

Annual Review
2017/18



With you from the beginning through every age and stage

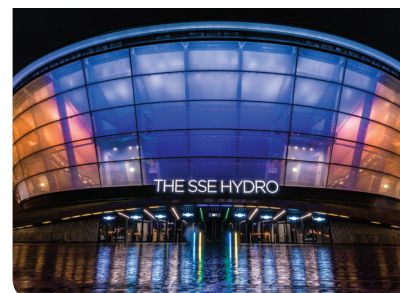
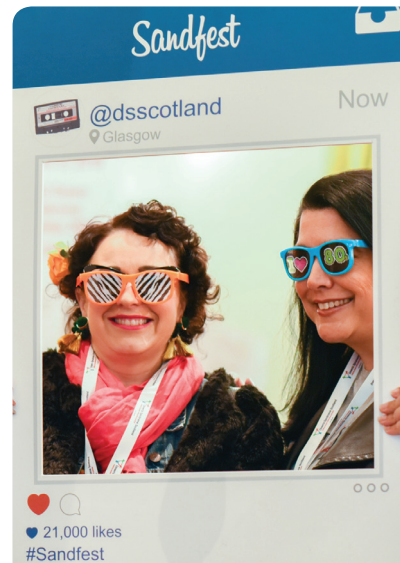
For more information or to obtain
any of our other publications
please visit www.dsscotland.org.uk





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Welcome to the annual review of Down's Syndrome Scotland



Ian Fraser

Ian Fraser,
Chairman

2017-18 saw the organisation take a momentous leap forward. As you will read in this report we reached the £1 million mark in income which is incredible – thank you. We also saw the biggest Awareness Week to date where 6,596,065 people had the opportunity to hear or read about Awareness Week and our Sandfest concert.

Our Policy work continued to play a key role in helping us achieve our goals. A significant step was achieved in November when we were invited to give evidence to the Health & Sport Committee of the Scottish Parliament as part of their inquiry into clinical governance.

This helped us follow up on the points raised in our health report Listen to Me, I Have a Voice published the previous year. We continue to be a major player in policy development affecting learning disabilities and see the government as a real partner in our cause.

March 2018 saw the biggest fundraiser to date take place. Thanks to the generosity of some of Scotland's finest pop artists and our very own Katy Lironi, over 1,500 fans descended on the Royal Glasgow Concert Hall to help raise £50,000.

Thank you to all the keen, energetic and innovative fundraisers who have raised funds and donated to help make 2017/18 the biggest yet.

Excitement continued to grow surrounding the World Down Syndrome Congress and I was delighted to see the Commissioners Programme coming to fruition with the selection of 12 adults with Down's syndrome who are going to play a key role in the 2018 Congress. I look forward to the year ahead and as Chair, welcoming over 1,000 delegates to Glasgow who will meet new friends, share in experiences from other families and hear about the latest research and some of the best practice out there today. I hope to see many of you there.

On behalf of my fellow Trustees, I'd like to thank you for everything you do for Down's Syndrome Scotland.

Responding to the needs of people with Down's syndrome, their families and carers through every age and stage of their life



Family Support – There from the beginning through every age and stage

Our Family Support Service responds to the needs of people with Down's syndrome, their families and carers through every age and stage of their life.

The demand for the Family Support Service continued to increase resulting in the appointment of one more Family Support Service Officer to help meet the needs of all those we support across the country.

The Team continued to deliver parental workshops on various topics including, 'Supporting your Child's Early Years Developing & Learning', 'Supporting your Child to Learn Numbers', 'Supporting your Child to Learn to Read', 'Understanding & Supporting your Child's Behaviour' and 'Preparing for Puberty'. 2017 also saw the move towards our first digital support tool which you can read more about on page 14.

A new workshop was developed this year for parents and carers of adults with Down's syndrome who have been diagnosed with Dementia to provide them with a good understanding of Dementia and how to positively support the person they are caring for.

