

# Newsletter

Summer 2011



A message from Christine Cryne, CEO

## Hello

The last six months has been an interesting one for Brainwave with lots of highs including three special visitors.

In June, our President, HRH The Countess of Wessex, visited our South East Centre in Witham, Essex, for the very first time. The occasion was the Centre's fourth birthday and the Countess cut a birthday cake, donated by Marks & Spencer and iced by Brainwave therapist, Elizabeth Heath.

We were delighted that our President made time in her busy schedule to come and see us and meet both families and supporters. The local coverage we received was excellent with both Anglia TV and BBC East running pieces (<http://www.bbc.co.uk/news/uk-england-essex-13716157>), some excellent photos in the local press and BBC Essex Radio mentioning the visit every hour. As a consequence, our enquiry levels at the Centre have gone through the roof.

Other visitors were our Vice President, Her Majesty's Lord Lieutenant of Somerset, Lady Gass, to our South West Centre (see back page) and our Patron, Olly Murs, who came to the South East Centre to film the BBC Lifeline Appeal for us. The BBC chose Brainwave for their Lifeline Appeal on Sunday the 21 August. The Appeal is run once a month and takes place after the

Eastenders Omnibus. The programme lasts about nine minutes and we were delighted when singer, and our Patron, Olly Murs, agreed to front it for us.

Whilst on the South East Centre, we have been strengthening the therapy team there and this newsletter brings readers up to date with who the team are.



We hope you enjoy reading this edition and hearing of some of the stories from our families. Please feel free to pass the newsletter on to others.

Next year is our 30th birthday and we hope that you will help us celebrate. More in the next issue.

With every best wish

*Christine*

Chief Executive Officer, Brainwave  
[christinecryne@brainwave.org.uk](mailto:christinecryne@brainwave.org.uk)

[www.brainwave.org.uk](http://www.brainwave.org.uk)

Enquiries: [enquiries@brainwave.org.uk](mailto:enquiries@brainwave.org.uk) See what we do at: [www.youtube.com/BrainwaveCentre](http://www.youtube.com/BrainwaveCentre)

# Ben

by Ben's mum, Louise

When we first approached Brainwave to help my son, we were living in a remote part of the Highlands in Scotland. We found the NHS very negative and dismissive about our son's condition and he wasn't getting the help he needed.

With our first contact with Brainwave we felt as if a big weight had been lifted off our shoulders. We travelled down to Bridgwater for Ben's two day Initial Assessment. Where the NHS was so negative about Ben, we found that Brainwave focused on all the positives. We got so many answers to my son's behaviour and we were able to see the world through our son's eyes.

The therapists developed a Programme to fit around Ben's needs for us to carry it out at home. We were able to borrow equipment such as a peanut ball, for Ben to use.

*Since starting the Programme, Ben's co-ordination and balance has improved dramatically.*



Then, and every time we attend the Centre, we are given a DVD of Ben doing his Programme, which helps us with his day to day Programme. It is useful for showing to relatives and to his school just what he is working on.

We relocated back to Lancashire last year to be nearer to family. Since then we have attended the Warrington Brainwave Centre every four to six months for a Reassessment of Ben's Programme.

We keep in touch with our Family Facilitator, Sally Preston, on a regular basis and she is a great support. She is not only there to help with the Programme but she is there for any day today problems we face.

Since starting the Programme, Ben's co-ordination and balance has improved dramatically. He is now able to jump and is starting to dress himself.

Brainwave has been such a positive experience and we don't know where we would be without them. Thank you so much from the bottom of our hearts.



*Therapy Room at the NW Centre*

# Declan

by Colette, Declan's mum

Our Son Declan was born two weeks early in December 2007. Our Consultant was able to tell us within minutes that 'Declan may have characteristics of a child with Down Syndrome', my husband's immediate reaction 'well, he choose us'. This set the tone for how we have perceived his Syndrome and never for a moment has it affected our love for Declan.

We loved Declan immediately and although we worried about what the future held for Declan and his 16 month old sister, Anna, we took a simple view of caring for our baby and any issues that might arise for him. Despite open heart surgery at four months old (which was very successful), Declan is now a healthy 3.5 year old boy.

*He has gained more strength and stability but most of all, his confidence and self esteem has excelled.*

Declan's second and youngest sister was born when Declan was 22 months old. The birth of our third child magnified Declan's difficulties and we began researching how we could help Declan further. We found accounts from Irish families who had worked with Brainwave.

We had our first meeting with Brainwave in May 2010, when Declan was two years old. It was an inspiring and enlightening experience. From the moment we arrived at the Bridgwater Centre we were greeted with wonderful warmth and hospitality. The staff were so informative. Every question was answered with an honest



evidenced based reply and we never felt fudged. The ease with which they worked with Declan was brilliant. We received so much guidance and felt very confident with the Programme they developed for Declan. It was very comprehensive; and 90% of the content was totally new to us.

