



# Reaching full potential together

Annual Review  
2016/17

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Down's  
Syndrome  
Scotland

helping people realise their potential



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# Welcome to the annual review of Down's Syndrome Scotland.



*Ian Fraser*

Ian Fraser,  
Chairman

**2016-17 was a considerable year of growth for the organisation both in monetary terms and our move to new premises. This allowed us to increase the support we were able to offer to people with Down's syndrome and their families.**

It was a year where, thanks to funding from the Scottish Government, we saw the first TV advert raising awareness of Down's syndrome screened on TVs across Scotland. A few years ago there was little mention of Down's syndrome in government circles. Now we are a major player in learning disability policy development and see the government as a real partner in our cause.

The launch of our Health Report, 'Listen to Me, I Have a Voice', was a significant step in allowing us to analyse and evidence the healthcare experiences of our members. Over 400 members took part in this major piece of work.

Following our consultation event in 2015 we listened to our members who asked for better communication from us. The team have done much work in improving communication and I was delighted to see in 2016 the launch of Limitless, a version of our Full Potential magazine specifically for adults with Down's syndrome. As we move in to next year we will continue to improve and expand our communication methods.

We continue to focus on raising the optimum amount possible to support the maximum number of people in the best way we can. Our fundraising volunteers are keen, energetic, innovative and successful in raising much needed funds and we simply would not be able to do our work without them.

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

# Providing tailored support through every age and stage of life.



## Teaching Communication Through our Achieving Better Communication (ABC) Groups

Last year we continued to deliver our Communications Skills Programme to 90 children a week thanks to further joint funding from RS MacDonald Charitable Trust and the Scottish Government who have jointly funded the service.

We continued to deliver weekly ABC groups in Edinburgh, Glasgow, Aberdeen and Orkney and have started a fortnightly service in Angus and Perth. We have also delivered parental workshops throughout the country. These workshops provide parents with the skills and knowledge to aid communication at home and school.

“ Logan enjoys coming to the ABC group and is learning many valuable things such as turn taking and listening to others. He has also managed to work on a lot of aspects of his speech and pronunciation. He has been a lot more chatty, and also can say a few things much clearer.

- Jacqueline, Parent from Angus.

## Joining People Together Through ‘Friends Connect’

Our Friends Connect project is funded for three years, August 2014 to August 2017 by The National Lottery, through the Big Lottery Fund. The project supports adults with Down's syndrome to develop and sustain friendships with each other and access social and mainstream community activities. We often find that making friends and keeping friendships going can be a challenge for people with Down's syndrome. Through the project they are supported by a volunteer mentor who helps with the practical arrangements as well as supporting them to try new activities and boost their confidence. Friends Connect has set up Friends Group's in Edinburgh, Glasgow, Fife, Dundee and Aberdeen.



It's great to see the change in confidence this programme has given people. Some people were so shy during their first home visit they didn't want to speak. Now they have interaction with everyone.

- Brenda Hepburn, Friends Connect Project Manager.



40 Volunteers

56 Adults with Ds supported

794 parents received support on a multitude of issues

170 families received ongoing support for complex issues\*

113 attended 15 parental workshops

## Family Support – at the heart of what we do

Our Family Support Service is at the heart of the organisation and continues to be a crucial part of what we do. The Family Support Service is made up of five part-time Family Support Service Officers. Each officer is dedicated to covering a specific geographic area. Together, they offer an 'all through life' service providing information and support to families throughout Scotland.

The Family Support Team have continued to deliver parental workshops, with new topics including 'supporting your child with numbers', 'supporting your child with reading' and 'preparing for puberty'. This brings the total number of Parental Workshops offered to six as well as several bespoke workshops offered to smaller groups.

\*more than three hours, not including travelling time



## Case study

Alison Raby

Service: Family Support

“Jo was first introduced to our family back in 2013 whilst Grace was attending a local mainstream nursery. The nursery manager had sought advice from Down's Syndrome Scotland and Jo had visited the nursery to observe Grace and provide them with some valuable information to assist them in supporting Grace better. It was deemed beneficial for Jo to also do a home visit and that was our first meeting.

On a personal basis Jo has supported me in times of crisis and self-doubt and I find her support and advice invaluable; her experience and knowledge in relation to raising and supporting a child with Down's syndrome is of great comfort to me.”