998 parents received support on a multitude of issues

280 families received ongoing support for complex issues*

100 people attended 12 parent and carer workshops

*more than three hours, not including travelling time



There from the beginning through every age and stage



Case study

Milanyia Harasymiuk-Mackenzie

Service: Family Support

“Down’s Syndrome Scotland (DSS) has proven to be an invaluable support to our family. My first encounter was 5 years ago in 2013 at the Loch Fyne Hotel in Inveraray. My husband and I went along with our 2 year old son, Findlay, to meet other families and members of DSS. It was an informative meeting and good to know that there was an organisation I could turn to for support and that we were not alone.

I did not realise until 3 years later how important that organisation would become in my life.



son through a very traumatic and challenging period.

It began with recommendations of experts who would be able to provide me with guidance and support with regards to my son’s congenital heart condition as well as contacts to support me through his sleep difficulties.

Findlay then began mainstream school and was faced with further challenges. Jo was with us every step of the way. Attending cross functional meetings, supporting me over the phone and in person, recommending child bereavement services, making presentations to adults and children on Down’s syndrome and it all proved to be a life line.

Sadly I lost my husband to Motor Neurone Disease and Findlay lost his devoted father. He then underwent further open heart surgery and all the trauma had a huge impact in our lives.

Over the last 2 years, Jo from DSS has been supporting myself and my



When I was at my lowest she was there for me, day or night, whether it was just to offer a supportive ear or sound advice. Her support is still with us as strong as ever and I would not hesitate to endorse such a worthy charity.”

World Down Syndrome Congress

25 - 27 June 2018
SEC Glasgow Scotland

We work to help people with Down's syndrome reach their full potential through every age and stage of life.

www.dsscotland.org.uk



Down's Syndrome Scotland

helping people realise their potential

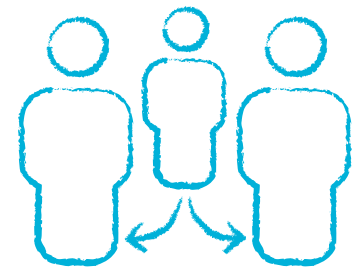
We are
Down Syndrome
Scotland

Year in review...

Board members and Commissioners at our Parliament event



Three years of friends connecting together through 'Friends Connect'



Our Friends Connect project was funded for 3 years (August 2014 to August 2017) by The National Lottery through the Big Lottery Fund. The project supported 59 adults with Down's syndrome to develop friendships with each other and access social and mainstream community activities.

Members in the Friends Groups enjoyed sharing hobbies and interests as well as participating in new activities with the help of volunteer mentors, to support them meeting up, finding out what's going on in their local areas, using local amenities and being better connected to their local communities.

Friends Connect ran Friends Groups in Edinburgh, Glasgow, Fife, Dundee and Aberdeen. This was the first project where the organisation recruited and worked with so many volunteers - 74 volunteers were recruited throughout the 3 year project.

Feedback was very positive and demonstrated that the project was successful in achieving its aims. The most important part for the mentees and families has been the friendships developed in the group; 'making new friends', 'meeting new people' and 'getting out more with friends.'

“ He now has a lovely group of friends to invite to his 21st. At his 18th he had hardly any.”

“ I feel like Friends Connect has changed my daughter's life – it helped her get out, see new things and do new things with friends she made.”

“ Confidence has greatly improved in all parts/ aspects of life throughout the duration of Friends Connect particularly in social circumstances. There has been a significant boost to self-image in that there is a friend to go out with, speak to and enjoy each other's company.”

“ It's changed my life getting to ken everybody. More confident as well.”

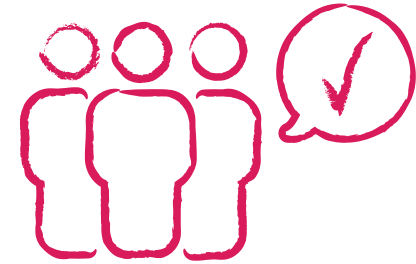
“ Amazing! Loved it! Friends, relationships, fun, excitement - Thank you Brenda!”

“ Great friends, great times, new experiences, more confident, fab!”

