



...building a brighter future for
children with Down Syndrome

Downright Special Update – October 2022

Welcome to our latest update. The aim of these half termly newsletters is to keep Downright Special families up to date with what is going on in Friday Group sessions, term dates, training courses, social and fundraising events, as well as health and education news.

******DOWN SYNDROME ACT UPDATE - Respond before 8th Nov******

The consultation on the guidance for the Down Syndrome Act continues to take place. Downright Special has provided its feedback as a charity organisation on health and education. **In addition, we really encourage you as individuals to give your views too. The deadline for feedback is the 8th November.** Feedback is being gathered from people with Down Syndrome, their families and the organisations that support them; to share their thoughts and ideas about the key issues the guidance should cover.

- Click [here](#) to respond to the official Call for Evidence webpage from the government.

There are lots of other organisations requesting feedback such as the National Down Syndrome Policy Group (<https://ndspg.org/consultation/>) and the Down's Syndrome Association;(<https://www.downs-syndrome.org.uk/our-work/campaigning/the-down-syndrome-act/>) because as a community, different groups are trying to ensure they gather as much information as possible so that our voices are heard. We are very aware you all have busy lives, and all these different Calls for evidence might be a bit confusing to navigate, so if you only have time to complete one form of feedback, we **strongly recommend as many people as possible respond to the government (DHSC) Call for evidence.**

Covid Boosters

All our children over 5 including their carers and anyone living with them (over 5) are eligible for the Autumn covid booster. If the NHS hasn't contacted you, click [here](#) to book on the NHS website and self-declare your reason. Click [here](#) for further information from the DSA. Click [here](#) to access an easy read explanation of what to expect when attending a COVID booster.

Training for professionals

Our exciting programme of training to support schools, nurseries and other professionals working with children/young people with Down Syndrome continues. *Whilst we do make professionals aware of future training, it is always worthwhile having a chat with your child's setting about relevant training opportunities, so they do not miss out.*

- Teaching Maths to pupils with Down syndrome: Numicon Firm Foundations and the Maths Mum – online course
Wed 9 Nov 2022, - 3:45PM - 5:45PM
- Teaching Maths to pupils with Down Syndrome: Numicon Breaking Barriers and the Maths Mum – online course
Wed 23 Nov 2022, - 3:45PM - 5:45PM
- Teaching Reading to pupils with Down syndrome: Comprehension Skills – Teams online course
Wed 7 Dec 2022 - 3:45PM - 5:15PM

Click [here](#) for more details and to book. Further training dates will be added to the calendar shortly.

Downright Special Social Events

As we continue to strive to make our social events more regular, tailored and accessible, they are becoming increasingly popular, with some events selling out. Please remember to book quickly to avoid disappointment. You will receive ticket confirmation from ticketsource. Please keep this confirmation in a safe place so you can readily access it as the event approaches. In the unlikely event you are unable to attend a social event, please let us know as soon as possible, so we can offer your ticket to another family.

Future events for our children and young people:

- Juniors Halloween Dance Party – Sunday 30th October 11am – **event closed for booking**
- Youth Club Halloween Dance Party – Sunday 30th October 1pm – **event closed for booking**
- Youth Club – Hollywood Bowl, Sunday 27th November – **EVENT SOLD OUT**
- Downright Special Family Christmas Party – Sunday 11th December – **only a few tickets remaining**. Click [here](#) to book your Christmas Party tickets. If tickets do sell out, we will operate our usual reserve list procedure.

Future events for parents:

'Chat and Wrap' - Thursday 24th November at Bodmin Road, from 9.30am.

Following the success of our last coffee morning, we have booked the next two. We have the room booked for a couple of hours, but stay as long as you can. At the next one, there

will be a festive focus. With the Downright Special Christmas Party looming (11th Dec), there are a LOT of presents to wrap! So let's chat whilst we wrap! Mince pies, tea and festive music provided. Just bring yourself and if you can cope with it, your Xmas jumper!

Date for the diary – Next Parent Power Coffee Morning will be February Thursday 23rd from 9.30am at Bodmin Road.

We are in the process of pulling together our Social Events Programme for 2023 including the Parent Power coffee mornings and will confirm this with you as soon as we can so you can reserve these dates in your diary.

