



**Annual Report**  
2010/2011

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**Trustees:** Lisa Bentley, Dr Christopher Bowlas, Dr Gillian Bowlas, Dr Liz Herrieven, Janette Waddingham  
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# About us

## Our Aim

To assist families and professionals in the Hull and East Yorkshire region in the care of children with Down syndrome.

## Who we are

We are a group of parents who met in 2006 and set out to provide support to each other and any other new parents we met along the way. This quickly developed into an organised group giving emotional, practical and educational support to families. In 2007 we became a registered charity and are now affiliated to the Down Syndrome Association.

## Our mission

- To provide antenatal support and information to prospective parents and emotional and practical support to new parents.
- To provide and operate such support, materials, training and events so that both parents/carers and professionals in health and education may be assisted in helping children with Down syndrome to achieve the best possible outcomes in their education, social, physical and emotional development.
- To strive to build a brighter future for children with Down syndrome in our area.

## What we do

- We visit families in their homes to offer our support as needed.
- We run a weekly group session which provides education, fun and play as well as support to parents and carers.
- We share best practice teaching techniques with teaching assistants and other professionals.
- We run a fortnightly baby group for children under two.
- We provide conferences and training for parents and professionals.
- We work closely with the health and education services.
- We communicate via our website and regular newsletters.
- We promote the awareness of Down syndrome and encourage successful inclusion.
- We hold social events for the whole family.

**There are around 60,000 people in the UK with Down syndrome.**

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# Report from the Chair



**Children with Down syndrome are perfectly capable of forming all types of relationships. They have the same feelings and moods as everyone else.**



This year it's been exciting to meet new babies and watch the older children blossom and grow. Personalities shine through and their enthusiasm for learning has kept us on our toes. Our challenge has been to keep abreast of this enthusiasm and build on the strengths of the children. Their achievements are testament to the fact that if expectations are high then they will rise to the challenge. We're not just teaching them, they are teaching us too!

It's been wonderful to see the older children don their school uniforms, put on their ballet dresses for ballet class and football boots for football practice, or if they are like my five year old, it's more likely to be street dancing! They are growing up and doing all the things that kids like to do and still constantly surprising us.

Both BP Chemicals at Saltend and the Smile Foundation and its partners supported us for a year and the financial benefits have been significant. In addition to the funding, it has been their advice and guidance that have been important to us. The Smile Foundation and its partners then extended their support for a further six months, encouraging us to organise a business plan and have a voice when raising funds. In 2011 we have been nominated as charity of the year by the Esteem Consortium and its partners and we look forward to working with them.

Downright Special Education is now well established as a recognised base for teaching. We have run a programme of training for teaching professionals and the feedback has been very positive, but it is the achievements of the children which are the real driving force. As the children get older, we are seeing the benefits from applying specific teaching techniques. We would like to generate funds to provide Education Information Packs to be given to the children as they embark on their schooling.

Downright Special Fridays are going well and we now have a new session once a fortnight on a Friday afternoon for children in Year One and Two. One of our aims for the coming year is to raise funding to employ an extra teacher.

We also felt that a separate session was needed to support parents and nurture babies under two and we now have a new group 'Downright Special Babies'. As well as giving support to parents and providing a place for them to make new friends, the group focuses on the very early development of the children. We are in the process of producing a DVD which will give information to new parents and show them aspects of bringing up a child with Down syndrome.

Last year, parents expressed concern about the fragmentation of services within health and education. We have been working hard with these services and have formed some good working relationships. We have been able to set joint targets and have come some way towards improving the care pathways for the children. A big part of our focus for the coming year will be to build on these relationships and improve things further.

Nothing stays static and we will always strive to improve the service and listen to the needs of our families. The charity will continue to evolve and grow as our children grow.

On behalf of the children and their families I would like to say a big 'thank you' to everyone who has helped Downright Special throughout the year. You all made a difference.