“ Both [mentees] now go on a bus on their own, both are now working with the PDSA. One is suggesting that he would like to live independently. I believe all of this has developed with their confidence and the friendship they have built.”



Helping Children Communicate with our Achieving Better Communication (ABC) Groups



It was a busy year for our Communication Skills Programme as we reviewed the programme with the aim of developing the service ahead of the new term. Our aspiration is that every young person in Scotland should be able to access support that will help them (and their families) to develop their communication skills. Thanks to the funding from the Scottish Government, Bank of Scotland Foundation and BlackRock we were able to continue rolling out the programme to our 6 groups across the nation to provide this vital service.

We asked those who used the service for feedback on the ABC groups. The key findings from our review were:

- Close to 85% were satisfied with the service (with almost half very satisfied)
- 79% felt that the service met their needs (very or extremely well)
- Almost 80% rated the quality of the service as high or very high
- Over 98% felt that their child's confidence and communication skills had improved as a result of using the service
- Over 55% are not receiving speech and language therapy input from anywhere else.

Over the course of the next year we will work hard to improve on the areas highlighted in the survey and develop a service that is the best it can be.

In 2017 and going into 2018 there was more demand for our service than we could accommodate. We hope this is something we can rectify in the new term as well as fulfilling our ambition of establishing new groups for Stirling, Kilmarnock, Inverness and Dumfries & Galloway.



 **BANK OF SCOTLAND**
Foundation

Our ABC Groups in Focus

"I think it supports the child and the parent. My daughter is encouraged in the class to do a range of activities appropriate to her abilities to help her to communicate better."

Jane McShane

"I can see the improvements in my son's speech already. Katie is a wonderful teacher & a great support for me as a parent."

Parent, Glasgow ABC Group

"It creates authentic and sustained opportunities for communication."

Morna Lawson

"Opportunity to get advice and support for both children and parents from staff with specific understanding of Down's syndrome. Small groups are really good as this helps the children remain focussed."

Tracy Ord

"It has made a significant difference to my child's conversation skills, and at the group he enjoys chatting with his peers"

Christine Williamson

"It's helping my daughter learn to talk. It truly is an excellent service. SALT don't offer anything like it in our area"

Charlotte Hanson-Hall

"It's an opportunity for my son to meet his peers on a regular basis and gain confidence in talking to them and discussing their interests."

Parent, Edinburgh ABC Group



Year in review...
Matilda promoting our
socks with Sanjeev Kohli
and Jane McCarry

Creating a more aware and inclusive Scotland



Influencing and Shaping Policy to Make a Difference.

Throughout the year we continued to work closely with civil servants and policy-makers to influence policy and improve the quality of life of all our members, thanks to funding from the CYPFEIF & ALEC Fund. In the past year we worked on a wide range of issues from pregnancy screening standards to employment and the health and wellbeing of children and adults with Ds. We also engaged with a variety of new partners and shared our views on the next public health priorities as well as ongoing work on the new social security system.

Most recently, we started developing a stronger relationship with the Royal College of Midwives and hope this will lead to significant improvements in the way midwives support parents.

A significant step was achieved when we were invited to give evidence to the Health & Sport Committee of the Scottish Parliament in November as part of their inquiry into clinical governance. Both our written submission and oral evidence focused on the information we gathered in our health report *Listen to Me, I Have a Voice* published last spring.

Supporting Professionals through Information and Training

Supporting professionals who work with people with Down's syndrome and their families is an integral part of our work. This includes health professionals, health visitors, maternity and midwifery staff, education staff including home visiting and specialist teachers and community care and support staff. During the last year the team supported professionals in areas related to ante and post-natal diagnosis and screening, positive inclusion, differentiation of the curriculum, school transitions, positive behaviour support, adolescence and puberty, dementia and community support.

The Family Support Service team also provides training sessions and specialist consultation support to staff working in mainstream and special schools, family centres, out-of-school care provisions, leisure/social facilities and hospital/health staff and community care and housing.

