



DOWN'S

Annual Review 2015/2016

SYNDROME

SCOTLAND



Contents



Welcome

Every year I'm inspired by the passion of you, our members and supporters in helping us to both set and then achieve our goals.

As I write, we're about to move premises and embark on the next phase of Down's Syndrome Scotland's story; this has given me cause to look back over the last eight years since I joined the organisation. I'm so delighted that over that time, we have been able to meet the aspirations of our members, who told me in 2008 that support with communication was their single biggest wish from our charity.

With the help of our supporters we have been able to grow our income by 250% over the last eight years. This has enabled us to expand existing services like Family Support, getting it nearer to each family's home location and develop new ones like ABC groups and our range of Parental Workshops across the country.

Of course it's very important that we support people of all ages with Down's syndrome and the impending 13th World Down Syndrome Congress in 2018, which we will be hosting in Glasgow, gives us an exciting way of doing so. Our plan is to have a large number of people with Ds be Commissioners for and during the congress. In early preparation, a delegation of us including Stuart

Campbell and Sam Ross, both lead Commissioners, travelled to Chennai, India to attend the 12th WDSC in July 2015. Our task was to find out as much as we could, to promote our congress in Glasgow and to participate in the handover ceremony. To see Sam and Stuart stand up on a world stage presenting our plans for Glasgow 2018 was one of the highlights of my career so far and I was thrilled at the reaction from the world audience, including their gasps at seeing our third lead Commissioner Andrew MacIntyre on film interviewing Scotland's First Minister, Nicola Sturgeon.

Over the next year, we will continue to grow as a charity in order to help and support even more families, carers and people with Down's syndrome as we move office and extend our services. I know this next big milestone would not be possible without the continued support we receive from you, as it is your help that makes our work possible. Thank you

Pandora Summerfield
Chief Executive

Pandora Summerfield

Welcome to the annual review of Down's Syndrome Scotland. I hope you enjoy reading the review and I hope you get the information you need about the organisation and increased knowledge from it. We are all in Down's Syndrome Scotland together; the professional staff of the organisation, the Board of Trustees, parents, carers and siblings and professional partners.

It's been another very good year. The organisation continues to grow and prosper. There are more staff involved in family support within DSS and consequently more support of parents and families. There are increased and deeper professional networks with education, social work and health staff. There is a terrific communication system including a super magazine and revised web-based material. Above all there is increased professional

fundraising to allow the organisation to do what it is supposed to do... support people.

There is great momentum and excitement and this will continue as we build towards the international congress in Glasgow. Planning is taking place and the event in July 2018 promises to be significant in highlighting and then supporting people with Down's syndrome in Scotland. Roll on!!

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

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

Ian Fraser
Chairman

Ian Fraser



The right help at the right time from the right people transforms lives.

Teaching communication through our Achieving Better Communication (ABC) groups

Thanks to RS MacDonald Charitable Trust and The Scottish Government we were able to further expand our Communications Skills Programme. Through our Achieving Better Communication (ABC) Groups we provided weekly communication skills

development workshops for children in Edinburgh, Glasgow, Perth, Aberdeen and Orkney – supporting 81 children each week. Our qualified Speech and Language therapist also ran parental workshops to help parents develop the skills they need to encourage their children's verbal and non-verbal communication.

"The ABC groups really help the confidence in my son. Daniel has hearing difficulties so the strategies for sound production have helped his speech"
– Angela, mum of a child who attends ABC groups

"Since my son has started at the ABC group I have noticed a significant improvement in his confidence in communicating with others"
– Sarah, mum of a child who attends ABC groups

Joining people together through 'Friends Connect'

Friends Connect is our exciting friendship and community connecting project which supports adults with Down's syndrome to connect with each other and develop friendships. Last year our project supported the adults to access local facilities and mainstream community activities aiming to help them to increase their skills. We aimed to match group members based on their hobbies and interests, each person had a volunteer mentor who supported the meet-ups and accompanied them on their chosen activity.