And as always, the final thank you has to go to the other trustees who work non-stop to ensure the smooth running of the charity.

*Janette Waddingham*

Janette Waddingham



## Volunteers A vital part of the charity!

Thank you to Jennifer Dent for providing snacks for the children and making everyone feel very welcome on a Friday. Thank you to Julie Foster who has now moved on to become a teaching assistant for one of the children from Downright Special. Thank you to Jane Motherby who helped out at the Friday session but who has now also moved on to do further training in assisting young children who have disabilities.

A big thank you to Paul and Liz Herrieven for updating the website and thanks also to Paul Leeson-Taylor for taking some more wonderful photos. Another thank you to Joanna Choromanski for making resources.

Well done to Sam Findlay for running Downright Special Babies and for the professional design work on invites, leaflets and other publications. Thanks also for the ongoing help on the production of the new DVD for parents.

We would also like to say welcome to Sophie Potter who has joined us to help on a Friday and thank you to Neil Findlay who has kindly agreed to be our Social Secretary.

Also thank you to Paul Herrieven who has now taken on the role of Treasurer. Finally, thanks to Wendy for the cakes every Friday!

## Downright Special Babies sharing first steps together

As the children who attended the Friday Session got older and more robust we realised that we needed a separate group for new parents and babies, away from the hustle and bustle of the older children - somewhere that parents could meet other parents who were also raising a baby who has Down syndrome.

Downright Special Babies runs once a fortnight on Mondays in term-time at the Bodmin Road venue. The group is for babies aged 0 to 2, their parents and siblings. At the group we have:

- a multi-sensory playtime,
- singing and signing,
- a chat over coffee.

After the initial shock of diagnosis we have come to recognise that our children are just as unique and special as any other. First and foremost, they are just babies and as such need all the love, cuddles and interaction that is given naturally to all babies.

At Downright Special Babies we look at early development and communication skills. We give lots of encouragement to each other and celebrate achievements together.

Here's a quote from a parent a little further down the line:

**“ I wish I'd known that children with Down syndrome are just as loveable, kissable, snotty, tantrum-throwing, bubble-blowing, huggable, and milestone-making as their siblings. ”**

Ava, Mum to Daniel (3 ½ years)



**Around one  
in every 800  
babies in the  
UK will have  
Down syndrome.**

# Downright Special Fridays

Downright Special Fridays run during term time and are for children from the age of two up to the end of Key Stage One. Siblings are welcome too of course! We provide education, play and fun at the sessions. As well as learning communication skills, reading, counting and motor skills, the children also learn about playing, sharing and turn taking - all the basic skills that help towards achieving successful inclusion. There are separate lessons within the session arranged around the capabilities of the children. Foundation stage children attend with their teaching assistant from school. All groups then come together for a well-earned snack followed by a sing and sign session called 'Magic Bag' which is a firm favourite with the children. All children have access to the excellent soft play area that the Bodmin Road venue provides.

The biggest change this year has been the addition of a separate session run fortnightly on a Friday afternoon. This session is for older children who have moved on from the Friday morning session. These children attend for a one and a half hour lesson with their teaching assistant.

All our sessions are built around the understanding of how a child with Down syndrome learns. By having the teaching assistants at the session, we are able to pass this on allowing them to utilise the most effective approaches within school too.

## During our sessions we introduce

- Signing
- Jolly Phonics
- See and Learn
- Numicon
- Talktools
- Use of the Developmental Journal for children with Down syndrome

These programmes represent the best and most up to date interventions for our children and will give them the best chance of making gains as they enter school life.



**If expectations are low then children will not achieve, if expectations are high then they will learn.**



## Downright Special Education

Downright Special has been running since 2007 and this has given us the opportunity to learn through our experience. We know from the first children who came to us that the small changes we made in the beginning have made a big difference to the way they learn. We have given them a sound foundation on which to build for the future. We also recognise that this best practice should continue through statutory schooling. Currently there is no specialist support given to mainstream schools who take on the responsibility of educating a child with Down syndrome. Addressing this deficit has been a major driving force for us at Downright Special Education.

