



Down's Syndrome Scotland

helping people realise their potential

**People helping people**

# Welcome

## A message from our Chairman



Welcome to the annual review of Down's Syndrome Scotland. The Board of Trustees think it's a fabulous organisation and would thank you for your own involvement in it. We are all in Down's Syndrome Scotland together; parents, carers and siblings, professionals and the Board of Trustees. I have come to realise how wonderful many people with Down's syndrome are and I have also realised how wonderful their family are.

It has been a very good year. The organisation continues to grow and flourish. There is great momentum and excitement and this will continue as we build towards the international congress in Glasgow in 2018. There are more staff involved in DSS and consequently more support of parents and families. There is a terrific communication system including a super magazine and web-based material. Just have a look at it. Above all there is increased professional fundraising to allow the organisation to do what it is supposed to do.... support people.

I have been really pleased with the development of Down's Syndrome Scotland over the year. The Family Support Service goes from strength to strength, and gives great support and information to many parents and carers who really appreciate the involvement and commitment they receive.

The annual review is worth a careful read. I hope you enjoy it and get something from it.

Thank you for doing what you do for Down's Syndrome Scotland.

A handwritten signature in black ink, appearing to read 'Lawrence'.

## A message from our Chief Executive



When I first came to Down's Syndrome Scotland in 2008 parents told me that the most important areas to focus on were communication skills and influencing policy. In our previous review I spoke of my delight in at last securing funding for policy work and in this one, you can read about the impact we are now beginning to have in policy and parliamentary affairs. We are now beginning to "get on the radar" of the Scottish Government and during the year have become

a "key delivery partner" for work on their learning disability policy. There's still a challenge, because the parts of the government that affect the lives of people with Down's syndrome are numerous and we need to influence them all. We've made a good start and we know there's more to do, but success breeds success, so onwards and upwards as they say.

I am particularly pleased that we are able to report about the developments in our work on improving communication skills. This has been a priority for me, as I have always felt acutely the injustice of a person with Ds being unable to communicate. The evaluation by University of Strathclyde of our work in this area has led to us being able to roll out the work in more areas of Scotland and to securing funding for yet more groups – including in Orkney from August 2015.

Just last week a parent recounted to me very movingly, the almost unbelievable impact our work has had on her son, who prior to going to the group had been non-verbal. Conversations like that make all our efforts worthwhile.

A handwritten signature in black ink, appearing to read 'Pandora Summerheld'.

# We help families with support & information

guardianship  
transitions into adulthood  
community care issues  
feeding  
tonsils  
exercise  
nursery/school education  
weight  
wills & trusts  
sleep apnoea  
thyroid  
heart surgery  
toilet training  
independent living  
dementia  
school transitions  
weaning  
power of attorney  
sleep disturbance  
adenoids  
diet



Increasingly, families are approaching us about transition to adulthood, community care issues, moving their son/daughter into their own home and issues of guardianship, power of attorney, wills and trusts as well as thinking about what will happen on their death.

In the past year our Family Support Service team has supported 40 families with a new baby who has Down's syndrome. Families are referred to our team by screening midwives, maternity hospital staff and health visitors.

## Our impact on families

We supported 824 parents on a wide range of issues:

➤ I felt quite isolated before I contacted DS Scotland. I am so glad I did, as they listened, were non-judgmental, and started the ball rolling for me. I felt that a huge weight had been lifted. ➤

- Mother of Child with Down's syndrome

## Our action

**We responded to family requests for information and support.**

Our Family Support Service team has continued to offer 'all through life' support for families. Many enquiries relate to developmental milestones such as feeding, weaning, learning to walk, nursery and school education particularly around transition periods. Medical issues across all ages were covered and typical enquiries were around sleep disturbance, tonsils, sleep apnoea, heart surgery, thyroid, diet, weight and exercise.

# We help families with complex cases

deferment decisions

Self-directed Support

complaints

education department placing

disability living allowance applications

Social work assessment

attending transition meetings

## Our action

**We responded to family requests that resulted in ongoing casework.**

Our Family Support Service's casework ranged from three hours to 10 days of staff time spread

over several months.

A great deal of our casework has involved supporting families to understand the raft of changes to regulations relating to such things as welfare reform and the introduction of The Self-Directed Support (Scotland) Act in April 2014.

Our team have helped families access statutory and local authority services to suit their needs.

## Our impact on families

**259 families received support for complex issues:**

## Care and support for Angel and her Mum



Amanda gave birth to Angel on the 20th March 2014 at 35 weeks gestation, the surviving baby of twins. Angel was diagnosed with Down's syndrome and a congenital heart condition that

would require surgery within three months. Amanda and Angel were visited by our family support service officer in the Neonatal unit in Edinburgh a few days after birth. Amanda very quickly accepted Angel's Down's syndrome but had lots of concerns regarding Angel's feeding which was proving very difficult and her upcoming heart surgery. Angel was discharged from hospital with a nasogastric (Ng) tube in-situ and a range of diuretic medication to help deal with the build-up of fluid due to her heart condition. Amanda was supported by our Family Support Team through this period via regular phone calls and text messages and also put in touch with a parent contact volunteer whose child had been through similar surgery. Angel's condition deteriorated quite quickly over the next few weeks and by the middle of May Angel was admitted to Intensive Care Unit at hospital with her heart condition worsening. Angel was then transferred to Yorkhill Paediatric Intensive Care.

Our Family Support Officer supported Amanda closely throughout this period through regular phone calls and visits to the hospital both before and after her heart surgery. At this time we also supported Amanda to complete Angel's Disability Living Allowance (DLA) application, which was successful for high rate care, and also to the family fund to help with costs of being in hospital for such a long period.

Angel is now nearly nine months old and is at home, still with her Ng tube in situ and on continuous oxygen, although hopefully both of these will be able to be removed in summer 2015. We have continued to keep in touch with Amanda via calls and home visits. Amanda said:

**Thanks for everything you have done in supporting me with Angel, I couldn't have travelled the road without you, you kept me strong – you do an amazing job!**

# We help professionals

**inclusion**

**individual school consultations**

**dementia support**

**bespoke training**

**behaviour management**

**phone support**

**e-mail support**

**new baby packs**



## Our action

**We provided training and support to professionals throughout Scotland.**

Our Family Support Service also supports a range of professionals including medical staff, teachers and support staff. We introduced a new training course called Teaching Reading which covers skills and techniques which focus on the typical learning profile of children with Down's syndrome.