*"John loves his time spent with his volunteer.
Once the visit is over he then counts down
the 'sleeps' until the next time"*

– Catherine, parent of a Friends Group Member

*"It allows her to spend time with others rather
than just her family. It also makes her go out;
otherwise she would stay in her room"*

– Sue, parent of a Friends Group Member

Supporting parents through parental workshops

Last year, our donors enabled our Family Support Service Team to roll out parental workshops across Scotland. The purpose of these workshops was to provide parents with information and help them to develop their skills – 86 parents attended these invaluable workshops.

*"Absolutely excellent behavioural workshop
last night in Forfar delivered superbly by Jo.
Thank you to everyone for organising"*

– June, mum of a child with Down's syndrome

Family Support – at the heart of what we do

Thanks to our funding partners and donations we were able to deliver our Family Support Service, together our team of five provided information and support to families throughout Scotland. The service continued to offer support 'all through life' with enquiries regarding screening, new diagnosis, early years milestones and nursery, then onto school education, particularly classroom support, periods of transition and social inclusion. Medical enquiries included sleep disturbance, sleep apnoea,

heart surgery, thyroid function, diet, weight and exercise. Increasingly, families approached us about transition to adulthood, community care issues, dementia, behaviour, moving their son/daughter into their own home, as well as issues of guardianship, power of attorney, wills and trusts.

*"I feel we will really get somewhere with you on
our side! You gave me a lot to think about and also
a lot of hope ... something I think I had lost!"*

– Fiona, mum of a child with Down's syndrome

*"It was great speaking to you yesterday,
your honesty and positivity is just what I
needed to hear. I am extremely grateful"*

– Sophie, an expectant parent

Supporting carers with Creative Breaks

We were delighted to partner with Shared Care Scotland for a fourth year to bring to our membership The Creative Breaks Fund. Through this fund we were able to support parents/unpaid carers of adults with Down's syndrome with a grant of up to £300 towards a trip or activity that gave them a break from their caring role, providing relief from stress and helping the parent/carer feel more able to continue to cope with their caring role.

*"The break was a detour from the daily routine and
worry of taking care of my son. It was like re-booting
my mind and body. My blood pressure measured
normal after our break. The best bit of our break was
having time together, just the two of us for a while!"*

– Jane, mum of an adult with Down's syndrome

*"It was super in the Lake District and the weather
wasn't bad either! After the horrendous year we have
had with my son, my daughter and myself all being in
hospital, it was just what we needed. It was especially
good for my husband who was able to unwind and
enjoy himself without all the stresses he's been
under travelling to and from the hospital to visit us"*

– Morag, mum of two adults
with Down's syndrome





When professionals and society hold outdated opinions and prejudices, the impact of having Down's syndrome can be exaggerated.

Supporting professionals through information and training

We supported professionals working with people with Down's syndrome by providing training and information sessions to medical and education staff. This included training for staff working in schools, out of school care provisions, leisure facilities and a wide range of medical and health care staff. We introduced a new training course called 'Teaching Numeracy' to add to the 'Teaching Reading' course we introduced last year. Both courses focus on the particular learning strengths and challenges that children with Down's syndrome experience as well as strategies to teach these particular skills. Our team also visited schools to provide individualised school consultations.

*"So informative! Very worthwhile!
Given ideas of ways to support young
people with Down's syndrome"*
– primary school teacher

*"I'm taking a lot away with me and
changing my approach to how I teach"*
– high school teacher.

*"Very informative...will take a
lot back to my nursery"*
– nursery assistant

Dispelling myths by raising awareness

In March 2016 we joined the growing worldwide campaign of having landmark buildings lit up




to raise awareness of United Nations World Down's Syndrome Day. We arranged for the Kelpies, The SSE Hydro, The Oran Mor Theatre, The McCaig Tower, The Titan Crane and the Kilmarnock Town Railway Station Clock to be lit in blue and yellow, the international colours for Down's syndrome. Around 50 of our members joined cast of the television shows Balamory and River City at the Hydro to watch the lights being switched on. Photos appeared in regional newspapers and on online news sites across Scotland and were seen as far away as Canada.

