



## **Downright Special Termly Update**

### **Edition 1 – Spring 2020**

**Welcome to our very first Termly Update!** This will help to keep you up to date with, among other things, what is going on in Friday Group Sessions, training courses and term dates, social and fundraising events, health (Care Pathway) and education news, and any particularly good hints, tips, and contacts that we come across. It is also a great place to share your ideas!

#### **Friday Group**

We have some new volunteers who are joining us after half term. Kim Mitchell is doing her student placement with us and Becki Harman is going to be taking over our EBay store, but will also be observing lessons and getting know our children so that she can take over 'Magic Bag'. They are both a great addition to the DRS team and I'm sure you will make them feel very welcome.

#### **Visitors**

So far we have the following visitors booked in for next Half Term.

28<sup>th</sup> Feb – Gillian Hills (physiotherapist), Rebecca Harman (Volunteer)

13<sup>th</sup> March – Jo Cole (Community Continence Nurse)

27<sup>th</sup> March – Sonia Camp (Health Visitor)

24<sup>th</sup> April – Sonia Camp (Health Visitor), Julia Brady (Physiotherapist)

## Term Dates

Term starts on Friday 28<sup>th</sup> February for all our **morning** children and we break up for the Easter Holidays on Friday 3<sup>rd</sup> April (this session will be morning only and no afternoon groups will be running)

## Social Events and Fundraising

Saturday 21<sup>st</sup> March - WDSO Pop Up Café 2pm – 4 pm (Priory Baptist Church)

Sunday 5<sup>th</sup> April – Easter Egg Hunt 1pm – 3pm (Frederick Holmes Special School)

Friday 24<sup>th</sup> April – Boutique Milla ‘Sip and Shop’ 7pm – 9 pm (Boutique Milla, 50 Main Street, Swanland)

Friday 1<sup>st</sup> May – Youth Club Pyjama Party 7pm – 9.30 pm (Space Dance Studio)

Sunday 17<sup>th</sup> May - Soft Play 10am – 12 pm (Kinderland)

The full programme for the year is on our website:

<https://www.downrightspecial.co.uk/social-events>

Events can be booked via <https://www.ticketsource.co.uk/downrightspecial>

## Awareness Week

During awareness week, as well as our pop-up café for World Down syndrome day, we will be very active on social media sharing our videos on this year’s theme of “We Decide”.

Don’t forget if you want to get involved then please send your videos to

[Gillian@downrightspecial.co.uk](mailto:Gillian@downrightspecial.co.uk) by Friday 6<sup>th</sup> March.

We are also encouraging schools and businesses to get involved by wearing #LotsOfSocks, organising a bake sale or coffee morning or raising awareness. Our new awareness week fundraising pack can be downloaded from our website or by you can ask for a copy by emailing [louise@downrightspecial.co.uk](mailto:louise@downrightspecial.co.uk).

## Training Courses

Thursday March 5<sup>th</sup> ‘Growing, Changing, and Keeping Safe’ is a course aimed for parents, and schools, with children in KS2 and above.

Thursday May 7<sup>th</sup> ‘Developing Language and Reading for Children with Down Syndrome’

Both courses will be run at Centre 88, Saner Street, Hull, HU3 2TR - 9.15 am – 3 pm.

## EHCP News - resources

Downright Special is in the process of compiling a list of helpful resources/links/websites and a Parent Pack, with our own Top Tips, to make the EHCP process a little less daunting! But in the meantime here are some useful resources we’ve come across:

- Norfolk Community Health and Care have a “Top Tips for Writing an EHCP”  
[www.norfolkcommunityhealthandcare.nhs.uk](http://www.norfolkcommunityhealthandcare.nhs.uk)
- IPSEA also have a very useful EHCP checklist - [www.ipsea.org.uk](http://www.ipsea.org.uk)
- DSA (Down Syndrome Association UK) have Primary and Secondary EHCP Packs available to download - [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)
- KIDS have a Timeline of what should happen, and when, at each stage of the EHCP process - [www.kids.org.uk](http://www.kids.org.uk)

We have also been working with the SALT Team and they are putting a document together, that will go into schools with our resource boxes, stressing the importance of using Makaton in all settings.

## Health

### Care Pathway

We continue to contribute to the Down Syndrome Care Pathway working party. There will be a revised edition ready for relaunch on World Down Syndrome Day. You’ll find the care pathway here: <http://www.hullccg.nhs.uk/downsyndromehull/>. Do let us know what you think of the pathway and if you have any comments about your experience of how it is being used.

### Bowel Management

We know constipation is a really common issue for people with Down syndrome. Parent Vicky Abbot has been working hard to understand the services that are available locally to support families with this. Jo Cole, from the children’s community nursing team based at

Marfleet Health Centre sees children and young adults aged 0-19 in Hull and East Riding and you can ask your GP, for a referral. Alternatively you can contact the team directly on 01482 344075 for advice on how to get referred to the service.

There's also lots of good advice on the Bladder and Bowel UK website, <https://www.bbuk.org.uk/> including this paediatric pathway: <https://tinyurl.com/qtu2xf8>

### Suggestions and Ideas

If you have any suggestions for social events, or fundraising events, please get in touch. We welcome anything that you come across that you think is a useful resource or link, and would love to know about any events that you think may be of interest to our families, such as the Special Needs evenings at Williams Den, and Sensory events at Miresbeck Nursery for example.

**If you wish to discuss anything on this update, book on a course, or pass on any tips, please contact us at the address below.**

**Hope you all had a fabulous Half Term!**