Wakefield and District Down's Syndrome Support Group

Charity number 1155866

Trustees' Annual Report and Accounts For the year ended 17 February 2016

Objectives and activities

The objects of our CIO are:

The promotion of social inclusion among people with Down's syndrome and those with other learning/additional needs including their families and carers within Wakefield and District and its immediately bordering areas who are socially excluded as a result of their condition by preventing them from becoming socially excluded, relieving their needs and assisting them to integrate into society by:-

1. **providing information, forums, advocacy and general support; and**
2. **by providing recreational facilities and opportunities.**

Our main activities are a mixture of regular and one-off activities and events which enable families to have fun and develop friendships and, ultimately, to support each other. We administrate and manage a very well-used closed social network group to encourage communication between our families and families from the wider local area.

We aim to make a difference by improving understanding of Down's syndrome in our community in as many ways as we can, and we are steadily increasing the opportunities for children and young people with Down's syndrome in our area, for example by establishing our Star Speakers sessions to provide much-needed speech and language therapy for our families.

We also work to raise awareness of Down's syndrome in a number of ways – we hold an annual Family Fun Day attracting thousands of people with a focus on raising positive awareness and we have increased our public profile at local events and on social media to spread information and positive awareness.

Achievements and performance in the last year

Quotes highlighted in blue within this report are all taken from our anonymous parent/carer survey carried out in April 2016 prior to producing this report.

Support

We continue to run our **Saturday club**, once a month on the first Saturday of every month, and it continues to be popular and well-attended. It provides a valuable opportunity for parents to meet and support each other, in a welcoming, informal and relaxed environment, and the children with Down's syndrome and their siblings are all able to access activities together.

"Great opportunity for a relaxed meeting with others who really understand the problems you have to deal with"

"Gives support to families, a place where they can be open and honest with each other and ask for advice from people who may have the same challenges"

We also run a busy **Facebook group**, which facilitates communication between our parents and offers a forum for advice and support whenever it is needed. As we are volunteer-led, we are have no facility to offer formal support, but we have created a network, reinforced every day by our trustees, where questions are always answered or people are signposted to a service that will help them, people who have concerns are listened to, and people who have things in common come forward and make contact with each other, if they choose to.

We organised and funded a successful baby **First Aid** course in April for our families, which was very much appreciated. One parent said "it was brilliant, really put you at ease and went through it thoroughly, it was really laid back".

We have a specific named **new parent contact** if people are in need of someone to talk to after they have received a diagnosis, who is able to signpost to others as well.

There are lots of ways that we **support** families in line with our objectives: as well as the ways in which we encourage a network of parents to support each other above, there are also small but useful practical ways that we offer support – such as giving out **RADAR keys** to help families access disabled toilet facilities, creating a **Makaton** signs folder for people to access and discuss at Saturday club, and regularly providing relevant **information** to families through our newsletter and social media.

Fun and friendship

We create lots of opportunities for making friends and having fun together throughout the year. We run a number of different **trips**, including our main summer trip – this year to Lightwater Valley. 39 families attended at least one of the trips arranged over the summer.

"it gives us the opportunity to meet other parents we would never have met and for our children to have fun with other siblings"

"Really love the summer trip. Seeing all of our families together at the picnic and catching up with people we don't see that often is great. It also helps families to have a fun day out, with people that understand what they are going through and that they don't find it unusual if your child is acting up. It is also a big day out that some families could not afford and so it is great that they can spend the day together, without worrying about the cost. THANK YOU for organising this every year."

We hold a **Christmas party** for our families, and also **nights out** for parents throughout the year.

Our events and activities are as inclusive as possible, the family events are usually free and funded by the group where possible and are guided by what families request. Our members are encouraged to offer suggestions and ideas, and are supported to organise activities by the group's trustees, and we are always looking for ways to encourage more people to do this.

We have created the beginnings of a **siblings group**, again based on the idea of building friendships between each other to help the siblings support each other as they grow up together – they got together for their first meeting in August, for a very noisy and happy dinner at Pizza Hut! They had fun together, and also started work designing a logo and coming up with a name for the group – they chose **Super Sibs**.

One of our siblings said: “I enjoy meeting up with my friends because we get to talk about anything. I like to go to different places to meet up such as bowling. I like that super sibs is a special time for us kids.”

We also run **a group for older children and young people**, which has some big annual events – a Valentine’s Disco and a Bonfire Disco – and also trips within the year, such as Lazerquest and pantomimes.

Making a difference

We are very proud of the introduction this year of our **Star Speakers** group – informal sessions were run before a fantastic launch event was held in January and regular monthly sessions are scheduled from now on. We have acquired grants, in particular a grant for £10,000 from Children in Need, and funding and help from a number of other sources to enable us to employ speech and language therapists to deliver groups to lots of our families, which will make a real difference to the children’s futures.

“ … enjoyed the session, and so did we!”, “ … was eager to look at his homework when he got home!” “lots of helpful advice for us to work on”

We ran a successful **Reading and Language Intervention (RLI) training** in March for 60 attendees, and a follow up session in November for 48. We have had lots of positive feedback about the impact in schools, for example 70% of attendees strongly agreed with the statement that the training helped them understand about how RLI techniques should be used in schools, and nearly 30% agreed. All that attended went away with a plan to change their practice. This will improve outcomes for children with Down's syndrome throughout our District, and ultimately, improve the practice of other local services.