To our amazement, Declan walked independently within three months of starting his Brainwave Programme. He has gained more strength and stability but most of all, his confidence and self esteem has excelled. He seems so much happier when playing with other children or in any social situation, and his coordination, concentration and focus have all improved.

Our children really enjoy doing Declan's Programme. At times we have found that fitting the Programme into our busy family has been challenging; but it is so worth the effort. The Brainwave staff have given Declan and our family great hope for the future and that is a great gift. A massive thanks to everyone who keeps the 'Brainwave' wheel turning, and to everyone there who has touched our family's life.

# The South East Team



When people telephone or arrive at the Centre in Witham, it is likely that the first person they talk to is **Helen Gilfillan**, who is the Centre's Administrator. Helen has been at the

South East Centre since it opened in February 2007. She is responsible for all the administrative areas within the Centre and is the first point of call for all outside public, professional, medical or business contacts with the Centre. Helen has worked as an administrator within Occupational Therapy Services for more than 19 years so she brings a wealth of experience and understanding to the role.



The Lead Therapist is **Lindsay Gilbert**. Lindsay is a Senior II Occupational Therapist. Lindsay joined Brainwave in November 2010. Lindsay gained a BSc (Hons) degree

in Occupational Therapy at the University of Cape Town in South Africa. After graduating, Lindsay worked in a general hospital, local clinics and set up stimulation programmes in local crèches. She has worked in the NHS in the Mental Health Sector, specialising in Forensic Occupational Therapy.

But her passion and speciality has always been paediatric occupational therapy, with a keen interest and knowledge in Sensory Processing Disorders. Lindsay has completed courses on Sensory Integration Techniques, Infant Massage, Baby Development and Handling and Treatment of Cerebral Palsy.



Lindsay is assisted by **Julie Westhorp** who joined Brainwave in May 2011. She qualified as an Occupational Therapist in 1977 and has worked with most client groups both in

the NHS and Social Services, including 15 years experience in paediatrics. She has experience of Sensory Integration, Neurodevelopmental techniques, Bobath, assessment and treatment of neonates and management of feeding.

For six years, Julie was Head of Paediatric Occupational Therapy with a large Essex NHS Trust, responsible for managing the service and was also the Clinical Specialist. She also lectured in Paediatrics at the Essex School of Occupational Therapy.



*South East Centre at Witham, Essex*

To provide a holistic approach, the Occupational Therapists are complemented by two physiotherapists and a Developmental Therapist.



**Elizabeth Heath** gained a BSc (Hons) degree in Physiology at Cardiff University and then went onto achieve a physiotherapist qualification at Masters level with Merit at the University

of Essex. During her studies she gained an award from the East of England Chartered Society of Physiotherapists for one of her clinical placement results. One of her clinical placements was based at Brainwave which is when she became interested in the work carried out by the Charity. Liz joined the Charity in 2009 and has since attended the Introduction to Bobath Course.



The second physiotherapist is **Holly Kaye**.

Holly joined Brainwave in April 2011. She recently qualified as a Physiotherapist from the University of Brighton in July 2010.

She has previously worked both as a Physiotherapist and Teaching Assistant (during her studies) in a specialist school and college with children with moderate learning difficulties and severe behavioral problems. Since her qualification, Holly has been trained in Rebound Therapy, Makaton Signing and has also attended an Introduction to Sensory Integration.



The team is completed by **Kim Mears**, who is a Developmental Therapist. Kim qualified as a Speech and Language Therapist in 1997 and since then she has worked in special schools

both in the UK and in New Zealand. In 2004, she set up her own private speech and language therapy business and worked with a range of children. Kim has specialist interest in children with multiple learning difficulties, eating and drinking difficulties and Autism. She joined Brainwave in February 2011 and specialises in speech and language as well as general developmental therapy.



# Ronan

by Paul and Shirley

Ronan suffers from a combination of Cerebral Palsy and Epilepsy. Due to his Cerebral Palsy, Ronan took longer than normal to reach certain milestones, and during the first year of his life Ronan had no purposeful active movement. His epileptic seizures also cause setbacks, making it more difficult for him to develop and learn new skills.

When we first took Ronan to Brainwave the therapists told us that his muscle tone was low. This meant that he tended to have a stooped posture and had to work harder to make his muscles work to complete tasks. His balance was quite poor and, although Ronan was able to walk, he couldn't balance when he was standing still. The result was that when he was standing, Ronan would take lots of quick little steps to keep his balance and then would sort of throw himself into someone, or something, so that he didn't fall to the floor.

