

DOWN'S SYNDROME SCOTLAND

Trustees' Report and Financial Statements

For the year ended 31 March 2019

Scottish Charity Number SC011012

Scottish Company Number SC356717

**DOWN'S SYNDROME SCOTLAND
2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS**

CHARITY INFORMATION

Trustees	Stuart Macintyre Ian Fraser Moira McIntosh Sharon Bandeen James Batchelor Alan Cunningham Mark Docherty Karen Gilligan Stephen Hughes Patricia McClure Stuart McCusker Theresa McDaid	Chairperson (from 1 October 2018) Chairperson until resigned 1 October 2018 Vice Chairperson Appointed 10 January 2019 Resigned 18 June 2018 Resigned 17 October 2018 Resigned 18 June 2018
Company Secretary	Moira Easson	Finance Consultant
Senior Management Team	Eddie McConnell Pandora Summerfield Rory Gaffney Jo Hughes Moira Easson Kerry Lindsay	Chief Executive (from 26 August 2019) Chief Executive (until 1 May 2019) Head of Operations Family Support Service Manager Finance Consultant Fundraising Manager (until 4 June 2019)
Charity registration number	SC011012	
Company registration number	SC356717	
Website	www.dsscotland.org.uk	
Registered Office	Riverside House 502 Gorgie Road Edinburgh EH11 3AF	
Auditors	Geoghegans Chartered Accountants 6 St Colme Street Edinburgh EH3 6AD	
Solicitors	Lindsays WS Caledonian Exchange 19a Canning Street Edinburgh EH3 8HE	
Principal bankers	Royal Bank of Scotland 142-144 Princes Street Edinburgh EH2 4EQ	Charities Aid Foundation 25 Kings Hill Avenue Kings Hill, West Malling Kent ME19 4JQ

**DOWN'S SYNDROME SCOTLAND
2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS**

CHAIRPERSON'S STATEMENT

2018 was an exceptional time for Down's Syndrome Scotland as we hosted the 13th World Down Syndrome Congress. I was honoured to become the new Chair of the charity in such a milestone year.

Although Congress dominated much of our work during the year, we also had an incredibly successful Awareness Week. Our members told us the use of language was a huge issue for them therefore we embarked on our Mind Your Language campaign to highlight to the general public, friends and family, the effect that the use of wrong language can have.

Our Achieving Better Communication Programme underwent a transformation, with more groups started across the country including a pilot of a sing and sign circle group for babies and toddlers. We still have demand for many more groups and, if we can secure sustainable funding, will be addressing this in the coming year.

The success of Congress propelled Down's Syndrome Scotland and awareness of Down's syndrome in Scotland to a new level. The quality of sessions provided, and information shared over the four days was immeasurable.

However, we do appreciate that hosting such a large, world class event has contributed to the large deficit experienced by the charity this year. I would like to reassure our members and supporters that the charity remains in a financially secure position. We did plan for this possibility by carrying into the year a significant surplus from the previous year, meaning we have sufficient reserves to manage this deficit.

As Chairperson of the charity I would like to assure all our members and supporters that in return for the support from you, we are doing all we can in the 2019-20 financial year to deliver our objectives within a tightly controlled budget.

On behalf of myself and my fellow Trustees I would like to thank you for your continued support. With the arrival of a highly accomplished new Chief Executive and dedicated and extremely capable staff team, I look forward with optimism to this new chapter in the charity's history.

**Stuart Macintyre
Chairperson**

DOWN'S SYNDROME SCOTLAND

2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS

TRUSTEES' REPORT

For the year ended 31 March 2019

The Trustees, who are also Directors for the purposes of Company Law, present their report and financial statements for the year ended 31 March 2019.

1. OBJECTIVES AND ACTIVITIES

Down's Syndrome Scotland (DSS) is a member led charity which was established in 1982. We are the only charity in Scotland dedicated solely to supporting people with Down's syndrome (Ds) and their carers. DSS provides "all through life" support nationally across Scotland.

As set out in its governing document, DSS was established to improve the quality of life for everyone in Scotland with Down's syndrome by the advancement of education, health and citizenship plus the relief of those in need by reason of disability.

We know that every person with Ds is a unique individual, full of potential. We work to help people with Ds reach their full potential by providing information and support to them, their families, carers and professionals at whatever age and stage of life. We also work to raise awareness and influence national policy to ensure that the society in which we all live reflects the needs of people with Ds.

Our vision is that society fully accepts and includes people with Ds.

Our mission is to support families and people with Down's syndrome to reach their full potential by providing a range of services, influencing public policy and by changing attitudes.

Our values are:

- Sensitivity
- Understanding
- Professionalism
- Pragmatism
- Openness
- Respectfulness
- Trustworthiness

Our values are embedded in all that we do.

To achieve our mission, we identified a number of strategic goals in the Strategic Framework 2016-2019. These are summarised below:

- Community – Engage in a strong global community by hosting the World Down Syndrome Congress.
- Support – Provide comprehensive evidence-based support to people with Ds, their families and carers and professionals through every age and stage of their life.
- Information – Provide high quality and accurate information, at the right time, to enable people to make informed choices and decisions.
- Inclusion – Promote a more inclusive society for people with Ds by challenging negative stereotypes through education, training and awareness raising and ensuring their voice is heard.

DOWN'S SYNDROME SCOTLAND 2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS

The achievement of our strategic goals is underpinned by the delivery of a series of key activities within the following focus areas:

- Delivering a World Down Syndrome Congress
- Supporting families and professionals
- Supporting adults with Ds
- Supporting the development of communication skills in children and young people
- Raising awareness and influencing national policy
- Establishing a vibrant community through our branch network

The delivery of these activities requires us to raise considerable funds each year. This is the focus of our professional fundraising team.

2. ACHIEVEMENTS AND PERFORMANCE

2.1 Delivering a World Down Syndrome Congress

2018 was a landmark year for DSS when, in July, we hosted the 13th World Down Syndrome Congress at the SEC in Glasgow.

It was a long road to Glasgow for DSS, with work on Congress starting many years before 2018. It was an event worth waiting for. The sun shone brightly as we welcomed 1,151 delegates from 92 different countries to Glasgow over the three days.

Deputy First Minister, John Swinney delivered a speech as part of the opening ceremony and Lord Provost of Glasgow, Cllr Eva Bolander spoke at the end of the first day, welcoming everyone to Glasgow.

"Tremendous privilege to attend #wdsc2018 in #Glasgow today. Stunning opening ceremony and heartfelt contributions on how society is strengthened by the participation of those with Down Syndrome. Well done @DSScotland." Deputy First Minister, John Swinney

From April to July 2018 preparation for Congress meant a huge amount of staff resource was focused on ensuring that DSS delivered on our aim to host an event by which all future Congresses would be measured. The organisation and delivery of the event drew upon the varied skills of each and every member of staff. Although it required considerable organisational resource to plan and deliver and significant financial investment, it has generated a legacy of learning and experience which will help to shape the formation of our strategic planning in the coming years. Since Congress, we have received countless positive comments, learning and memories that the event made possible for so many people, both in Scotland and from countries around the world.

We were honoured to welcome internationally renowned speakers and experts in the field of Ds including, Dr Brian Skotko, Prof Roy McConkey, Anthony Holland and Deborah Fidler.

At the very heart of Congress were people with Ds, many of whom played a pivotal role in Congress. Fiona Dawson, Sarah Merriman and Adam Sloan all gave plenary talks and many more gave workshop sessions.

Along with our own journey to Glasgow 2018, the Commissioners, a group of adults with Ds who helped to lead on the involvement of people with Ds from around the world at Congress, not only took that journey with us but led us the way in both the run up to and during the event itself.

DOWN'S SYNDROME SCOTLAND 2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS

Our Family Support Service team attended over 70 sessions throughout Congress, whilst also supporting families and responding to enquiries from professionals at the event.

We have already started putting our learnings from Congress into practice, helping support families across Scotland. Our key learnings came from hearing about new research as well as sharing best practice within education and health with other professionals from around the world.