Building a Brighter Future – Preparing for Adulthood

This group is facilitated by Gillian Bowlas, Charity Manager and Lizann Lowson, Chair of Trustees, and has been meeting monthly, with 8 parents involved who have children of secondary age and above. They have been looking at the four areas of preparing for adulthood – education and employment, good health, independent living and friends, relationships community. As well as identifying the issues faced and looking at what could be done to help resolve some of these issues, the group has enjoyed sharing experiences, knowledge, and resources. This is an ongoing project and if anyone else wants to get involved at any time then just let Gillian know. gillian@downrightspecial.co.uk

Complex Needs Steering Group Update

This group is facilitated by Sam Findlay, supported by Kate Long and includes three parents who identify their child as having complex needs and continues to gain momentum. Our last meeting was on Thursday 13th Oct where the topic of Connection and Belonging as well as the Emotional Impact of being parent/carer to a child with complex needs was explored.

We were pleased to hear the group recognise how social events are becoming more inclusive and as such did not feel there was a need for stand-alone social events for children with complex needs. There was consensus however that as a group, parents felt more isolated and found it very difficult to connect with other adults socially.

The group wanted to highlight the role the new Coffee Morning can play in helping parents to connect whilst children are at school. (See above for details)

The group requested as much notice as possible for future events, to facilitate parents (including parents who work) being able to arrange time-out to attend. We have taken this on board and have already confirmed the date for the February Coffee Morning with the church. We will be in touch about other dates.

This is a long-term project so please do get involved if you would like to contribute to shaping our strategy around Complex Needs. Email Sam for more details and to join: sam@downrightspecial.co.uk

Term Dates

Our Friday morning group will run on the following dates:

*****Autumn Term*****

Nov 4th, 11th, 18th, 25th

Dec 2nd, 9th

*****Spring Term*****

Jan 6th, 13th, 20th, 27th

Feb 3rd, 10th

*****Half Term*****

Feb 24th

March 3rd, 10th, 17th, 24th, 31st

*****Easter*****

If your child attends a Friday afternoon session, you will receive a separate email confirming new dates.

Our team put so much time and effort into preparing resources, so please email us on office@downrightspecial.co.uk as soon as you can, or contact your group leader if you are unable to attend a session.

Down Syndrome UK Conference

At the end of September Gillian attended DSUK Conference for parent support group leaders and was proud to present the work Sam has been doing on Health Passports and the Emergency Department Alert. There were lots of great speakers including 21&Co who spoke about including members with complex needs. They had very similar themes and ideas to those identified by our own complex needs group.

Prof Simon Gainsford from UCL, presented the results from a recent study on the use of probiotics (specifically Symprove -) in improving gut health and bowels in children with Down syndrome. The study showed very promising results with a very large number of the 235 children who took part no longer needing laxatives after the 12-month trial. The results should be published soon and he hopes that these probiotics may be made available free or at a much reduced price for children with Down syndrome.

Bev Dean from Special iApps also talked about recent changes/improvements to the suite of Apps offered (and which we would 100% recommend you / your school purchase), including the fact they now have Numicon and Makaton resources available. Find out more here; <https://www.specialiapps.org/en>

Easy ways to support Downright Special

The Movement for Good awards are donating £1000 to Charities.

To nominate Downright Special please click [here](#) to complete the short nomination form below: Our Charity Number is: 1175863 Charity Type: Disability

Winners are drawn end of December.

Easy Fundraising

Easy Fundraising is an online shopping directory which features major online stores, including ebay and Amazon. Visit www.easyfundraising.org.uk whenever you shop online and we'll receive a free donation of up to 15% from every purchase you make.

Asda Foundation Green Token Giving

Vote for Downright Special online as part of the **Asda Foundation Green Token Giving**. The local cause with the most online votes will receive a **£500 donation** with second place receiving £400 and third place £300.

Vote now until midnight on Saturday 31st December 2022.

Its quick and easy, visit this link www.asda.com/green-tokens and select Kingswood from the drop-down box.

Amazon Wishlist

Buying something from our **Amazon Wish List** is a really simple way to directly support Downright Special.

We have just updated our wishlist with some Christmas bits, including wrapping paper for our Xmas party. Click here for the [link](#).

Thank you to everyone who has already supported us. It really does make a difference.

PADS Parent Portal

PADS (Positive About Down Syndrome) is a wonderful source of information, and we strongly recommend our families join the PADS Parent Portal (open to all age groups). Please use [this link](#) . Once you sign up, this portal uses your data to tailor resources tailored to your child's age and particular health conditions and interests. In the future, this will be where PADS disseminate information on new resources, courses and upcoming events (alongside their closed Facebook groups) so it is well worth signing up!

Suggestions and Ideas

If you wish to chat about anything in this update, have suggestions or ideas for events, training or support you would like, or you'd like to pass on any tips, please do get in touch.

We would like to wish all our Downright Special Families a healthy, happy half term break.