Our other training courses focus on awareness and inclusion, positive behaviour support and improving communication skills.

Our courses are accredited by Education Scotland for Continued Professional Development purposes. We delivered 32 bespoke training courses and 24 consultation visits to education staff in their own venues.

Our new baby packs are available in every maternity unit in Scotland. Training and information sessions have taken place across the country, with our team making several visits to speak to hospital staff in Aberdeen, Dundee, Edinburgh, Forth Valley, Kirkcaldy, Perth and Kinross, South Lanarkshire, Vale of Leven and the Western Isles. We held a full-day conference for professionals who support parents of children and young people with Down's syndrome in conjunction with NHS Ayrshire & Arran. Over 120 people attended.

## Our impact on professionals

**We supported 495 professionals on a wide range of topics:**

☞ This type of training would be excellent for all teachers. Very informative and I'll definitely be recommending it for other teachers! ☞  
- Primary school teacher

☞ Great course, really helpful, informative and practical could have stayed for longer. ☞  
- Depute Head Teacher

# A day in the Life of a Family Support Service Officer, by Morag Dalrymple

👉 *There's no such thing as a typical day as a Family Support Service Officer with Down's Syndrome Scotland. I usually head into the office for 8.30am to check my emails and messages, though today I am heading straight to a review for Gemma, a girl with Down's syndrome who has been attending mainstream school. The review was a really positive experience for me – all the professionals round the table including the teaching staff and the Speech and Language Therapist were working together to make sure Gemma is getting a brilliant experience at school. I leave with a little spring in my step.*

*I cover the South East of Scotland which is a large area so I constantly rely on my Sat Nav and seem to have an innate ability to get lost.*

*I check my ever growing to-do list, which can include writing reports, phoning other agencies to chase up referrals that have been made, returning calls, adding things to it as the day progresses as quickly as I check things off!*

*Next I enjoy a cup of tea and a biscuit with John, a man with Down's syndrome and his family. After 16 years of being on the housing list with the local authority, his parents contacted us last year. They were supported through the lengthy and daunting process of going for guardianship which means they now have power to speak on John's behalf. John is expecting to hear about a new tenancy soon and is looking forward to living independently with some support. This is great for me to see: John is currently living as independent a life as possible, with a*



*support package that suits his needs and is very much part of his community.*

*As we support families from when they receive a positive screening test result right through the life of a person with Down's syndrome the issues that people come to me with are as individual as each person with Down's syndrome.*

*This means that I literally have to be ready for anything. I don't pretend to know all the answers but I make it my mission to find out. I love the challenge of learning a new topic and I have excellent colleagues that have a broad range of experience, whose brains I can pick. 'Every day is a school day', as they say.*

*I have my mobile on me at all times: families and carers of people with Down's syndrome need to be able to speak to someone straight away if they have a problem or question about something. They can be at crisis point and need an unbiased, non-judgemental ear to talk things through with. Sometimes I can be the first person to say "It's OK" and I pride myself in being on the families' side, working with them to make things better. Families say they feel better when they have a plan of how to deal with things.*

*My goal is that every man, woman and child with Down's syndrome lives a positive, full and happy life. I believe that it's everyone's responsibility in the community to ensure this happens, from the bus driver who says "Hello" to John everyday on his way to work, to the parents whose child is in Gemma's class, accepting that everyone has different strengths. If our children grow up seeing children like Gemma in their class, taking part in the lessons, our next generation will be a more tolerant, inclusive one which is to everyone's benefit. 🙌*

# We help carers

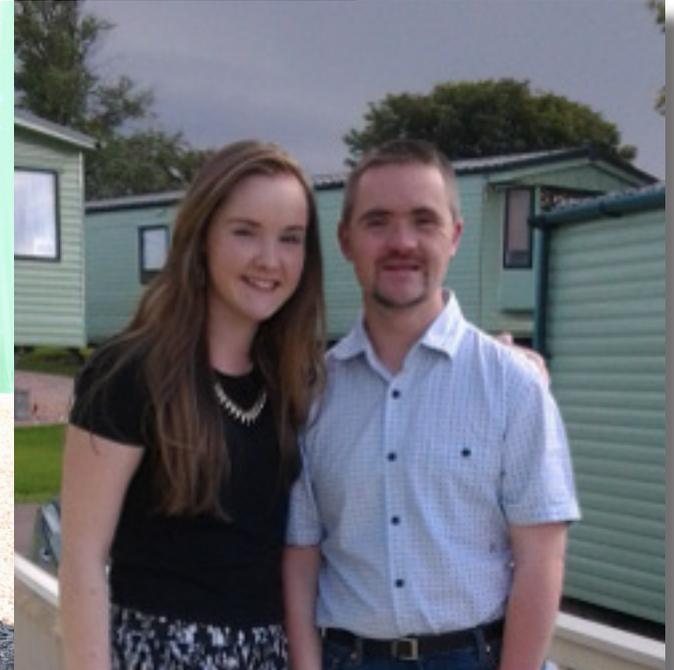
Gym membership

garden furniture

Tuition fees

exercise classes for adults with Down's syndrome

Short break to a caravan or hotel



## Our action

We provided funding to parents/carers of children and adults with Down's syndrome to take a break from their caring responsibilities.

Our 'Creative Breaks' and 'Keys To Life Time For You Fund' offered carers the opportunity to apply for a grant (between £300 and £500) towards providing the right type of break for them. Our funding for families caring for a child with Ds was hugely popular and was fully granted eight months before the fund was due to close. Many carers took a short break with

the person they care for, others took a break with friends or other family members whilst the person with Down's syndrome was cared for by someone else. We also made grants for garden furniture, audio visual equipment, sports equipment and gym memberships, class and tuition fees and towards the cost of passports.

From April 2014 to March 2015 we awarded £54,432 to 154 carers. The Funds ran in conjunction with Shared Care Scotland on behalf of the Short Breaks Fund.