“Very helpful, has helped me understand my pupil's behaviour and learning style.”
High School Teacher, Glasgow

Dispelling Myths by Raising Awareness

Our Awareness Week took place between 18th – 25th March 2018 with the objective of increasing awareness of Down's syndrome in communities across the country and breaking down the negative stigmas that still exist today. Through our Awareness Week activities, we encourage society to be more accepting and inclusive of people with Down's syndrome.

The secondary message that we focussed on during Awareness Week was that of employment. We promoted inclusion in the workplace and showcased positive employment stories from our members. Our hope is that this will lead to increased opportunities for adults with Down's syndrome to engage in meaningful paid employment.

We also targeted schools and companies to inform and educate them about what Down's syndrome is and how they can better promote inclusion and diversity in their school or place of work. This was backed up by an information pack that contained posters describing Down's syndrome and also posters highlighting how they could include someone with Down's syndrome in their community.

Across STV Channels our Awareness Week TV advert was seen by 39.6% of all adults in Scotland at least once.

Year in review...

Choir 21 performing
at Sandfest 2018



Year in review...

The Bluebells rocking the socks at Sandfest 2018.



The right information at the right time allows people to make informed choices and decision.



Going digital with our 'Hub'

Our online hub resource has two very clear objectives; firstly, to support parents and carers to be more able to support the learning, social and behavioural development of their child, and secondly, that the relationships within families will be stronger as a result of family members having a better understanding of how people with Down's syndrome learn. We visited over 12 different groups across Scotland and met with, and sought feedback from, over 170 families, parents and carers, who have helped to shape the format, design and content of the hub. This will be a much welcomed resource by our membership and we are confident that we will achieve our project objectives and have the hub available to users by the spring of 2019.

Working with the Media

Work continued to build relationships with journalists to promote positive press stories and ensure that we were in a position to respond to any relevant news items. However, going forward we still have much to do to combat the issue of the press not using person first language and shortening Down's syndrome to Down's. This will continue to form part of our work with the press over the next year.

We were delighted to work with a different element of the media in March 2017 when we formed a media partnership with the Herald newspaper group in order to help promote the Sandfest 2018 concert. Our press coverage received during Awareness Week and Sandfest added up to what would have been an advertising equivalent value of £68,000, if we had to have paid for the coverage. This complimented our TV advert which ran for the 2nd year in a row. Together between the TV advert and our media work, this ensured 6,596,065 people had the opportunity to hear or read about Awareness Week and our Sandfest concert.

Quality information empowers people to make decisions.

During the course of last year we produced a series of new resources to help raise awareness and challenge the use of language referring to someone with Down's syndrome. This included resources for explaining to children what Down's syndrome is and an updated Preferred Language Guide.

Our Family Support Service Team worked hard to ensure that our New Baby Packs are in every maternity unit in Scotland making sure that new parents get the right information at the right time. We also have a range of publications in the Let's Talk About range which will all be updated in the coming year.

Thanks to volunteers we developed our library this year, now in its new home in our office at Gorgie Road. Our library is full of information for individuals with Down's syndrome and for their parents/carers, siblings and professionals.

“ I love your kid friendly 'What is Down's syndrome' sheet. I was struggling to explain chromosomes to my kids yesterday, this is fab!”

Claire Gray, Parent, via Facebook

“ This poster deserves to be plastered everywhere - simplest explanation - and I love the final sentence. I want this poster glued to every wall in nursery, before my child attends in a couple of years.”

Bjorg Elisabeth commenting via Facebook on our Awareness Week poster that was part of the pack.





2,637

Twitter followers



18

**Different publications
available**



8,060

Facebook likes



42,023

Website visitors



49

Press mentions



2,698

Magazines distributed

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



Bringing the Worldwide Down's syndrome community to Glasgow

Major inroads were made during the year to prepare and organise for the World Down Syndrome Congress in July 2018. Our call for abstracts attracted 366 submissions over four strands – Scientific, Practice, Lived Experience and Performance. This resulted in 160 fantastic sessions being selected, on a range of subjects such as; Critical aspects of intervention for young children with Down's syndrome; Defeating Dementia Together; and Mental Health of adults with Down's syndrome. We also were delighted to design our first ever tartan that will be on sale during the Congress.

