## DOWN'S SYNDROME SCOTLAND

**Trustees' Report and Financial Statements** 

For the year ended 31 March 2024

Scottish Charity Number SC011012

Scottish Company Number SC356717

## **CHARITY INFORMATION**

Trustees	Andrea Tonner	Chairperson (appointed 25 November 2023)		
	Stuart Macintyre	(resigned 25 November 2023)		
	Patricia Jackson OBE	Vice Chairperson		
	Rob Molan James Batchelor	Treasurer		
	Jamie Blackport Aidan McEvoy	Resigned 3 June 2024		
	Katrina Leese	Appointed 12 April 2023		
	Amy Dalrymple Andrea Nolan OBE	Appointed 30 May 2023 Appointed 30 May 2023		
Company Secretary	Michael Cunningham Laura Wright	Appointed 23 May 2023 Resigned 23 May 2023		
Senior Management Team	Eddie McConnell Jo Hughes Michael Cunningham	Chief Executive Head of Service Development Finance and Resources Manager		
Charity registration number	60044040			
Charity registration number	SC011012			
Company registration number	SC011012 SC356717			
Company registration number	SC356717			
Company registration number Website	SC356717 www.dsscotland.org.uk SCVO Edward House			
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Company registration number Website	SC356717 www.dsscotland.org.uk SCVO Edward House 199 Sauchiehall Street	Т)		
Company registration number Website Registered Address	SC356717 www.dsscotland.org.uk SCVO Edward House 199 Sauchiehall Street Glasgow G2 3EX Chiene + Tait LLP (trading as C 61 Dublin Street Edinburgh EH3 6NL Lindsays WS Caledonian Exchange 19a Canning Street	Τ)		
Company registration number Website Registered Address Auditor	SC356717 www.dsscotland.org.uk SCVO Edward House 199 Sauchiehall Street Glasgow G2 3EX Chiene + Tait LLP (trading as C 61 Dublin Street Edinburgh EH3 6NL Lindsays WS Caledonian Exchange	Τ)		

#### **CHAIRPERSON'S STATEMENT**

I am pleased to present my first Annual Report of Down's Syndrome Scotland for the year ended 31<sup>st</sup> March 2024, following my appointment as the new Chair of the Board of Trustees in November 2023.

I begin this report by thanking my predecessor, Stuart Macintyre, who stepped down from the position of Chair after five years in that role and an initial year as a Trustee. Stuart's commitment to good governance means that the charity is in a far stronger position today than when he began his tenure. He led the appointment of our current Chief Executive with whom he worked closely throughout a series of challenging years dominated by the pandemic. We are most grateful to Stuart, for everything he has done to significantly improve the fortunes of our charity.

It will come as little surprise to those of you who support our work, that the past 12 months have witnessed further significant increases in demand for our services and support. We are challenged by a 26% increase in calls from families and a consequential increase (+32%) in the hours of support we have provided, compared to the previous year. While this demonstrates that our services are vital and that we are more needed than ever, it also presents an ongoing challenge in terms of sustainability.

Ensuring sufficient funds are raised helps us respond to rising demand. I am pleased to report that we have again ended our financial year in a surplus position. This is a smaller surplus than in previous years which reflects both increasing competition for funds across the sector and the impact of the cost-of-living crisis on charities such as ours. We are grateful to everyone who provides the charity with funding and support particularly in challenging financial times – we could not undertake our work without your ongoing generosity and kindness.

As we consider the capacity challenges that lie ahead, we recognise the wonderful work of our ten local branches – all led by dedicated volunteers who embody the aims of the charity. As Trustees, we highly value our partnership with local Branch Chairs, and are committed to working closely with them to support them as they, in turn, support people with Down's syndrome and their carers throughout their whole lives in communities across Scotland.

In our detailed report we demonstrate how Down's Syndrome Scotland continues to deliver great impact for a charity of our size. That we can perform in this way year-on-year is primarily due to the skills and efforts of our staff team who consistently exceed our expectations in their support for individuals with Down's syndrome and their families.

As we plan for the coming year and consider the future ambitions of the charity, we do so with full confidence in our services, staff, and volunteers. We remain mindful that we have so much still to do to secure commitments that enable every individual with Down's syndrome to reach their fullest potential in society. Expectations have rightly been raised during the Scottish Government's consultation on its proposed Learning Disability, Autism and Neurodivergence (LDAN) Bill. We eagerly await its publication later this year and the subsequent improvements we hope its passing may bring to the lives of people with Down's syndrome.

At Down's Syndrome Scotland, we believe in the potential and value of our fellow citizens who just happen to have an extra chromosome. We invite you to join our 'movement for change' and bring about a more inclusive, more rewarding, and more equal Scotland for people with Down's syndrome.

Include Sources.

Andrea Tonner Chair of the Board of Trustees

## TRUSTEES' REPORT

#### For the year ended 31 March 2024

The Trustees, who are also Directors for the purposes of Company Law, present their report and financial statements for the year ended 31 March 2024.

#### 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 and their carers throughout their whole life, 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.

In furtherance of its objects the charity undertakes the following activities:

- (1) facilitate the personal development of people with Down's syndrome in order that they may realise their full potential;
- (2) address the support needs of people with Down's syndrome and their parents, relatives and carers;
- (3) raise awareness and challenge inaccurate perceptions about Down's syndrome; promote the rights and ambitions of people with Down's syndrome to lead rewarding and inclusive lives; and
- (4) influence and support research and the development of policy for the benefit of people with Down's syndrome.

We know that every person with Down's syndrome is a unique individual, full of potential. We work to help people with Down's syndrome 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 Down's syndrome.

Our vision is that society fully accepts, includes and values people with Down's syndrome.

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

Our values are:

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

To achieve our mission and purpose, the Board of Trustees agreed a new a new Strategic Framework for DSS in December 2021. Our key strategic objectives for the three years are summarised below:

- **Support for Families:** Families are at the heart of our work. We will support the needs of the whole family parents and carers, siblings and family members with Down's syndrome.
- **People of Potential:** Every individual with Down's syndrome is a person of immense potential. We will facilitate their personal development and champion their value and worth.
- **Policy and Research:** Advancing the inclusion of all people with Down's syndrome demands both system and society change. We will seek to influence policy and research that facilitates this change.
- Awareness Raising: We believe in people with Down's syndrome they have so much to teach us. We will raise awareness about their potential and we will challenge out-dated negative perceptions.

In addition to these core strategic objectives, our Strategic Framework identifies four key programmes for change:

- **Better Health:** We have known that there is a pressing need to address health inequalities and improve health outcomes for people with Down's syndrome across Scotland. That need became even more acute as our community emerged from the disproportionate impact of the COVID-19 pandemic.
- **Greater Employment Opportunities:** People with Down's syndrome have an immense range of qualities and skills. And yet, less than 7% of people with learning disabilities are in paid work. We know that lots of people with Down's syndrome who want to work, don't have a paid job.
- Improved Transition Planning: People with Down's syndrome and their families experience many key transition moments in the course of their lives. Leaving school and starting your young adult life can be a challenge for everyone but for people with Down's syndrome this key transition step is often fraught with additional hurdles and difficulties.
- Living Well in the Community: People with Down's syndrome tell us they want to be active members of their communities, they want to be visible, valued and included. When we ask adults with Down's syndrome what would make their lives even better, they tell us they want to build friendships and have more opportunities to socialise.