£17,900

awarded to help provide breaks for 62 parents/carers.

## Supporting Carers with Creative Breaks

Once again we provided funding for parents and carers. During the year we granted £17,900 through the Creative Breaks Fund, run in partnership with Shared Care Scotland, on behalf of the Short Breaks Fund. The grants allow parents and carers who have a significant caring role for an adult with Down's syndrome living with them to apply for funding towards something that will give them a break from their caring role.

“ I feel more able to continue with my role having been away just myself and my son. I am very proud as he did well in his swimming. Thank you all very much”.

Stella from Lockerbie

# Creating a more aware and inclusive Scotland.



## Supporting Professionals Through Information and Training

We provide support to professionals, including medical professionals, education staff and support staff. Other professionals such as health visitors and home visiting teachers have also contacted the organisation for support and information. Our team have supported 371 professionals during the year.

We also provided training and support to staff working in mainstream and special schools, family centres, out-of-school care provisions, leisure/social facilities and hospital and health staff. We have continued to deliver our programme of courses which focus on the particular learning strengths and challenges that children with Down's syndrome experience as well as strategies to develop these particular skills.

“ I found the training very helpful, it has helped me understand my pupils behaviour and learning style.”

- Heather, High School Teacher, Glasgow.



# 38k

Awareness week video watched 38,000 times on social media alone.

## \* Dispelling Myths by Raising Awareness

In March we celebrated Down's Syndrome Awareness Week with our first ever TV advert which aired on STV. The advert featured Natasha and was aimed at raising awareness of the general public and challenging the perception of Down's syndrome. Our awareness articles were covered throughout Awareness Week, with 16 mentions in newspapers, six radio shows and a feature on BBC Reporting Scotland. These allowed us to share families stories and experiences in both local and national media.

Watch the advert here:

<https://www.youtube.com/watch?v=iqe95VUbX4Q>



# Delivering high quality and accurate information.

## Reaching out via Social Media

Our website serves as a useful resource not only for our members, but people interested in finding out more about Down's syndrome, whether expectant or new parents or professionals. We continued to produce our monthly e-bulletin which we use to communicate news and updates about our work to our subscribers. Our social media sites (Twitter, Facebook, YouTube and Pinterest) continued to grow, especially Facebook. Last year also saw the launch of our new Instagram account.

## Working with the Media

As well as proactively working with journalists to increase awareness of Down's syndrome, we also work with the media to provide news responses to issues relating to people with Down's syndrome and their families. We encourage our members and branches throughout Scotland to promote fundraisers' events and profile stories to their local papers.

A big focus in the media during the past year has been pre-natal screening and the non-invasive pre-natal test. We responded to 12 enquires from journalists regarding this topic.

“Your recent radio piece with Stuart and Emma was brilliant. They all made some great points and everyone came across really well.”  
- Lisa, parent of a child.

## Providing the Right Information Through our Publications

Our bi-annual magazine, Full Potential, is now in its eighth year of print and is distributed to our members every spring and autumn. It features a range of articles written by medical specialists, researchers, as well as staff. Last year we issued our new supplement, Fundraising Focus, which updates supporters on fundraising related news, activities and stories from our fundraisers. We also launched 'Limitless' a magazine specifically for adults with Down's syndrome. This features articles from our members in 'Easy Read' format.

“Your language guide is great. I'm always correcting people about 'child' first language. If we can get people to change this they will think about the child first and condition thereafter. Thank you.”  
- Maj, mother of a child with Down's syndrome.



2,367

Twitter followers



2,730

E-bulletin subscribers



6,909

Facebook likes



35,974

Website visitors



42

Press mentions



2,972

Magazines distributed

# Influencing and shaping policy to make a difference



2016/17 was the first year of funding from the CYPFEIF & ALEC\* Fund towards our policy work that will help us continue to work towards a fairer and more inclusive Scotland for people with Down's syndrome and their families.

We continued to work closely with the Scottish Government in delivering the Keys to Life implementation framework and to share feedback from members with civil servants on a wide range of issues to improve services throughout the country. The new funding has also allowed us to further develop partnerships with public agencies like NHS Health Scotland and other third sector organisations such as the Coalition of Care Providers in Scotland (CCPS).