During the year our team of Commissioners and Hosts (adults with Down's syndrome) who will volunteer at the event were recruited to join the three lead hosts of Sam, Stuart and Andrew. The Commissioners commenced a training programme to help them lead on the involvement of people with Down's syndrome from around the world at the World Congress. Part of the training during the year was to support the

Commissioners to undertake formal duties during the event, which will include introducing and thanking speakers, delivering sessions about their lives in Scotland, ceremonial duties during the opening and handover ceremonies and leading parts of the programme for people with Down's syndrome that will run during the Congress.

Making an Impact Locally with our Branches

We welcomed our 9th Branch towards the start of 2018 in Dumfries & Galloway. Our Branches work throughout the year to provide local contact and support to members who are parents and or carers of people with Down's syndrome, as well as adults and children with Down's syndrome. The Branch committees are always trying to think of new fun activities for both children and adults with Down's syndrome and social activities for their parents and carers.

Angus, Ayrshire, Central, Dumfries & Galloway, Edinburgh & the Lothians, Grampian, Highlands & Islands, Tayside & Fife, West of Scotland

Fundraising Together for One Common Goal

As a charity who relies on support from individual donors, fundraisers, Trusts and Corporates we are extremely grateful for all the support we receive. We would not be able to do the work we do without this support. 2017/18 was an incredibly successful year in fundraising thanks to the extraordinary support we received. From walking the Kiltwalk, to running marathons, abseiling down the Forth Rail Bridge and even trekking across the Arctic, our supporters more than went that extra mile for Down's syndrome. The year also saw our largest fundraiser to date with Sandfest 2018.





“We were delighted to work with Visit Scotland in training the hospitality industry in Glasgow ahead of Congress.”

- Jo Hughes

How we raised funds



Community Fundraising

Our dedicated supporters gave their time, skills and energy to take part in and organise their own events for Down's Syndrome Scotland. Each and every one of them played a vital part in helping us to support people with Down's syndrome and their families.

Fundraising & Donations

Thank you to all the individuals and companies who gave generously to support our work throughout the year. Our annual campaigns and fundraising events helped to support our ongoing work supporting children and adults with Down's syndrome to reach their full potential.

Grants and Trusts

We very much appreciate the amazing ongoing support from many Charitable Trusts and Foundations and the Scottish Government without whom our work would not be possible and this includes a grant towards the costs of the World Down Syndrome Congress.

Legacies

Legacies make a significant difference to our charity and help us plan for the future. We are extremely grateful to all those who choose to remember Down's Syndrome Scotland in their Will.

Membership

The annual contributions we receive from our members allow us to help support families across the country.

Branches

Our nine dedicated Branches around the country not only hold activities, offer peer support and provide an opportunity for families to come together but also tirelessly fundraise throughout the year in their local areas.