## Our impact on carers

72 carers of children with Down's syndrome and 82 carers of adults with Down's syndrome received a grant towards the cost of a break which most suited their family situation. This resulted in carers being able to focus on the positive aspects of their family life and having a chance to find new energy to continue with their caring role.

## Our funding benefited the Lockhart family

Last year Grahame and Hazel Lockhart decided that a short break to Peebles Hydro would be extremely therapeutic for them and their daughter Susan.

Like many families who have benefitted from the Creative Breaks funding, the Lockharts were looking for some time away from the house to feel more relaxed and under less pressure. A chance for someone else to take responsibility for planning meals and activities.

Hazel said:

- 👉 We enjoyed exploring the grounds of Peebles Hydro and Peebles town itself. The break definitely helped me in my caring role and I came home refreshed and relaxed after having such a great time. It was lovely to be in such beautiful surroundings and have all meals etc. taken care of!

The break was excellent from start to finish. It is hard to pick out the most memorable part, but I would probably say having time to sit in the gardens in the sun and read a magazine! I don't normally get the opportunity to do things like that. Susan thoroughly enjoyed herself and was very relaxed too as you can see from her photo! Thank you very much! 👉



# We help children with Down's syndrome

## communicate

communication skills

social skills

speech development

sentence structure



### Our action

We continued our popular Achieving Better Communications (ABC) Groups in Edinburgh and started our new Communications Skills pilot project delivering ABC groups in Glasgow, and parental workshops in Aberdeen and Perth.

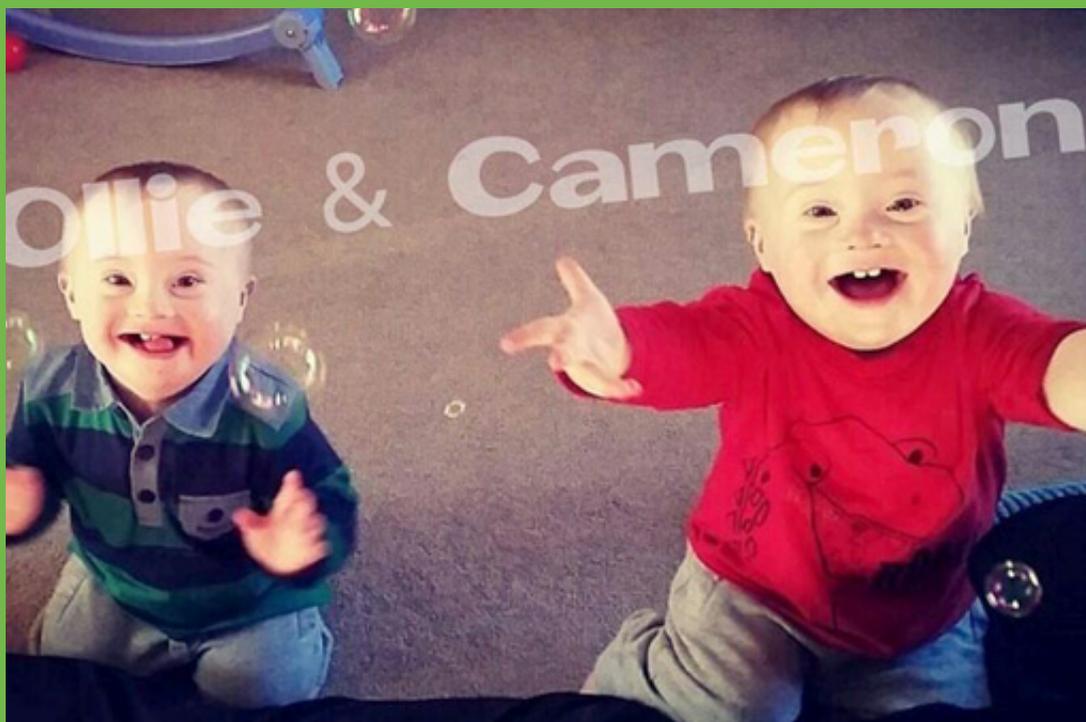
Our Communication Skills pilot project was completed in June 2014 and during the Summer the University of Strathclyde carried out a formal evaluation study of parental perceptions of our Achieving Better Communications (ABC) Groups and parental workshops. Their findings were overwhelmingly positive and as a result of

their recommendations, in the last year we held ABC groups weekly during term time in Edinburgh, Glasgow, Aberdeen and Perth. Sixty seven children (from 6 months to 18 years) attended the groups. We have now received confirmation of funding to allow us to start a three year programme commencing in August 2015. This will allow us to expand the ABC groups in Glasgow where demand is great and start a weekly group in Orkney.

In 2014-15 our communication projects were funded by Bank of Scotland Foundation and The Equitable Charitable Trust.

My child has really benefitted from attending the ABC group. As his family, we can sense his communication is improving, but in an essentially non-verbal child it's wonderful to see the objective proof in his formal assessment. I feel more positive practicing his specific activities, rather than floundering around trying to work out what I could be doing to help him.  
- Parent of child who attended ABC groups

## *Improved communication skills for the Scougal twins*



Ollie and Cameron started attending the groups when they were 15 months old. Initially their Mum, Elaine was worried that the boys would find the formal classroom environment daunting and overwhelming as the boys were so young. But they both loved the groups and would be happy and excited all day. The classroom setting was a really benefit, encouraging the boys to improve their attention span and listening skills. They loved the routine of the groups and quickly picked up on when it was time to move onto the next exercise- bubbles was always a favourite! The groups were the first time the boys had listened and taken instruction from an adult outside the family, which was great preparation for nursery and school. Both boys made a lot of progress with their speech. The groups also gave Mum the confidence to do more exercises at home that she hadn't thought they were ready for.

Mum, Elaine commented;

☞ We were very grateful to have been included in the groups. It was a very positive experience! ☞

☞ Yesterday we went to our communication class in Perth and had a great session. We were more vocal (we've been quite shy the past few weeks) and even started to try and match some pictures. The highlight was Cameron saying 'teddy' clear as crystal a couple of times but we're still waiting to hear it again! When we got home we practised a couple of the things we had learnt and did really well, especially Ollie with his picture matching! ☞

*- Comment about the ABC group posted on Elaine's popular Facebook page for the boys.*

# We help adults with Down's syndrome develop their lives

planning for the future

learning social skills

speaking up

gaining hobbies/interests

gaining independence



LOTTERY FUNDED



## The end of Making Your Way through Life Project

We celebrated the end of our five year project in July 2014.