Over the past 12 months we have increased opportunities for the voices of children and young people with Down's syndrome and their families to be heard at national and local level and worked towards improving the quality of life of children and adults.

We have also increased awareness of the issues affecting our members through various activities in the past year. This has included the publication of our new report 'Listen to Me, I Have a Voice' on the healthcare experiences of children and adults with Down's syndrome and their families in Scotland.



\*Children, Young People and Families Early Intervention Fund and Adult Learning and Empowering Communities Fund

## 01 'Listen to Me, I Have a Voice' report

A major piece of work over the last year has been to gather and analyse evidence from our membership on their experiences with healthcare professionals and services. Over 418 members responded, including 201 adults with Down's syndrome. This led to the publication of a report 'Listen to Me, I Have a Voice'. We shared the findings at an event in the Scottish Parliament during Awareness Week 2017 - it was attended by MSPs and sponsored by Jeremy Balfour MSP.

## 04 Pregnancy Screening

We sent a briefing on the new Non-Invasive Prenatal Test (NIPT) to all MSPs as well as the Chief Medical and Chief Nursing Officer and contributed to the considerations of the Nuffield Bioethics Committee. We were also contacted by the NHS Health Scotland team in charge of redesigning the pregnancy screening leaflet and were encouraged to provide feedback on the new publication. We were pleased to see that some of the points raised were included in the final publication.

## 02 Blue Badge Pilot Scheme

April 2016 saw the pilot extension project for Blue Badge parking go live. During the year we asked members to give us feedback on their experience with the new scheme in order to provide evidence to the Scottish Government. Thirteen members shared their experience with us on the application process and/or on how a Blue Badge affects their daily life. Further to their evaluation, the Scottish Government has decided to extend the scheme for another 6 months and we will continue to monitor this as it progresses.

## 05 National Advisory Groups

We are a member of the Learning Disability Employment Task Group. Their remit is to deliver a plan to take forward the recommendations in the Mapping the Employability Landscape for People with Learning Disabilities in Scotland Strategy, published by SCLD last Summer. During Awareness Week, our Policy Officer took part in the Kaye Adams show on BBC Radio Scotland to talk about the issue of employment for young people with Down's syndrome.

## 03 AHP Care Pathway

Our work with NHS Education Scotland on an Allied Health Professionals care pathway is progressing well; A set of postcards for new parents is due to be launched in the coming year and will be added to our baby packs which are delivered to all maternity units across Scotland. The postcards will help parents identify when they and their babies may need extra support from specialists such as physiotherapists, occupational therapists etc. We hope that this project will lead to improved practice and better healthcare for our youngest members.

## 06 Consultations/Calls for Evidence

We submitted responses to five Scottish Government consultations/calls for evidence on a wide range of issues including national health & social care standards, mental health and social security.

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



### Reaching Out to the World with our World Congress

We submitted a bid and won the rights to host the 13th World Down Syndrome Congress which will be held in Glasgow in 2018. Last year saw the establishment of the National Scientific Committee and the work to create the programme and event is well underway.

Our Commissioners Programme Project Worker started during the year and has been working with the three lead commissioners (adults with Ds) who are defining their roles and that of the other commissioners and designing the advertising, application and selection process for the other commissioners.

### Making an Impact Locally with our Branches

We currently have eight branches throughout Scotland and each of these branches run activities for children and adults with Down's syndrome and their families. We would encourage all of our members to get involved and help bring our local communities together.