Underpinning all of this work are two foundation principles articulated by the people we support:

- **My Human Rights:** "Like everyone else in society, I have human rights too. I just want that to be respected and understood. I want people to see me first, a human being who just happens to have an extra chromosome."
- Equal and Included: "I rarely feel equal and only occasionally do I feel included. I want to contribute my ideas and my thoughts. I am not less than everyone else just because I have Down's syndrome. I want the prejudice and discrimination to stop."

The implementation of our strategic objectives is directed through a series of operational programmes, as follows:

- Supporting families and working with a wide range of professionals.
- Supporting the development of communication skills in children and young people.
- Supporting teenagers and adults with Down's syndrome to live a full life.
- Raising awareness, challenging perceptions and influencing national policy.
- Establishing a vibrant community through our local branch network.
- Raising funds to support our objectives.

#### 2. ACHIEVEMENTS AND PERFORMANCE

Like so many charities operating in the disability space, Down's Syndrome Scotland (DSS) has experienced a year of further increased demand for support from families and people with Down's syndrome, right across Scotland. In the 12 months to 31<sup>st</sup> March 2024, we recorded a **26%** increase in enquiries to our family support line and a **32%** increase in the level of support we provided to families reaching out to us for help and assistance.

This is the third consecutive year of substantial increases in demand for support and it presents the charity with an ongoing challenge in terms of sustainability while maintaining the progress made in recent years. It is self-evident that we are doing more with less and that the vital services we provide have never been more needed. As the expectations, that we become 'first responders' across a wider range of social issues facing families and individuals with Down's syndrome continue to grow, it is imperative that the value and contribution of our work is more readily and equally recognised within the public service landscape.

DSS continues to evolve and innovate in its practice and service delivery – it is vital that we do so, if the needs of families are to be met and people with Down's syndrome, of all ages, are to fulfil their fullest potential as active and contributing citizens.

Our performance in the last 12 months is set out here, under each of our key operational areas:

#### 2.1 Supporting families and working with professionals

For over 40 years, our Family Support Team has been providing timely information, advice and support for families and people living with Down's syndrome throughout their lives; from new-borns to the early years, from school-aged children through to the teenage years, and from young adults through to older adults. Our support is available all over Scotland, all through life.

In the last 12 months, our Family Support Team has responded to **1,185** enquiries from families (up **26%** from the previous year). The team provided **1,445** hours of intensive support (up **32%** from the previous year) to 174 families who presented with more complex support needs.

Although demand for our 'Grab a cuppa' sessions has reduced in the past year, the team still hosted **18** sessions throughout the year bringing together **74** families and carers to discuss a wide range of topics including Self-Directed Support, Guardianship, Starting School and Home Energy Advice.

For the second year running, we are seeing a drop in the number of new parents getting in touch with us looking for advice and support. **31** parents with either a pre-natal diagnosis or a post-birth diagnosis received support from the team in the past 12 months. There are likely to be a number of factors contributing to the reduction in the number of newborn babies coming to our attention and we will continue to explore and understand what might be causing this change.

Our online secure platform for our members (Hub21) continues to see more sign-ups from families and member households. A **10%** increase on the previous year has taken the number of active accounts on Hub21 to just short of 700 (**692**).

Families are at the heart of our work at DSS and we recognise that, for many, they also receive support from a wide range of professionals who can become involved in the life of their daughter or son with Down's syndrome. We know, from families, that this can be a crucial and supportive relationship and we know that professionals have the potential to make a hugely positive impact.

We also know, however, that not everyone's experience has been a positive one and that's why we prioritise professionals as a group with whom we work closely, to ensure they are up to date and fully equipped with the knowledge and skills to provide excellent support, every time.

In the last 12 months we have brought all this work together under a new Professional Engagement and Development Programme and we have seen a hugely encouraging uptake in professional engagement and participation in our training and teaching sessions. In the last year **2,422** professionals have engaged with us – a **76%** increase on the year before.

**129** teaching and training sessions were delivered in the past year to a wide range of health and education professionals. This is a **13%** increase on the previous year's provision and a number of our teaching modules have now secured CPD (Continuing Professional Development) accreditation.

The work of the Family Support Team is highly valued by our families and our growing professional network. The following testimonials are evidence of that appreciation:

"My family started working with Karen about May last year. To say she has been a God send would not be enough. From my very first conversation with Karen, it was clear that she had a wealth of knowledge when it came to Down's syndrome and because her own son Matthew has Down's syndrome she knows exactly what family life can be like for us. I felt comfortable talking to Karen straight away and have been able to talk to her about how I am feeling on good days and bad days (when I really need someone to talk to).

Karen has attended every TAC meeting I have had for my son Ben, wither that be in person or more recently through Teams. Karen has been a great support for me at these meetings as I have had some issues with the school over Ben. Karen has explained things to the school and to me about how things need to be put in place for Ben because of his understanding and the way he learns.

Karen also came with me to visit another school for Ben when I was thinking about moving him somewhere better equipped to his needs. It turned out that it was not the right place for him but having Karen there was a massive support to me.

Any time I need a question answered or I have a query Karen is there to help me and if there is something she doesn't know the answer to she will find out where to get it. She has made me aware of different things that I could be applying for Ben to help him and us as a family. From me ranting, being upset, being happy, needing a question answered or just to have a chat about things, or visiting schools for Ben, Karen has been there. I really cannot put into words how much she has done for our family; I am so glad that we got her as our support worker. Thank you Karen."

#### (Nicola, Mum to Ben, age 7)

"As a Midwife working within antenatal clinic and Pregnancy Assessment Unit where I am regularly involved in screening and counselling families with regard to Down's syndrome, this webinar has been very informative & interesting. I will take away all of Katherine's advice about discussing Down's syndrome with these families. It was so lovely to hear Katherine's passion for Gregor and also to see what a lovely, happy, thriving little boy he is."

(Midwife attending NES Webinar run by DSS on 'sharing the news')

#### 2.2 Supporting the development of communication skills in children, young people and adults

As we strive to ensure that people with Down's syndrome, of all ages, achieve their fullest potential, we know the importance of addressing and developing their individual communication support needs. This is where our ABC programme (Achieving Better Communication) continues to have its much-valued impact.

The programme now delivers across all **32** local authority areas and routinely delivers **35** ABC sessions every week.

In the 12 months to 31<sup>st</sup> March 2024, the team delivered **1,538** live online ABC sessions to **86** children and young people and a further **1,560** pre-recorded (ABC Anytime) sessions were also made available to a further **53** families. The programme prides itself in its flexible model of delivery with sessions taking place online, in schools and nurseries as well as the pre-recorded sessions which allow families and others to run the sessions at a time that suits them best. There are **139** participants in the core ABC programme (a small increase on last year) and the majority of our sessions are now accessed from school and nursery settings.

The ABC programme has continued to evolve and develop with its ABC First Steps for 0-3 year olds now supplemented, more recently, by an ABC Songs, Stories and Signs groups for 3-6 year olds and 5-12 year olds. All of these groups involve face-to-face sessions and feedback has been extremely positive.

"This is a fabulous group. We have seen such an improvement in Ewan's communication, and desire to communicate since he started. Thank you June, Annette and Marie (ABC volunteers)."

#### (feedback from an ABC Songs, Stories and Signs parent)

At the other end of the age group, the ABC Next Steps sessions for young adults (16-25) continues to prove popular and the spin-off ABC Music Club has become well established with **30** music sessions delivered in the last 12 months.