Highlights from the event included:

- 1,151 delegates attended from 92 different countries
- 160 speakers over 3 days
- 11 adults with Ds who became Commissioners and 9 who became Hosts
- 10 workshops for adults with Ds

Feedback from delegates:

"It was one of the most well-integrated events I have been to, combining all delegates regardless of background into the entire event. A great mix of participants and high-quality, informative presentations."
Kerry Britt

"Where best to spend a few days, Madrid, Jerusalem, Dublin, or Glasgow? Some might not choose Glasgow, but if you wanted an exciting, informative, challenging, entertaining experience and you have any connection with Down's syndrome, then Glasgow wins. A world class Congress surpassing in quality our three previous Congress experiences." Sam & Janette Campbell

2.2 Supporting families and professionals

The exact number of people with Ds in Scotland is not centrally collated and is therefore not available from any national statutory sources. This can be challenging when developing capacity and resource plans to meet potential demand. To clarify this, DSS commissioned research in 2015 and the estimate, based on established academic processes, was that there was 3,261 people at that time.

Our Family Support Service (FSS) is at the very heart of what we do and are there to support people with Ds, their families, carers and professionals from the beginning through every age and stage of life.

In addition to their work supporting efforts in the lead up to and delivery of Congress, the FSS team has continued to experience a sustained increase in requests for support. In early 2019 we appointed a full time Family Support Service Officer (FSSO) to cover South West Scotland, including Argyll and Bute, Ayrshire and Dumfries and Galloway. The addition of the new Officer to the team has enabled the Service Manager to concentrate on the management and future development of the service.

As a result of a continuing increase in the level of enquiries received, we have been reviewing how we can better manage incoming enquiries for help and advice from the FSSOs, whilst still maintaining a high level of service and support to families and carers. We are looking at changing the model of our service to provide a "triage-based" system for new incoming enquiries and providing a more proactive service to prepare families and carers for key stages ahead of them.

With the introduction of improved access to information and a triage system, the FSSOs will be able to support additional demand and dedicate more time to focus on situations where families require more intensive support. They will also have time to spend engaging and working with members of the local

DOWN'S SYNDROME SCOTLAND 2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS

branches. These groups provide a wonderful opportunity for families to come together to socialise and take part in organised activities.

The activity of the Family Support Service in line with key outcomes over the past year is as follows:

Outcome 1 - *Those families/carers supporting an adult or child with Ds are better informed on any aspect of living with Ds and their associated rights and access to services.*

Over the year, the FSS team responded to 852 parent/carer enquiries, through providing information and support via telephone, email and by visiting families at home. FSSOs have also attended meetings, in support of families, which related to the education, health and social care of their relative. 213 families were supported through ongoing, more detailed casework for complex issues.

The parents of 72 babies born during the reporting period, who contacted the FSS, received a visit from their local FSSO whilst they were in hospital or once home. New parents were also put in touch with other parent members, if this is something that they wanted. We continue to provide New Baby Packs to all maternity hospitals and screening clinics in Scotland so that new parents can contact us, if/when they wish.

"DSS are so brilliant at supporting families and we really do count ourselves incredibly lucky to be living in Scotland with Tansy."

"DSS is an amazing charity and such an amazing support to new parents what a lifeline they were and still are to me and my son. Thank you DSS."

Outcome 2 - *Professionals are better informed and are more able to support families/carers or adults with Ds appropriately.*

The FSSOs supported professionals by responding to 309 enquiries between during the year to 31 March 2019. The year figures are slightly down on the targeted figures however the last year saw a new chapter in the development of the FSS team, whereby they worked specifically on raising the profile of Ds to maternity services and health professionals in Scotland and developed a new teaching programme specifically for midwifery staff. Over the year the team delivered five teaching sessions to over 400 student midwives across Scotland and these teaching sessions are now part of the yearly programme for student midwives. This is a remarkable step forward in ensuring we are there to support professionals who are supporting parents through prenatal screening and testing and at diagnosis.

As part of the development of their training programme, the FSS also introduced new teaching sessions to HNC Additional Support Needs students at two colleges in the West of Scotland and to undergraduate and postgraduate Radiography students at the West of Scotland University. In total 42 training courses were delivered to 600+ health and education professionals across the country and it is expected that increased proactive support to professionals reduced some of the general enquiries our team receive. In addition to these developments, a number of home nation professionals attended Congress and had face-to-face access to their local FSSO who were available to answer any questions or offer support during that week.

"Your presentation was pitched perfectly for us and presented in a warm, friendly and knowledgeable way. It was very well received by my colleagues and created a good dialogue after the meeting."

"Delivery of course excellent, explained things I had no idea about, short term memory being one of them."

"I have attended a lot of training during my time employed by NHS Tayside and I can honestly say this training ranks up in the top 5 easily."

DOWN'S SYNDROME SCOTLAND 2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS

Outcome 3 - *Parents/carers of children with Ds are better informed and feel more able to support their child's learning and behavioural development.*

From April 2018 to March 2019 the FSS team delivered eight parental workshops across Scotland, providing parents with information and techniques on how to support their child's learning.

Our FSS Manager has also been working on the development of an online information platform called 'Your Hub'. Through fully utilising the information that we provide via the online Hub to ensure that we are giving timely and relevant information to parents and carers, we hope to reduce the time FSSOs spend dealing with the more straightforward enquiries at the same time as upskilling parents and providing them with easy access to information whenever they need it.

"As a new parent myself, I was at this workshop where I met Claire and Iain. DSS has been a great resource to me and my family and has allowed me to meet other parents and share experiences."

FSS Case study

Louise is a single parent and main carer for her 13 year old daughter Teegan, who has a dual diagnosis of Ds and Autistic Spectrum Disorder. Teegan has significant care needs and can be physically challenging and needs a considerable amount of high level support.

Louise first contacted the FSS in March 2015 as she was finding it difficult to manage Teegan's challenging behaviour and her input and support from social work had reduced. Louise was feeling isolated and worried about the future.

The FSSO visited Louise at home for her first visit – that was four years ago, and we have been giving support since.

The team helped with input and support on Teegan's development and gave Louise practical and emotional support to allow her to fulfil her role as Teegan's carer to her best ability.

"My Family Support Service Officer has done so much for me and Teegan in every way possible, we appreciate all she does and the time she takes to help and support us, helping us get grants so we can get a holiday, helping with Teegan to get her afterschool club paid for, helping me with my money and benefits and speaking to social work and other professionals that I really struggle with. I can't thank her enough for everything she does for us - we just love having her in our lives. I am so lucky she helped me attend the Congress, it was the best thing I have ever done. What an experience, it totally blew me away. My Family Support Service Officer told me she was proud of me for going, and I was so proud of myself too, it was a big thing for me to do on my own....but I really wanted to do it and if I had never had her in my life I wouldn't be where I am now, and I thank her from the bottom of my heart." Louise Cross

2.3 Supporting adults with Ds

Commissioners Programme

A key highlight in the 2018-19 year was the culmination of our two year Commissioners Programme. This saw the recruitment of and a development programme for a total of 20 adults with Ds who acted as leaders and facilitators (Commissioners) or volunteers at World Down Syndrome Congress in Glasgow. The Commissioners undertook a training programme to ensure that they could effectively lead on the involvement of people with Ds from around the world at Congress. They were trained and supported to undertake formal duties during the event – introducing and thanking speakers to the audience at the

DOWN'S SYNDROME SCOTLAND 2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS

beginning and end of sessions, delivering sessions about their lives in Scotland, ceremonial duties during the opening and handover ceremonies, and leading parts of the programme for people with Ds that ran during Congress.

Our three Lead Commissioners had attended the 2015 World Congress in Chennai and promoted Scotland at that event. They worked with the project staff in developing the training and recruitment materials and processes needed to ensure that a wide range of people with Ds were involved from around Scotland in the Commissioner and volunteer training programmes. In addition, they co-delivered training to over 300 hotel staff and taxi drivers in Glasgow in preparation for the influx of people with Ds in July 2018.

The Lead Commissioners were also trained and supported to participate in the organising structure of the entire Congress. This included helping to develop the programme and working with the organising Committee. This ensured that the Congress programme for people with Ds was shaped by people with Ds.

Our Commissioner training programme developed participants in a wide range of areas including effective participation and advocacy as well as specific topics around health and wellbeing, public speaking and chairing meetings. The training they undertook and the experience of utilising these new skills equipped the participants with increased confidence, life and travel skills, all of which will help to increase their employability.

This project was a strong example of how individuals with Ds can participate on the world stage as ambassadors for Scotland's Learning Disability policy, using the skills they developed to demonstrate to a world audience the capabilities and capacities of people with Ds to reach their full potential.

