

# THE DYSTONIA SOCIETY

England & Wales · Charity number 1062595

## Details

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Status	Registered
Legal form	Charitable company
Company number	<a href="#">03309777</a>
Registered	1997-06-02
Register	<a href="#">View on the Charity Commission register</a>

## Contact

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Website	<a href="http://www.dystonia.org.uk">www.dystonia.org.uk</a>

## Activities

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**Objects:** (1) TO PROMOTE THE WELFARE OF THOSE PERSONS SUFFERING FROM THE MOVEMENT DISORDER KNOWN AS DYSTONIA OR FROM SIMILAR OR RELATED CONDITIONS, AND (2) TO ADVANCE THE EDUCATION OF THE PUBLIC ABOUT ALL ASPECTS OF THE SAID CONDITIONS.

**Activities:** Promoting the welfare of people who are afflicted by Dystonia, a neurological movement disorder, via the following activities: Linking people affected by dystonia, including a network of local groups Raising awareness of dystonia and the Society Providing information and support Improving access to treatment and other services and promoting best practice Progressing research

## Classification

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- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** People With Disabilities

## Geography

- **Area of benefit:** NATIONAL
- Northern Ireland
- Scotland
- Throughout England And Wales

## Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£422,337	£402,567	-	-
2024-03-31	£692,353	£321,276	£702,295	5
2023-03-31	£277,412	£285,775	-	-
2022-03-31	£293,052	£262,278	-	-
2021-03-31	£421,975	£310,100	-	-

## Trustees

Name	Role	Appointed
Christopher Paul Southon		2026-06-23
Dr Amit Batla		2023-11-28
Emily Birden		2023-09-04
Fermanda Perez		2023-09-07
Ntonella Macerolla		2023-11-28
Penny Ritchie-Calder		2019-05-09
Qamar Khan MBE		2024-01-15
Robert Harold William Semple		2021-03-01
Sophie Eleanor Norman		2023-09-07
Timothy John Gannicliffe		2019-09-12

**THE DYSTONIA SOCIETY**

England & Wales - Charity number 1062595

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# Accounts

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**The Dystonia Society**

A company limited by guarantee

Trustees Report & Financial Statements for the year  
ended 31 March 2025

## **Contents**

Reference and administrative information	2
Report of the trustees	3-21
Independent examiner's report	22
Statement of financial activities	23
Balance sheet	24-25
Statement of cash flows	26
Notes to the financial statements	27-36

## Reference and administrative information

### Charity registration number

1062595 (England and Wales) and SC042127 (Scotland)

### Company registration number

03309777

### Patron

Tully Kearney, OBE

### Trustees and Directors

Amit Batla

Emily Birden

Timothy Gannicliffe

Ross Grant

Qamar Khan, MBE (Chair from 1<sup>st</sup> April 2024)

Antonella Macerollo

Sophie Norman

Fernanda Perez

Penny Ritchie Calder, MBE

Robert Semple

### Secretary

Roger Edmonds FCA

### Medical Advisers

Prof. Mark Edwards

Mr. Daniel Ezra

Ms. Lucy Hicklin

Dr Jean-Pierre Lin

Dr. Marie-Helene Marion

Dr. Kathryn Peall

Prof. Tom Warner

### Registered Office

3<sup>rd</sup> Floor

89 Albert Embankment

London

SE1 7TP

### Independent Examiner

Michael Williams ACA

30 Retford Drive

Sutton Coldfield

B76 1DG

### Bankers

CAF Bank

Kings Hill

West Malling

Kent ME19 4TA

Bank of Scotland

14/16 Cockspur Street

London SW1Y 5B

## **Objectives & Activities**

The trustees, who are also the directors of the company, submit their report and the financial statements of The Dystonia Society ("the Society") for the year ended 31 March 2025 on the basis of the accounting policies set out in Note 1 to the financial statements, and comply with the requirements of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial reporting Standard in the UK and Republic of Ireland (FRS102) (effective 1 January 2015) (Charities SORP, FRS102). The reference and administrative information on the previous page forms part of this report.

## **Principal Objective**

The Society, as derived from the objects set out in our Articles of Association, are to promote the welfare of people who living with any form of the neurological movement disorder known as dystonia, or from similar or related conditions and to advance the education of the public about all aspects of the said conditions. Under our operating name of Dystonia UK, we provide support and information for our community both nationally and locally. We are the only national charity dedicated to supporting people with dystonia throughout the UK.

## **About Dystonia UK**

We are the only national charity dedicated to supporting people living with dystonia across the UK.

Dystonia is a neurological movement disorder estimated to affect at least 100,000 people in the UK. It is the third most common movement disorder. Dystonia is caused by incorrect signals from the brain resulting in uncontrollable muscle spasms, which can, for some, be painful. It can affect any region of the body. Dystonia is a lifelong condition, which can affect both adults and children, and currently has no cure. There are several treatments available that can help relieve the symptoms and scientists around the world are actively pursuing research toward new therapies.

Established in 1983 as The Dystonia Society, by a small group of people living with dystonia, in 2019 we rebranded to become Dystonia UK to better reflect our growing community. For over 40 years we have worked with the dystonia community, never forgetting our founders' aim to support all people living with dystonia. Being a patient led organisation is still at the heart of our ambitions today and we currently have 13 local support groups run by volunteers from the community and a membership of 1454 including 11 lifetime members.

We remain committed to our mission:

***"We exist to give hope and support to everyone living with dystonia and to create UK and worldwide awareness."***

## Review of Activity

During year 2024-25 we have continued to evolve to meet the needs of both members and the wider dystonia community. Developed with and for our community, our strategy sets out what we want to achieve. In response in particular to the 2023 Your Voice Heard survey we committed to further development work of our Strategy. To greater serve the dystonia community, our strategic goals for the year were adjusted and have been:

- **Connect our Community**  
Dystonia UK will create a connected community for people living with dystonia that acts as both a source of support and movement for change.
- **Enhance quality care and support**  
Dystonia UK will ensure that no matter who they are or where they come from, everyone living with dystonia receives a timely diagnosis, has access to the best possible information, care, and treatment and has the tools and support to live a good life.
- **Reach Out, Reach All**  
Dystonia UK will reach the whole of the dystonia community across the UK and be an inclusive organisation that is accessible to all. We will ensure that no one who needs our support goes without it.
- **Ensuring our future**  
We will increase revenue by mobilising all communities affected by dystonia, engaging with individuals, corporations, and organisations to accelerate our progress and maximise the impact we make.

The Annual Report of the Trustees for 2024/25 is set out under these four strategic goals.

### Connect our Community

We have continued to build a connected, empowered community for people living with dystonia - one that offers vital support and drives meaningful change through a wide range of activities. This year, we:

- Rebuilt connections after Covid-19 through our local support group networks
- Took awareness to Parliament with an event at the House of Lords
- Continued our commitments to members
- Celebrated our community at The Dystonia UK Awards 2024
- Delivered direct support through our new Hospital Roadshow initiative

### Rebuilding and reconnecting after Covid-19

We greatly invested in our **local support group network** with the appointment of a new Community Project Officer. Thanks to their efforts, several groups that had not met since before the pandemic resumed their activities. We also boosted group visibility through increased marketing, enhanced our volunteer support resources, and reinstated regular coordinator catch-ups to further build relationships and shared learning across our network.

*"I really enjoy the social side of being with others with the same condition; we have all become friends!"*

*- Kent group attendee*

### **Taking awareness to Parliament**

In September, during **Dystonia Awareness Month**, we gathered experts, clinicians, and advocates at the House of Lords for a powerful discussion on how our community can raise its collective voice. This inspiring event helped generate fresh ideas and built momentum for raising awareness as a united community - reminding everyone in the room that dystonia must no longer be overlooked.

### **Championing members**

Our membership remained strong throughout the year, with 1,454 individuals standing with us. We continued to keep members connected and informed through *Dystonia Matters* – our magazine available both digitally and in print. Members also played a direct role in shaping our governance by voting on trustee ratifications, ensuring representation and transparency at the heart of our organisation.

### **Celebrating our community**

We were delighted to host the **Dystonia UK Awards 2024** for the third consecutive year. These awards shine a spotlight on the exceptional individuals making a difference within our community. In front of our largest audience yet, we proudly recognised the winners of the Dystonia Superstar Awards (England, Wales, Scotland and Northern Ireland), the Masked Hero Award, and the Popular Podcast Award. New categories this year included the Young Champion, Fundraiser of the Year, and Volunteer of the Year, helping us to celebrate a wider breadth of contributions from across our network.

### **Delivering direct support**

This year marked the exciting launch of our **Hospital Roadshows** - a brand-new initiative bringing Dystonia UK into NHS hospitals across the country. Our team visited Salford Royal Hospital (Manchester), The Walton Centre (Liverpool), and Shawbirch Medical Centre (Telford), where we reached patients, clinicians, and the public face-to-face, raising awareness, providing trusted information, and creating meaningful connections with those affected by dystonia.

*"You did an excellent job in Manchester at Salford Royal Hospital, Dystonia awareness was well spread that day. A remarkable eye-catching display and sparkling atmosphere. For some it will be the best day of their lives because they have discovered Dystonia UK and that the Manchester group exists."*

*- Elaine, Manchester group member*

**Wherever our community is, we're right there beside them. Together, we are building a stronger, more connected movement for change.**

### **Enhance quality care and support**

Everyone with dystonia deserves answers, access to effective treatment, and support to live life on their own terms. This year, we made real progress, taking your voices to policymakers, shaping clinical conversations, and championing research that puts your needs first. This is how we made impact happen:

- Raised awareness and visibility of dystonia at major clinical events
- Drove change in national policies and promoted best practice
- Supported research putting patients at the centre

### **Promoting the needs of the community**

We renewed our investment in attending exhibitions and conferences to raise awareness among medical professionals and industry leaders. Highlights included:

- Presenting to around 100 clinicians, many of whom specialise in movement disorders, at the British Neurotoxin Network's annual meeting, emphasising the importance of collaboration with patient communities.
- Guest speaking at the East Hants Primary Care Network meeting, sharing best practice with social prescribers, pharmacists, care coordinators, and youth wellbeing coaches.
- Our Director of Operations and Development attending the Association of British Neurologists conference, in partnership with The Neurological Alliance, sharing early insights from the My Neuro Survey.
- Exhibiting at several professional events including the annual conferences of the DBS Nurse Association, the Association of British Neurologists Movement Disorder specialist interest group, and the Royal College of Paediatrics and Child Health.

*"Thanks so much for attending our meeting yesterday-I know the team found it really interesting finding out about dystonia. A few cogs turning regarding patients they see and if dystonia may be something that hasn't been considered."*

*- Hannah, Digital Transformation Lead, East Hants PCN*

### **Influencing national policies**

As the only UK-wide charity representing people living with dystonia, Dystonia UK continues to use its unique position to ensure the voices of those affected are heard at every level of decision-making.

During **Dystonia Awareness Month**, we arranged a key meeting with Dr Niran Nirmalanathan, the National Clinical Director of Neurology at NHS England. This provided an important opportunity to discuss the most urgent priorities facing the dystonia community and to advocate for greater recognition and resourcing.

We continued our strong support for The Neurological Alliance's #BackThe1in6 campaign, which called for a dedicated Neuro Taskforce. That campaign saw a significant success in November, when the new **UK Neuro Forum** was officially announced. We were proud to attend the celebration of this milestone,

where our Patron, Tully Kearney OBE, delivered a powerful keynote speech highlighting the lived experience of dystonia. We were also pleased to continue the impact of this work by attending a workshop in advance of the first UK Neuro Forum meeting providing the opportunity for us to share deeper insights.

Throughout the year, we shared surveys and promoted policy-related events that offered opportunities for the community to speak up and share experiences. A total of 658 people with dystonia completed **My Neuro Survey**, contributing powerful evidence of the need for better services. We were also involved in the survey's steering group, helping to shape its design and inform the communications strategy around its findings, ensuring it reflects the reality of our community's needs.