"Callum had a great time yesterday. It was so nice to see everyone and finally be able to meet M. after all these years in the group together. Thanks June for a great session! Callum had a great time meeting some new friends and some he hadn't seen for a long time."

#### (feedback from an ABC Next Steps parent)

In addition to its core programme of delivering ABC sessions, the team has developed a number of additional initiatives which consolidate the communication skills development and learning offered by the programme, the most successful of which has been CHOIR 21 for children and young people and now CHOIR 21+ for anyone over the age of 18. In the past 12 months **40** CHOIR 21 sessions have been delivered involving **36** young people and **39** CHOIR 21+ sessions with **15** adults in attendance. Summer 2023 got off to a great start with the ABC Summer Sensations event held in Dundee with **15** families in attendance.

Workshops delivering 'Makaton signing for babies and families' also took place in the past year with **18** families receiving their Makaton for Babies pocketbook and a bag of nursery rhyme finger puppets. Parents attending the Makaton for Babies sessions reported feeling **85%** more confident supporting their baby's communication after attending these sessions. A total of **25** Makaton training sessions

were delivered to a wide range of partner organisations in the 12 months to March 2024 attracting a total of **180** participants from nursery and primary school staff, third sector organisations, care homes and a national agency.

"Exceeded expectations, the presentation was excellent, and I felt I gained an insight into the use of Makaton and some helpful first words and sentences. I would like to thank the Trainer who showed a real passion for the use of Makaton and shared her own journey."

#### (Attendee at a Makaton Workshop)

#### 2.3 Supporting teenagers and adults with Down's syndrome

Born as a much-needed initiative to tackle loneliness and isolation among our young people during the pandemic, our Teenz Space programme is now fully established as a core service for teenagers with Down's syndrome throughout Scotland. In the last 12 months, the team delivered **395** TeenZ Space sessions (up **17%** on the previous year) and a core group of **44** teenagers are now regular attenders at the 8-9 sessions which take place five days of the week.

Two new initiatives have taken place this year with the introduction of three in-person events in June, December and February and the launch of the TeenZ Zine magazine designed and shaped by the teenagers themselves.

The in-person events were a great success and there is clearly a desire for more. Families have shown us that they are more than willing to travel to meetups wherever they are held. The Karaoke Disco in Stirling was the highlight of the year – over 30 young people signed up and two travelled from as far as Kyle of Lochalsh and Orkney to be there. We were touched by the warm welcome we received from the staff at King Robert Hotel, some of whom had a close family member with Down's syndrome. It was so much more than a karaoke night as this feedback from a grateful parent confirms:

"... thank you for all your arranging of the karaoke disco. What a great night! And what a really lovely group of teenagers! Lachlan had an amazing time. (Despite having very little sleep the night before). He loved every minute of it - and I loved it too! What a difference in him - even watching him get ready and showering and looking so confident. Honestly it was such a massive deal for him to have a social event like that."

#### (Krissy, mum to Lachlan)

Our programme for adults with Down's syndrome has developed significantly this year as a result of a substantial funding boost that has allowed us to introduce an in-person FriendZ Meetups programme across Scotland. **7** FriendZ Meetups have taken place engaging **37** adults with Down's syndrome with a further **19** adults expressing an intention to come along to future meetup events. The FriendZ Meetups have taken place in Aberdeen, Perth, Inverness, Glasgow and Edinburgh with future events planned for Falkirk and Fife.

The meetups are hugely significant in the lives of adults with Down's syndrome as it affords them the opportunity to connect with other adults, develop friendships and relationships while also having a lot of fun. The impact is also very positive for family members too:

'Thanks to you and Karen and Brenda for organising the bowling, Alison really enjoyed it. I also enjoyed catching up with Paul's mum who I knew when the children were about a year old and who I haven't seen for about 35 years!! In fact we didn't recognise one another. Also meeting

## Aaron's mum Lynne. I have their numbers and have contacted them about the bowling here in Aberdeen that's on the first Friday of the month'.

#### (Anne, mum to Alison)

Our online FriendZ Space sessions continue to be popular with a core group of **56** adults with Down's syndrome taking part in **167** online sessions delivered this year, up **5%** on the previous year. Delivering on average 2-3 sessions a week, the programme introduced Fit FriendZ (with a fitness instructor) this year and also a Live Disco every month in response to feedback from members.

A key development in our adults' space in the last 12 months has been the full establishment of our Expert Advisors Group – a group of eight adults with Down's syndrome who share their lived experience to inform national developments including policy making and new legislation. The group has met in person more frequently now and they have covered topics including human rights, speaking up, confidence building, leading meetings and delivering presentations. The group has been increasingly active in the work of the charity becoming involved in work around Annual Health Checks, participating in research, taking part in staff recruitment, delivering FriendZ Space sessions, volunteer training and, more recently, they engaged with Public Health Scotland on the Easy Read Screening booklet.

A major undertaking for the Expert Advisors Group in the past 12 months has been their engagement with the Scottish Government's consultation on the proposed Learning Disability, Autism and Neurodiversity (LDAN) Bill. The group ran four sessions throughout the consultation period and developed their own independent response which was submitted to the Scottish Government by the deadline. One of our Expert Advisors, Andrew Davies, is also a member of the Scottish Government's Lived Experience Advisory Panel (LEAP) for the proposed LDAN Bill. He has attended numerous meetings of the LEAP and, on every occasion, he has ensured that the LEAP and the Scottish Government understand the needs and aspirations of the Down's syndrome community in Scotland.

The Expert Advisors Group is now a key part of the fabric of Down's Syndrome Scotland, and we are keen to explore with them their increasing involvement and influence on all aspects of our work. The following members currently make-up the Expert Advisors Group:

- Andrew Davies
- Theresa Boyle
- Emily Aikman
- Sam Ross
- Megan Bilsland
- Andrew Macintyre
- Derek Jenkins
- Fiona Dawson

#### 2.4 Raising awareness and influencing national policy

At Down's Syndrome Scotland we believe in the potential of every single person who has Down's syndrome. Raising awareness and influencing national policy is key to ensuring that our ambition for every individual with Down's syndrome is understood and shared by key decision-makers in Scotland, at all levels. Our work in this area is driven by our two underpinning principles, as set out in our Strategic Framework – to promote the **human rights** of our fellow citizens with Down's syndrome and to fight for their **equality and inclusion**.

Both principles were at the forefront of our detailed evidence to the **Scottish COVID-19 Inquiry** and our substantial submission to the Scottish Government's consultation on the proposed **Learning Disability, Autism and Neurodivergence Bill** (the LDAN Bill).

In relation to the former, our Chief Executive supplemented our detailed submission by giving oral evidence to the Inquiry in which he sought to amplify the voices of our community by calling out the inequality and injustices that were the daily lived experiences of families and people with Down's syndrome throughout the pandemic.

In December 2023, the Scottish Government launched its consultation on its proposed LDAN Bill. Our Life Member, Andrew Davies, was a key influencer in shaping, challenging and informing the consultation document and our Chief Executive was pleased to support Andrew in his role as a member of the Government's Lived Experience Advisory Panel (LEAP) in this regard. To support the accessibility of the consultation document, the charity produced a short presentation which was used by many organisations to explain the consultation document and two of our members produced a short Makaton Video to explain the structure of the consultation document and the importance of responding to the consultation process. The Makaton video was widely used by many organisations and partners.