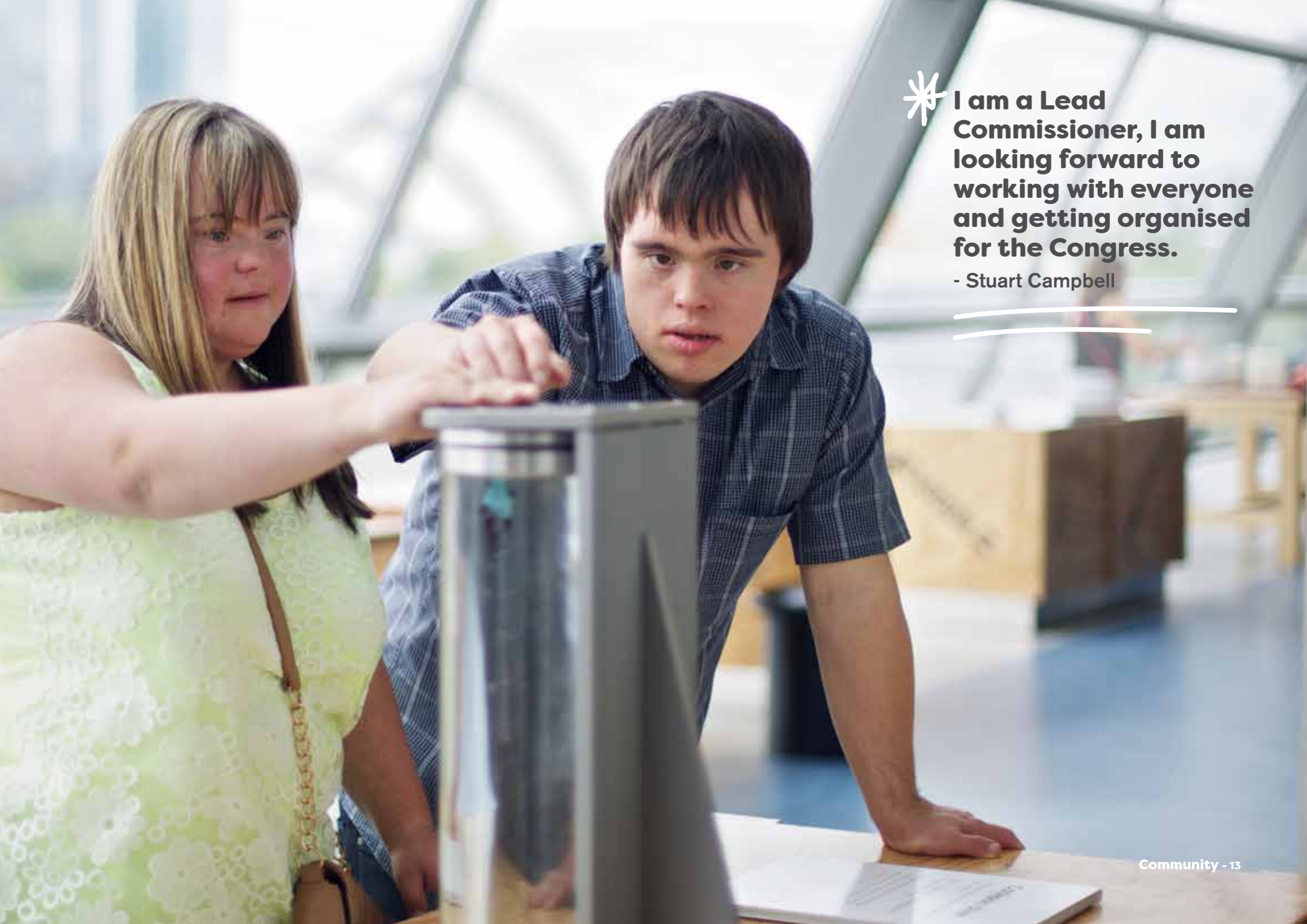
*Angus, Ayrshire, Central, Edinburgh and the Lothians, Grampian, Highlands and Islands, Tayside and Fife, West of Scotland*

### Fundraising Together for One Common Goal

We couldn't do our job without the help of our supporters. The dedication of our members in communities across Scotland who tirelessly raise money every year through a wide range of events. From sponsored walks, cycles and runs, to balls and coffee mornings our supporters are the backbone of our organisation.

 I am a Lead Commissioner, I am looking forward to working with everyone and getting organised for the Congress.

- Stuart Campbell



# How we raised the funds



## Community Fundraising

We cannot thank enough the dedicated volunteers who take part in and run events in their local communities to raise funds.

## Fundraising & Donations

Thank you to every single person who took part in one of our campaigns like Lots of Socks and to all the companies and individuals who generously donated towards our work over the year.

## Grants and Trusts

We very much appreciate the incredible ongoing generosity of all the charitable trusts and foundations who have made a significant difference to our work with families across Scotland.

## Membership

We are able to support families across the country thanks to the annual contributions from our membership.