Finally, this work was recognised as a leading example of excellence within the global meetings industry and we were selected (along with Down Syndrome International) by an independent panel of industry experts as winners of this year's International Congress and Convention Association's Incredible Impacts Awards.

Feedback from parents/carers:

"It's all good experience, helping to build confidence, becoming familiar with different situations."

"Gave him more confidence and awareness that Down's syndrome is universal as Chris always questions why has he got 'this' Down's syndrome."

"Learned a lot of new skills, helped a lot with her confidence around meeting new friends and new people."

"Emily is so much more confident. I loved (and so did she) that she met up with other young people with Down's syndrome. I think the support they got from each other was tremendous."

"Yes. Especially the week of the congress when visibly matured and developed an independent sense of himself. His confidence was definitely improved."

"Great experience for her and she really enjoyed herself, helped with independence and confidence."

"The project was an excellent means of the young people working together with people they didn't know. The Congress was a huge step towards independence."

DOWN'S SYNDROME SCOTLAND 2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS

Life Stories

People with Ds are known to be at risk of suffering from early onset dementia. One in three people with Ds are diagnosed with a form of dementia in their 50s, with the incidence increasing to higher than two in three as individuals live into their 60s and beyond. (Hithersay et al., 2017). Working with individuals and their family member(s) before any cognitive changes develop can help to maximise memories and recall of past events.

Research demonstrates that carers are reluctant to plan ahead (Foundation for People with Learning Disabilities, 2013). Our FSS team has reported incidences where an adult with Ds has been placed in care services or received support in emergency situations (due to carer ill health or dying) where nothing is known about their life. Having a life story can not only ease challenging transitions and help the person come to terms with changes, but can also help provide a routine and have a calming effect as well as being crucial for support services to 'know the person'.

This knowledge prompted us to launch our new project for adults with Ds in September 2018. The Life Stories project is running for 12 months enabling 16 to 20 adults with Ds, over the age of 30, and their families to gather and review a life story for that individual.

The aim of this project is to support adults with Ds to develop a life story that provides a sense of identity and helps the person share their story, memories, experiences, life events, what they like and don't like, their family, friends, work, hobbies, and favourite places. The compilation of a life story can be an empowering process, helping the person to feel valued and listened to and most importantly give them 'a voice' throughout their lives.

This could be a book, memory box, photographs, tablet device, memory board, DVD/audio, sounds, poster work or a combination. The project aims to involve the whole family and will deliver 20 family group sessions on life story work across Edinburgh and Glasgow.

2.4 Supporting the development of communication skills in children and young people

Communication is such an important part of life. It is vital in developing relationships with others and also to education. Being able to communicate means that people are less likely to feel isolated or lost and can help to build confidence and self-esteem. Improvement in speech and language skills will not only enhance a child's ability to learn, but also help them integrate within their family, their peer group and wider community. Experts agree that early speech and language interventions are crucial for children with Ds.

"If interventions based on our current knowledge were implemented throughout childhood many young people with Down's syndrome would have much better speech language and cognitive skills and consequently enjoy a much-improved quality of life." Professor Sue Buckley OBE, University of Portsmouth

We continue to recognise the important role that our Achieving Better Communications (ABC) groups play in supporting the development of children and young people's communication skills and confidence.

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.

We received feedback from parents during 2018 and used this to improve the way we deliver the ABC groups. The survey highlighted that there was considerable unmet demand for the ABC programme across the country, particularly in more rural areas. To address this, we started a new group in Kilmarnock and more regional groups were established around Edinburgh and the Lothians.

DOWN'S SYNDROME SCOTLAND 2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS

The newly developed sessions are targeted to the needs of the child and individual assessments are carried out by our Speech and Language Therapist. The sessions are fun and interactive and take into account the learning profile of a child with Ds.

In the West of Scotland, we introduced a pilot of new early years sessions for children aged under three years. These sessions are also being attended by the child's parent/carer and include work on muscle development to aid with articulation and speech development as well as non-verbal communication such as signing. Group work at this early stage also helps with the development of social skills vital to aid learning, such as listening and turn taking. This work will also mean that the children are ready to enter the main ABC programme from around age three. The information recorded though working with the young children in these sessions will help the ABC Programme Co-ordinator place them in the most suitable group for their development stage. The specialist early years work carried out by the West of Scotland group will be shared with the co-workers in the other ABC group locations so as to benefit children across the whole country.

As mentioned previously, we continue to experience more demand for the service than we can currently accommodate and have interest in new groups in Inverness, Stirling and Dumfries and Galloway. If we can secure sustainable ongoing funding, we hope to have sessions in more locations in the future.

Over the past year our Speech and Language Therapist has carried out assessments, and set learning and development targets, for the 79 children who attended regular sessions through the ABC programme. As at the end of March 2019, there were 40 additional children identified as awaiting assessments and placement in the programme.

ABC case study

Callum has been attending ABC in Edinburgh for nine years.

"Callum started attending ABC's while he was at nursery. Over the years I've seen the slow but gradual improvements in aspects of his communication, and he loves attending the sessions, it's the highlight of his week. With the changes to the way the sessions are run, Callum now attends his group with two others similar in age. From a social aspect he loves the camaraderie in the group and has a lot of fun without realising that he is learning at the same time.

Lorna, who teaches the session, has a great relaxed approach that gets the most out of the group. Lorna spends time with each of the parents at the end of the session and shares skills and tips that we can do at home too so it's great that as parents we are still learning.

Now that I don't need to sit in on the sessions with Callum I enjoy catching up with the other parents and the peer to peer support that it can offer." Mum, Moira

2.5 Raising awareness and shaping national policy

Influencing and shaping policy to make a difference

A real focus for our Policy team was the involvement of people with Ds in raising awareness with policy makers, employers and service providers in Scotland. We hosted a parliamentary reception in May 2018 to publicise Congress and politicians from all parties were able to hear directly from Megan about her journey as a Commissioner.

DOWN'S SYNDROME SCOTLAND 2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS

We responded to Scottish Government consultations on:

- Social isolation and loneliness
- Employment of disabled people
- Children's rights
- Mental health support for young people
- Adult social care reform

We also contributed to consultations from the GMC (General Medical Council) about decision-making and consent and the new Scottish Social Security agency about accessibility of information including responses from adults with Ds who reviewed the information.

We worked with NHS Education for Scotland (NES) and Health Scotland on the development of the Pregnancy and Newborn Screening Standards and the NIPT (Non-Invasive Prenatal Testing) Training Education and Communication Working Group. This involvement enabled us to raise awareness and challenge inappropriate language to ensure that parents receive accurate and unbiased information during pregnancy and throughout the screening process.

As a member of the SCLD (Scottish Commission for Learning Disability) Employment Task Group we contributed to a report for the Scottish Government called, 'The Route to Employment for People with Learning Disabilities in Scotland'. This has informed the development of the Scottish Government's Keys to Life Strategy and the Fairer Scotland for Disabled People Employment Action Plan. We remain a key delivery partner for Keys to Life and were involved in the consultation for the new implementation strategy (2019-2022). This included bringing together a group of young adults with Ds to meet and share their views with the policy team.

We partnered with SCLD and other organisations again to develop 'How's Life', a new quality of life survey. This is a national survey for adults with learning disabilities across Scotland and will give people a chance to say how they feel about their life and the opportunities they have, in areas such as work, social life, housing and transport. The survey, which includes a question to identify respondents with Ds, will provide useful information that will help inform our policy work. Several of our members helped to test the survey launched in May 2019.

Raising awareness

Over the past year we completed a brand re-fresh. Working with an external graphic designer, we have redesigned our existing publications and developed a set of brand guidelines. Not only has this given us a boost in interest for our publications, it has also helped give our brand a distinct and clear look.

Congress in July 2018 saw an increase in media attention. We got some fantastic coverage, including two pieces on TV, two radio appearances and one online video. The Flag ceremony was also covered on BBC News, the front page of the Scotsman and a two-page spread in the Herald.

During the course of 2018-19, we featured in the media and mainstream press 71 times. This is an increase of 22 from 2017-18.

In the final months of 2018, our focus shifted to digital campaigns. We took part in several national and international digital campaigns, including Giving Tuesday and a new campaign by the Scottish Government 'Make Someone's Day'. These aimed to drive donations as well as providing a platform for us to raise awareness and thank supporters.