Ronan was very dependent on us as parents to help him with all his daily care and activities, which would often lead to frustration as he was unable to complete anything on his own. This meant that he didn't really have any independence at all.



The first set of exercises we were given by the Brainwave's therapists worked mainly on strengthening Ronan's upper body to help with his balance skills, standing independently and moving with more control. His progression was striking and on our second visit the Programme was changed to accommodate his improvements.

We then began working on throwing and catching balls, and walking on more challenging surfaces such as slopes, steps and bumpy ground.

By practising these different activities Ronan has been able to develop a variety of skills enabling him to play football in the garden, where previously he would just have had to watch others enjoying the sport.

It isn't just us who have noticed how quickly he has progressed either. Even our neighbours have commented on how he seems like a different boy now when they see him kicking a ball around in the garden with his dad!

*It isn't just us who have noticed how quickly he has progressed either.*

But that wasn't all the changes. At Ronan's last Reassessment, the therapists introduced to his Programme deep pressure and proprioception exercises to his head to try to desensitise this area. He is now able to brush his own hair and even allows us to brush his teeth without trying to escape from the bathroom! This is something we are particularly excited about. It has made a huge difference to our daily living routine.

We cannot thank Brainwave enough for making these improvements, which we are so amazed about - and in such a short space of time too.

# William

by Kelly, William's mum

My son William suffers from a rare genetic disorder called Angelman Syndrome. William has just turned three years of age and is very behind in reaching his milestones.

A friend of ours told us about Brainwave and straight away we contacted them and booked William in.

We went to Brainwave, who gave us an exercise Programme to follow and, I must say, it has been one of the best things we could of done for William.

The Programmes the staff put together are individual to every child and allow us to do physiotherapy with William on a daily basis in his own environment.

Since following the Programme, William has learnt to push himself up into the sitting



position, which is something we did not think he would ever do. Over the past few months, his development has come on leaps and bounds.

The staff at Brainwave are so helpful and have helped William to achieve a lot. But they have helped us too. They have enabled us to understand

William's difficulties and the ways we can help and support him at home.

*It has been one of the best things we could of done for William.*

I would recommend Brainwave to anybody. Seeing how William has progressed is amazing and we look forward to seeing them again soon.

## BBC Lifeline Appeal

*Taking place on BBC 1 on Sunday 21 August after Eastenders, this 9 minutes programme covers the story of three families and the impact Brainwave has had on the children's lives. It also features the therapists at the South East Centre carrying out a Programme and is fronted by our patron, Olly Murs.*

*The Programme is repeated on the following Tuesday on BBC2 and, once broadcast, can also be found on he BBC website: [www.bbc.co.uk/programmes/b006nb6j](http://www.bbc.co.uk/programmes/b006nb6j). In addition, it will also be shown on Big Screens. These have been set up in 20 UK cities as a result of a collaboration between the BBC, the London Organising Committee of the Olympic and Paralympic Games and Local Authorities. You can find the locations at [www.bbc.co.uk/bigscreens](http://www.bbc.co.uk/bigscreens).*

# The South West Sensory Suite

July saw the formal re opening of the Beehive, our Sensory Suite at our Centre in Bridgwater.



Thanks to a number of supporters we had been able to replace some of our old equipment, bringing in some state of the art kit as well as the inclusion of a quiet room for children on the Autistic spectrum. Over the last few years, we have seen the number of children with a diagnosis of Autism grow six fold. Thus, this room is a welcome addition to the facilities at the Centre.

To add to the sense of occasion, we were fortunate to have Her Majesty's Lord Lieutenant of Somerset, Lady Gass, cut the ribbon for us and formally open the new facilities. Lady Gass is a Vice President of Brainwave and has been involved with the Charity since 2004. As well as performing the official duty, Lady Gass met a number of supporters and two families who were attending the South West Centre. The whole refurbishment cost £10,000 and was designed by Brainwave therapist, Becky Crump.

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

T: 01278 429089

[enquiries@brainwave.org.uk](mailto:enquiries@brainwave.org.uk)

**Brainwave SE Centre**  
Beechen House  
Rear of 16 Newland Street  
Witham  
Essex CM8 2AQ

T: 01376 505290 / 503608

[enquiriesse@brainwave.org.uk](mailto:enquiriesse@brainwave.org.uk)

**Brainwave NW Centre**  
Unit 602  
Birchwood One Business Park  
Dewhurst Road, Birchwood  
Warrington WA3 7PU

T: 01925 825547

[enquiriesnw@brainwave.org.uk](mailto:enquiriesnw@brainwave.org.uk)

[www.brainwave.org.uk](http://www.brainwave.org.uk)

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