Our Making Your Way Through Life (MYWTL) project, which was funded by the Big Lottery for five years until July 2014, delivered life skills courses and The Big Plan programme to young people and adults with Down's syndrome. The MYWTL project held two Big Plan Gatherings in April and May 2014 for all of the families who had participated in the programme over the five years of the project. Twenty five young people and adults with Down's syndrome attended and we found that they continue to benefit from the planning, life skills and motivation gained in their Big Plan. For most, their big plan achievements had led into further goals and to new opportunities.

## The start of Friends Connect

Friends Connect is our exciting new project funded by The National Lottery through the Big Lottery Fund for 3 years, August 2014 to August 2017. The project will support 64 adults with Down's syndrome to connect with each other, develop and sustain friendships and access local facilities and mainstream community activities. Members in the Friends Groups will be matched with each other according to hobbies and interests and will have a volunteer mentor to support them meeting up, accessing local amenities and be better connected to their local communities. By the end of the project we will have utilised the skills of 32-40 volunteers.

Making friends and keeping the friendship going can be an issue for many people with Down's syndrome who need support. Going along to social activities and meeting new people can be hard for anyone but it's much easier if you have a friend with you (and more fun!). Through the project and with the help of volunteers and each other, members will get support with practical arrangements, increase their confidence and social skills, meet new people and enjoy activities with their new friends.



It's been great meeting up, we've been doing lots of things and are good mates.

The Edinburgh Friends Group was set up in February 2015, followed by the Glasgow group in March. Further groups are being set up in Fife, Dundee and Aberdeen.

# Big Plan Gatherings

Well organised, friendly meetings. Excellent idea and a good start for families and friends as well as providing direction for the participants. Helped us recognise the skills the participants already have and can develop.

I have noticed Emily's confidence has increased in unfamiliar situations.  
- Parent of adult who attended the Big Plan in Glasgow



Big Plan Gathering Dundee



Big Plan Gathering Glasgow



Enjoyed the Big Plan. Good to see other young people who want to achieve things and get encouragement.



# We help local communities

weekend excursions

sports groups

drama groups

parent & toddler groups

special events



weekend excursion. This continued to be a popular event which included many children with more complex needs taking part in the fun. It also gave the rest of the family an opportunity to share their experiences.

## Central Branch

Our Central Branch continued to run the popular Activities Club for all ages. People with Down's syndrome and their siblings enjoyed ball games, board games, pool and toys. They also held individual music sessions with a music specialist.

Other events were ten pin bowling outings, as well as the branch's annual trip to Blair Drummond Safari Park, which was attended by 30 members. The branch's annual Christmas Party was attended by 50 members of all ages and 27 people attended a Christmas pantomime. The branch had a fun day on 1st November to celebrate its 30th anniversary and for Down's Syndrome Awareness Week in March held an Open Day at the Activities Club with a photographic display.

## Edinburgh and Lothians Branch

The Edinburgh and Lothians Branch held several groups throughout the year for parents, adults and children with Down's syndrome. The Parent, Baby and Toddler group was attended by 15

## Our action

We provided local branches where families and people with Down's syndrome could attend activities, families could share experiences and people with Down's syndrome could socialise.

## Ayrshire Branch

Our Ayrshire Branch continued to hold monthly meetings in Kilmarnock. Some members were involved in a music and drama group. This has proved to be a great confidence builder for many members and a chance to show their skills and talents. This branch also organised their annual

👉 The group is a way for new parents to make initial contact with Down's Syndrome Scotland and other parents and to receive the support they need in the early months. Also, having contact with a physiotherapist on an informal basis is a priceless asset. 🗍

**- Mum, Lothian parent group**



members. The group has provided a lifeline for families, as they come to terms with Down's syndrome. A physiotherapist also attended once a month to offer advice. The popular Boogie Bunch for adults with Down's syndrome enjoyed Zumba classes and other activities. This group had 15 regular members. A new group, Magic Stars, for young people aged 10 to 18 started up. Magic Stars encourages healthy living choices and includes making healthy snacks and an inclusive physical activity such as dancing, football or dodgeball. The branch also held Christmas events – an annual Christmas party, which 60 children attended, and a branch outing to see a Christmas pantomime.



The Boogie Bunch, Edinburgh and Lothian

### Grampian Branch

The Grampian Branch continued to hold its successful Sunday Group, for children five and under with any siblings and family welcome. They also continued to run a pool group for adults with Down's syndrome.

The branch held a family Christmas disco which 30 families from all over the area attended for a fun afternoon, with children as young as two and adults in their late 30's all enjoying the dance floor together. It was deemed a very successful party! One young lad even asked Santa for a special Christmas wish...a girlfriend!

It wasn't all groups and parties though, thinking of what was required to help communication, the branch decided to hold a special apps workshop. As iPads are getting used more at home and in the classroom, it was much sought after. With a mix of parents and a few professionals, 31 people filled the workshop.

### Tayside and Fife Branch

The Tayside and Fife Branch continued to provide two regular groups for its members. These groups took place once a month throughout the year.

The Ups and Down's group in St Madoes is an informal group for parents of babies and primary school-age children. The group provides a mixture of play, song and sign for the children while the parents can chat and share their experiences. During the year, the group had visits from Pyjama Drama, Eden Animal Handling, Disco Duck and also a Christmas party. Around 15 families regularly attend Ups and Down's.

The Beat it Out Drumming sessions, for branch members who are 12 years and older, provided musical activities which were enjoyed by a number of regular attendees. Parents and carers also attended this group and enjoyed a coffee and catch up.

Following the success of their 2013 visit, the branch organised another visit to St Madoes Community Centre from the Barrow Band to celebrate Down's Syndrome Awareness Week. More than a dozen families enjoyed the live music and singing and dancing to songs about fruit and vegetables.