We worked behind the scenes too. Through our membership in over ten alliances and coalitions, we helped shape responses to national consultations, co-signed open letters, and called directly on ministers to invest in neurological research. We also developed and submitted our own response to the NHS 10-Year Plan, using this as an opportunity to spotlight some of the specific challenges faced by people with dystonia including the urgent need for better workforce planning, improved transitions from paediatric to adult care, and stronger integration between services.

Finally, we took these messages to Parliament. In January, alongside member and Neuro Alliance of Scotland trustee, DK McPhee, we represented the dystonia community at the Neurological Alliance's **Parliamentary Neuro Reception**. There, we spoke to 35 MPs or their representatives, putting the realities of dystonia front and centre in political conversations.

### **Supporting dystonia research**

Our research support spans practical assistance and partnership working to ensure people with dystonia are included in shaping future treatments. We believe research should work for the dystonia community - and this year, we supported projects that do exactly that.

- We helped recruit 201 participants for a **Manchester Metropolitan University** study developing machine-learning imaging for more targeted botulinum toxin treatment.
- Remained involved in the British Paediatric Neurology Association's steering group to set **standards for paediatric dystonia** medication - improving confidence in care for families and clinicians.
- Continued our collaboration with students on the Clinical Psychology doctoral course at Lancaster University, most recently promoting a study exploring the use of self-compassion apps in people with neck dystonia.
- Shared a survey from a group of **UCL Queen Square Institute of Neurology** researchers examining access to physiotherapy services, helping understand barriers and enablers to treatment for our community.

**We will never stop pushing for better diagnosis, better treatment, and better lives for everyone living with dystonia.**

*"I felt it was an afternoon well spent as the research will ultimately lead to the training of more clinicians who understand dystonia and are able to treat it and the ability of medical professionals to build up a library of images of the neck for each patient so that injections will be more effective."*

*- Chris, MMU study participant*

### Reach Out, Reach All

We aim to reach the entire dystonia community across the UK, making sure that whoever you are and wherever you live, you can access our support, so no one has to face dystonia alone. This year we took meaningful action to expand our reach and deepen our impact.

- We magnified the voices of those living with dystonia on national platforms
- We expanded and improved how people access vital information and support
- We ran impactful campaigns to spread the message that *Dystonia Matters*

### Magnifying the voice of the community

People with dystonia often experience stigma and isolation. That's why we used our platform to increase understanding and visibility, ensuring the experiences of our community were heard and seen on a national stage. In 2024, our Director of Fundraising and Communications appeared live on **BBC Breakfast**, bringing dystonia to millions of viewers. We were additionally featured in *The Guardian* during Brain Awareness Week, and our digital reach soared with our social media content viewed 302,359 times and 109,074 visitors to our website over the year. These moments helped more people than ever understand what dystonia is - and why support matters.

*"Well done Dystonia UK! Brilliant job on awareness of dystonia."*

*- Lisa, Online member*

### Enhancing information delivery

Our *Reach Out, Reach All* programme continued to modernise how we deliver support and advice, ensuring that our resources remain accessible, inclusive, and available in the format that works best for each person.

- **In-person:** We met people at *Disability Awareness Day* in Warrington and The Brain Charity's open day, *Head Matters*, and continued our local support groups across the UK. These meetups - whether structured or social - create essential spaces for people to share experiences and connect. This year we ran 34 meet ups in 12 counties.
- **In print:** We remained committed to physical resources for those who may be digitally excluded. Our *Dystonia Matters* magazine, regular mailings, and the widely distributed *What is Dystonia?* booklet helped keep the community informed and supported. We additionally

invested more resource into clinical outreach to ensure our materials are distributed to patients more regularly when attending clinics.

- **Online:** Our website remained the go-to source for information, with over 109,000 views. We were proud to launch Season 4 of our *Dystonia Matters* podcast, sharing the real and honest stories from Rebecca, Emma & Gareth and their daughter Hayley, Jason, Mark, Emma, and Lola.
- **Direct support:** We responded to 561 support enquiries across phone, email, and post, offering personalised guidance to people when they needed it most.

*"Dystonia UK has been a massive support throughout my life. If you have dystonia or know someone, I highly recommend engaging with them and get on their newsletter. They offer friendly support to helpful information about the condition."*

*- Joe, Former podcast guest*

### Amplifying our message

In September, we ran Dystonia Awareness Month 2024 - a powerful reminder of what our community can achieve when we come together with lived experience, expertise, and shared purpose.

Before the campaign began, we launched a brand-new awareness guide packed with tools and templates to help individuals and supporters spread the word locally, ensuring greater impact from our collective awareness raising.

We then launched the month with a reception at the House of Lords, where clinicians, researchers, and industry leaders gathered to explore new ways of raising awareness and improving outcomes. The conversations held there set the tone for a month of action.

Soon after, we joined our incredible #TeamDystoniaUK runners at the Great North Run. Despite the rain, spirits soared as volunteers and supporters cheered them on. Every step taken and every pound raised helped amplify our cause.

Local meetups in the North East, Oxford, Kent, and Lancashire & Fylde showed the importance of peer support. These events offered safe, welcoming spaces for people to connect, share, and feel understood.

We continued our advocacy momentum going - meeting with Dr Niranjanan Nirmalanathan, National Clinical Director for Neurology at NHS England, and speaking at the British Neurotoxin Network meeting in Oxford to highlight issues of access and collaboration.

The month ended on a high note with The Dystonia UK Awards 2024, celebrating the remarkable individuals who inspire and support our community. A standout moment was our Patron, Paralympic Gold Medallist Tully Kearney OBE, sharing her journey to double gold in Paris 2024!

**Throughout the month, and every day of the year, we are proud to stand with and for every person living with dystonia.**

### Ensuring our future

We are building a resilient, sustainable organisation. That means investing in people, partnerships, and infrastructure, and working hand in hand with our community to maximise impact and accelerate progress. This year we:

- Invested in new roles and infrastructure
- Worked with our community and partners to raise vital funds
- Advocated for greater awareness through national collaborations
- Increased recognition of our organisation across sectors

### Investing in our organisation

We established new roles, including our Community Project Officer, which is helping us to develop and grow our support services, volunteer capacity and outreach work. We created a new Communications Officer role and recruited a new Fundraising Officer bringing additional capacity to the team.

We develop staff skills through regular training and this year updated our Induction training to ensure new members of the team are supported in their success. Our directors took part in advanced Safeguarding training and attended the Charity Times Leadership conference. Ensuring that our team can best support our community, this year they attended training on Neurodiversity and to reduce the effects of stress in the workplace we introduced new quarterly Mental Wellbeing sessions.

A remuneration review, benchmarked our current charity salaries against those in other similar sized charities across the sector, taking into account specific roles and responsibilities and making changes as relevant to ensure the charity is a competitor in the sector. Necessary equipment upgrades included updated laptops for some staff providing the team with the tools they needed to carry out their work.

We also deepened our investment in volunteering, beginning development of a volunteer strategy, reinstating coordinator catch-ups, creating new event roles, and recruiting an Office Admin Volunteer. Finally, we proudly welcomed our new Chair, **Q Khan MBE**, who brings deep experience and passion following his work as a Dystonia UK Ambassador.

*"I love attending events where I can get the word out about dystonia. I recently helped a pharmaceutical company in Chester with Dystonia UK to show the employees how their products affect the patients and to answer questions about my experiences with botulinum toxin injections."*

*- Margie, Events volunteer*

### **Working together to fundraise**

Once again, our amazing community played a huge and highly valued role in raising funds to sustain our essential services. We raised a fantastic £35,451 through community fundraising and events. Our Team Dystonia UK runners, including our patron Tully Kearney, OBE, raised all important awareness at the TCS London Marathon. 10 runners also took to the streets of Newcastle, raising £5,579 through the Great North Run. Our 3 runners, the winner of the Dystonia Superstar Award (England), Manoli, alongside Ryan and Mark in memory of Ryan's son Bailey, also took on the Royal Parks Half Marathon raising £3019.

Members of the community also took on some of their own incredible fundraising challenges including the K2B walk raising £2600, Our Fundraiser of the Year, Lola, ventured into the Peak district and having complete a rather impressive 16 miles of walking also raised £710.16

Encouragingly, we have seen strong growth across several other income streams - Facebook fundraising has increased by 233%, donations by 59%, and money raised by groups by 43%. We continued to raise funds through sales of eye-catching merchandise and were pleased to achieve sales of £2041.

Our Spring raffle raised over £1,140 and we were encouraged to see so much engagement from our community. We are grateful to our corporate partners for their support with prizes. We loved joining The Research Club's final networking night of the year, raising awareness and all important funds for Dystonia UK. Huge thanks to Tara and Bob in particular for their support!

Our members continue to extend support to the wider community, raising £34,240 through their generous subscriptions and donations. We are especially grateful too to those who chose to remember us in their wills through legacy gifts.

*"Dystonia UK helped me in so many ways, from telling me that my family and I aren't alone, to supporting me with setting up my fundraising event. On the 7th of August 2024, I left my house and my plan was to do a 15 mile walk in 7 hours, but it ended up 16.41 miles in 5 hours 6 minutes."*

*- Lola, Dystonia UK Fundraiser of the Year 2024*

### **Collaborating for success**

We continued to build strong partnerships across national networks including The Neurological Alliance, The Neurological Alliance of Scotland, Wales Neurological Alliance, Northern Ireland Neurological Charities Alliance, National Voices, The Alliance Scotland, Medical Technology Group, Specialised Health Care Alliance and Disability Benefits Consortium to champion the needs of the dystonia community and influence decision makers.

We deepened our relationships with Pharmaceutical and Medical Tech companies to further advance outcomes for the dystonia community. We were delighted to attend Medtronic's annual conference and welcomed the opportunity for our Director of Fundraising and Communications along with Dystonia UK member, Margie, to speak at Ipsen Pharmaceutical's annual conference on improving access to botulinum toxin services.

We also worked with a number of leading specialist clinical groups including the Association of British Neurologists Movement Disorder specialist group, DBS Nurse Association and British Neurotoxin

network - we are thankful to all of the professionals supporting our involvement in these groups for helping to further our cause. As well, we greatly appreciate the support of our medical advisory group and wider medical networks.

We continued to work with our Patron and Ambassadors and are grateful for their ongoing commitment to use their platforms to improve awareness of dystonia. We were especially grateful to Tully Kearney OBE, who spoke at both The Neurological Alliance AGM and our Awards ceremony, sharing her story of double gold in Paris.

Special thanks to Teresa for sharing her story during our BBC Breakfast appearance, and to all who used our Awareness Raising Guide to support our message: *Dystonia Matters*.

### **Strengthening our visibility**

We expanded our presence at professional events and exhibitions, invested in clinical outreach, and deepened connections through the launch of our Hospital Roadshow initiative. Additionally we sent out monthly e-newsletters and used our social media platforms and website to share updates on our work. These activities strengthened our visibility and reinforced our role as a trusted advocate for the dystonia community.

**Dystonia UK has stood beside the community for over 40 years - and we're building the future to stand strong for decades to come.**

### **Impact**

Our Year in Numbers:

- We estimate **340** people attended one of our meet ups, accessing direct support local to them.
- We reached **141** people through the launch of our Hospital Roadshows initiative.
- **9** winners were celebrated at The Dystonia UK Awards 2024!
- We reached over **400** professionals and members of the public through exhibition stands at conferences and events raising vital awareness.
- **658** people living with dystonia took part in My Neuro Survey.
- We reached at least **29,449** people through our BBC Breakfast interview!
- Our Dystonia Awareness Raising guide was viewed **426** times.
- Our Info Hub, a digital source of information resources received **1,685** visits.
- **30** volunteers supported our work!

