful ladies have offered to be our fund raisers and lots of people have also offered to help out and run events, which is so gratefully received. Just looking after Toby on a day to day basis is exhausting, and we also have all the logistics of arranging a month long stay in the USA, flights and accommodation to book. Our parents have offered to come with us for the whole duration, which is an amazingly generous offer and of course we took them up on it!"

We will include details of **Help Toby Walk** events on our community pages and on the What's On section of our website

www.bradleystokematters.co.uk. Local residents can help by supporting these events or donating on line at

www.help Toby walk.com.

Matters Magazines wishes Toby lots of luck and is pleased to offer him and his family £500.00 towards his fundraising.

Donna is also keen to encourage raising awareness to others that this is an amazing option for children with cerebral palsy and makes life changing differences.



"We feel that Toby is a very good candidate for the rhizotomy surgery. If he has the surgery we expect the following improvements: his sitting postures will be normal; he will walk independently in all environments; he will be able to participate with his friends in recreational sports including soccer and others; he will be able to participate in fitness activities."

T S Park MD

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Donna Cox