We welcomed the publication of the consultation document and immediately began work with our members, families and people with Down's syndrome to develop our organisational response to the consultation. Several of our local branches also facilitated local discussions which allowed them to respond on behalf of their local community. We held **9** online consultation events for our members throughout the consultation period and **75** families participated in these events adding their views and experiences to the organisational response which was submitted ahead of the deadline in April 2024. As noted earlier, our Expert Advisors Group (adults with Down's syndrome) prepared their own independent response which was also submitted to the Scottish Government.

We continue to believe that the proposed LDAN Bill has the potential to transform the wellbeing and inclusion of people with learning disabilities, including our own community, in all aspects of Scottish life. This will only be possible however, if people with Down's syndrome are recognised explicitly in the scope and definition of the proposed Bill as a distinct community covered by the provisions of the Bill and if the Bill is appropriately resourced at all levels. We eagerly await the publication of the draft LDAN Bill and its Financial Memorandum later in 2024.

Throughout the past 12 months, we have collaborated closely with our friends and allies at the Scottish Commission for People with Learning Disabilities (SCLD) and we have swung behind their responses and policy positions in relation to a number of policy development including the Scottish Human Rights Bill, the ongoing Review of Mental Health Law in Scotland, the development of the National Care Service and the National Transitions to Adulthood Strategy.

Down's Syndrome Awareness Week and World Down's Syndrome Day in March continue to provide us with a significant platform to celebrate the potential, value and contribution of our fellow citizens who happen to have Down's syndrome. We are always amazed at the generosity and kindness of so many supporters who join us during Awareness Week to raise awareness and vital funds for the charity. The theme this year was 'End the Stereotypes' and the CoorDown film from the Italian Down Syndrome Association quickly went viral, boosting our own efforts to challenge prejudice and misconceptions and promote the potential of everyone living with an extra chromosome.

#### 2.5 Establishing a vibrant community through our branch network

As a national charity covering the whole of Scotland, we are privileged to have **10** local branches which are based in local communities all over Scotland. Our branches are made up of committed parents, family members and people with Down's syndrome and they are the foundation stones upon which the charity has grown and developed. Keeping parents in contact and especially putting new parents in touch with other parents is a vital aspect of their work as are the large number of events, outings and development programmes they operate. All of their work is voluntary and often their success rests on the shoulders of a few very willing and committed individuals.

One such individual is Irene Barr who has chaired the Central Scotland Branch for a remarkable 40 years. We had the opportunity to celebrate and salute Irene's incredible contribution earlier this year when she decided to step down from the role of Branch Chair. Irene remains actively involved with the Branch and we are indebted to her for years of voluntary service to so many in Central Scotland.

Our Branch Chairs have continued to meet-up together and they have also continued their meetings with the Trustees of the Charity. Our Chief Executive maintains in close contact with the Branch Chairs visiting, when he can, a number of their local events and committee meetings.

Our current network of local branches is as follows:

- Aberdeen City and Shire (Branch Chair: Heather Wadih)
- Angus (Branch Chair: Jacqueline Watson)
- Ayrshire (Branch Chair: Margaret Hastings)
- Central Scotland (Branch Chair: Donna Smith)
- Dumfries and Galloway (Branch Chair: Ann Butler)
- Edinburgh and Lothians (Branch Chair: Margaret Russell)
- Highlands and Islands (Branch Chair: Lisa Douglas)
- Tayside and Fife (Branch Chair: Katie Jamieson)
- West of Scotland (Branch Chair: Morna Lawson)
- **Oban Area & Isles** (Branch Chair: Arlene McLeod)

Membership of the charity overall has now reached an all-time high reached an all-time high with **1,493** members (up **6.6%** from last year) of which **596** are adults with Down's syndrome (our Life Members), the remainder being household/family members and a small number of professional members.

Alongside the growth in membership, we have continued to witness significant growth in our online community. On Facebook, we now have **12,300** followers (up **5%** from last year, doubling previous year's growth) and we have seen even stronger growth in followers across our other social media platforms including LinkedIn (**882** followers, up a remarkable **34%** on the previous year), Instagram (**944** followers, up **13.5%**) and predictably slower growth on X (Twitter) (**4,138** followers, up just **2.2%**).

#### 2.6 Raising funds to support our objectives

Like so many charities operating in Scotland and across the UK, our ability to provide critical support and services to families in need and individuals with Down's syndrome is directly related to our ability to raise vital funds, year in year out. The past year has been no exception and, like so many others,

we are experiencing increased competition for funds while also experiencing increased costs and increased demand for services and support.

We remain grateful and humbled that so many individuals and organisations place their trust in us to deliver for our families and members by contributing so generously through donations and a raft of fundraising events. We simply could not carry out our vital work if it wasn't for this support.

Despite the competing pressure for funds, our small fundraising team (two members of staff) continued to perform ahead of target and a total of **£898k** was raised in fundraised income in the 12 months to  $31^{st}$  March 2024, an increase of **7%** on the previous year's figure (£840k).

This figure includes **£330k** of core funding awarded to Down's Syndrome Scotland from the Scottish Government to ensure we are able to respond to the needs of families and individuals with Down's syndrome as part of the Government's commitment to transforming the outcomes for the learning disability community in Scotland.

We continue to be hugely appreciative of the funding we secure from a wide range of Trusts and Foundations who have supported us over many years. Their belief in our work is as important as their continued funding of our programmes and services. A full list of the Trusts and Foundations that have supported us in the last 12 months can be seen on page 16.

#### 3. PLANS FOR 2024-25

We are now entering the final year of our three-year *Strategic Framework*, covering the period from 2022 to 2025. We sometimes refer to our strategic framework as our '4-4-2 strategy':

- the first '4' refers to our four strategic objectives as set by our core mission and purpose (providing support to families, supporting individuals with Down's syndrome to achieve their potential, contributing to national policy and research, and raising awareness and challenging out-dated perceptions);
- the next '4' refers to the four programmes for change identified by adults with Down's syndrome (better health, greater employment opportunities, improved transition planning, and active community living);
- the final '2' reflects our two underlying foundation principles (promoting human rights and securing equality and inclusion).

Against this framework, our priorities for the year ahead include:

- Responding to the publication of the Scottish Government's draft Learning Disability, Autism and Neurodivergence Bill (the LDAN Bill).
- Supporting a delegation of three adults with Down's syndrome to attend and deliver presentations at the World Down Syndrome Congress in Brisbane, Australia.
- Launching our new Inclusive Employment Programme to bring about more opportunities for meaningful employment for people with Down' syndrome in Scotland.
- Launching a new Down's Syndrome Scotland website that improves user experience and secures greater engagement from our friends and supporters.
- Ensuring every member of our adult community can access an Annual Health Check within their local health board area.
- Supporting our Branches to become more sustainable by allocating resources to a programme of branch development across Scotland.

- Developing and introducing a new Individual Giving Programme for the charity while enhancing the benefits and services available to our members.
- Preparing the groundwork for a major high-profile event in May 2025 that has the potential to significantly expand the reach and profile of the charity and its work.

Our core purpose in supporting families and individuals with Down's syndrome will remain central to all our work as we continue our efforts to reach more people with Down's syndrome, more quickly and more often through our ever-evolving services and programmes. In our determined efforts to get everyone to recognise the value, contribution and potential of our fellow citizens with Down's syndrome, we will consolidate our partnership working with our closest partners while reaching out to new supporters and new partners, encouraging them to join our movement for change.