Activities mapped against Dystonia UK's objectives				
Activity	Connect our community	Enhance quality care and support	Reach Out, Reach All	Ensure our future
Local support group meet ups	✓		✓	
The Dystonia UK Awards 2024	✓		✓	
Hospital Roadshow initiative	✓	✓	✓	
Dystonia Matters magazine	✓		✓	
Dystonia Matters podcast	✓		✓	
Digital & printed info resources		✓	✓	
Dystonia UK Membership	✓		✓	✓
Dystonia Awareness Month	✓		✓	
Parliamentary afternoon tea	✓	✓		
Attending exhibitions & conferences	✓	✓	✓	
Promoting My Neuro Survey		✓		

Activities mapped against Dystonia UK's objectives				
Activity	Connect our community	Enhance quality care and support	Reach Out, Reach All	Ensure our future
Partnerships with alliances		✓		
Consultation responses & lobbying work		✓		
Supporting research projects		✓		
Press & media work			✓	✓
Responding to enquiries		✓	✓	
Awareness raising guide	✓		✓	
Clinical outreach	✓	✓	✓	✓
E-news and social media presence	✓		✓	✓
Investments in staff and infrastructure				✓
Supporting fundraising				✓

Activities mapped against Dystonia UK's objectives				
Activity	Connect our community	Enhance quality care and support	Reach Out, Reach All	Ensure our future
Collaborating with medical groups		✓		
Partnerships with pharma and med techs		✓		✓
Engagement with Patrons & Ambassadors			✓	

### Our Future Plans

Together with our community, we will continue to build on the progress we have already made. As the only national charity supporting people living with dystonia, we recognise the need to prioritise carefully how our limited resources are used. Our focus will remain on the services and activities that deliver the greatest impact for the dystonia community.

We will amplify our service delivery through targeted investment and new projects. By designing and delivering information resources across a variety of formats (including print, digital and in-person) we will ensure our materials are relevant, inclusive and accessible to the whole dystonia community. We will continue to grow our network of support groups, and by increasing volunteer recruitment and strengthening volunteer resources, we aim to expand our influence and impact in local communities.

We will focus on core operations to ensure people living with dystonia, health professionals and the public receive timely, high-quality support. This includes investment in our infrastructure and IT systems to increase resilience and responsiveness.

Through our Hospital Roadshow initiative we will extend our reach, deepen our understanding of the needs of the dystonia community across the UK, and ensure our information and support services are delivered where they are most needed. At the same time, we will continue to build our medical network and enhance our clinical outreach via events and partnerships.

In research, we will develop our strategy further and create more opportunities for people living with dystonia to become involved. Partnering with universities and through our new Research Network, we will support research that matters to our community.

We will continue to 'Reach Out, Reach All' through targeted activities including those developed to better support people recently diagnosed with dystonia. We will continue to support our members

through *Dystonia Matters* magazine, listen to their feedback and ensure their insights shape our services. People's stories will remain at the heart of our communications, and we will use our platform to magnify their voices.

We will increase public awareness and understanding of dystonia through trusted information and national campaigns, including Dystonia Awareness Month. We will continue to work strategically with our lobbying work. Through collaboration with coalition organisations such as The Neurological Alliances, we will harness the strength of the wider neurological community to ensure dystonia is recognised and understood by policymakers.

We will celebrate our community and supporters, enhancing how we thank, involve and engage them, while focusing on increased income generation to sustain and expand our work. Above all, we will continue to be there for everyone in the dystonia community.

## **Financial Review**

### **Reserves**

The trustees feel it is prudent to maintain the Society's general unrestricted reserves at a level sufficient to cover commitments such as property rental, creditors and other liabilities and to reflect the relative uncertainty of income and potential restrictions on its use. The level of reserves is reviewed as part of the budget setting process and at Board meetings in conjunction with the trustees' review of the financial position.

As the Charity benefited from significant legacy income in 2023/24 and 2024/25, the trustees reviewed The Dystonia Society's reserves policy and designated £410,000 from unrestricted reserves in 2024.

The Board have reviewed this designated reserve and judge that it is appropriate to maintain it in 2024/25.

The level of unrestricted and undesignated reserves at 31st March 2025 represented 45% of unrestricted expenditure in the year (2024 43%).

Certain grants and donations received by the Society are given with for specific projects or initiatives. Restricted funds held in respect of these activities are carried forward if they are unspent or uncommitted. At 31st March 2025, funds of £144,216 were carried forward (2024: £157,315).

### **Investment Policy**

Trustees reviewed the Charity's Investment policy in October 2023. Trustees agreed that their priorities for investing surplus funds are to earn a reasonable return at low risk while being able to access funds immediately if needed.

Trustees approved using a combination of CCLA's COIF Charities Deposit Fund (low-risk money market investments via the UK's leading specialist Charity Fund Manager) and bank deposit facilities to invest legacy income when received.

## **Structure, Governance and Management**

The Society is a company limited by guarantee and is registered with the Charity Commission (Number 1062595) and with the Office of the Scottish Charity Regulator (SC042127). It is constituted by its Memorandum and Articles of Association. In the event of the insolvency of the Society, members can be asked to pay a maximum of £10 towards any unpaid debt.

### **Trustees**

Control of The Dystonia Society is vested in the trustees, each of whom is a member of the Society. All decisions are made by the board of trustees, and at the present time no sub-committees are in operation.

Existing trustees encourage potential trustees to stand for election to maintain an appropriate balance of skills and experience. Where specific skills are needed the recruitment of potential trustees may be expanded to look beyond the current membership. Where there are more candidates than vacancies, trustees are elected by the members at an AGM or by a postal ballot.

Trustees serve for a three-year term and then stand for re-election. A minimum of a third of the trustees stand for re-election each year. If less than a third of the trustees are due for re-election, then those nearest to the expiry of their term stand for re-election. Trustees serve for a maximum of three terms.

A trustee may be appointed by the Board if a vacancy becomes available during the financial year and the trustee would then stand for re-election at the year end. The maximum number of trustees is twelve and the minimum is three. All trustees are given a programme of induction and training. Further training is available when required and relevant.

### **Staff**

The board delegates operational planning and day-to-day management of the charity to the Senior Leadership Team (SLT), supported by the Chair of the Board. The SLT is formed of the Director of Fundraising and Communications and the Director of Operations and Development. This authority is delegated within approved limits. The Chair of the Board oversees the SLT's performance through reports and briefings. The SLT presents reports at board meetings and as part of the planning and budgeting process. The Chair of the Board carries out the appraisals for the SLT annually, on behalf of the board. The chair can involve another trustee in this appraisal work should they wish.

The SLT are supported by a small team of staff. They are a highly motivated team, dedicated to the needs of people with dystonia. We have found that hybrid working is a viable and efficient way of working as it allows staff to work flexibly and adapt appropriately to the needs of the organisation. Some trustees are more actively involved than their governance duties, supporting additional working groups, developing information and support and finance and administration. We are very grateful for this additional support.

### **Remuneration policy**

The trustees have responsibility for setting the pay and remuneration of the charity's key personnel and this is done on an annual basis, including a formal cost of living review. Salaries are benchmarked with other similar organisations across the sector.

### **Membership**

Membership of the organisation is governed by our Articles of Association. Subscribers to the Memorandum and individuals or organisations admitted by the Board of Trustees in accordance with the Articles are recognised as members of the Company and are recorded in the register of members.

#### **Full Membership**

Individuals and organisations may apply for full membership using the form prescribed by the Board of Trustees. The Board has full discretion to accept or decline membership applications and is not required to provide reasons for its decisions. The Board may also establish criteria for membership, though meeting such criteria does not automatically entitle an applicant to membership.

Where a member represents an unincorporated association or body, the register will reflect this representation. The association or body may nominate a replacement representative at any time by notifying the Company, without requiring a new application form or notice from the outgoing representative.

Corporate members must appoint an individual to represent them at meetings of the Company. They may change their representative at any time by notifying the Company.

#### **Associate Membership**

The Board of Trustees may also establish classes of associate membership. Associate members are not members of the Company for the purposes of the Articles or the Companies Acts. The Board determines the rights, obligations, and subscription requirements for each class of associate membership and has discretion to admit or remove associate members in line with agreed regulations.

#### **Membership Records**

We comply with the requirements of the Companies Acts and the Charities Act 1993 in maintaining a register of members and keeping accurate membership records. In accordance with these obligations, we also ensure proper maintenance of financial records, the audit or independent examination of our accounts, and the timely preparation and submission of annual reports, annual returns, and statements of account to both the Registrar of Companies and the Charity Commission.

### **Risk**

The trustees identify and review the major risks to which the Society is exposed and have established appropriate systems to anticipate further risks that may arise. The trustees consider that implementation of agreed actions and procedures will significantly reduce the probability and impact of these risks.

#### **Principal risks & uncertainties**

The most recent review identified the key risks to be financial and external. Financial risks relate to our ability to achieve sufficient income to maintain financial sustainability and meet our commitments. External risks centre on our ability to meet service needs, particularly where these are influenced by factors beyond our control.

It was recognised that our financial risks are largely mitigated by expected legacy income. The Society undertakes careful monitoring of projected cash flows and reserve levels to ensure it can meet its financial responsibilities. External risks are mitigated through detailed strategic planning and informed decision-making. We continue to review our staffing structure to ensure we have the right organisation, capacity, and capabilities in place to deliver our ambitious plans.

## **Public Benefit**

The trustees have referred to the Charity Commission's guidance on public benefit, and the guidance "Meeting the Charity Test" published by the Office of the Scottish Charity Regulator, when reviewing their aims and objectives, and planning the Society's future activity.

## **Statement of trustees' responsibilities**

The trustees (who are also directors of the Society 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 (UK Generally Accepted Accounting Practice (UK GAAP)).

Company law requires the trustees to prepare financial statements for each financial year. Under that law the trustees have elected to prepare the financial statements in accordance with UK GAAP. Under company law, the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and of the surplus or deficit of the charitable company for that period. In preparing those financial statements, the trustees are required to:

- Select suitable accounting policies and then apply them consistently.
- Observe the methods and principles in the Statement of Recommended Practice "Accounting and Reporting by Charities".
- 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 business.

The trustees are responsible for keeping adequate accounting records which are sufficient to show and explain the charitable company's transactions and which 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, the Charities Accounts (Scotland) Regulations 2006 and the charity's constitution. 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 information of which the charitable company's independent examiner is unaware.
- The trustees have taken all steps that they ought to have taken to make themselves aware of any relevant information and to establish that the independent 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.

## **Small company exemption**

This report has been prepared in accordance with the special provisions for small companies under Section 15 of the Companies Act 2006.

### **Thanks**

While it's impossible to name every individual and organisation who has contributed to our work this year, we want to express our sincere appreciation to all who have supported us. We are so grateful for your commitment. In particular, we would like to recognise:

#### **Our Patron & Ambassadors**

We are incredibly fortunate to work alongside a group of dedicated individuals who help raise awareness of dystonia and inspire others to get involved. Special thanks to:

- Tully Kearney, OBE
- Gemma Stevenson
- Ella Middleton

#### **Our Staff & Volunteers**

A sincere thank you to the Society's staff team and volunteers. Their dedication, loyalty and commitment to our cause continues to drive our progress and impact.

#### **Our Medical Network**

We're especially grateful to our medical advisory group and the wider network of professionals who have generously given their time and expertise throughout the year. Your support remains a vital part of our work.

#### **Our Members & Donors**

Thank you to everyone who joined or renewed their membership with Dystonia UK in 2024–25. Every member helps us amplify our voice and extend our reach. We're also truly thankful to all those who have made a donation - your generosity fuels our mission.

#### **Those who remembered Dystonia UK in their Will**

Legacy gifts have once again made a transformative difference, accounting for more than half of our income. We are deeply grateful to everyone who chose to leave a gift in their Will, helping to ensure we can continue supporting those affected by dystonia for years to come.