👉 There are very few local groups for our teenage son to attend so Beat it Out is a real life-line for him in terms of getting out and about and socialising with other people the same age as him who also have the same interests. 🗍

**- Parent member, Tayside and Fife Branch**



### West of Scotland Branch

The West of Scotland Branch provided four regular groups for various age groups: Parent and Toddler Group, Drama Groups, Saturday Sociables and Ten-Pin Bowling Group. The Newton Mearns Parent and Toddler group ran a music, movement and dance session with Jo Jingles and the Motherwell group ran a Sing and Sign session for parents and children to learn and expand Makaton signing. The sports group for 5-12 year olds is run by sports coaches from East Renfrewshire Council and runs at the same time as the Newton Mearns Parent and Toddler Group in the same building so children from the same family can attend whichever group best suits them.

Showdowns drama groups were attended by young adults. Saturday Sociables, a group for adults with Down's syndrome, ran a range of social activities. Adults could meet new and old friends while enjoying arts, sports, cooking and day trips. The Ten Pin Bowling Group in Kirkintilloch was also popular for people with Down's syndrome 14 years and older.



My daughter Claire attends Showdowns on a Saturday afternoon. I have seen her grow in confidence and her language and willingness to interact with others has improved. I stay with her whilst she attends Showdowns and I thoroughly enjoy it too.



The Tayside and Fife Branch enjoying a visit from the Barrow Band.

# We help influence policy affecting people with Down's syndrome & their families

AHPs Care Pathways

events

consultations

policy panel



## Our action

**We represented the interests of people with Down's syndrome and their families to policy and decision makers.**

Our Policy Officer leads on the development of DSS's policy and parliamentary activities. We aim to influence policy making and practice of national and local government on issues relevant to people with Down's syndrome and their families.

In 2014, as well as meeting with officials and politicians to raise specific issues, our policy work involved replying to consultations and calls for evidence on various topics including the new national care standards and Getting it Right for Every Child (GIRFEC).

### Consultations

We submitted responses to consultations on the Public Bodies (Joint Working) (Scotland) Act 2014 and the new National Care Standards.

We responded to a call for views launched by the Equal Opportunities Committee of the Scottish Parliament on the issue of age and social isolation.

We also submitted evidence to the Education & Culture Committee of the Scottish Parliament on the educational attainment gap.

The draft Statutory Guidance on Parts 4,5 and 18 (96) of the Children and Young People (Scotland) Act 2014 was open for consultation until 1 May 2015. This is a significant piece of work on the GIRFEC legislation that will be implemented from summer 2016. Through our Policy Officer, we were able to submit our response to this consultation.

### Policy Panel

We now have 16 members on the Policy Panel (compared with 10 last year). In November 2014, the first policy workshop was also held during

our annual conference. It was an opportunity to inform members of our policy work and of the importance of their personal experiences in developing future policy recommendations.

### Events

In February 2015, a motion was submitted (S4M-12434) by John Wilson MSP in Down's Syndrome Awareness Week which emphasised the need to improve communication skills for children and adults with Down's syndrome.

During Awareness Week, we held an exhibition sponsored by John Wilson MSP in the Garden Lobby of the Scottish Parliament. The focus was on communication skills and dementia. Two new leaflets (one on communication groups, the other on dementia) were distributed to MSPs and researchers, along with magazines, annual reports etc. Over sixty MSP's "learned a little more" about both Down's syndrome and Down's Syndrome Scotland and signed our board to say they had done so.

### Allied Health Professionals (AHP) Care Pathways

We worked with the AHP National Lead for Children and Young People looking at the role and support offered by AHPs to children with Down's syndrome and their parents/carers. We hope that this new project will lead to the development of a nationally agreed Down's Syndrome Specific Care Pathway and end the post code lottery of care.

# MSPs keen to learn a little bit more about Down's syndrome



Photos above: Left Duncan McNeil MSP. Right Ken Macintosh MSP and Sarah Van Putten.

During Awareness Week 2015 we spoke to MSPs interested in learning more about Down syndrome. We continue to work with these MSPs and ministers on issues which impact upon the lives of children and adults with Ds across Scotland.

Duncan McNeil MSP was interested to learn more about the difficulty some of our members experienced trying to renew their Blue Badge.

After speaking to us, Ken Macintosh MSP submitted two parliamentary questions which respectively focused on the importance of ABC groups and the national dementia strategy.

Dennis Robertson MSP (pictured below with Sarah Van Putten) was keen to know more about Erin's World Frames and the visual impairments which affect people with Ds.



# We help raise awareness of Down's syndrome & our charity to the general public

Media

*Do a Dish for Down's Syndrome*

businesses

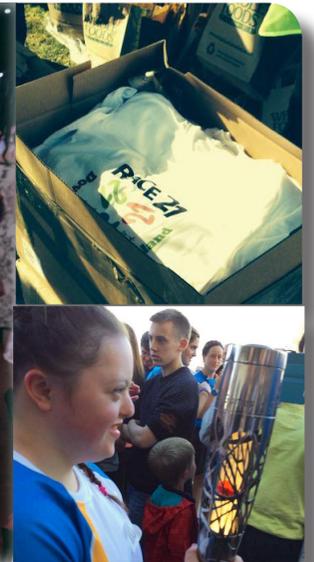
*World Down Syndrome Congress*

Exhibitions

conference

*Down's Syndrome Awareness Week*

*Race 21*



## Our action

We raised awareness of Down's syndrome and the charity through events and the media.

### Awareness through events

This year has been a whirlwind of activity for our fundraising and awareness events. In May we held a very successful Firewalk which attracted twenty

wonderful fundraisers who raised over £10,000 and was much enjoyed by all. Even Pandora, our CEO, warmed her toes and took part! We had 22 runners in the Edinburgh Marathon Festival in June which has been the most for us so far. The Spartan Obstacle course in September was a fun day with Falkirk Hockey Club teaming up with us to divide the spoils of the fundraising. In November we hosted our second gala ball in Glasgow for over 300 people. Paul Corbally (a young man with DS) gave a very amusing after-dinner speech

and showed absolutely no nerves at all. A natural!