## Branch

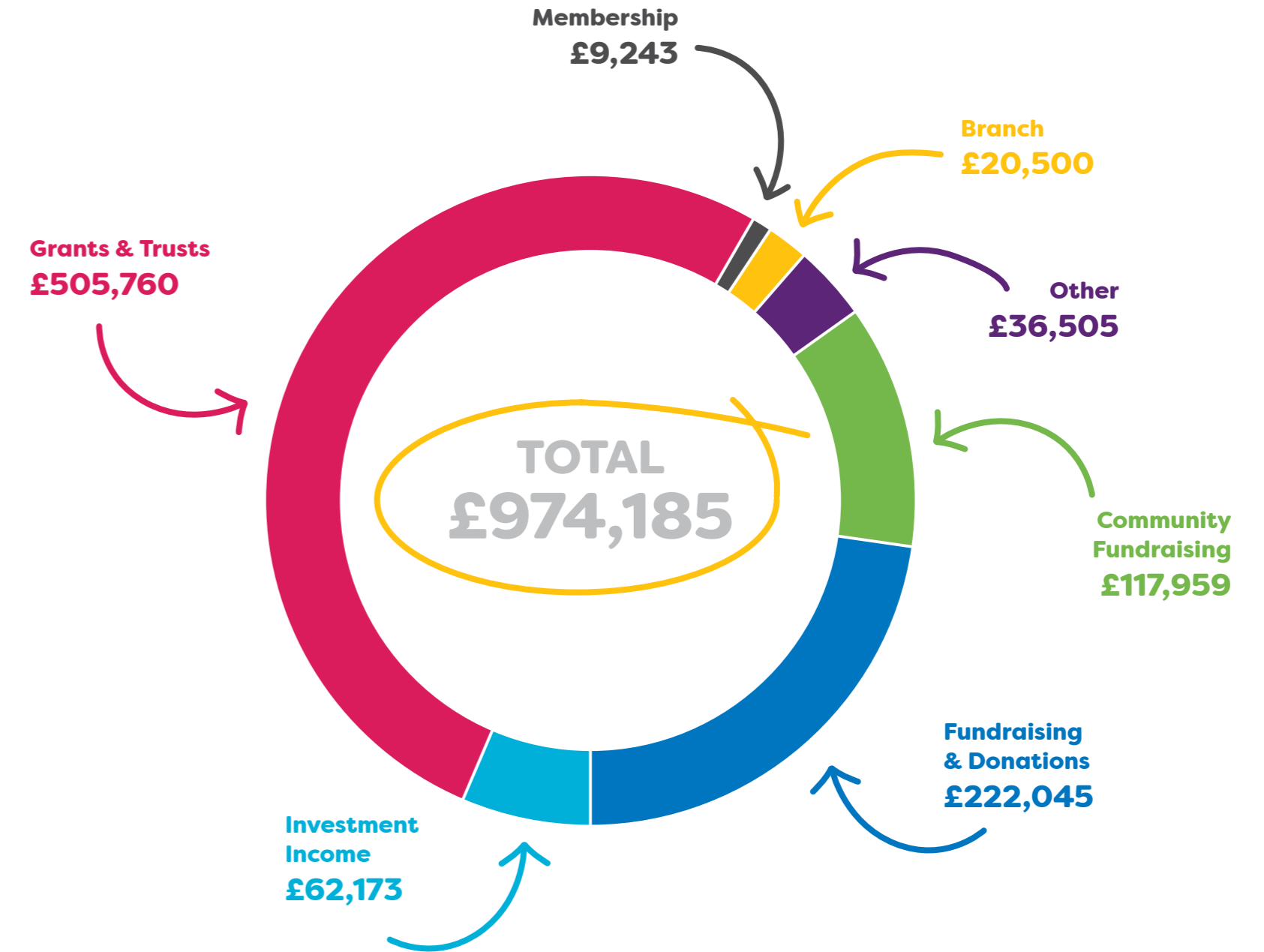
Our dedicated branches across the country not only held essential activities for children and adults with Down's syndrome, they also tirelessly fundraise throughout the year.

## Other

We also earn some additional income from bank interest and other activities that contribute to our total income for the year this includes the sale of our publications and resources to professionals working with people with Down's syndrome.