To ensure our voices were heard by policy makers, we also had information stands at Scottish Government buildings in Edinburgh and Glasgow. Members of staff and an adult with Down's syndrome met a range of civil servants and had the opportunity to discuss the key issues of employment, appropriate language and the importance of raising awareness in the general public.

Influencing and shaping policy to make a difference

Our role as a key delivery partner of 'Keys to Life' (the Scottish Government's learning disability strategy) has grown and we now meet with the team responsible for shaping and delivering policy for adults with learning disabilities regularly. We were delighted to continue working with our funding partner – the Scottish Government's Third Sector Early Intervention Fund through the Big Fund. As a result of our work over the last several years

raising awareness amongst MSP's, civil servants and ministers we are in a strong position to help to influence policy making at a local and national level. Here is just a few examples of how:

-  **Blue Badge Eligibility:** following our work in this area the group recommended the introduction of a pilot scheme for a year across all local authorities. This will allow children diagnosed with a 'mental disorder' to apply for a Blue Badge.
-  **Meeting with Minister for Youth and Women's Employment, Annabelle Ewing MSP:** discussion on access to modern apprenticeships for young adults with Down's syndrome. We are now working with civil servants and Skills Development Scotland to improve access to Modern Apprenticeships for young adults with Down's syndrome.
-  **National Advisory Groups:** we have been invited to take part in the Early Years Collaborative Seminar on Disability and Poverty (ongoing); the National Fathers Advisory Board (ongoing); and the workgroup on the Scottish Employability Programme.

Quality
information
can truly
empower
people,
especially
at crucial
moments in
their lives.



Staying in contact through social media

In July 2015 we launched our new website, providing a more user friendly and dynamic experience that meets the growing needs of our organisation, our supporters and members. We continued to produce our monthly e-bulletin which we used to communicate news and updates to over 1,600 subscribers. Our social media sites, Twitter, Facebook, YouTube and Pinterest, continued to grow. Our target audience for Twitter, which was initially just related organisations and professionals, expanded and we now have a number of members using this medium to communicate with us. Facebook continued to be our main social media site with over 5,392 followers. Through all our channels we shared positive stories and provided information which continues to raise awareness of Down's syndrome.

We provided a monthly 'Live Hour' on Facebook and Twitter; this gave parents/carers direct and immediate access to our Family Support Service Officers.

"I find the e-bulletin really useful and informative.

Thanks for putting so much effort into it"

– Kim, mum of a child with Down's syndrome

"I really like the new e-bulletin format and find it more accessible. The links are great as easily lead to more information should it be required. Very user friendly"

– Claire, mum of a child with Down's syndrome

Working with the media

We continually aim to be the charity of choice for the media when looking for a spokesperson on topics relating to people with Down's syndrome. We provided press releases and news responses to journalists on issues impacting the lives of people with Down's syndrome and their families. As part of raising awareness of Down's syndrome we promoted feature stories which appealed to the general public and provided an insight into the lives of people with Down's syndrome. We encouraged our members and branches to promote fundraising events and profile stories to their local papers too.

"You have summed up my thoughts exactly. Our world is such a better place from having our wee lad in it. There are no negatives, none that aren't balanced out by more positives. We do need diversity. That's what makes us think of others"

– Fiona, mum of a child with Down's syndrome

Providing the right information through our publications

Our bi-annual magazine, Full Potential, continues to be a great way to reach our membership with insightful, helpful and educational features which supports our members at different stages of their loved one's life.

For many years we have liaised with maternity units in Scotland to ensure new parents have access to well-presented information at the right time. We are pleased that our new baby packs are in every maternity unit in Scotland.