DOWN'S SYNDROME SCOTLAND 2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS

We continued to produce our bi-annual magazines, Full Potential, Limitless and Fundraising Focus. These magazines go out to our 1,175 members. The Autumn edition focused heavily on Congress, featuring photos from the event as well as reports from parents who had attended the event.

Our main activity of the year was Down's Syndrome Awareness Week. Work began on this in January 2019 when we put out a survey asking for members and supporters experiences of inappropriate language. We received 166 responses, and this informed the development of our Awareness Week campaign, 'Mind Your Language'. Analysis of the responses backed up our experiences of working with families and professionals and provided further evidence that culturally ingrained negative attitudes continue to exist and cause anger, hurt and frustration for people with Ds, their families and supporters.

Building on this, we produced a short film 'Words Matter'. The film starred four adults with Ds and highlighted that they were all individuals with different talents, interests and opinions. A strong message from the survey was that all health, social care and education professionals should be aware of the impact of the words they use and of the importance of person-first language.

"I thought the mind your language film was a positive way of raising awareness about the importance of language."

"People have to be made aware that people with Down's Syndrome are human beings just like them and deserve respect."

We were delighted to receive cross party support at the Scottish Parliament for our Awareness Week campaign in March 2019. We organised a photo shoot with the main party leaders and other MSPs, many sporting their odd socks in support of the international 'Lots of Socks' campaign to promote awareness week and raise awareness.

2.6 Establishing a vibrant community through our branch network

Members of DSS have the opportunity to become involved with their local branch. We currently have nine branches in the following regional areas:

- Aberdeen City and Shire
- Angus
- Ayrshire
- Central Scotland
- Dumfries and Galloway
- Edinburgh and Lothians
- Highlands and Islands
- Tayside and Fife
- West of Scotland

Our branches provide local contact and support to members through a range of activities and trips for both children and adults with Ds as well as social events for their parents and carers. Activities that took place during the year included Christmas parties and trips to the Pantomime, weekends away for all the family, monthly activities in their local branch areas and lots more.

Local branch committees are made up of volunteers who freely give of their time to support their local community and raise funds.

DOWN'S SYNDROME SCOTLAND 2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS

2.7 Raising funds to support our objectives

Over 60% of DSS's income is generated through fundraising and we can only do the work we do because of our supporters - the impact they make is immeasurable.

During 2018-19, our supporters came out in force to help fundraise for us and our Awareness Week was the most successful ever. We were thrilled to be the chosen charity of the year for the law firm Turcan Connell and Sainsbury's Local in Kelvinhaugh.

Our supporters again inspired us as they went that extra mile to raise much needed income for us. They gave their time, skills and energy to take part in events to support DSS. Some of the highlights included:

- Trekking 97Km across the Great Wall of China
- Participating in a 300km dog sledding challenge across Norway and Sweden
- Cycling across the Italian Alps
- Rowing from California to Honolulu
- Abseiling down the Forth Rail Bridge
- Taking part in the Kiltwalk
- Participating in our golf event
- Hosting dinners and fashion shows

We also received a legacy of almost £35,000, which will help secure future services for people with Ds.

We recognise and applaud the ongoing support of our fundraisers and have invested in our Community Fundraising Team, to enable closer working with our dedicated supporters in communities across the country.

3. PLANS FOR 2019-20

The future is exciting for DSS with the opportunity to build on the profile of Congress and the appointment of our new Chief Executive.

During the coming year we will listen to, and work with, our members to review our strategic priorities and build towards the launch of a new Strategic Framework.

Our initial key focus areas are:

- To transform our current service delivery models to improve and innovate on how we deliver our support.
- To raise the profile of the work of DSS in order that the information we provide will become more accessible to families, people with Ds and all who work to support them.
- To increase opportunities for people with Ds to develop skills, confidence, self-esteem and independence that lead to them experiencing the same opportunities in life (particularly employment, self-advocacy and independent living) as others.
- Maximise levels of sustainable funding to enable us to provide a more effective service to all people with Ds, their families and carers and professionals who work with them.
- To establish a fit for purpose infrastructure that encompasses best practice and continuous improvement.
- To become an employer of choice in the voluntary sector by building an engaged workforce, with the right skills, in the right roles to deliver the highest standards of service.

DOWN'S SYNDROME SCOTLAND 2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS

- To ensure that high quality, accurate information is available to prospective parents for the introduction of NIPT.
- To campaign on matters that affect people with Ds and their families.

4. RISKS AND UNCERTAINTIES

The Board of Trustees and the Finance and Risk Sub Committee regularly review and assess the major risks to which the charity is exposed. Systems and control measures are in place for the Senior Management Team to monitor and mitigate these risks. Key potential risk areas highlighted in the Strategic Risk Register include:

- Failure to adequately protect vulnerable individuals
- Drop in income
- Ineffective organisational structure and staff/volunteer management practices
- Inadequate procedures, systems and internal controls
- Non-compliance with legislation and regulations

Our delivery plans for 2019-20 outlined above encompass effective plans and strategies for managing these risks.

5. FINANCIAL REVIEW

Income and expenditure

For the year ended 31 March 2019, DSS is reporting net expenditure of £316,150 (2018: net income of £138,716) resulting in a reduction in funds of £279,001 (2018: increase of £139,857) after pension deficit remeasurement gains.

2018-19 was dominated by the hosting of the World Down's Syndrome Congress in Glasgow which alone represents net expenditure of £237,647 for the financial year, with income of £379,143 and expenditure totalling £616,790 including a share of DSS staff costs. Reserves were in place to cover this exceptional event, although actual net expenditure was higher than anticipated following lower income from delegate places than expected as well as more involvement of DSS staff in running and managing Congress.

Congress aside, income from fundraising and ongoing charitable activities amounted to £917,241 in 2018-19. Of this, funds raised from community fundraising, events, individual and corporate donations, legacies and membership fees totalled £343,632. The Scottish Government contributed £265,000 for our family support and ABC services as well as core costs, with a further £236,834 raised from other grants and trusts. Income from ongoing charitable activities, including specialist training, consultations and ABC sessions run by our staff, brought in £43,806. The remaining £27,969 was mainly generated from our investment property and sales of merchandise.

The following charitable trusts, foundations and other grant-giving funders (in alphabetical order) contributed to our income in 2018-19:

Alexander Moncur Trust	AM Pilkington Charitable Trust
Andrew Paton's Charitable Trust	Big Lottery Improving Lives Fund
Children's Aid Scotland	Cruden Foundation
David Solomons Trust	Martin Connell Charitable Trust
MEB Charitable Trust	Miss Agnes H Hunter Trust
Miss B W Muirhead Charitable Trust	Miss Caroline Jane Spence's Fund
National Down Syndrome Society	PF Charitable Trust

DOWN'S SYNDROME SCOTLAND 2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS

Saints and Sinners Club of Scotland	Scottish Government
Scottish Government (CYPFEI and ALEC Funds)	Souter Charitable Trust
St James's Place Charitable Foundation	Templeton Goodwill Trust
The AMW Charitable Trust	The Corra Foundation
The Enzo Londei Trust	The Nancie Massey Charitable Trust
The Hospital Saturday Fund	The Robertson Trust
The Northwood Charitable Trust	University of Strathclyde
The RS Macdonald Charitable Trust	

In addition, generous donations and sponsorship were from the following businesses:

Best Western Palace Hotel and Spa Inverness	EDF Energy plc
Glasgow Life	J W Filshill Ltd
PDI	Safestore
Sainsbury's Local Kelvinhaugh	Seven Incorporated Trades of Aberdeen
Totalize Media	Turcan Connell
Visit Scotland	

Expenditure for 2018-19 excluding Congress totalled £995,744. Of this, £777,199 was spent running ongoing services and projects and £218,545 was incurred raising funds. Included in these cost totals are central support costs of £314,895 and governance costs in running the charity of £36,507. Further details of expenditure are available in notes 7 and 8 of the financial statements.

Reserves

As at 31 March 2019, DSS had funds totalling £373,605. Of these, £56,236 are restricted for specific services and projects. Unrestricted funds totalled £317,369, with £181,491 relating to fixed assets and £72,719 held for the nine branches across Scotland. The remaining £63,159 represents general reserves following the significant deficit reported for 2018-19.