Our patron, John Barrowman, of Doctor Who, Torchwood and Arrow fame, secured collections for us at the SECC in Glasgow after his Christmas pantomime. These collections raised almost £24,500 for the charity. Our patron, Gary Coupland from The Singing Kettle fame, had a "special" birthday this year and asked his guests to donate in lieu of gifts. He raised £300 for the charity.

## Drop a Size for Down's syndrome

In January we launched Drop a Size for Down's syndrome a sponsored slimming challenge to lose 21lbs in 3 months. We had a good initial response and we intend to build on this again next year.

## Race 21

The concept of Race 21 came from Karen Gilligan, one of our Board members and is a fun run comprising a three person team connected at the wrists, that have to complete 1 mile course through seven check points. It is a fundraising event, an awareness raising event and is suitable for everyone to take part in. Everyone gets a medal and a T shirt and the message is that regardless of your ability you can rely on your team to help you finish. In March, the Glasgow Race 21 took place in Maxwell Park and we had a good turn-out. We hope to see more of these in the future.

## Awareness Week

Surrounding Down's Syndrome Awareness Week, we continued to run a month long fundraising and awareness campaign, Do a Dish for Down's Syndrome. The focus of this campaign is inclusion and bringing friends, families and communities together through sharing food. The event is now in its 6th year. We also took part in Down Syndrome International's Lots of Socks campaign, which was very successful with families, schools and colleagues. Social media was buzzing with lots of fab photos of people wearing an odd sock and we even had the strictly uniformed brigade of the Perth Firemen joining in and wearing odd socks!

## A Different Perspective

We also organised a photography exhibition in Eden Court, Inverness entitled "A Different Perspective". We displayed over 40 photographs by Oliver Hellowell, a young man with Ds.

Oliver's exhibition was visited by MSP Rhoda Grant who was very impressed, saying, "Down's Syndrome Scotland is working to show people the contribution that those with Ds make and it's fantastic to celebrate this through Oliver's artistic talent".

## Six Percent

This followed a showing of our Six Percent exhibition during February at Birnam Arts and Conference Centre near Dunkeld. This received local press attention when we arranged a photo call with photographer Graham Miller and Deputy First Minister John Swinney. We also arranged an event for Perth College students. STV picked up on this and aired a news piece in the Dundee area. Katrina, a branch member, was also interviewed for the Scottish Sun who ran a positive double-page spread in advance of the exhibition opening to the public.





### Awareness through the media

When we organised a Young Scot Award nomination for Amy Clark, we had a great interview live on BBC Radio Scotland where Amy did an amazing job talking about her passion – rhythmic gymnastics! Unfortunately Amy didn't win the Young Scot award but, with the nomination itself, winning gold in the Special Olympics in Los Angeles, she's a huge inspiration!

During the year we have had 23 press mentions. These have covered a range of mediums including radio, TV and printed press. We have had a presence both nationally and regionally including BBC Radio Scotland, STV, The Scottish Sun and the Sunday Herald. We have continued contributing to the Scotsman newspaper through our Friends of the Scotsman membership which allows us to write articles six times a year, regularly securing the main feature on this page. Our article from February 2015, discussing freedom of speech gave us our first front page mention as Friends of the Scotsman. Other topics covered have included the lack of employment opportunities for people with Down's syndrome and coverage of our work during Down's Syndrome Awareness Week. These features consistently generate positive feedback from our supporters.

## Parents share the benefits of awareness raising



'We found happiness in Down's Syndrome' appeared in The Sun on 30th January 2015. Parents Katrina and Colin Leese spoke to a journalist from the Sun about the photo exhibition 'Six Percent' which their son Matthew was part of.

"We were delighted to be one of the families featured in Six percent and we hope that we helped to raise more awareness of Down's syndrome by sharing our story with others."

# We keep members & supporters informed

monthly e-bulletins

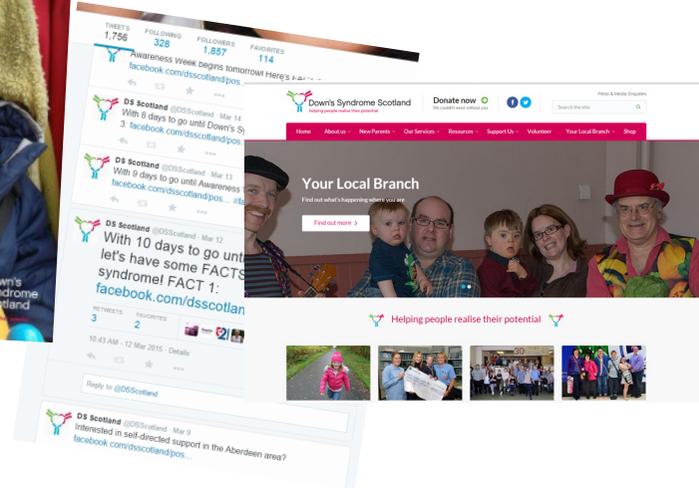
Twitter

Library

Social Media

Facebook

website



We maintained our presence on social media sites Twitter and Facebook. Our target audiences for Twitter are related organisations and professionals whilst parents and family members of people with Down's syndrome are our main audience for Facebook, we continued to see and welcome some cross over between the two sites.

We also conducted our monthly live hour on Facebook and Twitter, where families get the chance to ask questions and get immediate answers from our Family Support Service team. In July, we introduced a Speech and Language Facebook Hour with our Speech and Language Therapist, which became popular. Throughout the year, we received a total of 246 Facebook queries, 196 Facebook likes and 14 tweets during the monthly Facebook and Twitter Hours.

## Library

Our library resources were full of information for individuals with Down's syndrome and for their parents/carers and professionals. We publicised our library services, which is free to members, through our e-bulletins and magazine. Our Family Support Service promotes the library services to parents and professionals whom they meet. These resources cover: education, language, bereavement, adolescence, ageing, Alzheimer's disease, health and development.

## Our action

We provided information to members and supporters through various methods of electronic communication and through our magazine and library.

## Magazine

Our bi-annual magazine, *Full Potential*, was in its fifth year of print and was delivered to our members in spring and autumn. Articles focused on: news, lifestyle, family, health, research, events, opinion and are written by members, supporters, medical specialists and researchers. The four page supplement, *Fundraising Focus*, provided fundraising-related news, thank yous, activities and tips for our fundraisers. We had over 1,100 magazine subscribers throughout the UK and abroad.