As medical staff in hospitals and GP surgeries constantly change our work continues in this area. Last year we updated our range of resources for people with Down's syndrome and their parents and carers, including our publications on 'Diet, Weight, And Exercise', 'Puberty', 'Living with Dementia' and 'Coping with Death'. These resources help parents/carers to talk about these topics as well as providing helpful activities which can be completed. Our publications are available free of charge as downloads from our website.

Our library continues to be full of information for people with Down's syndrome and for their parents/carers, siblings and professionals. These resources cover a comprehensive range of subjects including baby's feeding and sleeping, early years development, behaviour, education, language development, adolescence, moving out, ageing and dementia.

"I always enjoy reading Full Potential. The latest edition had some really moving articles, which I found really inspiring"

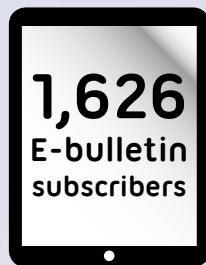
– Christine, mum of a child with Down's syndrome

"I would like to thank you for sending me the latest edition of 'Full Potential'. Thank you especially for printing my story about my daughter Megan's ice-skating achievements. We were overjoyed about this and Megan has enjoyed showing the article to everyone she knows"

– Siobhan, mum of a child with Down's syndrome



A year in figures



86 PARENTS
attended
workshops

Supported
488
PROFESSIONALS,
including

Open rate for
our e-bulletin is
20%
above the average



55
VOLUNTEERS
supported
our branch
activities



5392
FACEBOOK
likes

33
TRAINING
COURSES
& covering
25
LOCAL
AUTHORITIES

81 CHILDREN

each week
benefited from
ABC groups



106 new
subscribers
to our e-bulletin
in the last year



852
families
supported through
our Family
Support Service

We awarded

£17,691

in Creative Breaks
grants to
62
parents/carers

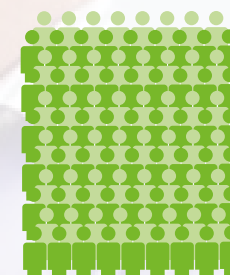


228 families
received ongoing
personal support
for complex issues

25
NEW

volunteers
worked
with adults
with

DOWN'S
SYNDROME
through
FRIENDS
CONNECT
PROJECT



Over
1,000
members



2089
TWITTER
followers



Communities joining together across the country and the world to raise awareness and foster inclusion.

Reaching out to the world with our World Congress

Down's Syndrome Scotland are privileged to have been chosen to host the 13th World Down's Syndrome Congress to be held in Glasgow in 2018. In August 2015 members of staff, parents and two adults with Down's syndrome (who will be our lead commissioners), attended the 12th Congress in Chennai, India. In preparation for the trip our third lead commissioner, Andrew MacIntyre, was filmed interviewing Nicola Sturgeon, Scotland's First Minister.

While in India the group attended some of the many talks and activities on offer. It was an excellent opportunity to hear from people with Down's syndrome from all over the world, as well as attending sessions from professionals who have dedicated their lives to working with people with Down's syndrome. As part of the closing ceremony the video of Andrew interviewing the First Minister was shown and our lead commissioners, Stuart Campbell and Sam Ross, gave a presentation to the delegates about our plans for Glasgow in 2018.

Making an impact locally with our branches

All our members can become involved with their local branch. In 2015 we grew to eight branches; each running activities for children and adults with Down's syndrome and their families. Our branches provided support through the year with a wide range of activities from social and sports groups, to cinema clubs to music and dance groups and parent and toddler groups. All of

which brought together local families and carers.