#### **Our Fundraisers**

A huge thank you to the individuals and groups across the UK and beyond who have taken on fundraising challenges and activities. Your creativity and enthusiasm bring both vital funds and awareness to our cause.

#### **Charitable Trusts & Foundations**

We remain grateful for the continued support of the charitable trusts and foundations who fund our work. Your backing is invaluable.

#### **Companies and other organisations**

Our thanks also go to our corporate supporters and partner organisations. Your contributions and collaborative efforts play a crucial role in helping us deliver our goals.

### **Approval**

This report was approved by the Board of Trustees on 12 November 2025 and signed on its behalf by:

Qamar Khan, MBE  
Chair of Trustees

**The Dystonia Society**  
**Independent Examiner's Report to the trustees of**  
**The Dystonia Society ('the Company')**



I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 March 2025.

**Responsibilities and basis of report**

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under the Charities Act 2011, s145 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under s145(5)(b) of the 2011 Act.

**Independent examiner's statement**

Since the Company's gross income exceeded £250,000 your examiner must be a member of a body listed in s145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am member of the Institute of Chartered Accountants in England and Wales, which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that:

- (1) accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
- (2) the accounts do not accord with those records; or
- (3) the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair view which is not a matter considered as part of an independent examination; or
- (4) the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

A handwritten signature in black ink that reads "Michael A Williams A.C.A.".

Michael A Williams ACA.,  
Chartered Accountant  
30 Retford Drive, Sutton Coldfield, West Midlands, B76 1DG

Date: 16/12/25

	Notes	Restricted funds £	General funds £	Total 2024/25 £	Restricted funds £	General funds £	Total 2023/24 £
<b>Income from</b>							
Donations and subscriptions		814	139,007	139,821	562	154,627	155,189
Grants	14	13,500	39,000	52,500	54,478	54,751	109,229
Legacies and in memoriam gifts		-	213,019	213,019	-	417,059	417,059
<b>Total donations, subscriptions, grants and legacies</b>	<b>3</b>	<b>14,314</b>	<b>391,026</b>	<b>405,340</b>	<b>55,040</b>	<b>626,437</b>	<b>681,477</b>
Other trading activities		-	2,329	2,329	-	1,958	1,958
Investments		-	14,668	14,668	-	8,918	8,918
<b>Total income</b>		<b>14,314</b>	<b>408,023</b>	<b>422,337</b>	<b>55,040</b>	<b>637,313</b>	<b>692,353</b>
<b>Expenditure on</b>							
Raising funds			126,460	126,460		75,741	75,741
Charitable activities	4,14	27,413	248,694	276,107	6,489	239,046	245,535
<b>Total expenditure</b>		<b>27,413</b>	<b>375,154</b>	<b>402,567</b>	<b>6,489</b>	<b>314,787</b>	<b>321,276</b>
<b>Net income/(expenditure)</b>	<b>4</b>	<b>(13,099)</b>	<b>32,869</b>	<b>19,770</b>	<b>48,551</b>	<b>322,526</b>	<b>371,077</b>
Transfers between funds		-			-		-
<b>Net movement in funds</b>		<b>(13,099)</b>	<b>32,869</b>	<b>19,770</b>	<b>48,551</b>	<b>322,526</b>	<b>371,077</b>
<b>Reconciliation of funds</b>							
Total funds brought forward		157,315	544,980	702,295	108,764	222,454	331,218
<b>Total funds carried forward</b>	<b>12</b>	<b>144,216</b>	<b>577,849</b>	<b>722,065</b>	<b>157,315</b>	<b>544,980</b>	<b>702,295</b>

	Notes	31 March 2025	31 March 2024
		£	£
<b>Non-current assets</b>			
Tangible fixed assets	7	-	-
Investment in subsidiary company	7	1	1
<b>Current assets</b>			
Debtors	8	233,557	100,455
Cash at bank and in hand	9	540,928	636,559
		<u>774,485</u>	<u>737,014</u>
<b>Creditors: amounts falling due within one year</b>	10	(52,421)	(34,720)
<b>Net current assets</b>		<u>722,064</u>	<u>702,294</u>
<b>Net assets</b>		<u><b>722,065</b></u>	<u><b>702,295</b></u>
<b>Represented by</b>			
General funds		167,849	134,980
Designated funds		410,000	410,000
<b>Total unrestricted funds</b>		<u><b>577,849</b></u>	<u><b>544,980</b></u>
Restricted funds	14	144,216	157,315
<b>Total funds</b>	12	<u><b>722,065</b></u>	<u><b>702,295</b></u>

The Trustees are satisfied that the Charitable Company is entitled to exemption from the provisions of the Companies Act 2006 (the Act) relating to the audit of the financial statements for the year by virtue of section 477, and that no member or members have requested an audit pursuant to section 476 of the Act.

The Trustees acknowledge their responsibilities for

- (i) ensuring that the charitable company keeps adequate accounting records which comply with section 386 of the Act, and
- (ii) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of the financial year and of its results for the financial year in accordance with the requirements of sections 394 and 395, and which otherwise comply with the requirements of the Act relating to financial statements, so far as applicable to the charitable company.

These financial statements have been prepared in accordance with the special provisions for Small Companies under Part 15 of the Companies Act 2006.

Qamar Khan, MBE  
Chair of Trustees

Robert Semple  
Treasurer

Company Registration Number: 03309777

The notes on pages 27 - 36 form part of these financial statements.

The Dystonia Society  
Statement of cash flows for the year  
ended 31 March 2025



	2025 £	2024 £
<b>Net income/(expenditure) as per the statement of financial activities</b>	<b>19,770</b>	<b>371,077</b>
Adjustments for		
Depreciation charges	-	-
Interest from investments	(14,668)	(8,918)
(Increase)/decrease in debtors	(133,102)	(53,976)
Increase/(decrease) in creditors	17,701	13,376
<b>Net cash generated /(used) in operating activities</b>	<b>(110,299)</b>	<b>321,559</b>
<b>Cash flows from investing activities</b>		
Interest from investments	14,668	8,918
<b>Net cash provided by/(used in) investing activities</b>	<b>14,668</b>	<b>8,918</b>
<b>Net increase/(decrease) in cash and cash equivalents</b>	<b>(95,631)</b>	<b>330,477</b>
Cash and cash equivalents at the beginning of the year	636,559	306,082
<b>Cash and cash equivalents at the end of the year</b>	<b>540,928</b>	<b>636,559</b>
<b>Check total</b>	<b>540,928</b>	<b>636,559</b>

## **1. Accounting policies**

### **a) Basis of preparation of financial statements**

- 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) (effective 1 January 2015), the Companies Act 2006 and the Charities and Trustees Investment (Scotland) Act 2005.
- The Charity constitutes a public benefit entity as defined by FRS 102.
- The accounts include the balances and transactions of 30 of the Society's support groups.
- The preparation of the financial accounts requires the Society's management to make reasonable and prudent judgements, estimates and assumptions that affect the amounts reported for assets and liabilities as at the balance sheet date and the amounts reported for income and expenses during the year. These judgements are detailed in these accounting policies.

### **b) Income**

Income is received by way of grants, donations and subscriptions. The income from fundraising ventures is shown gross in the period in which the event occurs, with the associated costs included in costs of raising funds. From time to time the Society receives donations of goods and services in kind and where there is a measurable material value to the Society, which can be ascertained with reliability, they are included as both income and expenditure. Equipment given for use by the Society is included as a donation at estimated value when received.

Legacy income is included in the period in which it is received, or, if earlier, the period in which the Society receives confirmation of entitlement and amount. If there is uncertainty as to the amount and timing of payment, the legacy is not recognised as income, but disclosed as a contingent asset.

Subscriptions are included in the accounts in the year in which they are received.

Revenue grants are credited to incoming resources on the date they are received or when they are receivable, unless they relate to a specific period, in which case they are deferred.

### **c) Expenditure**

Expenditure is recognised on an accruals basis and includes VAT which the charity cannot recover.

Direct expenditure on charitable activities is allocated to the Society's objectives in five streams of work.

Support costs are allocated to each of the charitable activities (and to the associated restricted funds) based on staff salary costs.

Costs of raising funds relate to expenditure incurred in approaching and facilitating people and organisations to contribute financially to the Society's work.

Grants payable are accounted for when paid or when the Society has, by communicating a commitment, created a valid expectation that it will make future payments.

Those costs shown as governance relate to the management of the Society's assets, organisational administration and compliance with constitutional and statutory requirements.

**d) Pension contributions**

The Society makes contributions to defined contribution personal pension schemes held by employees. Contributions are a percentage of gross salary and are charged to the same restricted or unrestricted funds, and in same the accounting periods, as the related salary costs.

**e) Tangible fixed assets**

Items of equipment are capitalised if their cost exceeds £1,000 and if they have an expected useful life of more than two years. Depreciation is then charged at a uniform rate over that life.

**f) Operating leases**

Rentals applicable to operating leases where substantially all the benefits and risks of ownership remain with the lessor are reflected in the Statement of Financial Activities on a straight-line basis over the period of the lease.

**g) Fund accounting**

Restricted funds are to be used for specific purposes as stated by the donor. Expenditure which meets these criteria is charged to the fund.

Designated funds are unrestricted funds earmarked by the trustees for specific purposes.

Unrestricted funds are donations and other incoming resources receivable or generated for charitable purposes, in line with the objects of the Society, but not restricted to any specific activity.

**h) Financial instruments**

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

**Income and expenditure account**

A separate income and expenditure account has not been prepared as the figures comprising net income for the year shown in the Statement of Financial Activities give the information required under the Companies Act 2006, together with details of other recognised gains and losses.

2	Analysis of income and expenditure by charitable activity	2025		2024	
		Income £	Expenditure £	Income £	Expenditure £
	Awareness and best practice	-	116,340	-	80,660
	Support and information	14,314	156,015	55,040	164,875
	Research	-	3,752	-	-
	<b>Restricted Income and Expenditure on Charitable Activities</b>	<b>14,314</b>	<b>276,107</b>	<b>55,040</b>	<b>245,535</b>
	Unrestricted Income	391,026	-	626,437	-
	Fundraising Expenditure	-	126,460	-	75,741
	<b>Total Income and Expenditure</b>	<b>405,340</b>	<b>402,567</b>	<b>681,477</b>	<b>321,276</b>
	Income is analysed according to restrictions imposed by donors and funders.	-	-	-	-
3	<b>Net incoming resources</b>			<b>2025</b>	<b>2024</b>
	Net incoming resources are stated after charging			£	£
	Operating lease - land and buildings			17,047	16,492
	Independent examiner's fees			1,800	1,800

4	Total resources expended	Support costs	Awareness & best practice	Information & support	Research	Fundraising	Total
		£	£	£	£	£	£
<b>4A</b>	<b>Year to March 2025</b>						
	Employment and training	79,361	64,061	45,292	2,348	56,182	247,244
	Premises and general overheads	46,513	-	1,838	-	-	48,351
	Printing and communications	5,570	5,055	6,019	-	779	17,423
	Independent examination and accountancy	1,800	-	-	-	-	1,800
	Conferences, meetings and travel	7,128	2,120	9,461	-	-	18,708
	Direct project costs	-	1,574	45,286	-	-	46,860
	Fundraising and prize draw expenses	-	-	-	-	22,181	22,181
	Grants awarded/(recovered)	-	-	-	-	-	-
	Apportioned support costs	(140,372)	43,531	48,119	1,404	47,318	-
	<b>Total</b>	-	<b>116,340</b>	<b>156,015</b>	<b>3,752</b>	<b>126,460</b>	<b>402,567</b>
<b>4B</b>	<b>Year to March 2024</b>						
	Employment and training	32,301	34,638	69,922	-	24,887	161,748
	Premises and general overheads	39,491	-	1,549	-	-	41,040
	Printing and communications	4,795	5,401	5,608	-	707	16,511
	Independent examination and accountancy	1,800	-	-	-	-	1,800
	Conferences, meetings and travel	4,142	4,028	1,242	-	-	9,412
	Direct project costs	-	15,446	45,029	-	3,298	63,773
	Fundraising and prize draw expenses	-	-	-	-	26,992	26,992
	Grants awarded/(recovered)	-	-	-	-	-	-
	Apportioned support costs	(82,529)	21,147	41,525	-	19,857	-
	<b>Total</b>	-	<b>80,660</b>	<b>164,875</b>	-	<b>75,741</b>	<b>321,276</b>

<b>5</b>	<b>Staff costs</b>	<b>2025</b>	<b>2024</b>
		<b>£</b>	<b>£</b>
	Salaries and wages	205,430	131,880
	Social security costs	15,941	8,662
	Pension contributions	8,743	6,808
		<b>230,114</b>	<b>147,350</b>
	Staff employed under service contracts	-	-
	Volunteers	1,838	-
	Other employment and training costs	16,793	16,198
	<b>Total employment and training costs</b>	<b>248,745</b>	<b>163,548</b>

The average number of employees during the year was 5.6 (2024: 3.6) of whom 4.8 (2024: 3.1) were full-time. No employee earned more than £60,000 during the year (2024: nil).