## Website

During this year our site received visitors from 85 different countries and received 23,120 new

visitors. We worked on the development of a new website with updated functionality and architecture, going live in Summer 2015.

## E-bulletin

We continued to produce our monthly e-bulletin through which we communicate with our 1,395 subscribers, with additional editions when required. This service is growing steadily each year; this year we received 99 new subscribers. Our open rates (i.e. instances where someone opens the file) have remained reasonably consistent with an average of 46%. We continue to be a success story for our e-bulletin company.

# Thank you to our Fundraisers and supporters

By Fundraising for DS Scotland, it's not only helping a great charity but it also helped me get off the couch and change my lifestyle and health.

- Alison McFarlane, cousin of Eilidh who has Down's syndrome



The Bremner Family enjoyed a trip to Disneyland



Winning the Down's Syndrome Scotland Hogmanay raffle was just brilliant. Our little boy, Michael had asked to go to Disneyland for several years and we kept saying, 'maybe next year' as we couldn't afford it. So we used the money to go to Disneyland Paris. It was literally his dream come true and we had a fantastic time!

# Thank you!



## Thank you to the following:

Charitable Trusts, foundations and other grant-giving bodies/funders (in alphabetical order)

- Agnes Hunter Trust
- Albert Hunt Trust
- AM Pilkington Charitable Trust
- AMW Charitable Trust
- Andrew Paton's Charitable Trust
- Bank of Scotland Foundation
- Big Lottery Fund
- Children's Aid (Scotland) Ltd
- Christina Mary Hendrie Trust
- Cruden Foundation
- DFRA Lloyds Banking Community Fund
- Emmanuel Kaye Foundation
- Gordon Fraser Charitable Trust
- McTaggart Third Fund
- Miss BW Muirhead's Charitable Trust
- Miss EC Hendry's Charitable Trust
- Northwood Charitable Trust
- P F Charitable Trust

- Scottish Government
- Shared Care Scotland
- Souter Charitable Trust
- Templeton Goodwill Trust
- The Enzo Londei Trust
- The Equitable Charitable Trust
- The Hospital Saturday Fund
- The Hugh Fraser Foundation
- The Robertson Trust
- The RS MacDonald Charitable Trust
- The Stafford Trust
- Widowers Children's Home Trust

We are extremely grateful to all the companies who have supported Down's Syndrome Scotland during the year, from taking part in our events, through giving sponsorship and matched giving and by donating generously to our work. The support we have received this year will help us ensure everyone living with Down's syndrome can realise their full potential.

**In 2014/15 Down's Syndrome Scotland received almost £289,000 from donations and both national and local fundraising events.**

**Our thanks go to all those supporters who gave their time and/or money to support us. You truly do make a difference.**

**We appreciate your support. Help us provide more support to families & professionals by:**

**Visiting:** [www.dsscotland.org.uk](http://www.dsscotland.org.uk)

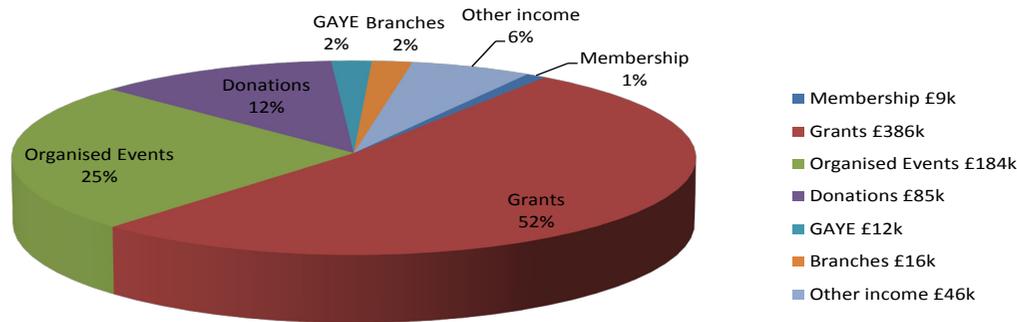
**Texting:** DOWN21 £3 to 70070

**Gifting:** a legacy in your will.  
Phone 0131 313 4225.

# Financial Summary

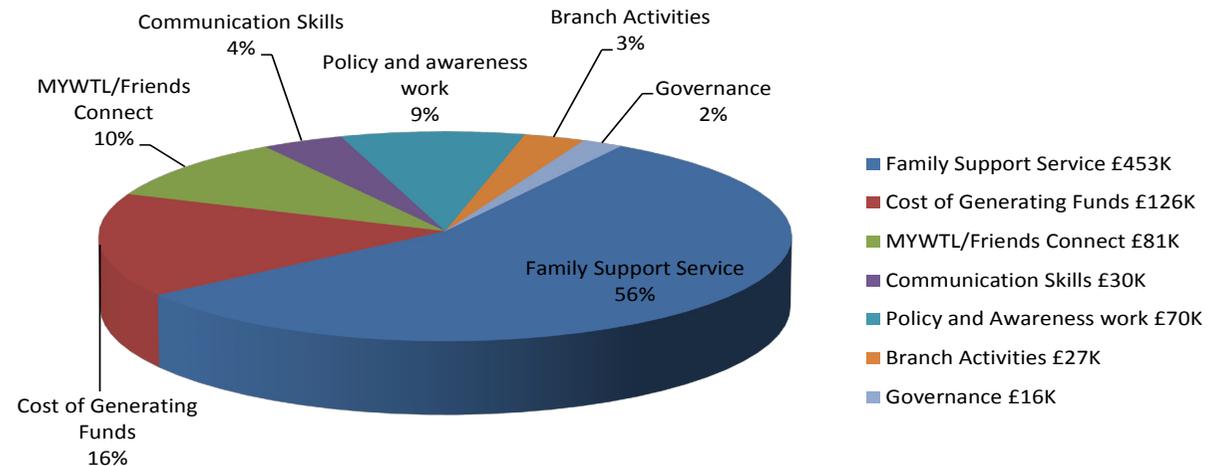
How we raised our funds:

Total Income 2014/15 (£741,454)



How we spent our funds:

Total Expenditure 2014/15 (£804,850)



## Income

During the year to 31 March 2015, total income increased to £741k (2013/14: £727k). In 2014/15 89% (2013/14: 90%) of the Charity's income came through generated funds – categorised as income directly influenced by the efforts of fundraising staff (i.e. donations, grants, legacies and organised events). There was a steady increase in most other areas of income.

