

## **Downright Special Termly Update**

### **April 2022**

**Welcome to our latest update.** The aim of these updates 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, health and education news, and any particularly good hints, tips, and contacts that we come across.

### **World Down Syndrome Awareness Week Fundraising**

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This newsletter must start with an update about World Down Syndrome Awareness Week and to let you know the current figure for fundraising is a mighty £8000+ with more to come.

This is an unbelievable amount and there are just so many people and businesses to thank: schools and nurseries, the swimathon gang, yogathon yogis, individual fundraising pages, businesses, local dance schools, cake sales, everyone at the Pop-Up Cafe, Bob and his new purple hair! The list goes on and on, and of course our sincere thanks to everyone who has donated their time. This includes Karl Svenson for putting the beautiful videos together to promote our theme #myfavouritethings. Eighteen children and young people took part in this campaign.

Also, thank you to everyone who supported our social media presence. We are delighted to see our social media reach has increased significantly. In fact, visits to our Facebook page are up 194% and Instagram visits are up 100% compared to World Down Syndrome Week last year. This is a fantastic result, allowing us to continue to raise awareness from our ever-growing social media platform. We will continue to update you as more pennies come in, but once again, thank you to everyone in the Downright Special Family Community for making such an achievement possible.

## Trustee News

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We are delighted to have Michelle Fargen join us this month as a trustee. Michelle is mum to Jaeden (11) who has Down syndrome and Autism, and Tristan (8). As well as being a parent, Michelle has previous experience of running a support group in the US. Michelle is looking forward to getting know a few more parents and getting involved in the charity.

It is so important to have parents, carers and other family members involved in shaping the future of the charity and we still have vacancies on the board of trustees so we would love to hear from you if you are interested. The role description is available on our website <https://www.downrightspecial.co.uk/our-current-vacancies> or you can contact Gillian ([gillian@downrightspecial.co.uk](mailto:gillian@downrightspecial.co.uk)) or Kate ([kate.long@downrightspecial.co.uk](mailto:kate.long@downrightspecial.co.uk)) if you'd like an informal chat about what the role involves.

## Social Events

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Thank you to everyone who has signed up for the Easter Egg Hunt on Sunday 10<sup>th</sup> April. We have over fifty children attending, our biggest year yet, and we are very much looking forward to seeing so many of you. Also, the Withernsea Bikers Easter Egg Run is taking place on Saturday 16th April East Park, Hull.

### Future dates for the diary:

#### **Sunday 15<sup>th</sup> May – YOUTH CLUB (11-25 yrs) – Pizza Party at Ask Italian at Hull Marina (bring a friend) 11 am**

- Chefs will demonstrate pizza-making; from how to stretch the dough, adding the sauce and toppings. And then everyone can make their own pizza with a selection of yummy toppings!
- A drink and ice cream will be included for the young pizza chefs.
- There will be a table for grown-ups to sit on while the pizza-making happens
- Attendees are welcome to bring a friend - just make sure they have a ticket booked too.
- Please state any dietary requirements in your booking. The restaurant offers gluten free options and are happy to advise about any other listed allergens.
  - More information on allergens - <https://www.askitalian.co.uk/italian/restaurants/hull/allergens>

Click [here](#) for more information and to book your tickets.

## **Sunday 22<sup>nd</sup> May – JUNIORS (0-11 yrs) – Soft Play Party at Monkey Bizness, Hull (12-2pm)**

- Soft Play followed by a selection of pizza/fries and an ice cream/lolly.
- Siblings are welcome to attend - just make sure to book a ticket.
- Please let us know of any allergies in the booking.

Click [here](#) to book tickets.

SAVE THE DATES...Exciting times ahead...

- **Sunday 12<sup>th</sup> June – Day at Densholme Farm – all ages welcome**
- **Sunday 18<sup>th</sup> Sept – Football Party at Soccer Kings, Hull – Juniors session (am) and Youth Club session (pm)**
- **Sunday 30<sup>th</sup> October – Halloween Fancy Dress Dance Party, Swanland Village Hall – Juniors session (am) and Youth Club session (pm)**
- **Sunday 11<sup>th</sup> December – Christmas Party, Lazaat's, Cottingham 12pm-3pm**

There will be even more events to come so keep an eye on your emails and social media.