The Society contributes to defined contribution personal pension schemes. The assets of these schemes are held separately from those of the Society in independently administered funds. At 31<sup>st</sup> March 2025, the Society owed £1,404 (2024: £891) to these pension schemes.

#### **6 Trustees' remuneration and expenses**

The trustees received no remuneration for their services (2024: nil). Three trustees (2023: four) were reimbursed £826 for travel expenses and other costs (2024: £811).

<b>7</b>	<b>Non-current assets</b>		
	Office equipment and fixtures		
			<b>£</b>
	Cost at 1 April 2024		22,317
	Additions		-
	<b>Cost at 31 March 2025</b>		<b>22,317</b>
	Depreciation at 1 April 2024		22,317
	Charge for the year		
	<b>Depreciation at 31 March 2025</b>		<b>22,317</b>
	Net book value at 1 April 2024		-
	<b>Net book value at 31 March 2025</b>		<b>-</b>
	<b>Investment in subsidiary</b>		
	Investment in Dystonia UK Ltd		1

<b>8</b>	<b>Debtors</b>		
		<b>2025</b>	<b>2024</b>
		<b>£</b>	<b>£</b>
	Prepayments	28,574	11,780
	Other debtors and accrued income	204,983	88,675
		<b>233,557</b>	<b>100,455</b>
<b>9</b>	<b>Cash at bank and in hand</b>	-	-
		<b>2025</b>	<b>2024</b>
		<b>£</b>	<b>£</b>
	Bank investment accounts	417,885	446,059
	Other bank and building society accounts	122,215	189,017
	Petty cash and groups	828	1,483
		<b>540,928</b>	<b>636,559</b>
		-	-
<b>10</b>	<b>Creditors: Amounts falling due within one year</b>		
		<b>2025</b>	<b>2024</b>
		<b>£</b>	<b>£</b>
	Taxation and social security costs	5,013	3,805
	Other creditors	18,507	15,046
	Accruals + Deferred Income	28,901	15,869
		<b>52,421</b>	<b>34,720</b>
<b>11</b>	<b>Commitments under operating leases</b>	-	-
		<b>2025</b>	<b>2024</b>
		<b>£</b>	<b>£</b>
	Office Lease + Service Charge	14,289	12,436

<b>12A</b>	<b>Analysis of net assets between funds (2025)</b>	<b>Restricted funds</b>	<b>Designated funds</b>	<b>General funds</b>	<b>Total funds</b>
		<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>
	Fixed assets	-	-	1	1
	Current assets	167,911	410,000	196,574	774,485
	Creditors	(23,695)	-	(28,726)	(52,421)
		<b>144,216</b>	<b>410,000</b>	<b>167,849</b>	<b>722,065</b>
		-	-	-	-
<b>12B</b>	<b>Analysis of net assets between funds (2024)</b>	<b>Restricted funds</b>	<b>Designated funds</b>	<b>General funds</b>	<b>Total funds</b>
		<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>
	Fixed assets	-	-	1	1
	Current assets	157,315	410,000	169,699	737,014
	Creditors	-	-	(34,720)	(34,720)
		<b>157,315</b>	<b>410,000</b>	<b>134,980</b>	<b>702,295</b>

**13. Contingent liabilities**

No contingent liabilities exist as of 31st March 2025 and the date of this Annual Report & Accounts

**14. Related party transactions**

There have been no related party transactions in the year ending 31st March 2025 (prior year nil)

**Dystonia UK is kids and adults with dystonia, carers and clinicians, fundraisers and families, medical professionals and our amazing members and supporters, all working side by side.**

**Dystonia UK  
89 Albert Embankment  
London  
SE1 7TP**

**020 7793 3651  
[www.dystonia.org.uk](http://www.dystonia.org.uk)**

Dystonia UK is the operating name of The Dystonia Society. The Dystonia Society is registered as a charity in England and Wales (1062595) and in Scotland (SC042127).

**THE DYSTONIA SOCIETY**

England & Wales - Charity number 1062595

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# Accounts

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## The Dystonia Society

A company limited by guarantee

Trustees Report & Financial Statements for the  
year ended 31 March 2024

## Contents

Reference and administrative information	2
Report of the trustees	3 - 15
Independent examiner's report	16
Statement of financial activities	17
Balance sheet	18-19
Statement of cash flows	20
Notes to the financial statements	21-29

## Reference and administrative information

### Charity registration number

1062595 (England and Wales) and SC042127 (Scotland)

### Company registration number

03309777

### Patron

Tully Kearney MBE

### Trustees and Directors

Amit Batla	From November 2023
Daniel Berry	Until September 2023
Emily Birden	From August 2023
Christopher Bradshaw (Chair)	Until 31 <sup>st</sup> March 2024
Timothy Gannicliffe	
Ross Grant	
Qamar Khan, MBE (Chair)	From 1 <sup>st</sup> April 2024
Antonella Macerollo	From November 2023
Nick Morgan	Until June 2023
Sophie Norman	From August 2023
Fernanda Perez	From August 2023
Penny Ritchie Calder MBE	
Andrew Russell	Until July 2023
Robert Semple	
Katie Wells	Until January 2024
James Wishart	Until September 2023

### Secretary

Roger Edmonds FCA

### Medical Advisers

Prof. Mark Edwards  
Mr. Daniel Ezra  
Ms. Lucy Hicklin  
Dr Jean-Pierre Lin  
Dr. Marie-Helene Marion  
Dr. Kathryn Peall  
Prof. Tom Warner

### Registered Office

3<sup>rd</sup> Floor  
89 Albert Embankment  
London  
SE1 7TP

### Independent Examiner

Michael Williams ACA  
30 Retford Drive  
Sutton Coldfield  
B76 1DG

### Bankers

CAF Bank  
Kings Hill  
West Malling  
Kent ME19 4TA

Bank of Scotland  
14/16 Cockspur Street  
London SW1Y 5B

## Objectives & Activities

The trustees, who are also the directors of the company, submit their report and the financial statements of The Dystonia Society ("the Society") for the year ended 31 March 2024 on the basis of the accounting policies set out in Note 1 to the financial statements, and comply with the requirements of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial reporting Standard in the UK and Republic of Ireland (FRS102) (effective 1 January 2015) (Charities SORP, FRS102). The reference and administrative information on the previous page forms part of this report.

## Principal Objective

The Society, as derived from the objects set out in our Articles of Association, are to promote the welfare of people who living with any form of the neurological movement disorder known as dystonia, or from similar or related conditions and to advance the education of the public about all aspects of the said conditions. Under our operating name of Dystonia UK, we provide support and information for our community both nationally and locally. We are the only national charity dedicated to supporting people with dystonia throughout the UK.

## Review of Activity

Our mission is "We exist to give hope and support to those living with dystonia. Creating UK and worldwide awareness." During year 2023-24 we have continued in developing the charity to meet the needs of both members and the wider dystonia community.

Our goals have been:

- **Reach Out, Reach All**  
-Providing support and information for people living with dystonia.
- **Your Voice Heard**  
-Influencing national policies and promoting best practice to meet the needs of the dystonia community
- **Ensuring Dystonia Matters**  
-Raising awareness about dystonia and Dystonia UK
- **Dystonia Research**  
-Supporting research and development for improved treatment and management of dystonia

The Annual Report of the Trustees for 2023/24 is set out under our four strategic goals.

## Reach Out, Reach All

-Providing support and information for people living with dystonia.

Dystonia UK is committed to becoming a more equal, diverse and inclusive organisation. We believe this commitment is key to delivering our strategy, and our organisational mission to be there for the whole dystonia community. Our 'Reach Out, Reach All' programme to improve and modernise the information and advice available for people with dystonia continues to grow and develop. We aim to make information as accessible as possible to people by using a variety of different channels – online, in print and in person.

### In person –

[Dystonia Matters Live 2023](#) was the largest community event for people living with dystonia in the UK. The event brought content usually found in our Dystonia Matters magazine to an audience live. The aim of the event was to support people living with dystonia across the UK with information and to provide an opportunity for them to connect with others.

*"Excellent day, thank you so much for organising it! We spoke to others who felt the same!"*

The event was held over 2 days in Newcastle at the end of June 2023, we hosted around 200 people – a mixture of adult and children with dystonia, family & friends, carers, and professionals. On our 'Main Stage' we hosted an assortment of sessions including interactive workshops, panel discussions and presentations. Our 'Acoustic Stage' was the setting for more informal sessions including live demonstrations, film screenings and deep dive workshops. We had 24 sessions and in total 33 patient & professional speakers.

*"What a fabulous event, thank you to everyone in involved and all the amazing speakers, such an open and honest event."*

We also included a 40<sup>th</sup> anniversary party where we celebrated with our success and impact over the years with members of the community at an 80s themed party.

We continued to run our [local support groups](#) across the country with the support of volunteer group coordinators. With a mix of content, some including more formal speaker sessions and others more social, these small meet ups provide the opportunity for people to share experiences, meet others with dystonia and to find out more about dystonia. In 2023-24, we ran 24 meet ups in 6 counties.

### Online –

Our [website](#) continues to serve as the primary source of information for people looking for information about dystonia with over 209,000 views across the year. Since the launch of our Info Hub in early 2023, we have had 1956 views also. Through our website we were also able to release recordings from Dystonia Matters Live 2023, with the first recording '100,000 voices' receiving nearly 300 views.

Our [webinars](#) enable people to access up to date information without the need to attend conferences or in-person events. Where people can access these in real time there is also an opportunity to put questions to our experts. They are also available on our website and YouTube channel to view later. This year, we hosted a further 4 in the 'Reach Out Reach All' series reaching 1000 views and attendees:

- Get involved with research
- Your Questions Answered with Dr Marie-Helene Marion
- Your Questions Answered with Dr Miles Humberstone
- Your Questions Answered: Dystonia and the cerebellum

*"This webinar has been outstanding. I feel so much more positive. The support out there is amazing!" (Attendee of 'Your Questions Answered with Dr Miles Humberstone)*

In our [Dystonia Matters Podcasts](#), people with dystonia and their families can share their stories in their own words as well as offering useful tips for their listeners. During 2023 we released Series 3 featuring Tajana, Beccy, Katie and Claire and we began releasing Series 4 in 2024 with stories from Rebecca, Hayley, Jason and Mark.

#### [In print –](#)

We continued our commitment to producing printed materials to reach those in particular who could be digitally excluded from information and support. As part of this we distributed our [Dystonia Matters magazine](#) to members 3 times across the year with updates on activities, research and news & stories from the community. We also sent out over 1000 of our '[What is dystonia?](#)' [booklet](#) which includes an overview of dystonia symptoms, causes and the different forms and types of dystonia.

*"Thank you for the amazing booklet on dystonia. My husband who doesn't have dystonia said it was very informative and simple to understand."*

Additionally, we responded to 561 [support enquiries](#) by phone, email and post.

