



A Message to you from PJ'S Mum



www.brainwave.org.uk

Enquiries: enquiries@brainwave.org.uk

See what we do at: www.youtube.com/BrainwaveCentre

We are please to share this testimonial by a parent named Fiona. Fiona's son Patrick (aka PJ), pictured below, is four years old and has been on a Brainwave Programme since June 2006.

I'm not very sure where to start with this. PJ's arrival was pretty standard, no big dramas or worries. He was a bit late and I was a bit fed up but that's nothing unusual.

PJ hit his milestones perfectly although he was pushing the limits for crawling - 11 months! Come on lazy bones, get a wriggle on! When he tried to progress from cruising round the furniture to walking unaided the alarm bells started to ring.



'Give him a month or two', 'He's doing so well, he'll get there'. I'm sure he knew everyone (family, medics, and nursery staff) was watching with baited breath for him to master this all important skill. He didn't. At the age of 2 the medical profession decided that something was wrong with our beautiful boy, many tests and months revealed that PJ has an hereditary condition called Hereditary Spastic Paraparesis - HSP (I still think it sounds like a bank).

HSP normally manifests at 30-40 years of age. We knew it ran in my husband's family but were absolutely knocked for six that it could affect from birth. It's a rare enough condition in the 30-40 age group - I know of only 4 other under 10s affected by it - Worldwide.

The NHS didn't know what to make of us; we knew more than they did about HSP. That's not a criticism just a fact. You wouldn't expect to find a specialist in such a rare condition. The NHS are almost cornered into giving the 'worst possible' prognosis these days. The outlook wasn't looking great.

A friend I used to work with had had a little girl during all this. The birth was traumatic and her daughter has Athetoid Cerebral Palsy. All of a sudden I was looking to my friend for help - she recommended Brainwave.

We called them and they sounded amazing - people who sounded positive about the future. No one promised miracles but they were hopeful and that's all anyone needs - hope.



Our first visit to Somerset was just ... I don't know ... exhilarating, exhausting, inspiring ... everything we needed? The staff believed us when we told them PJ's capabilities and his limitations. None of us wanted to leave but they made us go as another family was booked in, so mean!

As we were leaving Carl bent down to speak to PJ, 'I'll see you back here and we'll get you running and jumping,' he said. I sort of smiled but didn't dare to believe he really meant what he said. At that point PJ could not cross a level floor without falling over, tripping over nothing.

You know what? PJ can jump. Two feet off the floor and land without falling - most of the time!

He practises running daily, stylish and fast it's not.. but it's running. 9 times out of 10 PJ crosses that level floor without falling, his balance has improved and he gets to be a 4 year old boy. His biggest worry right now is that he won't be able to be a Power Ranger.

I cross my fingers that this ambition will wear off in time.



PJ's life will always be different to that of his peers. No one, not even Brainwave, can reverse the genetic mutation.

But.. PJ is a 4 year old about to start mainstream school in September. Brainwave have given us the ability to live life to the full, the belief that the abilities are there and we can find them.



All this hope is given without pressure, no one ever 'fails' with Brainwave, every child and every family gains so very much.



For further information contact:

SW Centre:	01278 429089	enquiries@brainwave.org.uk
SE Centre:	01376 505290	enquiriesse@brainwave.org.uk
NW Centre:	01925 825547	enquiriesnw@brainwave.org.uk

Brainwave SW Centre, Marsh Lane, Huntworth Gate,
Bridgwater, Somerset TA6 6LQ

Registered Charity No. 1073238 & SC039137 (Scotland) Company No. 3666739