## Investment Income

Our Investment income received a considerable growth last year. This was due to our property at Balgreen Road no longer being occupied by Down's Syndrome Scotland and becoming a rented property. As a result of renting the property we were required to revalue it and this has resulted in a gain of £59,000 as investment income.





# How we spent the funds



## Supporting Families

At the heart of what we do is supporting families through our Family Support Service. We also provided breaks for carers looking after adults with Down's syndrome and our branches were instrumental in providing activities locally for adults and children with Down's syndrome and their families.

## Supporting Adults

We delivered our Friends Connect project for adults with Down's syndrome, supporting friendships and helping adults to establish community connections.

## Supporting Children & Young People

Our team delivered ABC Groups to children in eight different locations across Scotland during the year including a new group in Angus. Communication Skills Parental Workshops were also rolled out to help parents and carers teach communication skills.

## Policy & Awareness Raising

We continued our work to influence policy at local and national levels and helped raise awareness of Down's syndrome and our organisation through our first TV advert.

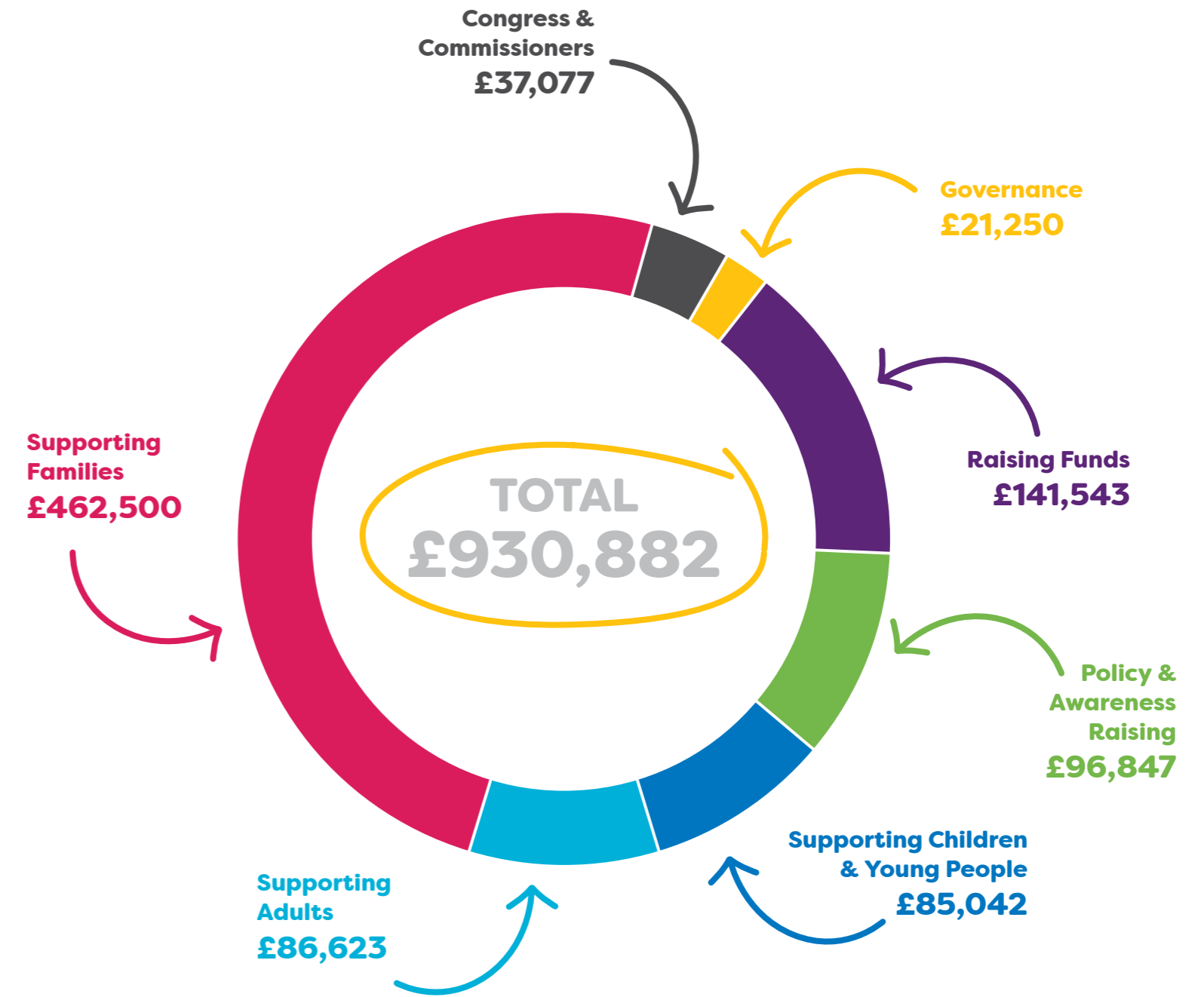
## Raising Funds

We always strive to raise more by spending the least. We spent funds on fundraising campaigns such as our Lots of Socks Day, fundraising events and on donor care. Raising funds also included giving us the ability to apply for trusts & grants and managing corporate partnerships.

**For every £1 spent on fundraising we raised £6.**

## 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](http://www.dsscotland.org.uk)



# Looking forward



Pandora  
Summerfield,  
Chief Executive

## This year we reached a great milestone for our charity as we moved to our new location on Gorgie Road.

One of the biggest highlights for me being in our new office, has been the frequent opportunity it has allowed for me to meet the people we support. Whether it's the children and teenagers who come to the Lothian ABC group on a Friday or the parents coming to the Parental Workshops, the ability to meet you face to face and discuss your needs and aspirations has been hugely beneficial.

Over the next 18 months our office will become the hub for the organisation of the 13th World Down Syndrome Congress. During the year we will work with our colleagues at Down Syndrome International and our other partners to build a unique programme with renowned international speakers that will help us to make this Congress the best yet. We aim to deliver more than 100 sessions over three days to approximately 1,200 delegates. You can find out more information at [www.wdsc2018.org.uk](http://www.wdsc2018.org.uk).