#### [Your Voice Heard](#)

[-Influencing national policies and promoting best practice to meet the needs of the dystonia community.](#)

As the only UK-wide charity representing people living with dystonia, Dystonia UK uses its position to ensure your voice is heard. Our policy work and medical network are an important part of helping to raise awareness of dystonia at governmental and national level to help you get the best possible support, care and treatment. Some of the key work in which we have been involved is summarised below:

- We joined The Neurological Alliance and other member organisation representatives at the #BackThe1in6 petition hand in. - The parliamentary event was attended by 22 MPs or their representatives.
- We attended The Brain Charity's parliamentary drop in event to launch their report 'It's all in your head'. The report focussed on the importance of early diagnosis in neurological conditions and featured a dystonia story.
- We responded to the Major health conditions strategy call for evidence. We noted neurology has not been included in this, although few neurological conditions such as stroke and dementia have. Our response outlined the importance of including neurological communities particularly in the context of co-existing mental health issues (an area that has been included in the strategy).
- We co-signed the National Voices report Vision for the Future of Primary Care.
- We co-signed an open Letter to Secretary of State for Health and Social Care from Huntington's Disease Association on mental health.
- NeuroLifeNow' findings, included experiences of people with dystonia, were used to inform neurology transformation programmes nationally, influence major Government health initiatives and influence healthcare practice. 'NeuroLifeNow' is a social research platform owned by The Brain & Spine Foundation in collaboration with the Neurological Alliance.
- We presented to around 100 clinicians, many of whom specialise in movement disorders, at the British Neurotoxin Network's annual meeting, highlighting the importance of treating non-motor symptoms of dystonia.
- We were asked to contribute to the updates to the NHS inform (Scotland's equivalent of the online NHS condition page) page on dystonia.
- We took part as the patient representative in a NICE Scientific Advice project for Tardive Dyskinesia (TD).

Magnifying the voice of the dystonia community is of vital importance. Too often we hear that delays in diagnosis and treatment or support in education and employment are due to a lack of knowledge and understanding of the condition in its many forms. Our members provide valuable support by responding to surveys and giving their personal stories to provide evidence for the need for change. Throughout the year we have publicised surveys and policy related events to provide opportunities to magnify the voice of our community. We are members of more than 10 organisations working together on issues that will improve lives for people living with dystonia.

## Ensuring Dystonia Matters

### Raising awareness about dystonia and Dystonia UK

It's been 40 years since Dystonia UK was first founded, and the importance of raising awareness of dystonia is still one of our most important goals. 'What is dystonia?' is more than just a question on repeat for our community. It impacts the time to diagnosis, access to treatment and increases stigma and isolation. As part of our mission to combat this every September we run [Dystonia Awareness Month](#) in the UK with the aim to raise as much awareness of dystonia in the general public and across health services. During this month:

- Our social media content was seen 75,175 times
- There were 9846 views of our 'What is dystonia?' mini animation
- We had 10,000 visitors to our website
- We spoke to 30 MPs or their representatives at Houses of Parliament
- 733,731 subscribers were reached through an article in The Telegraph
- We presented to around 100 injectors at the British Neurotoxin Network meeting

Outside of this awareness raising never stops and we continuously push with the dystonia matters movement. We were pleased to support Alliance's across the country with their 'Brain Awareness Week' digital campaign, attend the Dystonia Ireland patient day and Brain Charity's Head Matters day, and also record an interview with the BBC to be aired on BBC Breakfast.

For the second year running we hosted the [Dystonia UK Awards](#). Shining a spotlight on our community, our awards applaud outstanding individuals making a difference to the community. We were delighted to announce the winners of the Dystonia Superstar Award, Masked Hero Award and Popular Podcast Award and at an awards ceremony held during Dystonia Awareness month where we further combined 40<sup>th</sup> anniversary celebrations.

## Dystonia Research

### Supporting research and development for improved treatment and management of dystonia

As a small charity, our support of research is often based around patient recruitment, general guidance and support and dissemination activities. We do this to promote research into dystonia research and to ensure that people with dystonia have opportunities to directly contribute to research as patients or by sharing their own experiences. In addition to this, when we have funds available, we will support projects with a financial contribution. We currently hold funds for research into blepharospasm will be reviewing how best to utilise these funds when resources allow.

Every year we endeavour to support a wide range of support studies that focus on different aspects of dystonia. Examples of activities we have supported this year are:

- Following a pilot study which we funded a couple of years ago, a full study is being conducted by Manchester Metropolitan University with a commercial sponsor. This study is developing computer machine-learning aided imaging of

neck muscles to enable greater accuracy in targeting the correct muscles for botulinum toxin injections. Dystonia UK is supporting this study by publicising the study to recruit the volunteer patients needed for the project.

- We have partnered with the British Paediatric Neurology Association and sit on the steering group for a project designed to establish Consensus Standards for the use of medications in paediatric dystonia. We think that in setting these standards, it will help to improve the quality of care for children with dystonia, and help reassure parents, carers and clinicians alike navigating the dystonia journey that management is on the right track.
- Dystonia UK has a history of working with students on the Clinical Psychology doctoral course at Lancaster University to support their research projects focused on the psychological effects of dystonia. We continue our support with the advertising and dissemination of several projects including most recently 'How are coping strategies used and experienced by people with cervical (neck) dystonia?'.
- We supported international research in attending the Dystonia Medical Research Foundation's 6<sup>th</sup> International Symposium.
- We were also pleased to share a survey from a group of researchers in Ireland examining the use and effectiveness of complementary therapies, such as acupuncture, in focal dystonia.
- Additionally, we were pleased to support Medtronic's event revealing the latest advances in deep brain stimulation devices including the BrainSense™ technology.

## Feedback

In 2023 we surveyed our community on their views of our current services and future needs in our '[Your Voice Heard](#)' survey. We were pleased to capture a broad range of responses and to understand how our service users interact with our support. For example, when we asked respondents how satisfied they were with each of our services, our website and leaflets or booklets performed best with a positive satisfaction rating for each of 82%. We plan to use the full findings to help guide decisions about our future plans and services. We would like to take the opportunity to thank all of the people who took part and shared their views.

## Fundraising

Despite a challenging landscape for the sector, we have had some great successes throughout the year. This is in part due to the increase in legacy donations as well as the increased revenue associated with Dystonia Matters Live 2023. Activities of note include:

- The London Marathon where our runner raised £2305
- The Great North Run where we had 12 runners who raised over £5990
- An increase in Dystonia UK members
- Raising £1020 at The Research Club's black-tie dinner and dance
- An increase in support from Trust and Foundations & Corporate sponsors through their support of Dystonia Matters Live 2023

We would also like to take the opportunity to thank the incredible generosity of people remembering us in their wills through Legacy gifts.

## Our Future Plans

We aim to continue building on what we have achieved over the last few years with a strategy centred on four long term goals:

- [Connect our Community](#)

Dystonia UK will create a connected community for people living with dystonia that acts as both a source of support and movement for change. We will do this through local support groups, national events, and by building our community of members.

- [Enhance quality care & support](#)

Dystonia UK is continually working towards ensuring that no matter who they are or where they come from, everyone living with dystonia receives a timely diagnosis, has access to the best possible information, care, and treatment and has the tools and support to live a good life. We will continue to deliver improved information resources, support research and collaborate with relevant organisations and networks.

- [Reach Out, Reach All](#)

Dystonia UK seeks to reach the whole of the dystonia community across the UK and be an inclusive organisation that is accessible to all. We want to ensure that no one who needs our support goes without it. We will aim to achieve this through maintaining a varied offering of support, clinical outreach and increased public events.

- [Ensure our future](#)

We will endeavour to increase revenue by mobilising all communities affected by dystonia, engaging with individuals, corporations, and organisations to accelerate our progress and maximise the impact we make. We will strive to accomplish this through campaigns, partnerships and increased awareness.

## Financial Review

Our financial position for the year ending 31st March 2024 was a surplus of £371,077 compared to a deficit of £8,363 in the previous year. Income was £692,353 (2023: £277,412) including £414,380 of legacy income (2023: £37,892). These exceptionally generous bequests have allowed the Charity to deliver our services, while investing in the future. Expenditure totalled £321,276 (2023: £285,775). This has increased due to higher level of activity (including Dystonia Matters Live) as well as inflation.

Fundraising continues to be challenging, but the impact that we have achieved from our new initiatives will, we hope, demonstrate the benefit of grants and donations. We will continue to promote the welfare of those living with the impact of dystonia and those who support them. To do this, we need to work to ensure that our income streams enable us to operate at break-even financially without reliance on legacy income. The trustees and staff have agreed a budget which assumes improvement in fundraising from charitable trusts, foundations and corporate sponsorship as well as the continued support of our many members and supporters. They will continue to monitor this income closely and to take action to ensure that reserves are sufficient to ensure that the charity can meet its obligations as they fall due.

## Reserves

The trustees feel it is prudent to maintain the Society's general unrestricted reserves at a level sufficient to cover commitments such as property rental, creditors and other liabilities and to reflect the relative uncertainty of income and potential restrictions on its use. The level of reserves is reviewed as part of the budget setting process and at Board meetings in conjunction with the trustees' review of the financial position.

As the Charity benefited from significant legacy income in 2023/24, the trustees reviewed The Dystonia Society's reserves policy and designated £410,000 (total legacy income received in the year) from unrestricted reserves. This designated fund is made up of 2 elements:

- £350,000 - invested separately post year-end to earn additional income and to support future development of our services for the dystonia community, recognising that the Charity's non-legacy income does not currently cover all its expenditure.
- £60,000 – to be used as a reserve for DM Live in 2025 to be released in the 2025/26 Financial Year ensure that the event can go ahead as planned.

The level of unrestricted and undesigned reserves at 31st March 2024 represented 43% of unrestricted expenditure in the year (2023 97%).

Certain grants and donations received by the Society are given with for specific projects or initiatives. Restricted funds held in respect of these activities are carried forward if they are unspent or uncommitted. At 31st March 2024, funds of £157,315 were carried forward (2023: £108,764).

## Investment Policy

Trustees reviewed the Charity's Investment policy in October 2023. Trustees agreed that their priorities for investing surplus funds are to earn a reasonable return at low risk while being able to access funds immediately if needed.

Trustees approved using a combination of CCLA's COIF Charities Deposit Fund (low-risk money market investments via the UK's leading specialist Charity Fund Manager) and bank deposit facilities to invest legacy income when received.

## Structure, Governance and Management

The Society is a company limited by guarantee and is registered with the Charity Commission (Number 1062595) and with the Office of the Scottish Charity Regulator (SC042127). It is constituted by its Memorandum and Articles of Association. In the event of the insolvency of the Society, members can be asked to pay a maximum of £10 towards any unpaid debt.

### Trustees

Control of The Dystonia Society is vested in the trustees, each of whom is a member of the Society. All decisions are made by the board of trustees, and at the present time no sub-committees are in operation.

Existing trustees encourage potential trustees to stand for election to maintain an appropriate balance of skills and experience. Where specific skills are needed the recruitment of potential trustees may be expanded to look beyond the current membership. Where there are more candidates than vacancies, trustees are elected by the members at an AGM or by a postal ballot. Trustees serve for a three-year term and then stand for re-election. A minimum of a third of the trustees stand for re-election each year. If less than a third of the trustees are due for re-election, then those nearest to the expiry of their term stand for re-election. Trustees serve for a maximum of three terms. A trustee may be appointed by the Board if a vacancy becomes available during the financial year and the trustee would then stand for re-election at the year end. The maximum number of trustees is twelve and the minimum is three. All trustees are given a programme of induction and training. Further training is available when required and relevant.