"The kids always enjoy whatever is going on and it's good for them to meet other children. It's also great for meeting other families and being able to share tips and experiences – just the same as any parent and child group except the parents at this group are in the same boat as a special needs parent. Mainstream groups are great but it's good to meet someone who understands the little things"
– family who attend Ups and Down's regularly

"I look forward to the Activities Club as it is a chance for parents to get together informally and support each other while my son enjoys all the activities"
– parent from Central Branch

"The Highlands and Islands branch of Down's Syndrome Scotland has been invaluable for us, coming from the Isle of Skye. Being from somewhere so rural means we were missing out on the support of the Down's syndrome community. Being able to go through to Inverness for monthly meetings has meant a lot to us. We may not make it every month but it's lovely for us to spend time with other families and more importantly it will allow Rogan to grow up knowing other children with Down's syndrome. We are so thankful to the lovely ladies that set it up and gave us this wonderful opportunity"
– parent from Highlands Branch

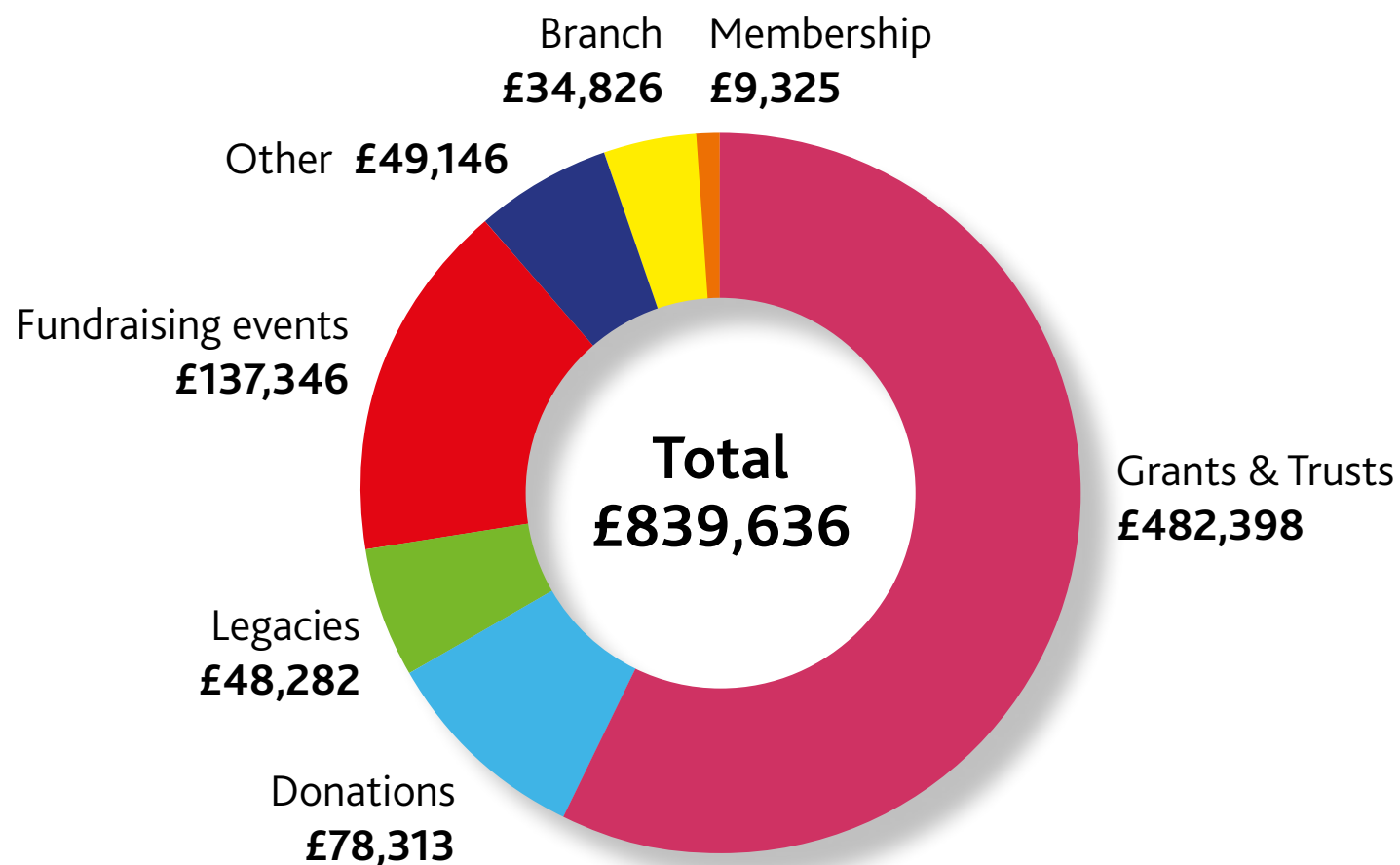
"I personally feel that the 'Down Right Fun Angus' group is amazing. My experience with the group is great. Not only does my daughter love joining in with everything going on and interacting with the other kids, I myself also really enjoy watching all the activities, and have managed to learn a lot of new information regarding Down's syndrome from the other parents. The group is absolutely brilliant, and a pleasure to go to"
– mum from Angus Branch