The Finance and Risk Sub Committee regularly monitors and reviews the level of reserves and cash, aiming to hold available funds at an acceptable level in order to maintain continuity of existing services and operations. The Trustees currently endeavour to retain funds (excluding those relating to fixed assets) to cover at least three months annual operating expenditure. This Reserves Policy is reviewed annually by the Board and adjusted as appropriate. As at 31 March 2019, total funds (excluding those relating to fixed assets) represented just over two months total expenditure for 2018-19 (excluding costs relating to Congress). The Trustees are reviewing fundraising strategies, operating costs, and other options available to them to ensure the Reserves Policy can be met at future financial year ends.

6. STRUCTURE, GOVERNANCE AND MANAGEMENT

DSS is a registered charity and company limited by guarantee and is governed by its Memorandum and Articles of Association dated 13 November 2010. Its members are interested individuals, families and professionals. Individuals with Ds aged 16 and over are awarded Life Membership. All members are entitled to one vote at Annual General Meetings.

Board of Trustees

DSS has a Board of Trustees which is responsible for overall governance of the charity. For the purposes of company law, the Trustees are also Directors. The Trustees who served during the year are listed on page 2 of this document. Further information on each Trustee is available on our website.

DOWN'S SYNDROME SCOTLAND 2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS

There must be at least three Trustees on the Board up to a maximum of twelve. Up to nine trustees are elected by and from members and up to three can be appointed by the Board on the basis that he/she has specialist experience and/or skills that could be of assistance to the Board. Potential candidates are interviewed by the Board Nominations Sub Committee before their appointment is approved by the full Board. New Trustees go through an induction process with both existing Trustees and Senior Management upon joining the Board.

All Trustees must be members and are elected at the Annual General Meeting following their appointment. Trustees are entitled to hold office for three years and are then eligible for re-election for a further three year period. The maximum period each Trustee can serve is nine years unless agreed otherwise by the Trustees.

Trustees hold regular meetings throughout the year covering strategic planning and performance, financial reporting, risk management, fundraising, and key policies as well as regular updates on each area of activity. All Senior Management attend these regular meetings of the Board.

Board Sub Committees

The Board delegates some of its responsibilities to three Sub Committees, each made of up at least three Directors. Each Committee has agreed Terms of Reference and exists to consider, advise and make recommendations to the Board on their specific area. Minutes of all meetings are submitted to the full Board.

<i>Sub Committee</i>	<i>Area</i>
Finance and Risk	All aspects of the charity's finances, risks, financial policies, controls and strategy including regular review of budgets, management accounts and cash flows
Nominations	Board, Chief Executive and Senior Management Team appointments
Remuneration	Remuneration and Benefits policy for all staff and remuneration, benefits and other terms of employment of the Chief Executive and Senior Management Team

Executive Management

The Chief Executive has overall responsibility for the day to day management of DSS and for implementing strategies and policies agreed by the Board. The Chief Executive is supported by the Head of Operations, Family Support Service Manager, Fundraising Manager and Finance Consultant, together making up the Senior Management Team. The Remuneration Sub Committee reviews and approves individual pay awards for the Chief Executive and Senior Management Team members as well as cost of living pay awards for all staff. At 31 March 2019, there were 31 members of staff in total (21.7 full time equivalent).

7. TRUSTEES' RESPONSIBILITIES STATEMENT

The Trustees (who are also Directors for the purposes of Company Law) are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

DOWN'S SYNDROME SCOTLAND 2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS

Company Law requires the Board of Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing these financial statements, the Board of Trustees is required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP 2015 (FRS 102);
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK accounting standards have been followed subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in operation.

The Board of Trustees is responsible for keeping proper accounting records and disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006 (as amended). The Board of Trustees is also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the Trustees are aware:

- there is no relevant audit information of which the charitable company's auditor is unaware; and
- the Trustees have taken all relevant steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

This report has been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies.

Approved by the Board of Trustees and signed on its behalf by:

Stuart Macintyre
Chairperson

James Batchelor
Trustee

9 September 2019

**DOWN'S SYNDROME SCOTLAND
2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS**

INDEPENDENT AUDITORS' REPORT TO THE TRUSTEES AND MEMBERS OF DOWN'S SYNDROME SCOTLAND

Opinion

We have audited the financial statements of Down's Syndrome Scotland (the 'charitable company') for the year ended 31 March 2019 which comprise the Statement of Financial Activities, the Balance Sheet, the Statement of Cashflows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2019, and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the Trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charitable company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

**DOWN'S SYNDROME SCOTLAND
2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS**

INDEPENDENT AUDITORS' REPORT TO THE TRUSTEES AND MEMBERS OF DOWN'S SYNDROME SCOTLAND (continued)

Other information

The Trustees are responsible for the other information. The other information comprises the information included in the Trustees' annual report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' report for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Trustees' report has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of our knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 require us to report to you if, in our opinion:

- adequate and proper accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of Trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the Trustees were not entitled to prepare the financial statements in accordance with the small companies' regime and take advantage of the small companies' exemptions in preparing the trustees' report and from the requirement to prepare a strategic report.

**DOWN'S SYNDROME SCOTLAND
2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS**

INDEPENDENT AUDITORS' REPORT TO THE TRUSTEES AND MEMBERS OF DOWN'S SYNDROME SCOTLAND (continued)

Responsibilities of trustees

As explained more fully in the Trustees' Responsibilities Statement, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

We have been appointed as auditor under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with regulations made under those Acts.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Use of report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006, and to the charitable company's Trustees, as a body, in accordance with Regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members and Trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company, the charitable company's members as a body and the charitable company's Trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Paul Marshall

Senior Statutory Auditor

For and on behalf of Geoghegans, Statutory Auditor

6 St Colme Street, Edinburgh, EH3 6AD

9 September 2019

Geoghegans is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

**DOWN'S SYNDROME SCOTLAND
2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS**

STATEMENT OF FINANCIAL ACTIVITIES

Scottish company number: SC356717

(including Income and Expenditure Account)

For the year ended 31 March 2019

	Note	2019 Unrestricted £	2019 Restricted £	2019 Total £	2018 Total Restated £
INCOME					
Donations and legacies	3	502,057	343,409	845,466	898,239
Trading activities	4	14,398	-	14,398	9,103
Investment income	5	13,571	-	13,571	13,722
<i>Income from charitable activities:</i>	6				
World Down Syndrome Congress		-	379,143	379,143	131,500
Ongoing charitable activities		12,852	30,954	43,806	34,385
		<u>542,878</u>	<u>753,506</u>	<u>1,296,384</u>	<u>1,086,949</u>
EXPENDITURE					
Cost of raising funds	7	(218,545)	-	(218,545)	(191,453)
<i>Cost of charitable activities:</i>					
World Down Syndrome Congress	7	(217,612)	(399,178)	(616,790)	(112,042)
Ongoing charitable activities	7	(352,910)	(424,289)	(777,199)	(644,738)
		<u>(789,067)</u>	<u>(823,467)</u>	<u>(1,612,534)</u>	<u>(948,233)</u>
Net (expenditure)/income		(246,189)	(69,961)	(316,150)	138,716
Other recognised gains/(losses):					
Remeasurement gains on defined benefit pension scheme deficit	13	37,149	-	37,149	1,141
Net movement in funds		(209,040)	(69,961)	(279,001)	139,857
Funds brought forward	15	526,409	126,197	652,606	512,749
Funds carried forward	15	<u>317,369</u>	<u>56,236</u>	<u>373,605</u>	<u>652,606</u>

The Statement of Financial Activities includes all gains and losses in the year. All income and expenditure derive from continuing activities.

**DOWN'S SYNDROME SCOTLAND
2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS**

BALANCE SHEET
As at 31 March 2019

Scottish company number: SC356717

	<i>Note</i>	2019 £	2018 Restated £
Fixed assets			
Tangible assets	10	56,491	41,053
Investment property		<u>125,000</u>	<u>125,000</u>
		181,491	166,053
Current assets			
Stock		4,942	-
Debtors	11	53,635	83,423
Cash at bank and in hand		<u>265,297</u>	<u>567,735</u>
		323,874	651,158
Creditors: amounts falling due within one year	12	<u>(85,262)</u>	<u>(75,970)</u>
Net current assets		<u>238,612</u>	<u>575,188</u>
Total assets less current liabilities		420,103	741,241
Creditors: amounts falling due after more than one year:			
Property dilapidation provision		<u>(10,000)</u>	<u>(10,000)</u>
Net assets excluding pension liability		410,103	731,241
Defined benefit pension scheme liability	13	<u>(36,498)</u>	<u>(78,635)</u>
Net assets		<u>373,605</u>	<u>652,606</u>
The funds of the charity:			
Restricted funds	15	56,236	126,197
Unrestricted funds			
General	15	63,159	218,650
Designated	15	<u>254,210</u>	<u>307,759</u>
		<u>373,605</u>	<u>652,606</u>

These financial statements have been prepared in accordance with the special provisions relating to small companies within Part 15 of the Companies Act 2006.

