

**Subject:** Downright Excellent May Newsletter  
**Date:** Thursday, 7 May 2020 at 18:46:45 British Summer Time  
**From:** Downright Excellent on behalf of Downright Excellent  
**To:** James Davis



Enabling children with Down syndrome to maximise their potential

## Welcome to our May Newsletter!

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### Introducing James, the DEx Chair

When we said goodbye to Lucy, DEx Chair, at the end of January, after nine years of giving her time and skills to DEx as a Trustee, it seemed she would be an impossible act to follow. Thank you for everything, Lucy.

But, hey presto! James had offered to leap into the role, and has brought great skills and the experience that DEx needs now. Welcome from us all and huge thanks to James – see his own words below...

### Message from James

Hi Everyone!

I am extremely proud to be joining DEx and whilst we find ourselves in challenging times, I strongly believe it is an equally exciting time for us. I am confident that despite the circumstances we find ourselves in, we will continue to operate an efficient and supportive service as our clinical and non-clinical teams go above and beyond to deliver DEx services. So, a big Thank You from the Board and me.

Our youngest child Abi, now eight, has been attending DEx since she was a few years old, so I have seen first-hand how the team operate. Looking forward, the Trustees and I are committed to developing DEx into a scalable organisation, expanding the breadth and depth of its service offerings for our children and young people. This vision is underpinned by the incredibly strong foundations of DEx, and I hope that by joining the team, my skill set will assist in taking the charity into the next chapter of its journey.



COVID-19 has forced the charity to advance its service model through delivery of online resources. Long term, we would like to support children through access to online resources in addition to face-to-face activity. We recognise the importance of repetition for our children's development so developing a pool of online resources will address this.

I am incredibly thrilled to have joined DEx. I've already said it, but we really do have an amazing team in position who work incredibly hard behind the scenes to ensure service continuity. With opportunity for the charity to grow over the coming months and years, these truly are exciting times for us.

Stay safe and stay well,

**James Davis**

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### **The fantastic new DEx website will go live this summer! Hooray! But it won't launch without your input**

We want to quote you to bring the site alive... we don't need much from you – just 3 or 4 lines:

- or even single words
- short anecdote about your experience of DEx or a particular achievement
- photos of your child, your child and family or you delivering therapy etc
- short video clips

If you would prefer us to call you and take notes, please let us know! Contact Ann or Georgia [annreynard@btopenworld.com](mailto:annreynard@btopenworld.com) and [georgia@downrightexcellent.org](mailto:georgia@downrightexcellent.org).

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**Lockdown diary entry from Sandra - DEx Tweens Facilitator and Friday Makaton trainer**

My primary focus was making lots of resources to post out to Tweens families – a lot of printing and laminating occurred to ensure everyone had the resources required to learn from home (#LFH).

The second phase of #LFH included setting up weekly 1:1 sessions with the Tweens via Zoom; there was a lot of 'I can hear you but I can't see you' but we overcame that and it was lovely to hear what everyone had been up to! The Tweens began working on new targets including sorting washing and hanging it out to dry, baking and drawing, all of which was shared on our Tweens WhatsApp Group.

Week three of lockdown consisted of fun games sessions in groups over Zoom, including scavenger hunts and Play Your Cards Right. The best bits included dancing and fitness with volunteer Hannah Larkin, which lifted everyone's mood!

Now that half term is over, 1:1 sessions will resume and the learning will continue throughout the next stage of lockdown. We look forward to sharing our progress with you.



*A huge thank you to Hannah for hosting the Tweens live dancing session.*

### **More fun and games!**

#### **BIG DEX Quiz**

When? Saturday 9 May 2020

Where? Via Zoom and Kahoot

When? 7:15pm for a 7:30pm start

How do I register?

<https://www.eventbrite.co.uk/e/dex-virtual-quiz-tickets-103722402498>

Registration fee: £5 via Virgin Money Giving

<https://uk.virginmoneygiving.com/DExQuiz>

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## **It is essential to keep fundraising for DEx while in lockdown - calling the whole DEx community**

This is the time of year when DEx calculates how much more funding is needed to keep the organisation going for the next 12 months. Then we develop a plan for the necessary fundraising. This year we will need your help more than ever – that is, everybody’s help – because so many routine fundraising activities are now impossible.

As usual, we have saved enough to keep going for at least six months but we will use that time to fundraise for the following half year – and the year after. Plans so far: Family contributions amount to approx. 20% of costs; our Trustee, Anasuya, is assisting to train a virtual bid-writing team; and Octopus continues to fundraise in-house for us.

But we still need to generate more income to sustain DEx. We know our families and team are brilliant at coming up with ideas and doing fundraising - so, here’s how you could help and it doesn’t all need to cost you! You choose.

- Join the virtual bid-writing team
- Online shopping - sign up for Amazon Smile and/or Easyfundraising - they donate when you shop
- Can you think of some wacky sponsored activity that your own friends and networks will support? (see the box below). Don't ask the DEx families and team or they will be overloaded with requests for donations!
- Continue filling your green collecting tub and when it is full, bank the money for DEx. If you don't yet have a tub, please make one with your child one rainy day!
- Have an idea! Is there anything else we can do to raise other people's money while everyone is at home?

Finally, please take photos this term and make notes so we have interesting current information about DEx activities to send to potential funders.