Fundraising together for one common goal

We couldn't do our job without the help of our supporters and the dedication of our members in communities across Scotland who tirelessly raise money every year through a wide range of events. Read more on our fundraising on page 13.



How we raised the funds



Every year we are humbled by the hundreds of volunteers who take part and organise fundraising events on our behalf. These efforts form the backbone of our charity and allow us to deliver the work we do.

Volunteers from all over Scotland took part in organised events such as the Edinburgh Marathon Festival, the Edinburgh Night Ride, The Kilt Walk and runs, walks and cycles up and down the country.

John McCole from Perth also took on the incredible challenge of running the Great Wall of China and raised over £5,000.

We were extremely grateful to the three people who left us a gift in their Will during the course of the year. This totalled over £48,000. Gifts in Wills really do make an incredible difference to us, they make an everlasting impact on our charity and allow us to plan for the future to ensure we can keep supporting people with Down's syndrome and their families for years to come. We understand it is a huge decision to commit to leaving a gift to a charity in your Will, after you

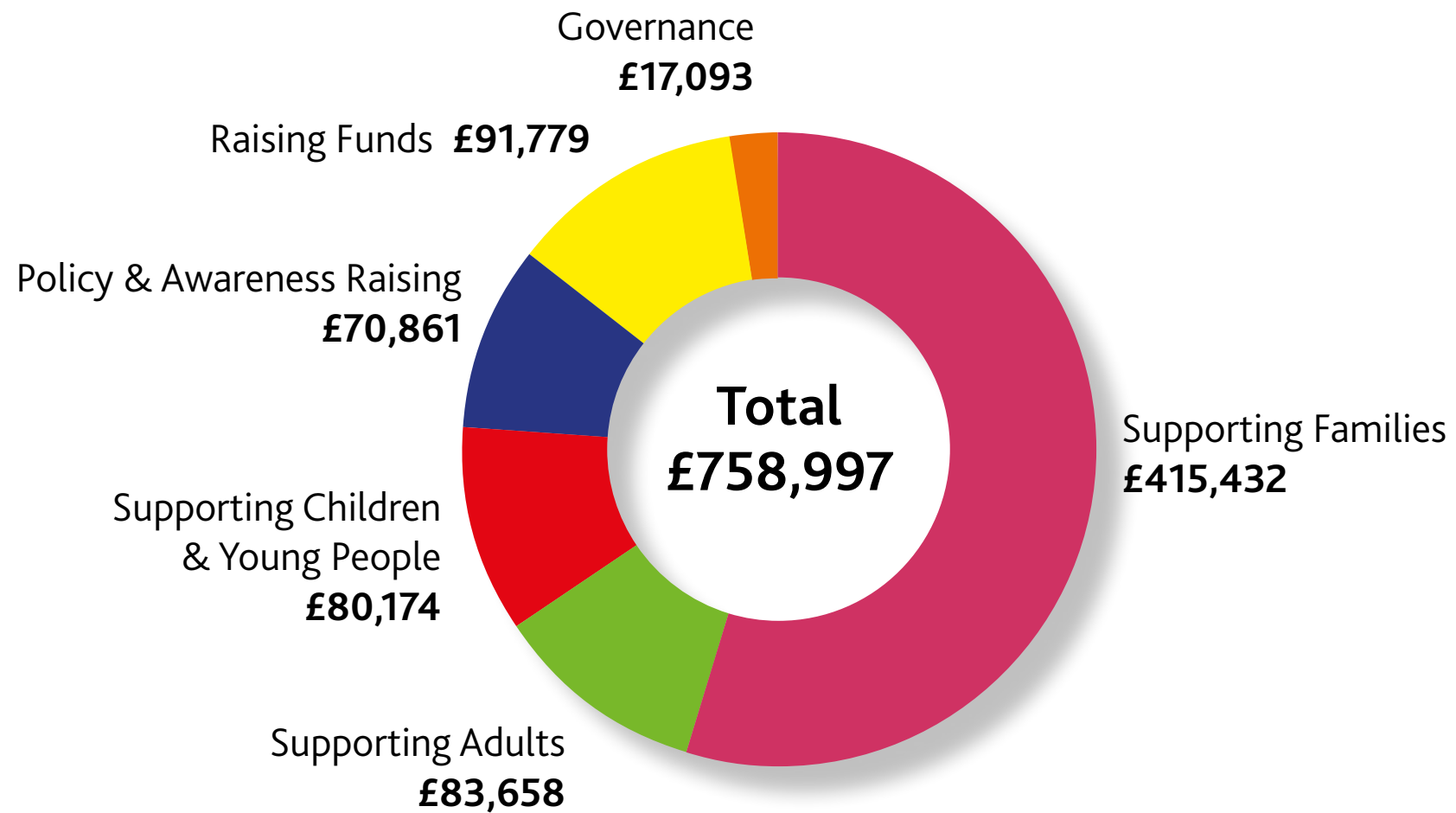
have taken care of your loved ones. We pledge that we will direct your gift to where it is needed most, to ensure that your generosity has the greatest possible impact for years to come.

Members, volunteers, fundraisers and staff from across Down's Syndrome Scotland came together to make Down's Syndrome Awareness Week 2016 the biggest yet. Buildings were lit up from the Kelpies in Falkirk to the Hydro in Glasgow to mark World Down's Syndrome Awareness Day which was amazing to see and great press