Lisa Bentley, our specialist teacher, has taken on the challenge of addressing some of this deficit by successfully writing and delivering a set of training courses for teaching assistants. The training has been based around a set of classroom-based issues and will continue into the academic year for 2010/2011. By giving help and advice to teaching assistants on how to understand the specific learning profile of children with Down syndrome, they can then adapt lessons to suit this profile.

As well as running the Friday sessions, Lisa has also:

- Delivered inset training.
- Provided consultancy work within schools helping to set targets, plan work and deal with specific issues.
- Delivered child-specific teaching programmes in schools on numeracy and literacy.
- Given advice and written reports for the Statement of Special Educational Needs process.
- Run whole school training sessions about the understanding of Down syndrome and the specific learning profile of children with Down syndrome.
- Helped schools formulate effective IEPs (Individual Educational Plans).
- Attended annual reviews, transition meetings and Common Assessment Framework meetings.
- Attended joint visits to school with the Speech and Language Service and Education Service for Hearing and Vision.

# Training & conferences

At Downright Special we aim to make training accessible to schools, parents/carers and professionals. We are the only organisation in our local area doing the work that we do.

The value of the work that we do at Downright Special is recognised by many health and education professionals in the region. Some of the training that Lisa has delivered has been done jointly with these professionals whereas other training has been written specifically with these professionals in mind.

Lisa has successfully delivered a programme of training for teaching assistants covering a range of classroom-based issues. This programme will continue into the new academic year 2010/2011.

Lisa also continues to deliver her training courses for schools on 'An Introduction To Down syndrome' and 'Teaching Children With Down syndrome'.

In the coming year, we will develop a training session for doctors and medical staff who deal with children with Down syndrome.

**Many children with Down syndrome will attend mainstream school.**



# Pastoral support

We are a parent-led charity and firmly believe that no one understands like another parent or carer. There are things that you simply don't have to explain to someone who has been through, or who is going through, the same things as you.

We have welcomed new families and babies and ensured that all parents of a newborn baby have had the opportunity to talk to other parents with a newborn. We have developed a close relationship with the Walker Street Children's Centre and they make sure that any new family is automatically made aware that we are there to talk to them whenever they are ready.

We have visited new parents during the year and continued to give support to our existing families. The support we have given has been in many forms, from simply having a chat to visiting parents in hospital or accompanying parents to children's medical appointments.

It's a brave step for some people to come forward and seek us out. We are keen to extend a listening ear to anyone who feels that they may need our support and understanding.

As a group lots of our parents have had one experience or another, for example coming to terms with a medical condition, or seeing a child through surgery. There is always someone who will share their experiences with someone going through a similar event.

Most of all we share our pride and enjoyment of bringing up a child with Down syndrome. We like to celebrate the big and the little achievements - the reaching of milestones we only dared to dream about but which now make us so proud.

As well as the serious stuff, we love to get our families together and have fun! During the last year we have had some giggles at a number of social events including: an Easter Egg Hunt (hosted by BP Chemicals); a breakfast with Peter Rabbit at Kinderland; a trip to the Sundown Children's Theme Park (hosted by the Smile Foundation with transport by Jim Bell Coaches and lunch from P+O Ferries) and a Christmas party at the Southcoates Lane Fire Station hosted by Blue Watch. Santa's grotto and access to the Fire Engines made it something special. Thank you to everyone involved in these events. It was worth it to see the smiles on the children's faces!

**The best understanding you can have comes from other parents.**

## Work with other agencies



## Training attended

We aim to consolidate our skills base and build on what we learn.

