



Downright Special Update – February 2023

Welcome to our first update of 2023! 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.

Welcome to Downright Special Film

Have you seen our new 'Welcome to Downright Special Film' yet? We were so delighted to launch it in January. We hope this film will give new families an idea of what to expect when they first get in touch with us and give potential funders some further information on what we do and how they can make a difference to our work.

This has all been made possible by the generous support of the Matthew Good Foundation, working with Big Picture Charity Films. Huge thanks also to the families and schools who agreed to take part in the filming.

Check out the film on our website or click direct on the link here: <https://vimeo.com/790811879>

Down Syndrome Awareness Week 20th - 26th March

We are working hard to prepare for the biggest week in our calendar with Awareness Week and World Down syndrome Day on 21st March!

There's lots of ways you can get involved:

- **Come to our Pop-Up Café** on Saturday 18th March 12-2pm and celebrate with all the other Downright Special families, our friends and supporters. (See social events below for more info)
- **Send us your videos/photos on the theme of 'I can'** and have your child or young person included in our social media campaign video. Submissions to gillian@downrightspecial.co.uk by Friday 4th March
- **Cheer on our football players** in the Downright Special First Touch UK charity match on Sunday 26th March 12pm-2pm at Haworth Park, Hull. A separate field next to our football match field will be set up with activities/lawn games for any spectating children and young adults should they wish to take part. Can't come but would like to support? You can donate to their fundraising page here and help reach their £1000 target: <https://bit.ly/JustGivingDRSfootballmatch>
email lisa.bloomer@downrightspecial.co.uk for further information

- **Organise a bake sale or coffee morning** at your home, workplace, school or college
- **Lots of Socks** – Raise awareness by wearing your lots of socks and posting your pictures on social media using the hashtags #LotsofSocks #WSDSD2023 Don't forget to tag us in too! You can wear whatever socks you like but official socks can be purchased from <https://www.downs-syndrome.org.uk/product/lots-of-socks-2023/>
- **Create a Facebook Fundraiser:** : www.facebook.com/fund/DownrightSpecialNetwork
- **Download our Fundraising Pack for more ideas** <https://bit.ly/DRSFundraisingPack>

If you would like any collection buckets, leaflets, balloons, or posters please email louise@downrightspecial.co.uk or contact 07923 600160

Downright Special Social Events

This term we've had fun at Monkey Bizness Soft play and at our Valentine's Dance Parties led by Joanna from The Little Yorkshire Dance Academy. The use of social stories, quiet areas and sensory toys has continued to get good feedback so we will continue to put these adjustments in place. In advance of any event please do give us a call if you'd like to chat about any other adjustments that might be helpful for your child or young person.

Events Round-Up

Thursday 23rd February – Parents/Carers Coffee and Chat

- 9.30-11.30 Bodmin Road Church – No need to book just turn up!

Saturday 18th March – Awareness Week Pop-Up café

- 12pm-2pm, Darby & Joan Hall, Cottingham
- Everyone is welcome to our pop-up cafe to celebrate Down syndrome Awareness Week.
- There will be baby and sensory toys, activities for children and entertainment.
- No need to book. For further information or to donate a raffle prize or cake contact Louise on 01482 420160 or louise@downrightspecial.co.uk

Sunday 26th March – Downright Special First Touch UK Charity Football Match

- 12pm-2pm, Haworth Park, Hull. All welcome to cheer on the players or for children/young people to have a kick-about / play lawn games on the field next to the match pitch.
- Email lisa.bloomer@downrightspecial.co.uk for more information

Saturday 1st April – East Riding Bikers Easter Egg Run

- 11.15am at East Park, Hull
- See over 350 motorbikes arrive at East Park and receive Easter eggs from the bikers.
- For more information and to book <https://www.ticketsource.co.uk/downrightspecial/t-krygokj>
- Any questions email louise@downrightspecial.co.uk or call 01482 420160

Sunday 2nd April – Easter Egg Hunt

- 12.30pm - 3.00pm, Frederick Holmes School, Inglemire Lane, Hull
- There will be Easter Crafts, an Egg Hunt (with a special guest!) and a raffle!
- Tickets for each child must be booked in advance using the link below.

- Bookings close 12 noon Friday 24th March
- <https://www.ticketsource.co.uk/downrightspecial/t-ealarag>
- Any Questions? Email social@downrightspecial.co.uk or call 01482 420160

Sunday 7th May – Circus Starr, West Park, Hull 4pm.

- We have been allocated 50 tickets.
- Please email louise@downrightspecial.co.uk to register your interest stating how many tickets you would like.

