



Downright Special Update – May 2024

In this issue you will find info about:

- Volunteers
- Down Syndrome Awareness Week 2024
- Health: Care Pathway, Training, and Immunisations
- Downright Special Social Events
- Downright Dance
- Training
- Downright Special Friday Groups
- Social Care Survey
- Research Opportunities
- Fundraising

Thank you to our volunteers

3rd -9th June is Volunteers Week and we wanted to start this issue by giving a massive shout out to all the volunteers at Downright Special. Our volunteers take on lots of different roles in the charity and we simply couldn't do what we do without you all!

Here's just a few the activities our volunteers do:

- Setting up/tidying up on Fridays
- Welcoming visitors, making teas and coffees
- Helping with social events
- Keeping our social media up to date
- Designing leaflets, flyers and other resources
- Fundraising and organising fundraising events
- Managing our IT and website
- Being a trustee

So next time you see one of our volunteers in action do give them a massive high five as we are so grateful for everything they do for us!

Down Syndrome Awareness Week 2024

Huge thanks to all our families and friends who got involved in this year's awareness week by doing some fundraising, wearing lots of socks, taking part in an event or sharing our social media posts! We are delighted to say the final amount raised was £4587!!! Thank you so much! This will make a massive difference to our ability to fund all the work that we do to support children and young people with Down syndrome in our area.

Health

Down Syndrome Care Pathway - New Leaflets

We've just updated and redesigned the leaflets to publicise the Down Syndrome Care Pathway. If you would like any to take to places such as your GP surgery then please let us know.

As a reminder, the latest version of the Care Pathway can be found here:

<https://humberandnorthyorkshire.org.uk/our-work/downsyndromepathway/>

Training for Health Professionals

New Parent Contact Susanne and Charity Manager, Gillian have been busy delivering training to the Hull Health Visiting teams on what it means to have DS nowadays, the common health issues for babies and children with DS, the things health visitors can do to support families and how they can refer families to Downright Special. We are also excited to finally make contact with the neonatal doctors' team and we will be delivering some training to the new intake of trainee doctors in June. We will hopefully then get on the training rota to be delivering sessions every six months as the new rotation of doctors join. Health Lead Sam is also in the process of writing some training for GPs on the Down Syndrome Care Pathway.

Immunisations and Down Syndrome

The DSA have created a very up to date (March 2024) guide to immunisations and Down Syndrome, which Community Paediatrics kindly alerted us to. See link. <https://www.downs-syndrome.org.uk/wp-content/uploads/2024/03/Immunisation-March-2024-FINAL-.pdf>

This could be helpful to show to your GP, especially if/when there are any issues with accessing any of the non-routine vaccinations and your GP deciding whether these are appropriate for your child/young person. It also provides some clarity about the chicken pox vaccine, which has been a point of discussion for some at times.

It can't be emphasised enough how important vaccinations are to keep your loved one in good health so hopefully this will be supportive evidence and information to help you advocate for everything needed.

Downright Special Social Events

Since the March newsletter we've had several events covering all ages: East Yorkshire Riders Easter Egg Run, a Youth Club Pottery Workshop (age 11-25); Monkey Bizness Soft Play & Pizza Party.

We've continued to send out social stories before events and we've been using the events checklist created from the work of our parents' complex needs group but please do give us a call if you'd like to chat about other adjustments that might be helpful for your child or young person.

Any other questions or suggestions for social events? Email social@downrightspecial.co.uk

Coming up we have:

Saturday 22nd June – Coffee Morning for Families and Friends

- 10am-12pm Priory Baptist Church, Hotham Road South, Hull, HU5 5RN
- Entertainment, Raffle, Activities for children
- No need to book – just come along! We'd love to see you all there. It is an open invite to anyone including your wider family and friends, supporters of the charity and anyone we work with so please spread the word!

Friday 28th June – Youth Club Mocktails (11-25)

- Join us at our Mocktails Mixing Party 6-8pm at Humber Street Gallery, Humber Street, Hull
- Learn to make 3 Mocktails and enjoy some pizza.
- Book your free ticket here: <https://www.ticketsource.co.uk/downrightspecial/t-qjkjaym>

Saturday July 6th – Densholme Farm Visit

- Note change of date! (was 13th July, now 6th July)
- Join us for a fun-filled day at Densholme Farm
- Arrive at 10.30am, ready for farm tour at 11am
- This event is open to all Downright Special families (including any siblings under 16 years - just remember to book them a ticket)
- Book your free places here: <https://www.ticketsource.co.uk/downrightspecial/t-yamvyny>

NEW!!!!!! Downright Dance (11-25s)

Our new Downright Dance sessions for young people are now well underway with everyone really loving the classes which are led by Joanna Harker with support from volunteer Rose Bielby. So far they have been learning a number from the musical 'School of Rock' as well as a routine to Dance the Night by Dua Lipa!