The financial statements were approved by the Trustees on 9 September 2019.

Stuart Macintyre, Chairperson

James Batchelor, Trustee

The notes on pages 25 to 36 form part of these financial statements.

**DOWN'S SYNDROME SCOTLAND
2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS**

**STATEMENT OF CASH FLOWS
For the year ended 31 March 2019**

Scottish company number: SC356717

	2019 £	2018 Restated £
Cash flows from operating activities:		
Net cash (used in)/provided by operating activities	(289,976)	99,998
Cash flows from investing activities:		
Rent received	12,000	12,000
Bank interest received	1,571	1,191
Payments to acquire tangible assets	(26,350)	(3,748)
Receipts from disposal of tangible assets	317	-
Net cash flow used in investment activities	(12,462)	9,443
Change in cash and cash equivalents in the year	(302,438)	109,441
Cash and cash equivalents at the beginning of the year	567,735	458,294
Cash and cash equivalents at the end of the year	265,297	567,735

Reconciliation of net (expenditure)/income to net cash flow from operating activities

	2019 £	2018 Restated £
Net (expenditure)/income for the year	(316,150)	138,716
Adjustments for:		
Depreciation during year	8,403	7,328
Loss on disposal of tangible assets	2,192	-
Remeasurement gains on defined benefit pension scheme deficit	37,149	1,141
Rent received	(12,000)	(12,000)
Bank interest received	(1,571)	(1,191)
Increase in stock	(4,942)	-
Decrease/(increase) in debtors	29,788	(33,997)
(Decrease)/increase in creditors	(32,845)	1
Net cash (used in)/provided by operating activities	(289,976)	99,998

**DOWN'S SYNDROME SCOTLAND
2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS**

NOTES TO THE FINANCIAL STATEMENTS

1. Accounting policies

1.1 Basis of preparation

The financial statements for Down's Syndrome Scotland (the charity) have been prepared under the historical cost convention and in accordance with the Companies Act 2006, the Charities Accounts (Scotland) Regulations 2006 (as amended) and Accounting and Reporting by Charities Statement of Recommended Practice applicable to charities preparing their financial statements in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014, the Financial Reporting Standards applicable in the UK and Republic of Ireland (FRS 102) as read with the update bulletin entitled "Charities SORP RFS 102 Update Bulletin 1" published on 2 February 2016. The charity meets the definition of a public benefit entity under FRS 102.

The financial statements are prepared on a going concern basis and all operations are continuing. The Trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern. The financial statements include the results of the charity's nine branches.

1.2 Prior year restatements

The financial statements of the prior year have been adjusted to correct the allocation of costs between unrestricted and restricted funds. This adjustment changes the brought forward split of funds between restricted and unrestricted (general and designated), but has no impact on the overall value. A reconciliation of the balances is set out below:

	Restricted	General	Designated	Total
At 31 March 2018:	£	£	£	£
Reserves as previously stated	181,406	288,441	182,759	652,606
Reallocation of costs in 2017-18	(55,209)	55,209	-	-
Transfers	-	(125,000)	125,000	-
Restated reserves	126,197	218,650	307,759	652,606

1.3 Income

Income is recognised when the charity has entitlement to the funds, when it is probable that the income will be received and the amount can be measured reliably. Income, including donations, legacies and grants, are recognised in the period in which they are receivable, which is when the charity becomes entitled to the resource. Income generated by individuals and groups who fundraise on behalf of the charity is recognised in the period in which it is received by the charity.

Trading income includes Christmas card and other merchandise sales, which are recognised when the charity has sold the goods and is therefore entitled to the income. Investment income is made up of rent and interest receivable, and is recognised in the period when receivable and the amount can be measured reliably by the charity. Income from charitable activities which includes charges for training and consultations are recognised when the charity has delivered the session and is therefore entitled to the funds, receipt is probable and the income can be reliably measured.

1.4 Expenditure recognition

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required, and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and includes any irrecoverable VAT.

Charitable expenditure includes those direct costs incurred by the charity in the delivery of its activities, as well as those of an indirect nature which are necessary to support them. Support costs include central function costs and

DOWN'S SYNDROME SCOTLAND 2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS

have been allocated to activity categories on the basis consistent with the use of resources ie with reference to staff salary costs. Governance costs, which are those associated with meeting the constitutional and statutory requirements of the charity such as the statutory audit and the strategic management of the charity, are allocated to activity categories on the same basis.

Rentals payable under operating leases are charged on a straight line basis over the lease term.

1.5 Pension schemes

The charity operates a group personal pension scheme on a defined contribution basis. Contributions payable are charged to the Statement of Financial Activities in the period to which they relate.

The charity is also a member of the Scottish Voluntary Sector Pension Scheme which is a multi-employer defined benefit scheme. This Scheme closed to future accrual on 31 March 2010. It is not possible to confirm the charity's share of the underlying assets and liabilities of the Scheme. This Scheme is currently in deficit and a deficit funding arrangement is in place with the charity involving monthly payments. The net present value of the deficit reduction contributions payable under the arrangement is reflected as a liability on the balance sheet and movements in the net present value of this liability in each year are charged or credited through the Statement of Financial Activities.

1.6 Tangible fixed assets and depreciation

Tangible fixed assets costing more than £500 are capitalised and are stated at cost less depreciation. Depreciation is provided at rates calculated to write off the cost, less their estimated residual value, over their expected useful lives on the following bases:

<i>Category</i>	<i>Basis</i>	<i>%</i>
Fixtures and fittings	Straight line	10
Tenants improvements	Straight line (lease term)	10
Office equipment	Straight line	25

1.7 Investment properties

Investment properties are measured at fair value with any changes in the year reported in other recognised gains/(losses) in the Statement of Financial Activities. The Trustees have assessed the fair value as at 31 March 2019 and do not consider there is any significant change to the fair value in the year.

1.8 Stock

Stocks of goods purchased for resale are stated at the lower of cost and net realisable value.

1.9 Debtors

All debtors are recognised at the settlement amount due and prepayments are valued at the amount prepaid.

1.10 Cash at bank

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

1.11 Creditors

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discount due.

**DOWN'S SYNDROME SCOTLAND
2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS**

1.12 Funds

All income and expenditure is dealt with through the Statement of Financial Activities. Funds are classified as restricted funds, unrestricted funds or designated funds, defined as follows:

- Restricted funds are funds subject to specific conditions which may be declared by the donor or with their authority (eg by the restrictive wording of an appeal).
- Unrestricted funds are expendable at the discretion of the Trustees in furtherance of the objects of the charity.
- Designated funds are unrestricted funds that have been earmarked by the Trustees for a specific purpose.

2. Taxation

The charity is exempt from tax on income and gains to the extent that these are applied to its charitable purposes. No tax charges have arisen in the charity in the year.

3. Income from donations and legacies

	2019	2019	2019	2018 Total
	Unrestricted	Restricted	Total	Restated
	£	£	£	£
Scottish Government Grants	150,000	115,000	265,000	214,206
Other grants and trusts	14,000	222,834	236,834	278,577
Community fundraising and events	173,290	5,050	178,340	218,891
Individual and corporate donations	94,828	525	95,353	86,683
Legacies	34,713	-	34,713	75,839
Branch fundraising activities	25,171	-	25,171	14,544
Membership subscriptions	10,055	-	10,055	9,499
	<u>502,057</u>	<u>343,409</u>	<u>845,466</u>	<u>898,239</u>

Income from donations and legacies in 2018 was £898,239 of which £533,502 was unrestricted and £364,737 was restricted.