- Lisa attended a conference on 'Inclusion' run by the Down's Syndrome Association.
- Lisa attended the Downs Ed online training sessions.
- Janette attended training sessions run by the Speech and Language Service.
- Lisa, Janette, Gillian, Liz, Sam and Neil Findlay attended a training session by the Down's Syndrome Association on counselling.

## Fundraising & grants

We have been working closely with many of the services within health and education. Our children access many services and our aim is to improve the way that these services work together. All professionals who work with the children have been welcomed to the Friday sessions. We have been working hard with these services and have formed many good working relationships. A big part of our focus for the coming year will be to build on these relationships and improve things even further.

- We have built a close working relationship with the Walker Street Children's Centre, especially Helen Perring and Anna Daniels who inform parents of newborn children of the services we offer.
- We work closely alongside the Speech and Language service with S+L Therapist Julie Robinson attending the Friday sessions on a regular basis. The working party set up last year has helped to integrate our services and work towards shared targets.
- Chris Lee from the Educational Service for Hearing and Vision works alongside us, attending the Downright Special Friday Session once a month to give advice and support to parents/carers.
- We work alongside the Hull Transition Co-ordinator, Karen McPhee, to ensure that accurate and helpful education information is given to schools before and in the early months of a child's school career.
- We work with the Education Service for Physical Disability.
- We work with the Women's and Children's hospital to ensure that new and expectant parents get our information packs with good quality, up to date information about Down syndrome.
- We are in active discussion with the Eye Clinic.
- We work with the Down's Syndrome Association to set up local training courses.

Plans for the coming year include working with the paediatric services to improve the care pathways for children with Down syndrome and to provide training for medical staff on the learning profile of children with Down syndrome.

We are truly amazed by the generosity and dedication of people when raising funds on our behalf. Every penny goes towards making a difference to the children. We know that it has been harder than ever to raise money in the current economic climate and we are very grateful for your support.

### A heart felt thank you to:-

<b>BP Chemicals Limited</b>	<b>Blue Watch at Southcoates Lane Firestation</b>	<b>Ray Todd</b>
<b>Smile Foundation</b>	<b>Billy &amp; Sam Bell</b>	<b>Rotary Club Hull</b>
<b>Hull and East Riding Trust</b>	<b>Tracey and Craig Ellis</b>	<b>Swanland Primary School</b>
<b>Gemtec and Eric Shackleton</b>	<b>Barbara Craig</b>	<b>Karen Atkin (CSW) &amp; Zoe Loftus (Staff Nurse) from A&amp;E, HRI</b>
<b>Lee Creative Marketing Limited</b>	<b>D3 Office Group Ltd</b>	<b>Jim Bell Coaches</b>
<b>Hull Trains</b>	<b>Jenny Young</b>	<b>Keith Earle</b>
<b>Fiona Miller</b>	<b>Waitrose</b>	<b>Craig Burdick</b>
<b>Sarah Coates-Madden</b>	<b>Paediatric A&amp;E and A&amp;E Housekeepers at HRI</b>	<b>Canteen Staff at BP Chemicals Ltd</b>
<b>Nick Smart</b>	<b>Chris &amp; Howard Green</b>	<b>Tracey Coates</b>
<b>T. Copley</b>	<b>David &amp; Pam Waddingham</b>	<b>Paul Leeson-Taylor</b>
<b>Holderness Sewing Group</b>	<b>Cath Smith</b>	<b>Hymers College</b>

Thank you to Lee Creative and Hull Trains for the design and printing of last year's Annual Report. A special thank you to BP Chemicals Limited and the Smile Foundation and its partners. Also, an apology to Eric Shackleton from Gemtec for missing you off last year's report. Sorry Eric!

# How you can help

As a charity we rely on the vital support of generous people and their fundraising in order for us to do the job that we do.

There are many things that you could do to help us in our fundraising efforts and all your help will be very much appreciated.