In order to consolidate and grow activities, the charity continues to invest in fundraising activities supporting the receipt of both voluntary donations and grants. Success in this area has allowed the Charity to broaden its activities, with an expansion of the Family Support Service in 2014/15.

The charity achieved continuation funding during 2014/15 which allowed the on-going restricted activities which included:

- ▶ A Communication Skills programme supporting communication skills in children with Down's syndrome;
- ▶ Project funding from the Third Sector Early Intervention fund which aims to influence national policy and help local authorities' delivery of best practice;
- ▶ Funding received from the Short Breaks Fund to facilitate breaks for carers.

The charity also received new funding to facilitate the Friends Connect project.

Our original budgeted outcome for the year 2014/15 was a deficit of £169k, but we returned a net deficit of £63k due to increases in funding from Charitable Foundations as well as increases in donations.

The ratio of unrestricted to restricted income remains fairly constant at 46:54 compared to 47:53 in 2013/14.

## Expenditure

The Statement of Financial Activities (SoFA) shows the analysis of resources expended between charitable activities, governance costs and fundraising costs. Further detail is given in note 3 of the accounts. Total expenditure has increased in comparison with 2013/14 due to increased spend in charitable activities.

The ratio of Funds raised compared to fundraising costs means that for every £1 we spend we bring in £5.50.

## Reserves Policy

The General Unrestricted Reserve Fund represents the free unrestricted funds of the charity not designated or invested in tangible fixed assets. These are held to meet general current and future running costs of the charity and to fund activities for which it does not prove possible to obtain specific funding. Our policy is that reserves of the equivalent of six months average unrestricted expenditure should be held in the General Reserve Fund to provide sufficient time to replace any lost funding or to make the necessary alterations to activities. Maintaining this level of reserves is regarded as good practice and one we strive towards, although currently we have reserves of



less than 6 months: as at 31 March 2015 the free reserve balance on the General Reserve Fund was £110,910 as against the required holding under this policy of £188,701.

## Restricted Funds

These funds are tied to a particular purpose, as specified by the donor. At 31 March 2015, unspent restricted funds were £154,048 (2013: £177,358), these will be spent during 2014/15.

## Designated Funds

These are unrestricted funds that have been allocated by the Trustees for particular purposes.

## Financial Position

The Trustees consider that there are sufficient reserves held at 31 March 2015 to manage any foreseeable further downturn in the UK and global economy.

## For more information

A full set of annual accounts is available on our website ([www.dscotland.org.uk](http://www.dscotland.org.uk)) or from the office.

# Finance

## Statement of Financial Activities (including Income and Expenditure Account)

For the year ended 31 March 2015

	Notes	Un- Restricted £	Restricted £	2015 £	2014 £
<b>Incoming Resources</b>					
<i>Incoming Resources from Generated Funds</i>					
<i>Voluntary Income</i>					
Grants and Trusts		7,700	378,413	386,113	365,173
Donations and Gifts		87,012	-	87,013	89,387
Legacies		-	-	-	17,009
Give As You Earn donations		11,871	-	11,871	13,787
Membership subscriptions		8,850		8,850	8,672
<i>Activities for Generating Funds</i>					
Organised Events		184,091	200	184,291	169,264
Branch Activities		15,979	-	15,979	16,735
Conferences and Literature		5,507	11,561	17,068	16,621
Other Income		17,553	10,964	28,517	28,719
<i>Investment Income</i>					
Bank Interest Received		1,753	-	1,753	1,738
		340,316	401,13	741,454	727,105
<b>Resources Expended</b>					
Cost of Generating Funds	3	126,322	-	126,322	98,056
Charitable Activities	3	235,024	427,448	662,472	516,263
Governance Costs	5	16,056	-	16,056	18,528
		377,402	427,448	804,850	632,847
<b>Net movement in funds in the year</b>					
		(37,086)	(26,310)	(63,396)	94,258
Fund Balances brought forward at 1 April 2013		359,295	177,358	442,395	313,477
Fund Balances carried forward at 31 March 2014		322,209	151,048	473,257	536,653

The Statement of Financial Activities includes all gains and losses in the year. All incoming resources and resources expended derive from continuing activities.

## Our Balance Sheet

As of 31 March 2015

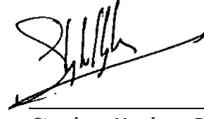
	Notes	£	2015 £	2014 £
<b>Fixed assets</b>				
Tangible assets	6		83,356	89,616
<b>Current Assets</b>				
Debtors	7	41,050		21,950
Cash at bank and in hand	8	367,935		458,069
		<u>408,985</u>		<u>480,019</u>
<b>Creditors: amounts falling due within one year</b>	9	<u>(19,084)</u>		<u>(32,982)</u>
<b>Net Current Assets</b>			<u>389,901</u>	<u>447,037</u>
<b>Net Assets</b>			<u>473,257</u>	<u>536,653</u>
<b>Funds</b>				
Restricted Funds	11		151,048	177,358
Unrestricted Funds				
General	11		110,910	130,329
Designated Funds	11		<u>211,299</u>	<u>228,966</u>
			<u>473,257</u>	<u>536,653</u>

These accounts have been prepared in accordance with the special provisions relating to small companies within Part 15 of the Companies Act 2006 and with the Financial Reporting Standard for Smaller Entities (effective April 2008).

The accounts were approved and authorised for issue by the Board of Trustees on behalf of the Trustees on 24 June 2014 and are signed on its behalf by:



Ian Fraser, Chairperson



Stephen Hughes, Director

Company Registration Number: SC356717





Down's  
Syndrome  
Scotland

helping people realise their potential

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**Twitter:** @DSScotland

**Facebook:** Down's Syndrome Scotland

A Charitable Company Limited by Guarantee, registered in  
Scotland No. 356717, Charity No. SC011012.