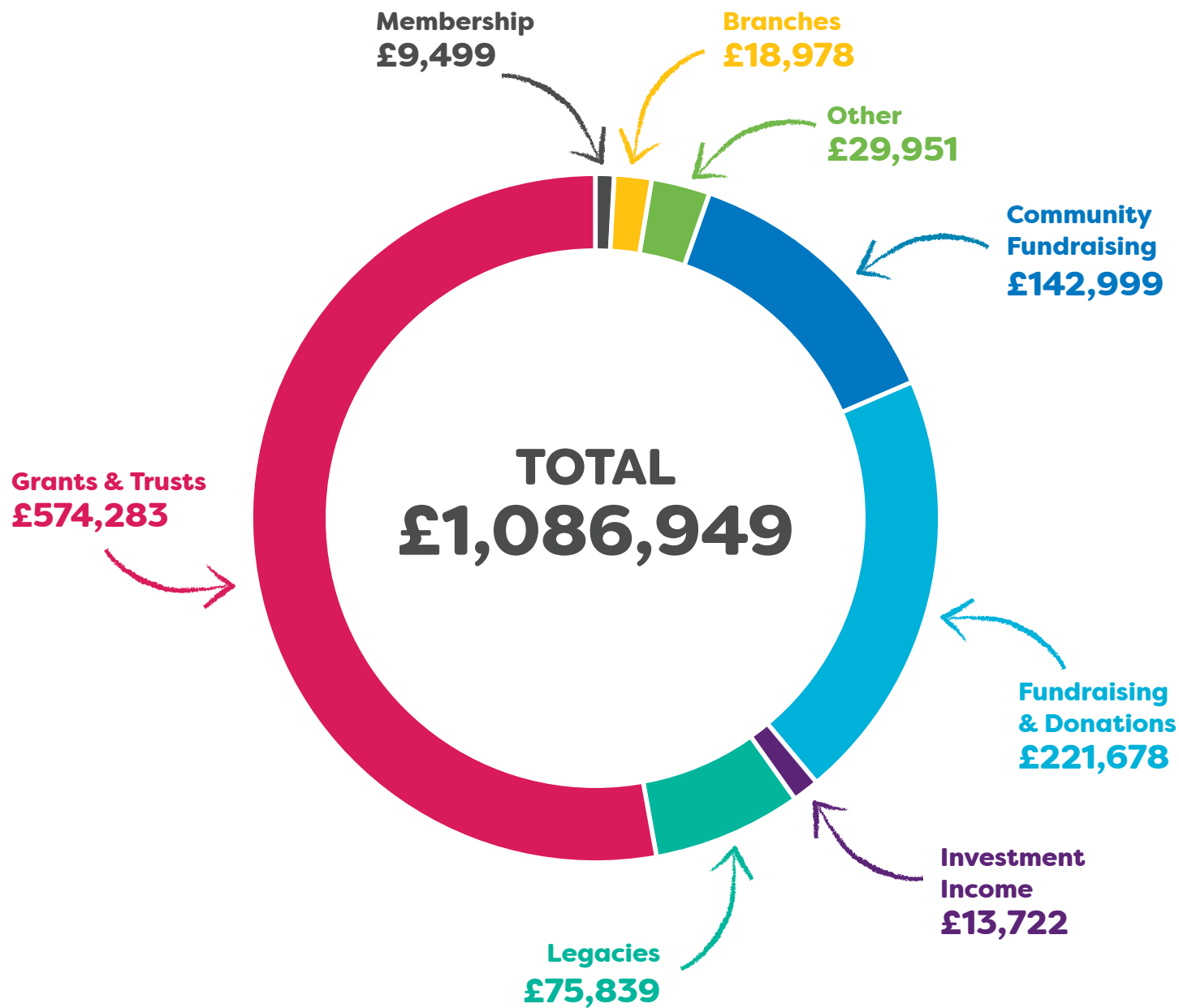
Investment Income

We successfully rented out our premises at Balgreen Road for the duration of the year.

Other

Our Family Support Service Team carried out training courses and consultations with professionals throughout the year. We also gave careful management to banking interest and other sources of charitable activity.





How we spent the funds



Supporting Families

At the very centre of what we do is supporting families. Much work was done during the year on developing our Learning Hub in order to be able to provide support digitally also. We continued to support our branches who are an integral part of our organisation. These funds also helped to train professionals and to provide resources for families and professionals.

Supporting Adults

2017 saw the cumulating of our three year Friends Connect Project, which supported friendships and created community connections for adults with Down's syndrome. During the year we also recruited our Commissioners for the World Down Syndrome Congress and they quickly got busy learning all they needed to ahead of July 2018.

Supporting Children and Young People

Our Achieving Better Communications Groups continued to be rolled out to children and young people in locations across Scotland. Much work was done in evaluating the groups and determining the best direction for the programme in the future.

Policy & Awareness Raising

We stepped up our policy work by taking part in our first live session of giving evidence in Parliament. We once again invested in a television advert during Awareness Week to help increase the awareness of Down's syndrome in communities and reduce stigmas that remain in society.