If you have any queries or comments about the suggestions above please contact Ann on [annreynard@btopenworld.com](mailto:annreynard@btopenworld.com).

DEx bank details: Downright Excellent, Sort Code: 40-52-40, CAF Bank Account No.: 00092491

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**DEx Challenge 21**

The phenomenal fundraiser Captain Tom Moore has gripped the nation's hearts over the past few weeks. To date he has raised over £30m for NHS charities and here at DEX HQ we have been incredibly inspired by his story. So, DEX are launching Challenge 21, to encourage everyone to continue to fundraise for DEX during the crisis and beyond. The only rule is that the activity follows the government's guidelines on exercise and social distancing. The idea is that you choose a challenge associated with the number 21 or 2.1 (like the 2.6 challenge) and fundraise for it. Every little helps!

Please share your challenges with us. Tag us on social media or send us your photos!

#Challenge21

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### **Lockdown diary entry from Campbell – one of the great volunteers from our incredible sponsor, Octopus**

The first time I visited DEX was for a Friday Stay and Play. I was a bit nervous as I wasn't sure how I could possibly be of any help.

I needn't have worried as Ann, Joana and all the therapists were so welcoming. Initially, all that was required of me was to play with a cheerful group of kids of various ages. After a few weeks, Ann challenged me to do more - what skills could I offer? We settled on exercise and fitness as this is something I enjoy and is beneficial and fun for the children and their families. When I'm able to join, I run the kids through a variety of movements – we discovered there are some great yogis in the group!

COVID-19 means therapy sessions have stopped in the usual form. When I asked Ann what the biggest challenges would be during this time, she advised that donations are important but harder to raise during such uncertainty. I decided, along with a friend, to do a run in order to raise funds for DEX. My target was to run 15 km in one hour, doing laps around Victoria Park. I was very pleased to meet this goal but, more importantly, with support from Octopus and the community we raised £968. I understand this will go towards Zoom Pro accounts so speech and language therapy, and other services DEX provide, are able to be offered online.



*Campbell demonstrating*

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### **Great news - new email server for DEx – no more spam from DEx**

We know that some DEx emails are going into people's spam folders. Please continue to check these regularly – especially at this time of non-stop online communication. Launch of the new server has been slightly delayed because of lockdown but it should be up and running very soon, which we hope will mean an end to the email issues.

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Can you guess who this is?

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### **Lockdown diary entry from Matilda – DEx Volunteer & past Trustee**

#### **'Sister Sister'**

It's safe to say, 2020 will go down in history as an extremely bizarre year! The most difficult thing for me has been explaining to my sister, Lydia, why I can't visit her. As she understands it, the world is poorly, and that is perhaps the most apt explanation I have heard to date! I live in London, she lives in Leeds and, like anyone currently back living with their parents at the moment, she is getting 'fed up'.

So, I've made a conscious effort to stay connected with her and, by virtue of technology, FaceTime has been our saviour. Midweek we tend to chat over a puzzle – her favourites are pictures of her with my friends (I am not allowed to feature) which I have had printed onto jigsaws. They are tricky, but great for developing her fine motor skills. Baking dominates the weekend and we have almost nailed the banana bread that is trending in everyone's kitchens. Mum weighs out all the ingredients beforehand and I guide her through the step by step process of combining them together. I am told a lot of it ends up on the floor– but hey, that's half the fun!

Bedtime continues to be a challenge so as soon as she is ready, my face appears back on the screen and we chat about what has been good and what has been rubbish about the day. I usually get a couple of missed calls after this, but I don't mind. If anything, the importance of social interaction for Lydia's development has never dawned on me more. She thrives in the presence of others and this lockdown is certainly making it more difficult. Whilst video conferencing is great, is certainly doesn't provide the same stimulation as 1:1 interaction in person does.

This week, my friends and I have book club. I'll be dialling Lydia in to catch up with the girls and I know she can't wait to see some different faces!



*In sunnier times - Matilda and her sister Lydia who happens to have DS*

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**Heartfelt thanks to the amazing DEx community of our children and young people, DEx families and extended families, Trustees, freelancers, volunteers and sponsors.**

You are all an inspiration! Everybody has worked together so hard to keep DEx going

through these difficult times and to plan ahead with vision. Everyone's great commitment means that DEx will continue to provide high quality specialist support for our children and families – whatever the challenges. The under-10s freelance team, with Beth's stimulating leadership, have worked throughout the 'holidays' to plan an amazing online development programme which will continue to evolve. For the Tweens (the 10s – 16s), Sandra began delivering fun, activity-based learning sessions as soon as possible after lockdown.



*Our Beth in action*

All our families have shown tremendous support by committing to the new DEx sessions and learning to Zoom! Trustees are helping out, our volunteers have offered distance volunteering and our sponsor, Octopus, is assisting in many ways from bid-writing to sharing the Octokids TV programmes. DEx children seem to have taken to Zoom and clearly demonstrate they belong to the digital age, which is the best help as we launch online DEx! Thanks to everyone for your emails of encouragement and for feedback from every perspective. The Downright Excellent aim through this time is to ensure that all families and team members feel professionally and warmly supported so please let us know how we – all of us – are doing as we journey through the summer term.

I know these times are a challenge for everyone, and can be overwhelming, but we will pull through this crisis together and DEx and the Downright Excellent community will emerge stronger, and more innovative and united than ever.

**Ann, DEx CEO**



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