coverage. We had over 66 schools and organisations take part in 'Lots of Socks' and sold nearly 500 pairs of the official socks! We were delighted so many people got their socks on and raised over £13,000. Our Do a Dish campaign was equally as successful over the month of March with people holding bake sales, dinners at home and community coffee mornings. All the dishes together raised over £7,000.

Everyone's efforts really did make a huge impact and collectively the events from Awareness Week raised over £35,000 – thank you to everyone who got involved.



How we spent the funds

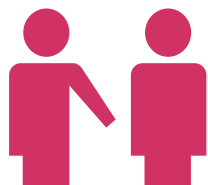




Supporting families

£415,432

was spent on directly supporting families through our Family Support Service, providing breaks for carers looking after adults with Down's syndrome and supporting and running branch activities across the country. These funds also helped train professionals and provide a library resource for both families and professionals.



Supporting adults

£83,658

was spent delivering our Friends Connect Project for adults with Down's syndrome, supporting friendships and community connections.



Supporting children and young people

£80,174

paid for our team to deliver ABC Groups to children and young people in locations across Scotland and for Communication Skills Parental Workshops.



Policy and awareness raising

£70,861

ensured we were able to influence policy at local and national levels and helped to raise awareness of both the charity and Down's syndrome, all working towards a more inclusive and fairer Scotland.



Raising funds

£91,779

was spent on generating the funds we need to exist. This included our Lots of Socks campaign, fundraising events and donor care. This also includes giving us the ability to apply for trusts and grants and managing corporate partnerships.