Downright Special Training

Our Spring term training programme is now available to book with a range of courses to help your child's education. Although most of these courses are aimed at school staff, parents are very welcome to attend too. We'd particularly recommend the Supporting Positive Behaviour course as suitable for parents. Courses can be booked here: www.ticketsource.co.uk/downrightspecial

Wed 22 Feb 2023, 9:30AM - 2:30PM	Supporting Positive Behaviour - Teams online course
Wed 1 Mar 2023, 3:45PM - 4:45PM	Colourful Semantics for pupils with Down syndrome - Teams online course
Wed 15 Mar 2023, 3:45PM - 5:00PM	Curriculum Access and Differentiation for pupils with Down syndrome - Teams online course
Wed 29 Mar 2023, 3:45PM - 5:45PM	Promoting Social, Emotional and Mental Health and Wellbeing in pupils with Down Syndrome - Online

Complex Needs Steering Group Update

In the last update we shared with you the pledge that the group developed and that the charity commits to:

“Downright Special recognises that each individual with Down's syndrome is unique and that some may have more complex needs. We pledge to create an environment where all individuals and their families feel welcome and supported, regardless of diagnosis or ability.”

Sam is now in the process of creating an action plan with short, medium and longer term projects around supporting families, including developing training for ALL parents/carers to raise awareness about a dual diagnosis of Down syndrome and Autism.

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:** sam@downrightspecial.co.uk

Building a Brighter Future – Preparing for Adulthood

We had our final consultation/information gathering session with parents in January, completing our discussion on the four areas of preparing for adulthood, the issues and concerns parents have and ideas to resolve the issues. Gillian is now in the process of writing this up and creating an action plan ready to share with everyone. The aim is for the group to reconvene in around 3 months' time to look at progress and any future schedule of events. 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

Downright Special Fridays

A reminder that any parents are welcome to pop in to see us on a Friday morning, even if your child has never attended or has outgrown our sessions or only comes to the afternoon groups. You can come just for a cuppa or to ask our staff for some help and advice.

We've had three new children join our Friday groups in January and it is great to see Friday sessions feeling busy again. If your child doesn't currently attend and you would like a place, then please do get in touch and we will see what we can do.

Dates for this half-term

Feb 17th – no group (half term)

Feb 24th

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

April 7th & 14th – no groups (Easter holidays)

If your child attends fortnightly or attends an afternoon session, you will receive a separate email confirming 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.

Health

Down Syndrome Care Pathway <https://www.hullccg.nhs.uk/downsyndromehull/>

It is that time of year when Sam, our Health Lead focuses much of her time in leading the updates to the Care Pathway, ready for the latest version to be published on World Down Syndrome Day. This year's updates are concentrated on areas of the pathway that didn't undergo a refresh last year such as Audiology and Physiotherapy with a longer-term goal to incorporate social care into the pathway. Do get in touch if you are aware of something in the pathway that isn't correct or needs changed.

Sam has also been working with the hospital paediatricians (Neurodisability team) to develop a social story that our children can use for their paediatric appointments to help them (and their parents!) know what to expect. We will let you know as soon as it is ready to share and then hopefully, we can develop social stories for other regularly attended appointments too!

Student LD Nurse Placement

In January we welcomed John Lawler to the team who is on placement with us until Easter. John is in the first year of his Learning Disability Nursing degree but many of you will know him as Dad to Toby, one of our Downright Special children! John will be mostly spending his time supporting the work on updates to the Care Pathway, responding to health queries from individual families as well as shadowing our teaching staff on outreach visits and helping at our Friday groups.

Maternity

We continue to try to make sure new and expectant parents get the best experience they can when they first hear the news that their baby has Down syndrome. Susanne (new parent contact) and Gillian (Charity manager) have been invited to talk to the maternity ward staff at Hull Women and Children's Hospital about the charity, about Down syndrome and about how best to support new families. We will be delivering three sessions, in March, April and May.

Lending Library

Just a reminder that we have a huge range of books and resources that you can borrow from us.

Our entire catalogue can be viewed online. You can browse for books and resources and then request/reserve the ones you'd like to borrow. Books can be borrowed for up to four weeks.

Email louise@downrightspecial.co.uk to request library login details or to request a pdf version of the catalogue.

Parent Carer Forums

Are you a member of your local Parent Carer Forum?

Hull Parent Carer Forum and East Yorkshire Parent Carer Forum are for families of children and young people with SEND age 0-25.

Parent Carer Forums work to improve services for children and young people with SEND by ensuring families voices are heard.

Both PCFs offer lots of advice and signposting, run events for parents and carers and are generally very helpful organisations to join or to follow on social media!

For more information check out their websites:

<https://www.hullparentcarerforum.co.uk/>

<https://eypcf.co.uk/>

Easy ways to support Downright Special

Thank you to everyone who voted for us in the Asda Foundation Green Token Giving scheme. We were delighted to receive the greatest number of votes and receive a cheque for £500. Thanks also

to everyone who took time to vote for us in The Movement for Good awards. We weren't so lucky this time, but we really appreciate the support.

You may have heard the disappointing news that Amazon Smile is closing on the 20th of February, so we would like to say a huge thanks to everyone who supported us in this way when they shopped online. You can continue to donate to us when you shop with Amazon (and other retailers) if you sign up to 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 and it won't cost you a thing!

You could purchase items from our **Amazon Wishlist**. This list is regularly updated with items we need such as stationary, specialist books, items for events such as our Easter Egg Hunt or Awareness Week Café. https://www.amazon.co.uk/hz/wishlist/ls/1PGPTF1B55IEW?ref_=wl_share

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.