Bringing the Community to Glasgow

We are committed to putting on the best World Down Syndrome Congress that we possibly can. This involves providing over 160 sessions for people to attend, the opportunity to hear the latest research and listen to world renowned speakers.

Raising Funds

We always strive to raise the maximum amount of funds in the most efficient and cost effective way possible. We spent funds on our campaigns like Lots of Socks, Tea for 21 and putting on large events. This also includes giving us the ability to apply for trusts and grants and managing corporate partnerships. Every year we also proportion part of our costs to caring for our donors.

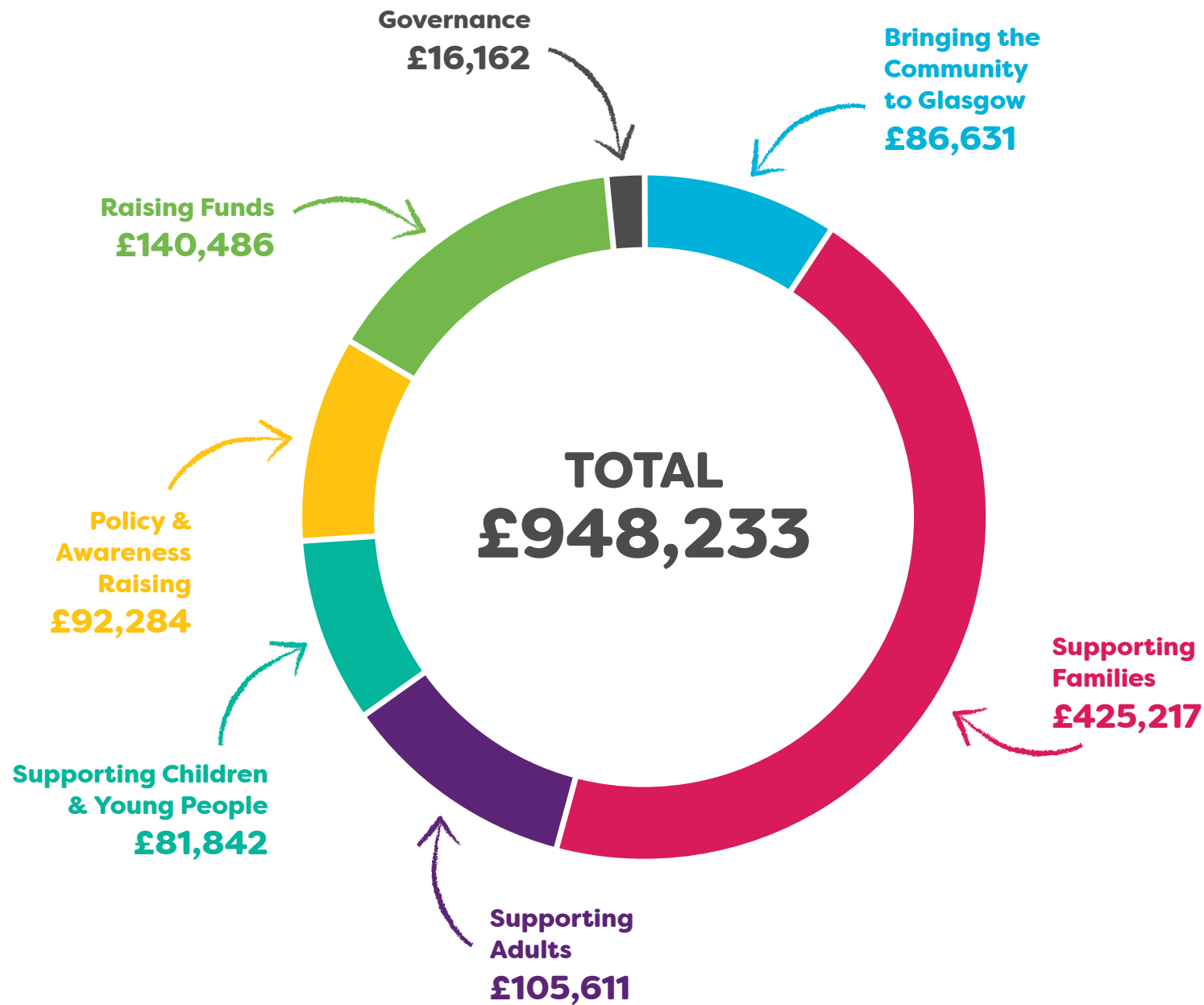
For every
£1 spent on
fundraising
we raised...