Any questions then email [social@downrightspecial.co.uk](mailto:social@downrightspecial.co.uk) or call 01482 420160

## **Friday Group**

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As we finish for the Easter break, we'd just like to remind parents (and schools) to let us know as far in advance as possible if they can't attend a session. Our staff spend enormous amounts of time planning lessons and preparing resources and it is really helpful for them to know who they are planning for or indeed if the lesson is going ahead. It costs us around £500 a week to deliver Fridays and we want to make sure as many children as possible are coming regularly to make the most of the sessions.

After Easter we will start our usual process of sorting out groups for September. We hope that by then the cases of Covid will be low enough that everyone can get back to attending every session.

Continuity and routine, wherever possible, is so important for our children and as such the lessons form part of a curriculum from birth, designed to help you and your child's development in all areas. Each lesson builds on previous skills and the more we get to know you and your child the more personalised we can make this.

We do have a waiting list for some of our groups and we want to do our best to accommodate those children so we will be looking at how we best organise staff and plan which children will be in which groups. If your child currently doesn't come and you would like to express an interest in your child joining, then do let us know.

We also know that lots of you with older children who no longer attend Fridays really miss coming, so if anyone just fancies popping in for a cuppa and catch up you are more than welcome!

## Term Dates

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Friday Term dates for next term are:

29th April, 6th, 13th, 20th, 27th May

3rd June – no group (Half Term)

10th, 17th, 24th June 1st, 8th, 15th July

For those of you whose lessons are fortnightly or monthly, previous emails from your Downright Special teacher will detail your lesson dates & times.

## Summer Term Training for parent/carers

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We are excited to be launching our Parent Power Programme, a package of support and training for parents/carers designed to upskill and empower our families.

### **The Maths Mum – A differentiated approach**

Thursday 28<sup>th</sup> April 7-9.30pm

We are delighted to be hosting a live webinar (via zoom) led by Karen McGuigan, founder of the Maths for Life programme, aka 'The Maths Mum'.

Do you ever look at your child's maths work and worry it is not pitched at the right level for them? Do you wish you had more confidence to know how to support your child's mathematical skills at home? If so, this is the course for YOU.

Cost: Downright Special is heavily subsidising the cost of this training and are only asking for the £10 contribution per participant to secure a place.

Click [here](#) for more details and to book.

### **Toilet Training for Children with Down Syndrome (all ages) Parents / Carers only**

Thursday 16th June 2022

Click [here](#) for more details and to book.

### **Summer Term Training for schools/nurseries**

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

### **Promoting Social, Emotional and Mental Health and Wellbeing in pupils with Down Syndrome - Online**

Thursday 19th May 2022

Click [here](#) for more details and to book.

### **Preparing for Successful Transition – online course**

Thursday 9th June 2022

Click [here](#) for more details and to book.

### **Introduction to working with children with Down syndrome - Teams online course**

Thursday 23rd June 2022

Click [here](#) for more details and to book.

## Colourful Semantics for children with Down syndrome - online course

Thursday 7th July 2022

Click [here](#) for more details and to book.

### Health

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#### Care Pathway

Over the last few months our Health Lead, learning disability nurse Sam Findlay has been working tirelessly to coordinate updates to the Care Pathway. We are really pleased that the latest version was published on World Down Syndrome Day.

The pathway can be downloaded here: <https://www.hullccg.nhs.uk/downssyndrome/hull/>

Do let us know what you think of the pathway, if it has helped you in anyway or if there is anything in the pathway that doesn't seem right. Keeping it updated is a never-ending task and we know there is more to do but we will collate any changes and incorporate them in next year's update.

#### 1:1 Support

Over the last term Sam has given several families individual support and advice on topics such as constipation, behaviour, feeding, autism. She is now also trained to be able to give sleep advice. If you would like to arrange to talk to her about anything health related then message her on [sam@downrightspecial.co.uk](mailto:sam@downrightspecial.co.uk). Sam's usual working days are Fridays.

### Health Visitor Dates

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Our Health Visitor, Louise Hobson, will be coming to Downright Special Friday mornings on the following dates:

29<sup>th</sup> April, 27<sup>th</sup> May and 17<sup>th</sup> June.

## Down Syndrome Bill

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At the time of writing, the Down Syndrome Bill has made it through the final stage in the House of Lords. All it needs now is Royal Assent (basically a signature from the Queen) and then it will become an Act (or law). Once this happens then there will be formal consultation on the guidance that will go alongside the law. We will keep you up to date with progress and as a charity we will look forward to getting involved with any consultation.

## Suggestions and Ideas

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**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.**

**Best wishes**

**The Team at Downright Special**