#### 4. **RISKS AND UNCERTAINTIES**

The charity's Risk Register is considered at every meeting of the Board of Trustees and is reviewed in detail at each quarterly meeting of the Finance and Risk Sub Committee (FRSC) of the Board. The Register details the actions, mitigations and controls in place to manage each of the identified strategic risks and each risk has a risk score (derived from likelihood of the risk happening and the impact should the risk occur). The Risk Register is a dynamic document with actions and controls updated at each quarter along with a review of the risk score for each identified risk.

The Risk Register identifies 19 strategic and operational risks facing the charity and sets out the range of actions, controls and mitigations in place to manage each risk. The Risk Register covers the following areas:

- **Community**: risks to which the community of Down's syndrome in Scotland is exposed and over which the charity can have some influence;
- **Financial**: risks around funding which could threaten the 'going concern' of the charity;
- **People**: risks which involve the welfare and wellbeing of the people involved with the charity including staff, volunteers and the safeguarding of vulnerable individuals;
- **Operational**: risks associated with the delivery of frontline services and the systems and processes in place to support operational matters including business continuity;
- **Strategy:** risks which arise from the implementation of our overall Strategic Framework and the proposed new Learning Disability, Autism and Neurodiversity Bill in Scotland;
- **Governance**: risks around non-compliance with legislation and regulations and good governance including cyber security, data protection and financial reporting; and
- **Reputation:** risks that could impact adversely the reputation and standing of the charity.

The following risks, including their actions and controls to manage the risks, are the highest scoring risks in the Risk Register:

## **Risk 15:** The Learning Disability, Autism and Neurodiversity (LDAN) Bill fails to meet the needs of the Down's syndrome community in Scotland.

(Summary of controls: Ensure DSS is a member of the Bill's Stakeholder Panel; support a Life Member of DSS to join the Lived Experience Advisory Panel; ensure members of DSS are fully engaged and participating in the public consultation exercise for the Bill, submit a comprehensive response from the organisation and support the Expert Advisers Group to submit their independent response.)

**Risk 3:** The cost of living crisis impacts on families/members' participation and membership of DSS.

(Summary of controls: engage proactively with families who we know may be in hardship; continue

to provide free access to member sessions (TeenZ Space and FriendZ Space); partners with other specialist organisations to provide cost-of-living advice (e.g. Home Energy Scotland, Citizen's Advice); continue to 50% discount of ABC subscription fees.)

#### **Risk 6:** Scottish Government core funding dramatically reduces and/or ceases.

(**Summary of controls:** identify alternative funding options; maintain close contact with LD Policy Team at SG; submit comprehensive reports on the impact and outcomes achieved by SG cire funding; maintain pressure for earlier notification of annual grant funding; develop scenario planning options as part of our three-year financial planning exercise.)

*Risk 8:* Welfare and wellbeing of staff deteriorates.

(Summary of controls: maintain weekly all staff briefing sessions online; increase number of staff inperson get together from 4 a year to 6 a year; monitor staff wellbeing and morale levels; review and support WFH arrangements and home working policy; ensure all staff take their holidays; introduce wellbeing app for all staff; promote access to staff wellbeing and support resources; promote family first/health first approach.)

**Risk 11:** Service delivery fails to adapt and evolve as demand continues to increase and poor service delivery is experienced..

(Summary of controls: Design, develop and introduce Hub21 online platform for members; expand ABC online delivery options; introduce a new refreshed Adults Programme; consider partnership working approaches to service delivery; work more closely with local Branches to pick-up local enquiries and promote parent to parent approaches; consider volunteer recruitment and development.)

#### **Risk 14:** Implementation of new DSS Strategic Framework and Implementation Plan stalls.

(**Summary of controls:** recruit key roles for delivery of the four programmes for change; introduce a 'strategy tracker' for presentation and discussion at each Board meeting; develop and introduce a 'performance dashboard' for the organisation; monitor and report annual evaluation of the implementation of the Strategic Framework.)

#### 5. FINANCIAL REVIEW

#### Income and expenditure

For the year ended 31 March 2024, DSS is reporting net income of £14,349 (2023: £30,548) resulting in an increase in funds of £14,349 (2022: £30,626) after pension deficit remeasurement gains.

Total income amounted to £955,026 in the year. Of this, funds raised from community fundraising, events, individual and corporate donations, legacies and membership fees totalled £280,753. The Scottish Government contributed £360,000 for our family support and ABC services as well as core costs. A further £261,459 was raised from other grants and trusts. Income from ongoing charitable activities, including specialist training, consultations and ABC sessions run by our staff, brought in £35,591. The remaining £17,223 was received from merchandise, miscellaneous income and bank interest.

The following charitable trusts, foundations and other grant-giving funders contributed to our income in 2023-24:

- Stafford Trust Alexander Moncur AM Pilkington TNL Improving Lives BWM Hillcrest Foundation The Gertrude Muriel Pattullo Trust for Disabled Young People The Mickel Fund RS MacDonald Charitable Trust The National Lottery Awards for All Children in Need Souter Charitable Trust
- Saints & Sinners Murdoch Forrest Cruden Foundation Impact Funding Partners Hugh Fraser Foundation PF Charitable Leng Charitable Trust Nancie Massey CT Enzo Londei Hospital Saturday Fund Northwood CT

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

Best Western Palace Hotel and Spa, Inverness **KAEFER UK & Ireland** Tesco Extra **Robertson Construction Tayside** J W Filshill Ltd Baillie Gifford and Co **Fife Fabrications Ltd Ebony Joiners Kingsfield Golf Centre Centurion Managements Systems Ltd** Centrica plc **CFSLA Lottery** Galloway Bridal Galloway Travel Lucky Dip Charters Peter Vardy Ltd Lady J's Hairdressing Forth Ports

Expenditure for the year totalled £940,677. Of this, £783,409 was spent running ongoing services and projects and £157,268 was incurred raising funds. Included in these cost totals are central support costs of £154,258 and governance costs in running the charity of £39,441. Further details of expenditure are available in notes 7 and 8 of the financial statements.

#### Reserves

As at 31 March 2024, DSS had funds totalling £607,779. Of these, £132,095 are restricted for specific services and projects. Unrestricted funds totalled £475,684, with £17,197 relating to fixed assets and £78,748 held for the ten branches across Scotland. The remaining £379,739 represents general reserves.

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 four months annual operating expenditure. This Reserves Policy is reviewed annually by the Board and adjusted as appropriate. As at 31 March 2024, total funds (excluding those relating to fixed assets) represented over seven months total expenditure for 2023-24.

#### 6. STRUCTURE, GOVERNANCE AND MANAGEMENT

DSS is a registered charity and company limited by guarantee and is governed by its Articles of Association updated and refreshed in January 2021. Its members are interested individuals, families and professionals. Individuals with Down's syndrome 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.

There must be at least three Trustees on the Board up to a maximum of twelve. The Board shall at all times ensure that lived experience of Down's syndrome is represented in the Board composition. A Trustee may be appointed by the Board of Trustees by way of a majority decision at any time, providing they are willing to act and on the basis that they have experience and/or skills which could be of assistance to the Board of Trustees. New Trustees go through an induction process with both existing Trustees and Senior Management upon joining the Board.