4. Trading activities

	2019	2019	2019	2018 Total
	Unrestricted	Restricted	Total	Restated
	£	£	£	£
Other merchandise sales	7,360	-	7,360	913
Christmas card sales	7,038	-	7,038	8,190
	<u>14,398</u>	<u>-</u>	<u>14,398</u>	<u>9,103</u>

Income from trading activities in 2018 of £9,103 was all unrestricted.

5. Investment income

	2019	2019	2019	2018
	Unrestricted	Restricted	Total	Total
	£	£	£	£
Rent receivable	12,000	-	12,000	12,531
Bank interest	1,571	-	1,571	1,191
	<u>13,571</u>	<u>-</u>	<u>13,571</u>	<u>13,722</u>

Income from investments in 2018 of £13,722 was all unrestricted.

**DOWN'S SYNDROME SCOTLAND
2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS**

6. Income from charitable activities

	2019 Unrestricted £	2019 Restricted £	2019 Total £	2018 Total Restated £
World Down Syndrome Congress	-	379,143	379,143	131,500
Training, consultations and ABC sessions	-	25,268	25,268	17,901
Caravan and other income	7,110	5,686	12,796	12,050
Branch activities	5,742	-	5,742	4,434
Ongoing charitable activities	12,852	30,954	43,806	34,385

Income from charitable activities in 2018 was £34,385 of which £16,484 was unrestricted and £17,901 was restricted.

7. Analysis of total expenditure

	Direct costs £	Support costs £	Governance costs £	2019 Total £	2018 Total Restated £
Cost of raising funds	153,129	58,619	6,797	218,545	191,453
Cost of charitable activities					
World Down Syndrome Congress	584,175	29,227	3,388	616,790	112,042
<i>Ongoing charitable activities:</i>					
Supporting families and professionals	200,587	86,251	9,999	296,837	241,190
Raising awareness and influencing policy	107,068	53,335	6,183	166,586	144,205
Developing communication skills	106,783	49,602	5,751	162,136	116,523
Supporting adults with Ds	77,753	37,861	4,389	120,003	117,034
Branch activities	31,637	-	-	31,637	25,786
	523,828	227,049	26,322	777,199	644,738
	1,261,132	314,895	36,507	1,612,534	948,233

Expenditure on raising funds of £218,545 in 2019 (2018: £191,453) was all unrestricted. Expenditure on charitable activities in total was £1,393,989 (2018: £756,780) of which £570,522 (2018: £158,003) was unrestricted and £823,467 (2018: £598,777) was restricted.

Both support and governance costs have been apportioned to charitable activities on the basis of salary costs for each activity. Support costs enable the activities set out above to be carried out and include senior staff costs (not directly allocated to activities or governance), finance, PR, and administrative staff, IT, HR and payroll support, and other costs incurred in running head office and support functions. An analysis of material categories of expenditure included within support costs is shown below:

**DOWN'S SYNDROME SCOTLAND
2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS**

7. Analysis of total expenditure (continued)

	2019	2018
	£	Restated £
Head office staff and related costs	157,248	110,345
Property	69,679	79,565
IT and communications	37,995	32,404
Office administration	24,800	19,910
Professional fees	13,062	14,136
Fixed assets depreciation and losses on disposal	10,595	7,328
Interest expense (re pension deficit)	1,516	1,435
	<u>314,895</u>	<u>265,123</u>

8. Governance costs

	2019	2018
	£	£
Senior management	28,977	10,500
Audit fee	5,000	4,850
Board meetings	2,473	602
Directors' expenses	57	210
	<u>36,507</u>	<u>16,162</u>

9. Staff costs

	2019	2018
	£	£
Wages and salaries	585,832	493,035
Social security costs	40,842	36,885
Pensions	27,418	21,642
	<u>654,092</u>	<u>551,562</u>

During the year, the average head count was 28.5 equating to 20.6 full time equivalent (2018: 17.9 full time equivalent).

There were no employees who received employee benefits of more than £60,000 (2018: nil). The total amount of employee benefits remunerated to key management personnel for the year was £232,377 (2018: £182,852). The charity considers that its key management personnel are the members of the Senior Management Team. 2018 included only two months of the new Family Support Service Manager role and ten months of the new Head of Operations.

None of the Trustees received any remuneration. During the year, a total of £57 (2018: £210) was paid to one Trustee (2018: two Trustees) in respect of reimbursement of travel expenses.

**DOWN'S SYNDROME SCOTLAND
2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS**

10. Tangible fixed assets

	Fixtures and fittings £	Tenants improvements £	Office Equipment £	2019 Total £
Cost				
As at 1 April 2018	20,050	29,626	71,873	121,549
Additions	-	-	26,350	26,350
Disposals	(6,408)	-	(4,893)	(11,301)
As at 31 March 2019	<u>13,642</u>	<u>29,626</u>	<u>93,330</u>	136,598
Depreciation				
As at 1 April 2018	7,155	5,926	67,415	80,496
Charge for the year	1,364	2,963	4,076	8,403
Disposals	(4,428)	-	(4,364)	(8,792)
As at 31 March 2019	<u>4,091</u>	<u>8,889</u>	<u>67,127</u>	80,107
Net book value as at 31 March 2019	<u>9,551</u>	<u>20,737</u>	<u>26,203</u>	<u>56,491</u>
Net book value as at 31 March 2018	<u>12,895</u>	<u>23,700</u>	<u>4,458</u>	<u>41,053</u>

11. Debtors

	2019 £	2018 £
Sundry debtors	21,250	61,444
Prepayments	32,385	21,979
	<u>53,635</u>	<u>83,423</u>

12. Creditors: amounts falling due within one year

	2019 £	2018 £
Sundry creditors	42,775	19,618
Accruals	40,491	49,752
Deferred income	1,996	6,600
	<u>85,262</u>	<u>75,970</u>

The movement on deferred income in the year is analysed as follows:

	2019 £	2018 £
As at 1 April 2018	6,600	-
Less: released to Caravan income	(6,600)	-
Add: refundable amounts received in advance relating to caravan and events	1,996	6,600
As at 31 March 2019	<u>1,996</u>	<u>6,600</u>

DOWN'S SYNDROME SCOTLAND 2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS

13. Pension commitments

Defined contribution pension arrangements

The charity operates a group personal pension scheme on a defined contribution basis. During the year, employee contributions were a minimum of 3% of pensionable salaries (2018: 1%), matched by employer contributions up to a maximum of 4% of pensionable salaries. Employer pension contributions payable in the year were £27,418 (2018: £21,642). The amount included within creditors at the year end is £4,204 (2018: £12).

Defined benefit pension arrangements

The charity participates in the Scottish Voluntary Sector Pension Scheme, a multi-employer scheme which provides benefits to some 102 non-associated employers. The scheme is a defined benefit scheme in the UK. It is not possible for the charity to obtain sufficient information to enable it to account for the scheme as a defined benefit scheme. Therefore it accounts for the scheme as a defined contribution scheme.

The scheme is subject to the funding legislation outlined in the Pensions Act 2004 which came into force on 30 December 2005. This, together with documents issued by the Pensions Regulator and Technical Actuarial Standards issued by the Financial Reporting Council, set out the framework for funding defined benefit occupational pension schemes in the UK.

The scheme is classified as a 'last-man standing arrangement'. Therefore the charity is potentially liable for other participating employers' obligations if those employers are unable to meet their share of the scheme deficit following withdrawal from the scheme. Participating employers are legally required to meet their share of the scheme deficit on an annuity purchase basis on withdrawal from the scheme.

A full actuarial valuation for the scheme was carried out with an effective date of 30 September 2017. This actuarial valuation was certified on 19 December 2018 and showed assets of £120.0m, liabilities of £145.9m and a deficit of £25.9m. To eliminate this funding shortfall, the Trustee and the participating employers have agreed that additional contributions will be paid, in combination from all employers, to the scheme as follows:

From 1 April 2019 to 30 September 2026: £1.5m per annum
(payable monthly and increasing by 3% each on 1 April)

From 1 April 2019 to 31 March 2024: £82,000 per annum
(payable monthly and increasing by 3% each on 1 April)

Note that the scheme's previous valuation was carried out with an effective date of 30 September 2014. This valuation showed assets of £88.2m, liabilities of £122.1m and a deficit of £33.9m. To eliminate this funding shortfall, the Trustee asked the participating employer to pay additional contributions of £1.3m per annum, increasing by 3% each 1 April until 31 October 2029.