### Staff

The board delegates operational planning and day-to-day management of the charity to the Senior Leadership Team (SLT), supported by the Chair of the Board. The SLT is formed of the Director of Fundraising and Communications and the Director of Operations and Development. This authority is delegated within approved limits. The Chair of the Board oversees the SLT's performance through reports and briefings. The SLT presents reports at board meetings and as part of the planning and budgeting process. The Chair of the Board carries out the appraisals for the SLT annually, on behalf of the board. The chair can involve another trustee in this appraisal work should they wish.

The SLT are supported by a small team of staff. They are a highly motivated team with dedication to the needs of people with dystonia. We have found that hybrid working is a viable and efficient way of working as it allows staff to work flexibly and adapt

appropriately to the needs of the organisation. Some trustees are more actively involved than their governance duties, supporting in work in responding to enquiries, developing information and support and finance and administration. We are very grateful for this additional support.

## Risk

The trustees identify and review the major risks to which the Society is exposed and have established appropriate systems to anticipate further risks that may arise. The trustees consider that implementation of agreed actions and procedures will significantly reduce the probability and impact of these risks.

### Principal risks & uncertainties

The most recent review identified the key risks to be an Income and financial risk, namely our ability to achieve sufficient fundraising and therefore maintain financial sustainability and People risk, namely our ability to avoid burnout while delivering planned activities.

It was recognised that our financial risk will be mitigated by significant legacy income. The Society undertakes careful monitoring of its projected cash flows and levels of reserves so that it can meet its financial duties. And our people risk will be mitigated by onboarding of new staff. We continue to review our staffing to ensure we have the right organisation, capacity and capabilities to deliver our ambitious plans.

### Public Benefit

The trustees have referred to the Charity Commission's guidance on public benefit, and the guidance "Meeting the Charity Test" published by the Office of the Scottish Charity Regulator, when reviewing their aims and objectives, and planning the Society's future activity.

## Statement of trustees' responsibilities

The trustees (who are also directors of the Society 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 (UK Generally Accepted Accounting Practice (UK GAAP)).

Company law requires the trustees to prepare financial statements for each financial year. Under that law the trustees have elected to prepare the financial statements in accordance with UK GAAP. Under company law, the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and of the surplus or deficit of the charitable company for that period. In preparing those financial statements, the trustees are required to:

- Select suitable accounting policies and then apply them consistently.
- Observe the methods and principles in the Statement of Recommended Practice "Accounting and Reporting by Charities".
- 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 business.

The trustees are responsible for keeping adequate accounting records which are sufficient to show and explain the charitable company's transactions and which 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, the Charities Accounts (Scotland) Regulations 2006 and the charity's constitution. 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 information of which the charitable company's independent examiner is unaware.
- The trustees have taken all steps that they ought to have taken to make themselves aware of any relevant information and to establish that the independent 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.

## Small company exemption

This report has been prepared in accordance with the special provisions for small companies under Section 15 of the Companies Act 2006.

## Thanks

It is sadly not possible to thank every single person or organisation who has supported us, but we hope they are all aware of our huge gratitude. We would like to take the opportunity to give particular thanks to our outgoing Chair, Chris Bradshaw, for the time, dedication and commitment he made to Dystonia UK during his time as both a trustee and Chair. Additionally, we would like to thank:

## Our Patron & Ambassadors

We're privileged to work with many individuals who help us by increasing awareness and encouraging others to support us. Our special thanks go to:

- Tully Kearney, MBE
- Gemma Stevenson
- Ella Middleton

## Our Staff & Volunteers

We are very grateful indeed to the Society's staff team and volunteers. Their loyalty and commitment is invaluable.

## Our Medical Network

We would like to thank our medical advisory group and other professionals who have attended meetings during the year and supported our work. They have donated both their time and expertise which is much appreciated by our members.

## Our Members & Donors

Thank you to everyone who joined Team Dystonia UK or renewed their membership in 2023-24. The more members we have, the bigger the difference we can make and we are appreciative for all of your support. We are also grateful to everyone who supported us with a donation this year.

## Those who remembered Dystonia UK in their Will

Once again, legacies were extremely important to our charity with the gifts we received representing more than half our income. We are enormously grateful to all those people who remember Dystonia UK with a gift in their Will allowing the charity to continue its work and support people living with dystonia.

## Our Fundraisers

Thank you to all the groups and individuals across the UK and beyond for your efforts to raise funds.

## Charitable Trusts & Foundations

We continue to value the generous support of all the grant makers that support Dystonia UK.

## Companies and other organisations

The contribution of our corporate supporters and partnership work remains vital to our success.

The Dystonia Society  
Report of the Trustees for the year ended 31 March  
2024 (Incorporating the Directors' Report)



Approval

This report was approved by the Board of Trustees on 12 November 2024 and signed on its behalf by:



Qamar Khan, MBE  
Chair of Trustees

**The Dystonia Society**  
**Independent Examiner's Report to the trustees of**  
**The Dystonia Society ('the Company')**



I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 March 2024.

**Responsibilities and basis of report**

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under the Charities Act 2011, s145 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under s145(5)(b) of the 2011 Act.

**Independent examiner's statement**

Since the Company's gross income exceeded £250,000 your examiner must be a member of a body listed in s145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am member of the Institute of Chartered Accountants in England and Wales, which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that:

- (1) accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
- (2) the accounts do not accord with those records; or
- (3) the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair view which is not a matter considered as part of an independent examination; or
- (4) the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

*Michael A. Williams*

Michael A Williams ACA.,  
Chartered Accountant  
30 Retford Drive, Sutton Coldfield, West Midlands, B76 1DG

Date: *6 December 2024*

	Notes	Restricted funds £	General funds £	Total 2023/24 £	Restricted funds £	General funds £	Total 2022/23 £
<b>Income from</b>							
Donations and subscriptions		562	154,627	155,189	423	136,571	136,994
Grants	14	54,478	54,751	109,229	47,000	33,274	80,274
Legacies and in memoriam gifts		-	417,059	417,059	(323)	57,950	57,627
<b>Total donations, subscriptions, grants and legacies</b>	<b>3</b>	<b>55,040</b>	<b>626,437</b>	<b>681,477</b>	<b>47,100</b>	<b>227,795</b>	<b>274,895</b>
Other trading activities		-	1,958	1,958	-	1,134	1,134
Investments		-	8,918	8,918	-	1,383	1,383
<b>Total income</b>		<b>55,040</b>	<b>637,313</b>	<b>692,353</b>	<b>47,100</b>	<b>230,312</b>	<b>277,412</b>
<b>Expenditure on</b>							
Raising funds	4		75,741	75,741	-	50,961	50,961
Charitable activities	4,14	6,489	239,046	245,535	56,068	178,746	234,814
<b>Total expenditure</b>		<b>6,489</b>	<b>314,787</b>	<b>321,276</b>	<b>56,068</b>	<b>229,707</b>	<b>285,775</b>
<b>Net income/(expenditure)</b>	<b>4</b>	<b>48,551</b>	<b>322,526</b>	<b>371,077</b>	<b>(8,968)</b>	<b>605</b>	<b>(8,363)</b>
Transfers between funds		-	-	-	-	-	-
<b>Net movement in funds</b>		<b>48,551</b>	<b>322,526</b>	<b>371,077</b>	<b>(8,968)</b>	<b>605</b>	<b>(8,363)</b>
<b>Reconciliation of funds</b>							
Total funds brought forward		108,764	222,454	331,218	117,732	221,849	339,581
<b>Total funds carried forward</b>	<b>12</b>	<b>157,315</b>	<b>544,980</b>	<b>702,295</b>	<b>108,764</b>	<b>222,454</b>	<b>331,218</b>

	Notes	31 March 2024	31 March 2023
		£	£
<b>Non-current assets</b>			
Tangible fixed assets	7	-	-
Investment in subsidiary company	7	1	1
<b>Current assets</b>			
Debtors	8	100,455	46,479
Cash at bank and in hand	9	636,559	306,082
		<u>737,014</u>	<u>352,561</u>
<b>Creditors: amounts falling due within one year</b>	10	(34,720)	(21,344)
<b>Net current assets</b>		<u>702,294</u>	<u>331,217</u>
<b>Net assets</b>		<u><b>702,295</b></u>	<u><b>331,218</b></u>
<b>Represented by</b>			
General funds		134,980	222,454
Designated funds		410,000	-
<b>Total unrestricted funds</b>		<u><b>544,980</b></u>	<u><b>222,454</b></u>
Restricted funds	14	157,315	108,764
<b>Total funds</b>	12	<u><b>702,295</b></u>	<u><b>331,218</b></u>

The Trustees are satisfied that the Charitable Company is entitled to exemption from the provisions of the Companies Act 2006 (the Act) relating to the audit of the financial statements for the year by virtue of section 477, and that no member or members have requested an audit pursuant to section 476 of the Act.

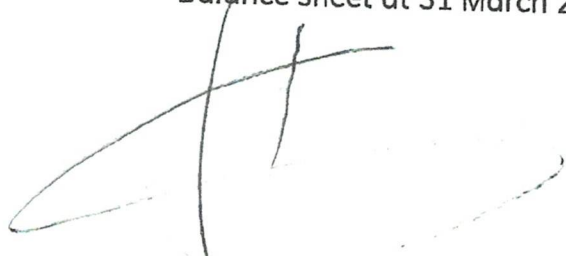
The Trustees acknowledge their responsibilities for

- (i) ensuring that the charitable company keeps adequate accounting records which comply with section 386 of the Act, and
- (ii) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of the financial year and of its results for the financial year in accordance with the requirements of sections 394 and 395, and which otherwise comply with the requirements of the Act relating to financial statements, so far as applicable to the charitable company.

These financial statements have been prepared in accordance with the special provisions for Small Companies under Part 15 of the Companies Act 2006.

The Dystonia Society  
Balance sheet at 31 March 2024

Dystonia  
UK



Qamar Khan, MBE  
Chair of Trustees



Robert Semple  
Treasurer

Company Registration Number: 03309777

The notes on pages 20 to 29 form part of these financial statements.

The Dystonia Society  
Statement of cash flows for the year  
ended 31 March 2024



	2024	2023
	£	£
<b>Net income/(expenditure) as per the statement of financial activities</b>	<b>371,077</b>	<b>(8,364)</b>
Adjustments for		
Depreciation charges	-	-
Interest from investments	(8,918)	(1,383)
(Increase)/decrease in debtors	(53,976)	(28,953)
Increase/(decrease) in creditors	13,376	1,494
<b>Net cash generated /(used) in operating activities</b>	<b>321,559</b>	<b>(37,206)</b>
<b>Cash flows from investing activities</b>		
Interest from investments	8,918	1,383
Purchase of equipment	-	-
<b>Net cash provided by/(used in) investing activities</b>	<b>8,918</b>	<b>1,383</b>
<b>Net increase/(decrease) in cash and cash equivalents</b>	<b>330,477</b>	<b>(35,823)</b>
Cash and cash equivalents at the beginning of the year	306,082	341,905
<b>Cash and cash equivalents at the end of the year</b>	<b>636,559</b>	<b>306,082</b>
<b>Check total</b>	<b>636,559</b>	<b>306,082</b>

## 1. Accounting policies

### a) Basis of preparation of financial statements

- 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) (effective 1 January 2015), the Companies Act 2006 and the Charities and Trustees Investment (Scotland) Act 2005.
- The Charity constitutes a public benefit entity as defined by FRS 102.
- The accounts include the balances and transactions of 30 of the Society's support groups.
- The preparation of the financial accounts requires the Society's management to make reasonable and prudent judgements, estimates and assumptions that affect the amounts reported for assets and liabilities as at the balance sheet date and the amounts reported for income and expenses during the year. These judgements are detailed in these accounting policies.

### b) Income

Income is received by way of grants, donations and subscriptions. The income from fundraising ventures is shown gross in the period in which the event occurs, with the associated costs included in costs of raising funds. From time to time the Society receives donations of goods and services in kind and where there is a measurable material value to the Society, which can be ascertained with reliability, they are included as both income and expenditure. Equipment given for use by the Society is included as a donation at estimated value when received.