All Trustees must become 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 two further periods of three years. 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 Trustees. 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.

Sub Committee	Area
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

#### Key Management Personnel and 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 Service Development and the Finance and Resources Manager, together making up the Senior Management Team. The Remuneration Sub Committee reviews and approves individual pay awards for the Chief Executive and

each member of the Senior Management Team members as well as cost of living pay awards for all staff. Key management personnel include the Trustees. At 31 March 2024, there were 26 members of staff in total (19.6 full time equivalent).

#### 7. STATEMENT OF TRUSTEES' RESPONSIBILITIES

The Trustees (who are also Directors of Down's Syndrome Scotland 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).

Company law requires the 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 Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP (FRS 102) (second edition October 2019);
- 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;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in operation.

The Trustees are responsible for keeping adequate accounting records that 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). They are 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 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.

The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

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:

Andrea Donner.

Andrea Tonner Chair of the Board of Trustees

2 September 2024

Rob Molan Treasurer

2 September 2024

# INDEPENDENT AUDITOR'S REPORT TO THE TRUSTEES AND MEMBERS OF DOWN'S SYNDROME SCOTLAND (a Company Limited by Guarantee)

#### **Opinion on financial statements**

We have audited the financial statements of Down's Syndrome Scotland for the year ended 31 March 2024 which comprise the Statement of Financial Activities, the Balance Sheet, the Statement of Cash Flows and the related notes. 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 2024, 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 Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

#### **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 charity 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

In auditing the financial statements, we have concluded that the Trustee's use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least 12 months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

#### Other information

The Trustees are responsible for the other information. The other information comprises the information included in the Trustees' 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.

# INDEPENDENT AUDITOR'S REPORT TO THE TRUSTEES AND MEMBERS OF DOWN'S SYNDROME SCOTLAND (Continued)

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 the 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 where the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 (as amended) require us to report to you if, in our opinion:

- the charitable company has not kept proper and adequate accounting records, 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 company's exemption from the requirement to prepare a strategic report.

#### **Responsibilities of Trustees**

As explained more fully in the statement of Trustees' responsibilities set out on page 18, 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.

# INDEPENDENT AUDITOR'S REPORT TO THE TRUSTEES AND MEMBERS OF DOWN'S SYNDROME SCOTLAND (Continued)

#### Auditor's responsibilities for the audit of the financial statements

We have been appointed 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.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

We gained an understanding of the legal and regulatory framework applicable to the company and the industry in which it operates and considered the risk of acts by the company which were contrary to applicable laws and regulations, including fraud. These included but were not limited to the Companies Act 2006, Health and Safety Regulations and Licensing Laws.

Our audit procedures were designed to respond to risks of material misstatement in the financial statements, recognising that the risk of not detecting a material misstatement due to fraud is higher than the risk of not detecting one resulting from error, as fraud may involve deliberate concealment by, for example, forgery, misrepresentations or through collusion.

We focused on laws and regulations that could give rise to a material misstatement in the company's financial statements. Our tests included, but were not limited to:

- agreement of the financial statement disclosures to underlying supporting documentation;
- enquiries of the Chief Executive and the directors;
- review of minutes of board meetings throughout the period; and
- obtaining an understanding of the control environment in monitoring compliance with laws and regulations.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

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

# INDEPENDENT AUDITOR'S REPORT TO THE TRUSTEES AND MEMBERS OF DOWN'S SYNDROME SCOTLAND (Continued)

#### Use of report

This report is made solely to the 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 section 44(1) (c) of the Charities and Trustee Investment (Scotland) Act 2005 and regulation 10 of the Charities Accounts (Scotland) Regulations 2006 (as amended). Our audit work has been undertaken so that we might state to the members and the charitable company's 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, its members as a body, and its Trustees as a body, for our audit work, for this report, or for the opinions we have formed.

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Jeremy Chittleburgh CA (Senior Statutory Auditor) For and on behalf of CT Chartered Accountants and Statutory Auditor 61 Dublin Street Edinburgh, EH3 6NL

11 September 2024

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

### **STATEMENT OF FINANCIAL ACTIVITIES**

(including Income and Expenditure Account) For the year ended 31 March 2024

	Note	2024 Unrestricted General £	2024 Unrestricted Designated £	2024 Restricted £	2024 Total £	2023 Total £
INCOME		-	-	-	-	L
Donations and legacies	3	367,546	24,433	513,988	905,967	851,360
Trading activities	4	2,120	-	-	2,120	566
Investment income Income from charitable	5	11,348	-	-	11,348	6,065
activities:	6					
Ongoing charitable activities		-	3,615	31,976	35,591	34,406
Total foresting			,			
Total income		381,014	28,048	545,964	955,026	892,397
EXPENDITURE						
Cost of raising funds	7	(157,268)	-	-	(157,268)	(169,068)
Cost of charitable activities:						
Ongoing charitable activities	7	(220,439)	(41,406)	(521,564)	(783,409)	(692,781)
Total expenditure excluding pension scheme adjustments		(377,707)	(41,406)	(521,564)	(940,677)	(861,849)
Net income/(expenditure) before pension scheme adjustments and investment property gains		3,307	(13,358)	24,400	14,349	30,548
Pension scheme adjustments – remeasurement gains	13	-	-	-	-	78
Net income/(expenditure) & net movement in funds		3,307	(13,358)	24,400	14,349	30,626
Funds brought forward	15	376,432	109,303	107,695	593,430	562,804
Funds carried forward	15	379,739	95,945	132,095	607,779	593,430

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

The notes on pages 26 to 38 form part of these financial statements

BALANCE SHEET As at 31 March 2024	Scottish company number: SC356717		
	Note	2024	2023
		£	£
Fixed assets		-	_
Tangible assets	10	17,197	27,454
		17,197	27,454
Current assets			
Stock		3,268	3,418
Debtors	11	57,588	22,011
Cash at bank and in hand		570,572	594,683
		631,428	620,112
Creditors: amounts falling due within one year	12	(40,846)	(53,549)
Net current assets	12	590,582	566,563
			500,505
Total assets less current liabilities		607,779	594,017
Creditors: amounts falling due after more than one year:	12	-	(587)
Net assets		607,779	593,430
The funds of the charity:			
Restricted funds	15	132,095	107,695
Unrestricted funds			
General	15	379,739	376,432
Designated	15	95,945	109,303
		607,779	593,430

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 2 September 2024.

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Andrea Tonner Chair of the Board of Trustees

Rob Molan Treasurer

The notes on pages 26 to 38 form part of these financial statements.

