

2nd Edition 2018 Friends OF DOWNRIGHT SPECIAL NEWSLETTER



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

New pathway set to transform care for people with Down Syndrome

A new Care Pathway which aims to bring together all health information needed for people with Down Syndrome has been launched, paving the way for a more consistent approach to services, advice and support for families.

In partnership with health and social care services, parents and involvement from Downright Special, NHS Hull Clinical Commissioning Group (CCG) has developed the pathway to provide the right information for people with Down Syndrome, who can often experience poorer health outcomes and struggle to access services.

Gillian Bowlas, Downright Special Charity Manager, welcomed the launch of the Care Pathway and said it will make a real difference to people with Down Syndrome, their families and carers.

She said: "There has never been anything like this in

"There has never been anything like this in Hull or the East Riding before and it is a very big and positive step forward."

"It has been driven by parents Vicky Abbott and Janette Waddingham and the launch was a huge success with the involvement of Anna Daniels, Clinical Trainer from City Health Care Partnership CIC and Colin Hurst, Engagement Manager at NHS Hull Clinical Commissioning Group, who ensured all of the right individuals and organisations were involved every step of the way.

"We are so happy to be involved in developing the Care Pathway with parents."

For more information, visit
www.hullccg.nhs.uk/downssyndromehull/



Dear Friends

Welcome to our second newsletter.

On behalf of the Trustees, I would like to say a big thank you to all those involved in the development of the Care Pathway, which was launched on March 21st –

World Down Syndrome Day. This tremendous piece of work should change the way in which babies, children and adults with Down Syndrome receive the care they so rightly deserve. You can read more about the Care Pathway in this edition of our newsletter.

During Down Syndrome Awareness Week we had lots of publicity on social media, featuring videos of our children on the theme of inclusion and 'what I bring to my community', newspaper articles, radio and television interviews, a trip to Gravity trampoline park and our Easter egg hunt.

We have an exciting summer ahead of us with fun runs, half marathons and other fundraising activities. If you could offer any support to these events, please do not hesitate to contact me via e-mail on:

angela@downrightspecial.co.uk

Thank you for your continued support. It is very much appreciated.

Angela Broekhuizen,
Chair of Trustees



Awareness Week support raises almost £1,700

The current total raised for Downright Special during Down Syndrome Awareness Week stands at £1,695.30!

We're so grateful for the support of schools, nurseries, businesses and individuals who organised coffee mornings, wore 'lots of socks' and held various other fundraising activities.

Thank you to: Kiddycare Nursery, Dorchester Primary School, Thorpepark Primary School, St Thomas Moore Primary School, rradar, Victory Leisure Homes, Molly and Jean Tea Room, St Andrew's Primary



School, Brigg Primary School, Patrington Primary School, East Hull Family Practice and City Health Care Partnership CIC (CHCP).

Capturing the fun on camera!

We've organised some fun-filled events for our families over the past few months!

From an Easter egg hunt, trampoline session at Gravity in Hull and the Care Pathway launch party, to soft play and dance sessions, there has been something for everyone. Here are a few snapshots taken since our last newsletter in February.



Friends of Downright Special take on major charity challenges

Great friends of Downright Special have completed gruelling charity challenges.

Isabel Turkington completed the Virgin Money London Marathon, raising £1,525.70, while one of our Trustees, Gavin Beresford, completed the Tough Mudder Midlands course alongside his wife and two friends.

Although donations are still coming in for Gavin's Team Rough Road, he plans to match fund the amount raised through his company, Gavin Beresford Consulting Ltd, taking the total to about £1,000. Damian Clancy also completed the Edinburgh half-marathon on 27th May, raising £515.

At the time of going to print, Gareth Wilkinson was part-way through his challenge of completing the Humber Bridge 10K in May, the Hull Half Marathon in June and the Hull Marathon in September.

Thank you, Isabel, Gavin, Gareth, Damian and everyone who is raising funds for us through various challenges! Also our fantastic team ran the Humber Bridge Half Marathon on June 24th. More about this in the next edition!

Do you fancy taking to the skies for Downright Special?

We're on the lookout for daring fundraisers who would like to take on the challenge of a skydive!

The date is set for September 16th at Skydive GB, Grindale, Bridlington, and we'd love to hear from you

if you're interested in taking part. There are 16 places available and a £49 deposit is needed to reserve your place. The fundraising target is £500 per person, of which £300 will be donated to Downright Special.

To register your interest, or for further information, please e-mail office@downrightspecial.co.uk

Would you like to join us for a black tie fundraising dinner?

Members of the De La Pole Social Group have organised a black-tie dinner in aid of Downright Special after very kindly announcing us as their Charity of the Year.

The event will take place at the Royal Station Hotel in Ferensway, Hull, at 7pm on Saturday, October 20th and it will be a fabulous night of food and music with a performance from vocalist Joel.

We'd like to have two tables at the event and we're looking for friends of Downright Special to join us. Tickets cost £25 each. If you would like to book your place, please e-mail office@downrightspecial.co.uk

How you can help

There are so many ways you can support Downright Special and help us continue our work with families of children with Down Syndrome in Hull and the East Riding.

Did you know lots of employers offer payroll giving schemes in which you can make regular donations to charities

through your wages? To out more, please speak to a member of your Human Resources department.

More information about fundraising is available online at: www.downrightspecial.co.uk/fundraising



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