## You could:-

- Make a donation direct to Downright Special.
- Raise funds when shopping online by visiting [www.easyfundraising.org.uk](http://www.easyfundraising.org.uk). Register selecting Downright Special as the organisation you wish to support. You still shop direct with each retailer as you would normally, but simply by accessing your chosen online shop from the links at [easyfundraising.org.uk](http://easyfundraising.org.uk) first, each retailer will make a CASHBACK DONATION of up to 15% to Downright Special.
- Organise a raffle.
- Have a coffee morning.
- Do a sponsored challenge.
- You could ask if your place of work, or business, would choose Downright Special as their charity to support.
- Ask if any businesses would match-fund an amount you will raise.
- Donate prizes for us to raffle.

We have a sponsor form that you can download from our website.

If you would like to do something 'Downright Special' and need a chat first, you can contact us by ringing Janette on 01482 420160 or by e-mailing us at: [enquiries@downrightspecial.co.uk](mailto:enquiries@downrightspecial.co.uk)

**Children with Down syndrome have more similarities with other children than differences.**



# Financial review

Income and expenditure increased as the work we do gathers pace. Please note that the income shown for BP Chemicals and the Smile Foundation is only the first instalment of a much bigger amount. The remainder will not show until next year's accounts.

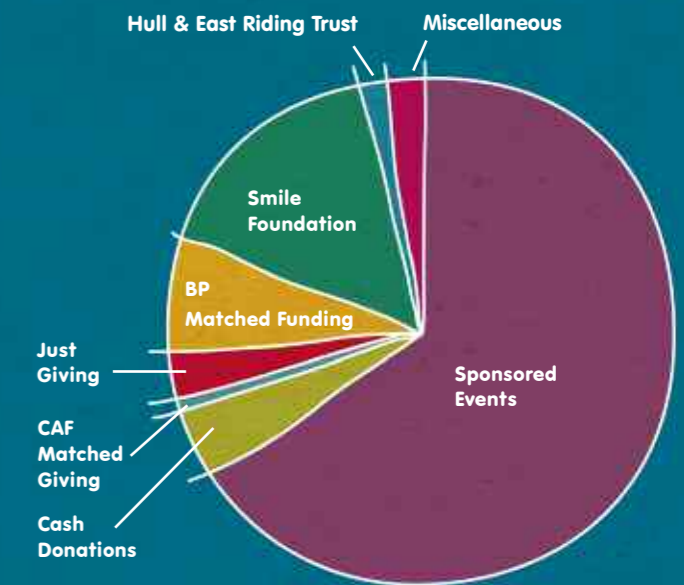
Expenditure has increased partly due to the fact that we now have one paid member of staff. We are still proud to say that the rest is used directly for the benefit of the children. We do not use any funds to generate voluntary income. The surplus shown at the financial year end is earmarked for future projects.

We keep our costs as low as possible by using parent volunteers to full advantage. Our specialist teacher donates all of her time free of charge.

The summarised financial information shows the income received and how we have used the funds. A full summary of the accounts has been submitted to the Charities Commission.

## Income

	£	%
Sponsored Events	21 137.22	66%
Cash Donations	1 276.00	4%
CAF Matched Giving	350.00	1%
Just Giving	876.00	3%
BP Matched Giving	2 232.94	7%
SMILE Foundation	5 000.00	15.5%
Hull & East Riding Trust	500.00	1.5%
Miscellaneous	798.38	2%
<b>TOTAL</b>	<b>£32 170.27</b>	



## Expenditure

	£	%
Office Supplies	3 672.99	13%
Salaries	8 976.36	32.6%
Professional Fees	373.75	1%
Resource Materials	7 034.51	25.5%
Training Courses	784.00	3%
Communications	1 039.78	4%
Website	349.17	1%
Social Events	629.80	2%
Marketing	2 912.64	11%
Building Rental	1 550.00	6%
Miscellaneous	217.82	0.9%
<b>Expenditure</b>	<b>£27 540.12</b>	

