

The PACE newsletter

winter/spring 2011/12



www.thepacecentre.org

The Children's Challenge

PACE children will aim to complete their personal physical challenges on Thursday, 24 May 2012 at the world famous Stoke Mandeville Stadium, birthplace of the Paralympics.

Beijing Gold medalist and Paralympian Dan Bentley is fronting our Olympic and Paralympic themed 2012 Children's Challenge. Dan has cerebral palsy himself but this hasn't stopped him topping the world in the sport of Boccia. Boccia is a Paralympic sport for athletes with disabilities that have a major impact on motor

skills. It's a target ball sport belonging to the same family as petanque and bowls. On a recent visit to PACE Dan inspired the PACE children, providing coaching, so that one day they might win Paralympic medals of their own.

Dan has made a short promotional film for PACE which is available from the official Challenge website at www.challengetime.org

Along with the Children's Challenge and its sister community event the Gold Challenge, we need to raise £100,000 to secure vital services. That's a huge challenge in itself, but luckily everyone can lend a hand! You can sponsor a PACE child, undertake your own 2012 themed challenge through the Gold Challenge or even help on the day by volunteering.



The children's individual challenges are now set, themed by or inspired by the 2012 Olympics and Paralympics. Every challenge will stretch each child's ability; some include taking their first ever independent steps. This is truly their 'Mount Everest' moment.

Visit www.challengetime.org to find out more, watch Dan's great promotional film and get involved. Alternatively call Simon on 01296 392923.



A charity providing intensive programmes for children with physical disabilities. Currently one in every 400 children in the UK is affected by cerebral palsy... help PACE to reach more of these children.

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Freddie's story

by Suzannah Goodchild

After three late miscarriages, we fought to have a baby. After falling pregnant with Freddie, we passed that magic twelve week mark, and set about telling the world. Our joy however, was short lived when, at 20 weeks, we were told, this baby was severely brain damaged. We were advised that termination was for the best. We were equally resolute in our belief that, whilst we would never judge others for doing it differently, for us life doesn't have to be perfect to be wonderful and worth it.

Once Freddie was born, we had some tough fights. For diagnosis, for therapy, and to get correct management of his intractable epilepsy. There were 54 hospital admissions in the first two years. Long nights by his bedside willing him to battle on, his epilepsy so bad that tomorrow's destiny hung delicately in the balance.

Freddie was born with a rare condition called congenital bilateral perisylvian polymicrogyria. What this



means is global developmental delay and epilepsy. There are many things that we and others take for granted that Freddie finds impossible to do. His condition is very rare - with less than 200 diagnosed cases worldwide and although we were prepared to face whatever was thrown at us - there were times when we felt lost and released into the world with no answers and little support.

During the first year, we discovered Conductive Education. The more we researched, the more we realised that it was the ideal ethos. From the moment we took him along for his assessment we were hooked. We'd found people who truly cared, understood and believed in his potential.

We attended Parent and Child



Services for nearly two years before Freddie transferred to the days without us. Freddie is encouraged and motivated to find his own way of doing the things he finds so difficult. We know Conductive education isn't a miracle. But we also know that the approach, delivered by a professional team at PACE, is by far Freddie's best chance.

PACE is much more than an education. It's a community. It provides a learning for life, a platform to share experiences, the confidence to try new things and self assurance. The changes we have seen in him have been phenomenal. He has made endless progress with his communication and to see the satisfaction on his face when he makes himself understood is a truly beautiful thing.

I'll tell you a story about Freddie at PACE. Every Monday is his show

and tell day using symbols in his communication book. The other day I picked him up and a staff member told me he'd been very clever and told her all his news. She explained that as well as going to feed the ducks he had watched TV. I groaned, knowing what a telly addict he is, and she said that he'd watched The X Factor. Well, I knew he hadn't and I explained

that it couldn't be true as all the children have a strict bedtime of 7pm. She loyally said he was so insistent and adamant he'd seen it! We said goodbye and I rang my husband to tell him about Freddie stringing the staff along. No sooner had I put down the phone, than a shocked Andy phoned me back saying, 'Oh my God. I forgot.

Freddie and I watched the X Factor repeat on Sunday morning while you were out shopping. So he is telling the truth!' I learnt a lot that day. I learnt that even we - his most loyal supporters know so little of his full potential and what

he's capable of.

Despite all the fights, we have so much to be thankful for. Amongst all our beautiful children we have an amazing and extraordinarily different little boy who can't sit or talk in the



conventional way, or walk unaided but he can smile and he can laugh and, he can bring enough love into a room full of strangers to light it up for all eternity. He has taught us so much and given us so much. He'll always be our beautiful Freddie.