£7.64

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





Looking forward



Pandora
Summerfield,
Chief Executive
Officer

The last year was a pivotal time for Down's Syndrome Scotland. With an income of over £1 million, we moved from being a small charity to a medium sized charity.

Looking forward to 2018 we are on the cusp of delivering a World Down Syndrome Congress that will put Down's Syndrome Scotland on the world stage and will see a culmination of 5 years of work reach fruition.

In July 2018 we will welcome people from the Down's syndrome community across the world to Glasgow. I am immensely honoured to be part of such a milestone occasion and I hope that all those who attend, especially from Scotland, go home with new learnings that will help make a significant and positive

impact to their lives. I have watched with great admiration and pride as our Commissioners have come together and worked as a team to start their preparation for being an integral part of the Congress. Adults with Down's syndrome will have the opportunity to come together the day before the Congress opens and will make new memories, experiences and friends for life.

When I joined this charity almost ten years ago, nearly all of the members I spoke to highlighted to me the need for better speech and language provision for their children. Eight years ago our ABC Groups became an integral part of the work at Down's Syndrome Scotland. It was with enormous pride in our team that in March, I read the results of the evaluation of the service, which showed that nearly 85% of those who attended were satisfied with the service.

The next year will be a significant step forward in our ABC Groups, as we welcome new Speech & Language therapists, Joanna and Natasha, to help us take forward the future of the programme. We have listened to the feedback we have received and are looking forward to this next stage in the development of delivering our Achieving Better Communications Programme.

During the coming year we will not fail to ensure that Down's Syndrome Scotland is fit for purpose following the Congress. During 2018 we will be working to develop a new strategic framework that will take in to account the capacity of our charity to meet the growing and changing needs of those whom we support.

This will be an extremely exciting time for the charity as we embark on new projects with a digital element, new projects that offer support to adults with Down's syndrome and as we continue to expand, evaluate and adapt our existing services. We will also review our governance structure in order to ensure that it is fit for purpose.

We won't do this alone, we will engage and involve all our stakeholders along the way as we meet the future head on. Of course we would not be in this position if it was not for all those who tirelessly support us with their time, money and energy – thank you.

*Pandora
Summerfield*

Thank You.



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
- Big Lottery Improving Live Fund
- Children's Aid (Scotland) Ltd
- Cruden Foundation
- John Watson's Trust
- Martin Connell Charitable Trust
- MEB Charitable Trust
- M E Bells Charitable Trust
- Muirhead Charity Trust
- Nancie Massey
- Northwood
- Saints and Sinners Club of Scotland
- Scottish Government
- Scottish Government
- (CYPFIEF and ALEC Fund managed by the Corra Foundation)
- Sir James Miller Edinburgh Trust
- Souter Charitable Trust
- Stafford Trust
- Templeton Goodwill Trust
- The Enzo Londei Trust
- The Hospital Saturday Fund
- The Hugh Fraser Foundation
- The Robertson Trust
- The RS MacDonald Charitable Trust

We would also like to give thanks to the estate of the late Mr D Stewart for his generous legacy donation to Down's Syndrome Scotland.

Thank you to our corporate donors and sponsors.

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

- Blackrock
- Craig Corporate
- Safestore
- Scotmid
- Scottish Equity Partners (SEP)
- Scotcoin

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

We would be delighted to give you more information on our work. Contact us today.

Down's Syndrome Scotland is a registered charity in Scotland and we rely on donations to carry out the vital work we do in supporting families.

If you are interested in supporting us please visit www.dsscotland.org.uk or give us a call today.



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