



21<sup>st</sup> March 2016

Dear MP

Downright Special is a charity which provides practical help, education, advice and support to children with Down Syndrome and their families in Hull and East Yorkshire, with many of these families living in your constituency.

Down Syndrome Awareness Week this year is from 20<sup>th</sup> to 26<sup>th</sup> March with 21<sup>st</sup> March being World Down Syndrome Day. As part of this week of celebration we want to make you aware of our local organisation and the work that we do in your area. We have included some information so you can hear directly from a few of our children about how they are welcomed, valued and respected within your constituency.

We also wanted to take the opportunity, on behalf of all the children and families that we support, to voice our reaction to the recent news reports about the roll-out of a new non-invasive pre-natal screening test for Down Syndrome.

The introduction of non-invasive screening for Down Syndrome was heralded in the media, for the most part, as a great step forward. As parents of children with Down Syndrome, however, we were left angry, upset and horrified at some of the negative language and incorrect information used in the news reports. We want to take this opportunity to speak up for our children and for their place in future society. Our concerns are that the media and some health professionals use language that instils a fear in prospective parents that Down Syndrome is a terrible condition. We believe it is vital that parents are given balanced information about Down Syndrome in order that they are able to make informed choices about their pregnancy. As a group we have a number of questions we would like you to consider:

1. **Why focus on Down Syndrome to screen out?** People with Down Syndrome have a learning disability but they are not “suffering” or “debilitated” (terms used by the media recently). Sometimes babies with Down Syndrome are born with serious medical problems but these are known about and can be, for the most part, fixed. Children and adults with Down Syndrome are shown to grow up to live happy, fulfilled, productive and often independent lives. They may have jobs and relationships and are very much loved and valued by their families and communities. The new screening test has left us wondering if decision makers within the health service see people with Down Syndrome as undesirable. Look at our children’s profiles and wonder with us, why focus on Down Syndrome as something to be feared and eradicated?



Affiliated to

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Fundraising Standards Board no FS01194.

2. **Why spend vital funds focusing on screening out Down Syndrome?** If there is money to be spent then spend it on giving children and adults with Down Syndrome a little extra help in school or in employment or daily life. Much research has been done and much is known about the learning profile of children/adults with Down Syndrome so use this information wisely. A strong society helps, includes and supports those who need it; it doesn't try and eradicate those who may need extra support through life. As a charity with no government funding we are relied upon in your area to provide the extra help and support these parents and children need at birth and at school because we see first-hand that not enough is put in place by statutory services. Down Syndrome is documented to have existed for thousands of years and we would hope that in 2016 instead of fearing Down Syndrome, this diversity could be accepted with funding directed towards enabling people with Down Syndrome to achieve the best of their potential whilst living with the condition.

3. **Will correct and up to date information about Down Syndrome be provided to enable expectant parents to make an informed choice?**

All our families have received mostly wonderful care and sensitivity from the local NHS as regards their child with Down Syndrome. However, many do have a story to tell about a misguided comment from a health professional or an inaccurate or unnecessarily bleak picture of Down Syndrome being painted for them before or after the birth of their child. This anecdotal evidence leads us to another concern about the new non-invasive screening. In the event of expectant parents being told that their unborn child has Down Syndrome, it is not up to us to judge anyone's decision on whether they wish to continue with their pregnancy or not. However we do want to make sure that they are provided with complete and accurate information about having a child with Down Syndrome. A choice is not a real choice unless it is informed and our worry is that it will not always be. Downright Special has worked hard to forge links with the ante-natal department at Hull Women and Children's Hospital to ensure that up to date and factually correct information is given to expectant parents, and we will continue with this work. We'd like to ensure that, along with the introduction of the screening changes, some time and money was being spent to train all staff fully in the facts about Down Syndrome to make sure parents are able to make a fully informed choice, supported by recently trained staff.

In summary, we hope that in this Down Syndrome Awareness week we have now made you aware of the children with Down Syndrome in your constituency. We hope that:

- you have heard their voices and our voices as concerned parents, friends and supporters.
- you have an understanding of our unique perspective regarding recent medical developments in Down Syndrome screening as it may be very different to what you have seen in the media over the last few weeks.
- you will consider our insights in any future decisions regarding Down Syndrome that you may be asked to make. You are most welcome to consult us directly, visit us to speak with our families and meet our wonderful children. Please enjoy reading more about them in the attached profiles.

Thank you for your time and attention and please don't hesitate to get in touch if you would like further information.

Yours sincerely,

A handwritten signature in cursive script, appearing to read 'S Findlay', written in black ink on a white background.

Mrs Samantha Findlay (Trustee)

On behalf of the parents and children in the Downright Special Family.



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



Hi I'm Oscar and sometimes I just love meeting up with my besties. I enjoy swimming, sports club and playing outside. I am planning a big party this year with dancing and lots of chocolate cake, seriously....LOTS of chocolate cake!!!

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Hello I'm Rachel and I'm 11. This is me getting ready to take my bronze-grade ballet exam with two of my friends from school. I've also been learning to play squash at my local club. School is great and I'm really good at reading but I hate French! I'd like to work as a hairdresser when I grow up

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I'm Theodore and I'm 10 and a half months old now. As you can see, I'm really really happy when I'm playing in the sensory room at my local children's centre in Goole

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



High five! I'm Jack. I decided in September that I wanted to socialise with people in my local community and for them to get to know me so I started at Cottingham High. This is me on my first day.

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