

Message from Lucy - DEx Chair

As we've just gone past the mid-way point in the DEx 'academic year' I thought I'd take this opportunity to update you on some recent developments. For Friday families, you should all have met our fantastic new coordinator Joana by now (pictured right) who has settled into the role brilliantly. If you have any suggestions about how we might improve our Stay and Play for 0-5s, please do have a chat with her.



For the last few weeks we have been trialling a different approach for our 5-9s, offering a range of therapies within the weekly session. Being able to offer this to parents each week is a fantastic development, but we still need to think about how to continue to respond to needs whilst balancing our resources and team time to deliver services.

A couple of our oldest Tweens (both teenagers!) have moved on from DEx to enjoy other Saturday activities. We wish them all the very best for the future!

We have launched a social media strategy to try to raise our profile among potential funders and supporters. If you are on Facebook, LinkedIn or Twitter do please follow us, comment and share our posts with your networks – it only takes a moment!

Spring is surely round the corner but for now I'll sign off with a quote from a parent which really touched me and shows the real impact our services are having....*"You are giving [our child] and our family literally life-changing support."*
Lucy Lloyd-Scott

DIARY DATES:

Last day of Spring term - 5th and 6th April
First day of Summer term - 26th and 27th April
Half term (no DEx) - 31st May and 1st June

#WDSD19

It's World Down Syndrome Awareness Week this month! On 21 March groups and individuals worldwide will be working hard to raise awareness of adults and young people with Down syndrome - the impact they make and the challenges they face.



Can you get involved?

How about getting your child's school or nursery to hold an assembly about DS or raise money by wearing odd socks or own clothes?

Can you come along to the second annual DEx Pub Quiz organised by the quiz master extraordinaire, Barry Sykes? #DExQuiz2019 (details below).

And don't forget to let us know what you get up to on Facebook or Twitter @DownrightExcel1

CHARITY PUB QUIZ & 'LOCAL LUXURIES' RAFFLE

FOR DOWN SYNDROME AWARENESS WEEK



#DEXQUIZ2019

WALTHAMSTOW TRADES HALL FRIDAY 22ND MARCH. 7PM. £5 ENTRY



Downright Excellent!
www.downrightexcellent.org
Enabling children with Down syndrome to maximise their potential

Call for help! - Ann Reynard

Huge thanks to everyone who contributes to DEx in some way and this actually means all the great DEx community. This year, we are asking our wonderful families, the team and other friends to raise the bar and help further. Our current Big Lottery Fund grant stops in 2020 and we don't know what will happen when EU funding to charities ceases so we are making a major push now to sustain DEx into the future. Although DEx is a lean machine, it will cost around £230,000 a year by April 2020.

Since 2007 (when DEx comprised 17 children under five) we have raised all our own funding - mainly relying on bid writing for grants. Now, 115 children aged 0 – 15 attend DEx and the regular family contributions raise around 21% of costs. In 2014, we started to look for alternative ways of fundraising and many families have since organised amazing fundraising activities.

But, in addition to those large fundraising ventures, we are asking every family in 2019 to pledge three 'low hassle' activities to bring in a constant background flow of income – you choose what appeals to you, eg the green Tub for Life or online shopping. If every family brought back two full tubs each year this would raise around £5,000. No shaking on street corners, just place in the kitchen or a local shop.

I will meet every family in the next few weeks to suggest low hassle ideas and ask for your commitment. At the same time, I will be writing bids. Can you help?

Funding thanks to....

The Funding Network for allowing us to pitch successfully to their members for crowd funding, DEx mum Selena Virrels for organising the fiendish Christmas quiz, Nicole Dearden for nominating DEx to become Ravenscourt Park Prep School's charity of the year (fingers crossed), and all our other fundraisers and generous standing order donators.



And not forgetting a HUGE thank you to our friends at Octopus, who continue to support us in so many extra and unexpected ways.

Goodbye Emily...

The DEX Trustees said goodbye to Emily Galvin-Cruz last month after four years working hard on the board. She used her experience in the charity sector to give support with fundraising and safeguarding, and will be hugely missed.



She said: "Having a sister with Down syndrome has had a profound effect on my life, shaping my attitudes to all kinds of difference in such a positive way. She has consistently challenged and overturned all the low expectations that my mum was helpfully presented with the minute she was born by a misinformed doctor: that she'd never talk, be able to learn like her sisters or ever live independently.

For the record, she's currently working, studying, volunteering and living independently with her husband. She's also much better at IT, dancing, bedroom tidying, performance arts and taking life in her stride than me!

I loved being on DEx's board and learnt a great deal from being around a group of such skilled and committed people. I will miss the team but will remain a close friend and supporter of DEx."

The Council for Disabled Children

is part of the National Children's Bureau and is the umbrella body for the disabled children's sector bringing together professionals, practitioners and policy-makers. You'll find an information hub on their website with resources about disability policy and practice which includes a selection just for parents.



councilfordisabledchildren.org.uk



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