"Training events and getting through to educators and other professionals is fantastic and the literature you use to accompany it is excellent"

We have started meeting with Mid Yorkshire Hospital NHS Trust about the **DS pathway**, a structured protocol for care for all people born with DS from pregnancy to adulthood, which will be vital in shaping the future for our children. This will be a long process but we are pleased that there is a plan and are looking forward to helping to guide it.

Our partnership with Normanton Sports Acro, a local gymnastics club, continues to go well. Their class specifically for school-aged children with DS – **TriStars21** – continues to be successful, and many of the gymnasts have achieved at least their first British Gymnastics badges and are working towards performing at displays in the future.

We continue to communicate well with our families and our beneficiaries through email and social media. We held our **AGM** in June which was open to all. We continue to make positive improvements, such as creating specific **email addresses for trustees** to enable better contact with our trustees if it is needed.

Raising awareness

Our **Family Fun Day** at Pontefract Park proved to be another great success this year, attracting thousands despite the chilly weather! The change of venue didn't affect the numbers, and families from far and wide come together to have fun – engaging in the wide range of activities together and watching the events in the arena including the hilarious Mascot Race.

Our group's own mascot, Superstar, is our pride and joy and very popular with the kids!

Activities include traditional fun day attractions such as fairground rides, bouncy castles and facepainting, but also offer some activities to bring families together such as Jo Jingles' singing sessions and inclusive activities such as inclusive golf and singing and signing. The success of the Fun Day in the local community is such a strong feature of our awareness-raising – if people have shared a positive experience with us, then they will know that we are here if they or anyone they know needs us in the future.

Our **new web site** was launched in February, and is a big improvement. One feature that has been praised in particular is the "What I Wish I'd Known" page in the section for new parents, where we have collected comments from our parents about what they had wish they had known when they received their baby's diagnosis.

"love the website so easy to view and use", "Very informative and inviting, easy to navigate", "Like the branding. Lovely photos, really bright happy feel to it. The balance of information and pictures to represent what the groups offer is good. Really like hearing about members of the group and what their stories are"

Our **public Facebook page**, which is used to promote positive awareness about people with Down's syndrome, has gone from strength to strength. Over 1500 people now like this page and see the posts, which is amazing. **Our newsletter** reaches around our district and is now shared electronically and posted on our web site too.

We have created **strong links** with our local Round Table, who have made us one of their charity partners for the Wakefield Festival of Beer, and have offered funding for resources for Star Speakers and support for next year's Family Fun Day. As well as the valuable funding, this link will help raise the profile of our group.

We have increased our **presence at local events** such as Normanton Gala, Featherstone Rovers Community Gala and local SEN marketplace events. Fundraising for our group has continued throughout the year, both at these events and through a wide range of different sources, often in a way that often strengthens bonds and friendships between our families.

We work to raise awareness in the hope of reducing social stigma and discrimination, and maximising opportunities and potential of children and young people with Down's syndrome.

Our charity, guided by our trustees, continues to be shaped by the families that are in it – by what they want, by what they are able to set up, and by what they create between them.

This **summary of our achievements** closes with some comments about the group from our parent/carer survey carried out in April 2016, just prior to the completion of this report:

"It brings together parents and carers that are going through the same things as you"

"Promotes a very positive image of people with Down's syndrome, supports families well and is actively creating a difference for all our children."

"Thank you to everyone that has helped to run the group. Our lives would be much harder without the support, fun and opportunities that the group offers. THANK YOU!!!!!!!!!!!!!!!!!!"

Reference and administrative details

Charity name: Wakefield and District Down’s Syndrome Support Group

Charity registration number: 1155866

Address: 2 Carleton Road, Pontefract WF8 3NA

Trustees during the year:

Geoff Tulley	Chair of Trustees / parent trustee
Ruth Noble	Treasurer / parent trustee
Andrea Arnold	Secretary / parent trustee
Sara Beaumont	Parent trustee – added February 2015
Alison Brown	Parent trustee
Neil Courtman	Parent trustee
John Crawshaw	Independent trustee – added September 2015
Emma Juckes	Parent trustee
Paula Rose	Grandparent trustee – added February 2015
Alexis Sharp	Parent trustee
Ann-Marie Sheard	Parent trustee
Alicia Tulley	Parent trustee – added February 2015

Structure, governance and management

Our group has run as a voluntary group since 2000, with a small committee of volunteers, and we became an affiliated local group of the Down’s Syndrome Association in 2003. Our charity has been formed as a Charitable Incorporated Organisation (CIO), which is governed by a constitution which was adopted on 20 February 2014.

We hold regular trustee meetings as well as any additional “sub-group” meetings where necessary. Our trustees have mostly remained the same from the previous year, we have one independent trustee and are seeking to appoint another one to strengthen our board.

We have chosen to continue with named elected positions of Chair of Trustees, Secretary and Treasurer, to be reviewed at each AGM. Geoff Tulley, Andrea Arnold and Ruth Noble were all re-elected unopposed at the AGM held in June 2015.

The trustees have taken the Charity Commission's public benefit guidance into account when making all decisions, and will continue to do so.

Financial review

The net receipts for the period were £24,239.05. £9,985 were restricted funds.

Reserves

The charity's free cash reserves at the year end were £17,090.15.

The trustees have not adopted a formal reserves policy, and the trustees note that, as the ongoing core costs are minimal due to being volunteer-led, the vast majority of reserves are available to be allocated to future projects.

Declaration

The trustees declare that they have approved the annual report as above.

Signed by the chair on behalf of all trustees:

…………………………………………………………………………… Date:

Geoff Tulley, Chair of Trustees