Read more at:

www.thepacecentre.org/extranewsletter

New space for PACE

In the last few months we've opened an additional classroom and therapy space at Riverside House (next door to our offices and training facility). This will enable PACE to develop much needed new services for young children and their families through additional early years Parent & Child services, and for children who have integrated into their mainstream school but need to attend PACE for specialist input once a week.

There's also space for nursery-aged children who currently attend PACE three days a week and now need additional input, and for children with specific sensory processing issues who need specialist assessment and individual therapy sessions.

The facility is kitted out with some neat equipment: a Platform Swing - a unique seated swinging device manually controllable by the child and a Linear Glider - a

suspended wooden platform that can be hung from two different ceiling points. Both are great at stimulating the a child's cerebral cortex through a swinging motion.



PACE families, Scotland bound!

This is the fourth year that a PACE residential week has been held at the Craighalbert Centre in Scotland.

The whole family stays to build on early foundation life skills, addressing each child's needs and learning objectives, building on the work that's been done throughout the year. The daily timetable includes self-care, mobility, play, hand skills and communication programmes. There's also daily hydrotherapy.

PACE provide training and support to parents to teach them how to help their children practice their skills and stimulate their learning and development.

As well as hard work, it's great fun; Charlie (pictured) loved his trike and by the looks of things Dad liked it too!

You can find out more about the Craighalbert Centre at www.craighalbert.co.uk



'Diamonds' for special achievements



At the core of PACE's approach lies key motivational techniques. The regular 'Diamond Diary' events reward every child for reaching their personal milestones.

These are some recent examples:

Adam 'For wonderful head control when in supported standing'

Ryan 'For consistently using his switches to choose what he would like to eat'

Freddie 'For rolling over independently when given verbal prompts'



Roisæ (pictured above) 'For walking completely independently'

Alice 'For very clever talking and joining in with her voice'

Leo



Sophie



Annie and Henry



Beth



Thanks for the memories

A final message from Director, Heather Last...

As most of you will know my family and I are off to New Zealand. Whilst this brings to an end my 21 years as Director, my commitment to PACE doesn't end here. Whilst away I'll be working on training, compiling DVD evidence of children's progress and producing tribunal evidence to secure funding for new children. I'll be back in May to provide training and further support. PACE has been a huge part of my life and I am delighted to have this opportunity to continue to contribute my expertise and skills.

A great deal of thought and time has gone into PACE's reorganisation. I would like to thank the Trustees, Patrons and Senior Staff who have given considerable time and energy to this process. Amanda Richardson has been appointed as Chief Executive. Having worked with Amanda for the past 15 years I know that her passion for PACE as a family organisation ensures that the needs of the families and children will be at the core of all future decisions and developments. Our Director of Finance and Resources, Ian Sansbury, will ensure PACE continues to be financially sound and capable of delivering its unique provision. Ian will also



manage the development of new facilities to accommodate our Early Years and Community Services, and hopefully there will be good news about this soon.

The creation of a number of "Heads of Service" roles will further strengthen operations. Julie Smith will take on the post of Head of Primary Services, Charlie Lyons, Head of Training Services, and Audrey Hopkins continues as Head of Secondary Services. Our Outreach, and Sessional Services, along with Early Years, will continue to be coordinated by existing staff with development planned from 2013. These are all carefully considered changes, required to meet the demands of a growing charity.

And now a request, as part of my pledge towards the special 2012 Children's Challenge, and to celebrate my 21

years at PACE, I want twenty volunteers to join me in a twenty one mile walk to raise £21k; along the Chiltern Ridgeway on Saturday 12 May. If you would like to join me, contact Simon on 01296 392923 or email simon.ekless@thepacecentre.org Alternatively, make a donation at www.justgiving.com/heathers21walk

Finally, as always, thank you for your support of PACE - we should all be proud of the children, families, staff and donors who have made the vision I had 21 years ago a reality beyond my dreams.

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You can give more than ever before by making your support tax efficient

Leave a gift to PACE in your will,
or donate in the workplace through payroll giving

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Designed by CK Mundy productions tel 07971 300923
All photography by Simon L'epine Ekless tel 07931 929685

the PACE centre

Philip Green House
Coventon Road
Aylesbury
Bucks HP19 9JL
tel 01296 392739

email info@thepacecentre.org

Registered Charity No. 1011133