### **STATEMENT OF CASH FLOWS**

For the year ended 31 March 2024

#### Reconciliation of net income to net cash flow from operating activities

		2024 £	2023 £
Cash flows from operating activities:			
Net cash provided by operating activities		<u>(35,459)</u>	<u>29,756</u>
Cash flows from investing activities:			
Rent received			
Bank interest received		- 11,348	- 6,065
Net cash flow provided by investment activities		11,348	6,065
		-	
(Decrease)/increase in cash and cash equivalents in th	e year	(24,111)	35,821
Cash and cash equivalents at the beginning of the year		F04 683	
		594,683	558,862
Cash and cash equivalents at the end of the year		570,572	594,683
		2024	2022
		2024 £	2023 £
Net Income for the year		- 15,157	30,548
Adjustments for:			
Depreciation during year		10,257	13,317
Gift in Kind donations of fixed assets		, _	(1,041)
Loss on disposal of tangible assets		-	-
Remeasurement gains on defined benefit pension sch	eme deficit	(1,394)	78
Bank interest received		(11,348)	(6,065)
Decrease in stock		150	85
(increase)/ decrease in debtors		(35,577)	6,107
Decrease in creditors		(12,704)	(13,273)
Net cash provided by (used in) operating activities		(35,459)	29,756
		(20, 100)	
Analysis of Changes in Net Debt	2023	<b>Cash flows</b>	2024
	£	£	£
Cash and cash equivalents	594,683	(24,111)	570,572

The notes on pages 26 to 38 form part of these financial statements

### NOTES TO THE FINANCIAL STATEMENTS

#### 1. Accounting policies

#### **1.1** Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (second edition – October 2019) - (Charities SORP (FRS 102), and the Companies Act 2006.

Down's Syndrome Scotland meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

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 ten branches.

#### 1.2 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.

#### **1.3** 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 have been allocated to activity categories on the basis consistent with the use of resources i.e. 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.

#### **1.4** 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.

## NOTES TO THE FINANCIAL STATEMENTS (continued)

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.

#### 1.5 Tangible fixed assets and depreciation

Tangible fixed assets costing more than £1,000 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:

Category	Basis	%
Office equipment	Straight line	25
	Strught inc	23

### 1.6 Stock

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

#### 1.7 Debtors

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

#### 1.8 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.

#### 1.9 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.

#### 1.10 Funds

All income and expenditure are 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 (e.g. 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.

## **NOTES TO THE FINANCIAL STATEMENTS (continued)**

#### 3. Income from donations and legacies

	2024	2024	2024	2023
	Unrestricted	Restricted	Total	Total
	£	£	£	£
Scottish Government Grants	75,440	284,560	360,000	330,000
Other grants and trusts	32,131	229,328	261,459	253,937
Community fundraising and events	157,314	-	157,314	145,240
Individual and corporate donations	90,955	100	91,055	92,760
Legacies	500	-	500	-
Branch fundraising activities	24,433	-	24,433	18,376
Membership subscriptions	7,451	-	7,451	11,047
Other Income	3,755		3,755	-
	391,979	513,988	905,967	851,360

Income from donations and legacies in 2023 was £851,360 of which £491,043 was unrestricted and £360,317 was restricted.

#### 4. Trading activities

	2024	2024	2024	2023
	Unrestricted	Restricted	Total	Total
	£	£	£	£
Christmas card sales and other merchandise	2,120		2,120	566

Income from trading activities in 2023 of £566 was all unrestricted.

#### 5. Investment income

	2024	2024	2024	2023
	Unrestricted	Restricted	Total	Total
	£	£	£	£
Bank interest	11,348		11,348	6,065
	11,348	-	11,348	6,065

Income from investments in 2023 of £6,065 was all unrestricted.

#### 6. Income from charitable activities

	2024 Unrestricted £	2024 Restricted £	2024 Total £	2023 Total £
Training, consultations and ABC sessions	-	31,976	31,976	29,184
Branch activities	3,615	<u> </u>	3,615	5,222
Ongoing charitable activities	3,615	31,976	35,591	34,406

Income from charitable activities in 2023 was £34,406 of which £29,184 was restricted and £5,222 unrestricted.

## **NOTES TO THE FINANCIAL STATEMENTS (continued)**

#### 7. Analysis of total expenditure

	Direct costs £	Support costs £	Governance costs £	2024 Total £	2023 Total £
Cost of raising funds	<u>141,126</u>	<u>12,855</u>	<u>3,287</u>	<u>157,268</u>	<u>169,068</u>
<b>Cost of charitable activities</b> Ongoing charitable activities: Supporting families and				-	
professionals Raising awareness and	215,809	64,273	16,434	296,516	271,800
influencing policy Developing communication	41,200	6,428	1,643	49,271	64,335
skills	143,470	38,565	9,860	191,896	186,946
Supporting adults with Ds	151,430	25,710	6,574	183,714	150,237
Social Meetups	18,592	6,428	1,643	26,663	-
Lived experience programme	4,200	-	-	4,200	-
Branch activities	31,149			31,149	19,463
	605,851	141,404	36,154	783,409	692,781
	746,978	154,258	39,441	940,677	861,849

Expenditure on raising funds of £157,268 in 2024 (2023: £169,068) was all unrestricted. Expenditure on charitable activities in total was £783,409 in 2024 (2023: £692,781) of which £261,845 (2023: £366,197) was unrestricted and £521,564 (2023: £326,584) was restricted.

Both support and governance costs have been apportioned to charitable activities on the basis of staff related 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, and administrative staff, IT, HR and payroll support, and other costs incurred in running central office support functions. An analysis of material categories of expenditure included within support costs is shown below:

	2024	2023
	£	£
Central office staff and related costs	86,656	90,897
Property	9,244	3,352
IT and communications	22,591	12,846
Office administration	15,199	7,196
Professional fees	10,174	10,474
Fixed assets depreciation and gains/losses on disposal	10,257	13,317
Interest expense (re pension deficit)	137	152
	154,258	138,234

### NOTES TO THE FINANCIAL STATEMENTS (continued)

#### 8. Governance costs

	2024	2023
	£	£
Senior management	29,083	28,796
Audit fee	9,300	8,400
Board meetings	1,013	-
Trustees' expenses	45	20
	39,441	37,216
9. Staff costs		
	2024	2023
	£	£
Wages and salaries	613,693	587,692
Social security costs	47,615	39,598
Pensions	28,342	26,237
	689,650	653,527

During the year, the average head count was 26.9 equating to 20.0 full time equivalent employees (2023: 25.4 average head count, 19.7 full time equivalent employees).

One employee received employee benefits of more than £60,000 (2023: £Nil). The total amount of employee benefits remunerated to key management personnel for the year was £178,389 (2023: £209,050). The charity considers that its key management personnel are the members of the Senior Management Team.

There were no payments included within wages and salary costs in connection with cessation of employment (2023, £Nil).

None of the Trustees received any remuneration. During the year, a total of £45 (2023: £20) was paid to one Trustee in respect of reimbursement of travel expenses.

#### 10. Tangible fixed assets

Office	2024
Equipment	Total
£	£
57,468	57,468
-	-
-	
57,468	57,468
30,014	30,014
10,257	10,257
40,271	40,271
17,197	17,197
27,454	27,454
	Equipment £ 57,468 - - 57,468 30,014 10,257 - 40,271 17,197

## **NOTES TO THE FINANCIAL STATEMENTS (continued)**

#### 11. Debtors

	2024	2023
	£	£
Sundry debtors	38,553	16,240
Prepayments	19,035	5,771
	57,588	22,011
12. Creditors		
Amounts falling due within one year:		
	2024	2023
	£	£
Sundry creditors	18,301	18,508
Accruals	17,773	29,307
Multi-employer pension scheme liability	724	4,228
Deferred income	4,048	1,506
	40,846	53,549
The movement on deferred income in the year is analysed as follows:		
	2024	2023
	£	£
As at 1 April 2023	1,506	-
RS MacDonald Trust income received in 2022/23 for financial year 2023/24	(1,506)	1,506
Parent Deposits for World Down's Syndrome Congress	4,048	
As at 31 March 2024	4,048	1,506
Amounts falling due after more than one year		
- · ·	2024	2023
	£	£
Multi-employer pension scheme liability	-	587
	-	587

#### **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 4% of pensionable salaries (2023: 4%), and employer contributions of 5% of pensionable salaries. (2023: 5%) Employer pension contributions payable in the year were £26,904 (2023: £27,534). The amount included within creditors at the year-end is £2,483 (2023: £2,289).