For every £1 spent on fundraising we raised £9.

Further information

You can get further information on our finances from our full accounts and trustees report which can be downloaded from our website

www.dsscotland.org.uk

Thank you to everyone who gave so generously towards our work. The following Charitable Trusts, foundations and other grant-giving bodies/funders (in alphabetical order) contributed greatly to the services and projects we run.

Agnes Hunter Trust
 Alexander Moncur Trust
 AM Pilkington Charitable Trust
 Andrew Paton's Charitable Trust
 Baily Thomas Charitable Fund
 Bank of Scotland Foundation
 Big Lottery Fund
 Children's Aid (Scotland) Ltd
 Cruden Foundation Limited
 John Watson's Trust
 Martin Connell Charitable Trust
 MEB Charitable Trust
 Miss B W Muirhead's Charitable Trust
 Miss Caroline Jane Spence's Fund
 Miss E C Hendry's Charitable Trust
 P F Charitable Trust
 Scottish Government

Shared Care Scotland
 Sir James Miller (Edinburgh) Trust
 Souter Charitable Trust
 Templeton Goodwill Trust
 The Emmanuel Kaye Foundation
 The Enzo Londei Trust
 The Garfield Weston Foundation
 The Hospital Saturday Fund
 The Hugh Fraser Foundation
 The Nancie Massey Charitable Trust
 The Robertson Trust
 The Rozelle Trust
 The RS MacDonald Charitable Trust
 The W M Mann Foundation
 Widowers Childrens Home Trust



We were delighted to receive the following support from business donations and sponsorship (listed in alphabetical order).

Enquest
 Fairfield Energy
 John Lewis
 Lloyds Banking Community Fund
 Lothian Buses
 RBS Corporate
 Safestore
 Scottish Consortium for Learning Disability
 Scottish Widows

Thank you to all our supporters and members who gave individual donations and fundraised tirelessly on our behalf.

In 2015/16 Down's Syndrome Scotland received almost £355k from membership subscriptions, donations and both national and local fundraising events (2015: £289k). Our thanks go to all those who gave of their time or money to support us.

Thank you

Our fundraisers continue to support and inspire us as we move in to 2016

As we move forward in 2016 with our new three year strategic framework there is still much to do to ensure our families receive all the support they need. Here's why Mark is fundraising for Down's Syndrome Scotland in 2016.

Mark's Story...

My name is Mark McDougall, and my youngest daughter, Amy (aged 4), has Down's syndrome.

My wife and I joined Down's Syndrome Scotland when Amy was a few months old, and we were still trying to come to terms with all the impacts that the condition would have on our lovely wee girl and us as a family.

Since then DSS has provided us with some invaluable support along the way: from the sage words of Jo Hughes in the Family Support Service (including advice on completing the daunting DLA forms), to Katy Lironi and the ABC group (through which Amy's speech has blossomed), the DSS magazine 'Full Potential' (which always has some inspiring content), and the conferences and training sessions (which we have learned a lot from).

The long and short of all this support is that we have a much greater understanding of the impacts that the condition 'could' have on our lovely wee girl and us as a family, and that we are much better placed to overcome any challenges ahead and support Amy in achieving her full potential.

I would now like to give something back to DSS, and play some small part in helping to ensure their continued championing and support of those with the condition and their families. Inspiration has also come from our eldest daughter, Cara (aged 6), who instigated and helped organise an afternoon tea party in our house in January, which raised £360 (50% of which is for DSS).

So, on Sunday 10th April 2016 I will start a solo and unsupported walk of the West Highland Way, there and back, in seven days. The official distance one way is 96 miles/154 km, so this equates to an average over the week of 27.5 miles/44 km per day.

Mark's fundraising adventure was fantastic and he raised over £2000 – thanks Mark!





Down's Syndrome Scotland
helping people realise their potential

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