Mondays (term-time only) 730pm-830pm, The Sports Hub, Wolfreton School and Sixth Form College, Willerby, Hull HU10 6HB

If you are interested in coming along then email office@downrightspecial.co.uk. We offer the first two weeks free of charge to anyone wanting to try it out. Sessions then cost £5 per week, payable half-termly in advance.

Downright Special Training

Occupational Therapy and Sensory Processing Webinars for Downright Special Parents/Carers

We are pleased to be able to offer our parents and/or carers the following three webinars, to be delivered online via Teams by Lizzie Huxford, senior occupational therapist and clinical director at 'OT4me' in York. Lizzie is an experienced OT with lots of knowledge about working with children with Down syndrome. There will be an opportunity for questions at the end of each session, but please note that Lizzie can only give generalised advice and guidance.

Whilst we have managed to secure some funding to enable us to provide these sessions, we will also require a nominal contribution of £10 per family to cover the remaining costs. To ensure that everyone can ask questions, each session has a maximum capacity of 20 spaces.

1. Functional Skills for secondary school-aged children and young people with Down syndrome. Wednesday 19th June 2024, 7-9PM

Lizzie will discuss functional and independent living skills for children and teens aged 11+. She will cover the skills needed to help manage both the home and school environment, plus tips for including occupational therapy provisions in your child's EHC Plan. Book here: www.ticketsource.co.uk/downrightspecial/t-lnmgepa

2. Functional Skills for primary school-aged children with Down syndrome. Thursday 11th July 2024, 7-9PM

Lizzie will discuss the functional skills, developmental milestones, and occupational therapy for children of primary school age. She will also offer tips for including occupational therapy provisions in your child's EHC Plan. Book here: <https://www.ticketsource.co.uk/downrightspecial/t-krmayja>

3. Sensory processing and occupational therapy for children with Down syndrome. Wednesday 2nd October 2024, 7-9PM

Lizzie will discuss what is sensory processing and sensory awareness, how they can impact our children, and how occupational therapy and sensory integration can help. Book here: <https://www.ticketsource.co.uk/downrightspecial/t-yakleo>

Training for Schools and Nurseries.

Although many of the Education courses are aimed at school staff, parents are very welcome to attend these too. All courses and information sessions can be booked here: www.ticketsource.co.uk/downrightspecial

Downright Special Education Training	
Wed 05/06/24 3.45pm-4.45pm	Preparing for Successful Transitions - Online
Wed 27/06/24 3.45pm-5.45pm	Introduction to Down Syndrome FS-KS1 - Online
Wed 03/07/24 3.45pm-5.45pm	Introduction to Down Syndrome KS2-KS4 - Online

Don't forget we also offer INSET training to nurseries and schools. Check out our website for more information. <https://www.downrightspecial.co.uk/inset>

Downright Special Fridays

It is that time of year when our teaching team start planning the groups for September! If your child doesn't currently attend and you think you might like to start coming, then please let us know so we can include you in our planning of how we might organise things! It is usually quite a long, detailed process as we look at each child's individual needs, and the resources we have, so do bear with us as we work through it all. We will let you know the plans as soon as we can.

Dates for next term (morning groups):

May 31st – No groups (half term)

June 7th, 14th, 21st, 28th

July 5th, 12th

Our team put a lot of time and effort into preparing resources, so please email us on office@downrightspecial.co.uk as soon as you can, or give one of us a call/text if you are unable to attend a session. We do ask that you do try your best to attend every session please. Many of the activities within lessons are repeated and built on from one session to the next, so the children will make more progress and probably enjoy the sessions more if they regularly attend.

Social Care

In May and June, East Riding Healthwatch will be gathering feedback on access to disability social care service. If any of you have attempted to access the disability social care service for a child or young person (0-25) who lives in the East Riding area, between May 2023 and present day, you can complete the survey here. <https://www.healthwatcheastridingofyorkshire.co.uk/social-care-support-request/>

Research Opportunities

We have been contacted by Cardiff University who are looking for young children with DS to take part in a study – see info below:

Cardiff Babylab is calling all little scientists with Down syndrome under 5 years to take part in our remote study from your homes! Help us to understand what your child sees and hears during their everyday experiences. To sign-up to receive more details, please follow this link:

<https://tinyurl.com/your-sign-up>.

You can also find more information on our website: <https://www.cardiff-babylab.com/>

Lending Library

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.

Easy ways to support Downright Special

Movement for Good - Nominate Downright Special for a £1000 award.

If you haven't done so already please nominate Downright Special by completing the short nomination form below. You can only vote once per year but your vote will be included in all remaining draws for the year.

<https://movementforgood.com/#nominateACharity>

Our Charity Number is: 1175863

Charity Type: Disability

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! We've had a few new people sign up to this recently and we are so grateful for the support!

Amazon Wish list

You could purchase items from our **Amazon Wishlist**. This list is regularly updated with items we need such as stationary, specialist books, resources for Fridays or items for events.

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.

We hope you have a lovely half-term break!