#### Defined benefit pension arrangements

The company participates in a multi-employer scheme which provides benefits to some 82 non-associated employers. The scheme is a defined benefit scheme in the UK. It is not possible for the company 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.

## **NOTES TO THE FINANCIAL STATEMENTS (continued)**

#### 13. Pension commitments (continued)

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 company 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.

The most recent estimated debt on withdrawal for Down's Syndrome Scotland has been calculated to be £57,593. This figure has an effective date of 30 September 2023. No current employees of Down's Syndrome Scotland are members of the scheme.

A full actuarial valuation for the scheme was carried out with an effective date of 30 September 2020. This actuarial valuation was certified on 21 December 2021 and showed assets of £153.3m, liabilities of £160.0m and a deficit of £6.7m. To eliminate this funding shortfall, the scheme and the participating employers have agreed that additional contributions will be paid, in combination from all employers, to the scheme as follows:

#### **Deficit contributions**

From 1 April 2022 to 31 May 2024:	£1,473,969 per annum
	(payable monthly and increasing by 3% each year on 1 <sup>st</sup> April)

Some employers have agreed concessions (both past and present) with the Pension Trustee and have contributions up to 29 February 2028.

Note that the scheme's previous valuation was carried out with an effective date of 30 September 2017. This valuation showed assets of £120.0m, liabilities of £145.9m and a deficit of £25.9m. To eliminate this funding shortfall, the Trustee asked the participating employers to pay additional contributions to the scheme as follows:

#### **Deficit contributions**

From 1 April 2019 to 30 September 2026:	£1,404,638 per annum (payable monthly and increasing by 3% each on 1st April)
From 1 April 2019 to 30 September 2027:	£136,701 per annum (payable monthly and increasing by 3% each on 1st April)

The recovery plan contributions are allocated to each participating employer in line with their estimated share of the scheme liabilities.

#### PRESENT VALUES OF PROVISION

	31 March	31 March	31 March
	2024	2023	2022
	£	£	£
Present value of liability	724	4,815	8,846

## NOTES TO THE FINANCIAL STATEMENTS (continued)

#### 13. Pension commitments (continued)

#### RECONCILIATION OF OPENING AND CLOSING PROVISIONS

	Period Ending 31 March 2024 (£s)	Period Ending 31 March 2023 (£s)
Provision at start of period	4,815	8,846
Unwinding of the discount factor (interest expense)	137	152
Deficit contribution paid	(4,228)	(4,105)
Remeasurements - impact of any change in assumptions	-	(78)
Remeasurements - amendments to the contribution schedule	-	-
Provision at end of period	724	4,815

#### INCOME AND EXPENDITURE IMPACT

	Period Ending 31 March 2024 (£s)	Period Ending 31 March 2023 (£s)
Interest expense	137	152
Remeasurements – impact of any change in assumptions	-	(78)
Remeasurements – amendments to the contribution schedule	-	-
Contributions paid in respect of future service*	-	-
Costs recognised in income and expenditure account	-	(78)

\* includes defined contribution schemes and future service contributions (i.e. excluding any deficit reduction payments) to defined benefit schemes which are treated as defined contribution schemes.

#### ASSUMPTIONS

	31 March 2024	31 March 2023	31 March 2022
	% per annum	% per annum	% per annum
Rate of discount	4.90	5.40	2.30

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 results as using a full AA corporate bond yield curve to discount the same recovery plan contributions.

## NOTES TO THE FINANCIAL STATEMENTS (continued)

#### 14. Movement on funds

	Balance at 1 April 2023	Income	Expenditure	Other recognised gains	Transfers during year	Balance at 31 March 2024
	£	£	£	£	£	£
Restricted funds						
Family Support Service	107,695	320,418	(296,181)	-	-	131,932
Communication skills	-	119,541	(119,541)	-	-	-
TeenZ Space	-	23,735	(23,735)	-	-	-
FriendZ Meetups	-	15,633	(15,633)			
Young People & Adults	-	66,637	(66,474)			163
Total restricted	107,695	545,964	(521,564)	-		132,095
Unrestricted funds						
General	376,432	381,014	(387,964)		10,257	379,739
Designated:						
Tangible assets	27,454	-	-	-	(10,257)	17,197
Branches	81,849	28,048	(31,149)	-	-	78,748
Total designated	109,303	28,048	(31,149)	-	(10,257)	95,945
Total unrestricted	485,734	409,062	(419,113)		-	475,684
TOTAL FUNDS	593,430	955,026	(940,677)		-	607,779

## NOTES TO THE FINANCIAL STATEMENTS (continued)

#### 14. Movement on funds (continued)

	Balance at 1 April 2022	Income	Expenditure	Other recognised gains	Transfers during year	Balance at 31 March 2023
	£	£	£	£	£	£
Restricted funds						
Family Support Service	44,478	304,720	(241,803)	-	-	107,695
Communication skills	-	48,032	(48,032)	-	-	-
FriendZ Meetups	-	-		-	-	-
TeenZ Space	-	36,749	(36,749)			
Total restricted	44,778	389,501	(326,584)	-	-	107,695
Unrestricted funds						
General	400,581	479,298	(515,801)	78	(12,276)	376,432
Designated:						
Tangible assets	39,730	-	-	-	12,276	27,454
Branches	77,715	23,598	(19,464)		-	81,849
Total designated	117,445	23,598	(19,464)	-	12,276	109,303
Total unrestricted	518,026	502,896	(535,265)	78		485,735
TOTAL FUNDS	562,804	892,397	(861,849)	78		593,430

## **NOTES TO THE FINANCIAL STATEMENTS (continued)**

#### 14. 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 Baily Thomas Charitable Fund and four other trusts as well as charges for specialist training and consultations.

*Communication skills (ABC)* – this core service received restricted funding from the Scottish Government, BBC Children in Need, the Hugh Fraser Foundation and one other trust as well as fees for sessions attended.

#### Purpose of designated funds:

Branches - Funds held on behalf of the ten branches.

## NOTES TO THE FINANCIAL STATEMENTS (continued)

#### 15. Analysis of net assets between funds

	Fixed	Net current	Long	Pension	As at
	assets	assets	term	scheme	31 March
			liabilities	liability	2024
	£	£	£	£	£
Restricted funds	-	132,095	-	-	132,095
Unrestricted general funds	-	380,463	-	(724)	379,739
Unrestricted designated funds	17,197	78,748		-	95,945
	17,197	591,306		(724)	607,779
	Fixed	Net current	Long	Pension	As at
	assets	assets	term	scheme	31 March
			liabilities	liability	2023
	£	£	£	£	£
Restricted funds	-	107,695	-	-	107,695
Unrestricted general funds	-	381,247	-	(4,815)	376,432
Unrestricted designated funds	27,453	81,849	-	-	109,303
	27,453	570,791	-	(4,815)	593,430

## **NOTES TO THE FINANCIAL STATEMENTS (continued)**

#### 16. Related party transactions

There were no related party transactions in the financial year or the previous financial year.