In January 2017 we welcomed Angela Turner to our team to work with our Lead Commissioners for the Congress and to start work on recruiting the remaining Commissioners who will play a major role in the delivery of a great event. I very much look forward to seeing this project grow over the coming year and welcoming the new Commissioners on board.

During the coming year we will also embark on an ambitious project to launch our first online Parental Learning Hub. This is a significant step forward for Down's Syndrome Scotland's digital future and sees just the start of what we hope will be many digital projects.

As we continue to grow and expand as an organisation, our Family Support Service will remain at the very centre of our work. The team will continue to build relationships with our local branches and health and educational staff, to ensure that all families receive a comprehensive support service.

Our Policy team made huge progress this year and during Awareness Week we saw the launch of our Health Report. The report carried several recommendations and received cross party support at the launch event, including from the Minister for Mental Health. Our team will ensure in the coming year that we follow through with the relevant authorities and politicians to help them in any way we can to implement the findings in the report.

It is with pride and sadness that after three years, this coming year sees the conclusion of our Friends Connect Project. This project had an immense impact on all those who took part and volunteered in the project and we very much believe that the friendships that were created will go on long after the project finishes in August.

We won't take for granted the challenging future ahead of us both economically and politically. We will instead meet the future head on as we prepare to host the Worldwide Down's syndrome community in 2018 and as we continue to grow and expand the services we offer at Down's Syndrome Scotland. We simply would not be able to carry out the work we do without the support of our funders and donors – thank you all.

*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
- AM Pilkington Charitable Trust
- Andrew Paton's Charitable Trust
- BBC Children in Need
- Big Lottery Fund
- Children's Aid (Scotland) Ltd
- Cruden Foundation Limited
- Geoffrey Clerk Charitable Trust
- Martin Connell Charitable Trust
- Miss B W Muirhead's Charitable Trust
- Miss E C Hendry's Charitable Trust
- MFR Radio
- Northwood Charitable Trust
- Scottish Government (CYPFIEF)
- Shared Care Scotland
- Sir James Miller (Edinburgh) Trust
- Souter Charitable Trust
- Tartan Army Children's Trust
- Templeton Goodwill Trust
- 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 RS MacDonald Charitable Trust
- The Stafford Trust
- WCH Trust for Children

## 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
- Scottish Equity Partners (SEP)

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

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