The recovery plan contributions are allocated to each participating employer in line with their estimated share of the scheme liabilities. Unless a concession has been agreed with the Trustee, the term to 30 September 2026 applies.

Where the scheme is in deficit and where the charity has agreed to a deficit funding arrangement, the charity recognises a liability for this obligation. The amount recognised is the net present value of the deficit reduction contributions payable under the agreement that relates to the deficit. The present value is calculated using the discount rate detailed in these disclosures. The unwinding of the discount rate is recognised as a finance cost.

**DOWN'S SYNDROME SCOTLAND
2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS**

13. Pension commitments (continued)

Present values of liability

	31 March 2019 £	31 March 2018 £	31 March 2017 £
Present value of liability	36,498	78,635	84,665

Reconciliation of opening and closing liability

	2019 £	2018 £
Liability at start of year	78,635	84,655
Unwinding of the discount factor (interest expense)	1,516	1,435
Deficit contribution paid	(6,504)	(6,314)
Re-measurements - impact of any change in assumptions	736	(1,141)
Re-measurements – amendments to the contribution schedule	(37,885)	-
Liability at end of year	36,498	78,635

Income and expenditure impact

	2019 £	2018 £
Interest expense	1,516	1,435
Re-measurements - impact of any change in assumptions	736	(1,141)
Re-measurements – amendments to the contribution schedule	(37,885)	-
Net (gain)/cost	(35,633)	294

Assumptions

	2019 % per annum	2018 % per annum	2017 % per annum
Rate of discount	1.46	2.01	1.76

The discount rates shown above are the equivalent single discount rates which, when used to discount the future recovery plan contributions due, would give the same result as using a full AA corporate bond yield curve to discount the same recovery plan contributions.

14. Financial commitments

At 31 March 2019, future lease payments under non-cancellable operating leases are as follows:

	2019 £	2018 Restated £
Within one year	39,699	39,699
In the second to fifth years inclusive	82,976	122,675
	122,675	162,374

**DOWN'S SYNDROME SCOTLAND
2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS**

15. Movement on funds

	Balance at 1 April 2018 Restated £	Income £	Expenditure £	Other recognised gains £	Transfers during year £	Balance at 31 March 2019 £
Restricted funds						
Family Support Service	60,500	139,786	(164,786)	-	-	35,500
Communication skills	500	71,246	(56,696)	-	-	15,050
Commissioners	33,714	40,686	(68,714)	-	-	5,686
Congress	20,035	379,143	(399,178)	-	-	-
Learning Hub	11,448	37,645	(49,093)	-	-	-
Policy	-	45,000	(45,000)	-	-	-
Life Stories	-	40,000	(40,000)	-	-	-
Total restricted	126,197	753,506	(823,467)	-	-	56,236
Unrestricted funds						
General	218,650	511,966	(697,430)	37,149	(7,176)	63,159
<i>Designated:</i>						
Investment property	125,000	-	-	-	-	125,000
Tangible assets	41,053	-	-	-	15,438	56,491
Branches	71,706	30,912	(31,637)	-	1,738	72,719
Congress	60,000	-	(60,000)	-	-	-
Capital renewal	10,000	-	-	-	(10,000)	-
Total designated	307,759	30,912	(91,637)	-	7,176	254,210
Total unrestricted	526,409	542,878	(789,067)	37,149	-	317,369
TOTAL FUNDS	652,606	1,296,384	(1,612,534)	37,149	-	373,605

**DOWN'S SYNDROME SCOTLAND
2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS**

15. Movement on funds (continued)

	Balance at 1 April 2017 £	Income £	Expenditure Restated £	Other recognised gains £	Transfers during year £	Balance at 1 April 2018 Restated £
Restricted funds						
Family Support Service	93,392	156,540	(189,432)	-	-	60,500
Communication skills	22,783	94,240	(116,523)	-	-	500
Commissioners	44,588	48,529	(59,403)	-	-	33,714
Congress	3,865	81,500	(65,330)	-	-	20,035
Learning Hub	-	41,045	(29,597)	-	-	11,448
Policy	-	45,000	(45,000)	-	-	-
Friends Connect	46,208	-	(46,208)	-	-	-
Core Communications	-	47,284	(47,284)	-	-	-
Total restricted	210,836	514,138	(598,777)	-	-	126,197
Unrestricted funds						
General	168,765	553,833	(323,670)	1,141	(181,419)	218,650
<i>Designated:</i>						
Investment property	-	-	-	-	125,000	125,000
Tangible assets	44,634	-	-	-	(3,581)	41,053
Branches	78,514	18,978	(25,786)	-	-	71,706
Congress	10,000	-	-	-	50,000	60,000
Capital renewal	-	-	-	-	10,000	10,000
<i>Total designated</i>	133,148	18,978	(25,786)	-	181,419	307,759
Total unrestricted	301,913	572,811	(349,456)	1,141	-	526,409
TOTAL FUNDS	512,749	1,086,949	(948,233)	1,141	-	652,606

DOWN'S SYNDROME SCOTLAND 2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS

15. Movement on funds (continued)

Purpose of restricted funds:

Family Support Service – this core service received restricted funding from the Scottish Government, Big Lottery Improving Lives Fund, The Robertson Trust and 12 other trusts as well as charges for specialist training and consultations.

ABC (Achieving Better Communications) – this core service received restricted funding from the Scottish Government, St James's Place Charitable Foundation and two other trusts as well as fees for sessions attended.

Commissioners – Funding was received from the Scottish Government to fund a project to support up to 24 adults with Down's Syndrome to play an active role in the World Down's Syndrome Congress in Glasgow in 2018. In addition, funds were awarded from Down Syndrome International for the charity to advise on the role of Commissioners for the next World Congress.

Congress – For the 2018 World Down's Syndrome Congress, income was generated from delegate fees, event ticket sales and corporate sponsorship, Scottish Government funding and a number of other grants.

Learning Hub - Funding received from the Scottish Government (CYPFEI and ALEC Funds) via the Corra Foundation for the development of an online learning hub. The hub will provide support and information to parents and carers on the learning, social and behavioural development of a child with Down's syndrome.

Policy – this core area received restricted funding from the Scottish Government (CYPFEI and ALEC Funds) via the Corra Foundation.

Life Stories – funding received from the RS Macdonald Charitable Trust for the 12 month project supporting 16 to 20 adults with Down's syndrome over the age of 30 and their families to gather and review their life story.

Friends Connect – This project was funded by the Big Lottery Fund from August 2015 to July 2018 to support 59 adults with Down's syndrome to develop and maintain friendships.

Core Communications – Funding was received from The Hugh Fraser Foundation in 2017-18 towards the costs of the Communications Officer.

Purpose of designated funds:

Investment property - represents unrestricted reserves invested in investment property.

Tangible assets – represents unrestricted reserves invested in tangible assets.

Branches - Funds held on behalf of the nine branches.

Congress - Funds set aside for the World Down's Syndrome Congress held in Glasgow in July 2018.

Capital renewal – Funds previously set aside to replace assets at the end of their working life.

**DOWN'S SYNDROME SCOTLAND
2018-19 TRUSTEES' REPORT AND FINANCIAL STATEMENTS**

16. Analysis of net assets between funds

	Fixed assets £	Net current assets £	Long term liabilities £	Pension scheme liability £	As at 31 March 2019 £
Restricted funds	-	56,236	-	-	56,236
Unrestricted general funds	-	109,657	(10,000)	(36,498)	63,159
Unrestricted designated funds	181,491	72,719	-	-	254,210
	<u>181,491</u>	<u>238,612</u>	<u>(10,000)</u>	<u>(36,498)</u>	<u>373,605</u>

	Fixed assets £	Net current assets £	Long term liabilities £	Pension scheme liability £	As at 31 March 2018 Restated £
Restricted funds	-	126,197	-	-	126,197
Unrestricted general funds	-	307,285	(10,000)	(78,635)	218,650
Unrestricted designated funds	166,053	141,706	-	-	307,759
	<u>166,053</u>	<u>575,188</u>	<u>(10,000)</u>	<u>(78,635)</u>	<u>652,606</u>

17. Related party transactions

Alan Cunningham was appointed as a Trustee on 10 January 2019. From this date until the year end, the charity paid £3,750 for social media services to Totalize Media Ltd, a company of which he and his wife are directors. There were no related party transactions in 2018.