Legacy income is included in the period in which it is received, or, if earlier, the period in which the Society receives confirmation of entitlement and amount. If there is uncertainty as to the amount and timing of payment, the legacy is not recognised as income, but disclosed as a contingent asset.

Subscriptions are included in the accounts in the year in which they are received.

Revenue grants are credited to incoming resources on the date they are received or when they are receivable, unless they relate to a specific period, in which case they are deferred.

### c) Expenditure

Expenditure is recognised on an accruals basis and includes VAT which the charity cannot recover.

Direct expenditure on charitable activities is allocated to the Society's objectives in five streams of work.

Support costs are allocated to each of the charitable activities (and to the associated restricted funds) based on staff salary costs.

Costs of raising funds relate to expenditure incurred in approaching and facilitating people and organisations to contribute financially to the Society's work.

Grants payable are accounted for when paid or when the Society has, by communicating a commitment, created a valid expectation that it will make future payments.

Those costs shown as governance relate to the management of the Society's assets, organisational administration and compliance with constitutional and statutory requirements.

d) Pension contributions

The Society makes contributions to defined contribution personal pension schemes held by employees. Contributions are a percentage of gross salary and are charged to the same restricted or unrestricted funds, and in same the accounting periods, as the related salary costs.

e) Tangible fixed assets

Items of equipment are capitalised if their cost exceeds £1,000 and if they have an expected useful life of more than two years. Depreciation is then charged at a uniform rate over that life.

f) Operating leases

Rentals applicable to operating leases where substantially all the benefits and risks of ownership remain with the lessor are reflected in the Statement of Financial Activities on a straight-line basis over the period of the lease.

g) Fund accounting

Restricted funds are to be used for specific purposes as stated by the donor. Expenditure which meets these criteria is charged to the fund.

Designated funds are unrestricted funds earmarked by the trustees for specific purposes.

Unrestricted funds are donations and other incoming resources receivable or generated for charitable purposes, in line with the objects of the Society, but not restricted to any specific activity.

h) Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

### Income and expenditure account

A separate income and expenditure account has not been prepared as the figures comprising net income for the year shown in the Statement of Financial Activities give the information required under the Companies Act 2006, together with details of other recognised gains and losses.



4	Total resources expended	Support costs	Awareness & best practice	Information & support	Research	Fundraising	Total
		£	£	£	£	£	£
<b>4A</b>	<b>Year to March 2024</b>						
	Employment and training	32,301	34,638	69,922	-	24,887	161,748
	Premises and general overheads	39,491	-	1,549	-	-	41,040
	Printing and communications	4,795	5,401	5,608	-	707	16,511
	Independent examination and accountancy	1,800	-	-	-	-	1,800
	Conferences, meetings and travel	4,142	4,028	1,242	-	-	9,412
	Direct project costs	-	15,446	45,029	-	3,298	63,773
	Fundraising and prize draw expenses	-	-	-	-	26,992	26,992
	Grants awarded/(recovered)	-	-	-	-	-	-
	Apportioned support costs	(82,529)	21,147	41,525	-	19,857	-
	<b>Total</b>	-	<b>80,660</b>	<b>164,875</b>	-	<b>75,741</b>	<b>321,276</b>
<b>4B</b>	<b>Year to March 2023</b>						
	Employment and training	25,383	30,814	63,213	-	38,056	157,466
	Premises and general overheads	39,014	-	-	-	3,551	42,565
	Printing and communications	6,468	3,683	28,686	-	1,152	39,989
	Independent examination and accountancy	2,272	-	-	-	-	2,272
	Conferences, meetings and travel	-	3,335	3,134	-	4,938	11,407
	Direct project costs	-	-	28,812	-	-	28,812
	Fundraising and prize draw expenses	-	-	-	-	3,264	3,264
	Grants awarded/(recovered)	-	-	-	-	-	-
	Apportioned support costs	73,137	17,671	31,660	-	23,805	-
	<b>Total</b>	<b>0</b>	<b>55,503</b>	<b>155,505</b>	-	<b>74,766</b>	<b>285,775</b>

<b>5 Staff costs</b>	<b>2024</b>	<b>2023</b>
	<b>£</b>	<b>£</b>
Salaries and wages	131,880	133,537
Social security costs	8,662	8,957
Pension contributions	6,808	7,100
	<b>147,350</b>	<b>149,594</b>
Staff employed under service contracts	-	-
Other employment and training costs	16,198	10,512
<b>Total employment and training costs</b>	<b>163,548</b>	<b>149,594</b>

The average number of employees during the year was 3.6 (2023: 4.1) of whom 3.1 were full-time. No employee earned more than £60,000 during the year (2023: nil).

The Society contributes to defined contribution personal pension schemes. The assets of these schemes are held separately from those of the Society in independently administered funds. At 31<sup>st</sup> March 2024, the Society owed £891 (2023: £827) to these pension schemes.

#### 6 Trustees' remuneration and expenses

The trustees received no remuneration for their services (2023: nil). Four trustees (2023: two) were reimbursed £811 for travel expenses and other costs (2023: £249).

<b>7 Non-current assets</b>	
Office equipment and fixtures	
	<b>£</b>
Cost at 1 April 2023	22,317
Additions	-
<b>Cost at 31 March 2024</b>	<b>22,317</b>
Depreciation at 1 April 2023	22,317
Charge for the year	-
<b>Depreciation at 31 March 2024</b>	<b>22,317</b>
Net book value at 1 April 2023	-
<b>Net book value at 31 March 2024</b>	<b>-</b>
<b>Investment in subsidiary</b>	
Investment in Dystonia UK Ltd	1

<b>8</b>	<b>Debtors</b>		<b>2024</b>	<b>2023</b>
			£	£
	Prepayments		11,780	10,087
	Other debtors and accrued income		88,675	36,392
			<b>100,455</b>	<b>46,479</b>
<b>9</b>	<b>Cash at bank and in hand</b>		-	
			<b>2024</b>	<b>2023</b>
			£	£
	Bank investment accounts		446,059	187,354
	Other bank and building society accounts		189,017	117,039
	Petty cash and groups		1,483	1,689
			<b>636,559</b>	<b>306,082</b>
			-	
<b>10</b>	<b>Creditors: Amounts falling due within one year</b>		<b>2024</b>	<b>2023</b>
			£	£
	Taxation and social security costs		3,805	3,122
	Other creditors		15,046	12,426
	Accruals + Deferred Income		15,869	5,796
			<b>34,720</b>	<b>21,344</b>
<b>11</b>	<b>Commitments under operating leases</b>		-	
			<b>2024</b>	<b>2023</b>
			£	£
	Office Lease + Service Charge		12,436	21,690

12A	Analysis of net assets between funds (2024)	Restricted	Designated	General	Total
		funds	funds	funds	funds
		£	£	£	£
	Fixed assets	-	-	1	1
	Current assets	157,315	410,000	169,699	737,014
	Creditors	-	-	(34,720)	(34,720)
		<b>157,315</b>	<b>410,000</b>	<b>134,980</b>	<b>702,295</b>
12B	Analysis of net assets between funds (2023)	Restricted	General	Total	
		funds	funds	funds	
		£	£	£	
	Fixed assets	-	1	1	
	Current assets	108,764	243,797	352,561	
	Creditors	-	(21,344)	(21,344)	
		<b>108,764</b>	<b>222,454</b>	<b>331,218</b>	

### 13. Contingent liabilities

No contingent liabilities exist as of 31<sup>st</sup> March 2024 and the date of this Annual Report & Accounts

### 14 Related party transactions

There have been no related party transactions in the year ending 31st March 2024 (prior year nil).

		Opening balance	Income	Transfers	Expenditure	Closing balance
		£	£	£	£	£
<b>15A</b>	<b>Movement In Funds (2024)</b>					
	<b>Restricted Funds</b>					
	Awareness and best practice	3,000	-	-	-	3,000
	Information and support	24,499	55,040	-	(6,489)	73,050
	Research	81,265	-	-	-	81,265
		<b>108,764</b>	<b>55,040</b>	-	<b>(6,489)</b>	<b>157,315</b>
	<b>Unrestricted Funds</b>					
	Designated Fund: Legacy Reserve Fund	-	-	410,000	-	410,000
	General Funds	222,454	637,313	(410,000)	(314,787)	134,980
		<b>222,454</b>	<b>637,313</b>	-	<b>(314,787)</b>	<b>544,980</b>
	<b>Total Funds</b>	<b>331,218</b>	<b>692,353</b>	-	<b>(321,276)</b>	<b>702,295</b>
<b>15B</b>	<b>Movement In Funds (2023)</b>					
	<b>Restricted Funds</b>					
	Awareness and best practice	3,000	-	-	-	3,000
	Information and support	33,144	47,423	-	(56,068)	24,499
	Research	81,588	(323)	-	-	81,265
		<b>117,732</b>	<b>47,100</b>	-	<b>(56,068)</b>	<b>108,764</b>
	<b>Unrestricted Funds</b>					
	General Funds	221,849	230,312	-	(229,707)	222,454
		<b>221,849</b>	<b>230,312</b>	-	<b>(229,707)</b>	<b>222,454</b>
	<b>Total Funds</b>	<b>339,581</b>	<b>277,412</b>	-	<b>(285,775)</b>	<b>331,218</b>

**THE DYSTONIA SOCIETY**

England & Wales - Charity number 1062595

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# Accounts

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**THE DYSTONIA SOCIETY**

**Report of the Trustees for the year ended 31 March 2023  
(incorporating the Directors' Report)**

**THE DYSTONIA SOCIETY**

**A company limited by guarantee  
Financial Statements  
31 March 2023**

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2023 (incorporating the Directors' Report)

<b>Contents</b>	<b>Page</b>
Reference and administrative information	2
Report of the trustees	3 - 10
Independent examiner's report	11
Statement of financial activities	12
Balance sheet	13
Statement of cash flows	14
Notes to the financial statements	15 - 20

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2023 (incorporating the Directors' Report)

### Reference and administrative information

#### Patron

Tully Kearney MBE

#### Trustees and Directors

Daniel Berry	
Christopher Bradshaw	Chair
Timothy Gannicliffe	
Nick Morgan	Resigned 6 <sup>th</sup> June 2023
Penny Ritchie Calder MBE	
Andrew Russell	
Robert Semple	
Katie Wells	
James Wishart	
Ross Grant	From 23 <sup>rd</sup> October 2022

#### Secretary

Roger Edmonds FCA

#### Independent Examiner

Michael Williams ACA  
30 Retford Drive  
Sutton Coldfield  
B76 1DG

#### Medical Advisers

Prof. Mark Edwards  
Mr. Daniel Ezra  
Ms. Lucy Hicklin  
Dr Jean-Pierre Lin  
Dr. Marie-Helene Marion  
Dr. Kathryn Peall  
Prof. Tom Warner

#### Bankers

CAF Bank  
Kings Hill  
West Malling  
Kent ME19 4TA

#### Registered Office

3<sup>rd</sup> Floor  
89 Albert Embankment  
London  
SE1 7TP

Bank of Scotland  
14/16 Cockspur Street  
London SW1Y 5BL

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2023 (incorporating the Directors' Report)

The trustees, who are also the directors of the company, submit their report and the financial statements of The Dystonia Society ("the Society") for the year ended 31 March 2023 on the basis of the accounting policies set out in Note 1 to the financial statements, and comply with the requirements of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial reporting Standard in the UK and Republic of Ireland (FRS102) (effective 1 January 2015) (Charities SORP, FRS102). The reference and administrative information on the previous page forms part of this report.

### Principal Objective

The Society was established to promote the welfare of people who live with any form of the neurological movement disorder known as dystonia. Under our operating name of Dystonia UK, we aim to do this by providing information and support, promoting awareness of the disorder and by supporting research. It does this on a national level and through its network of local support groups.

### Review of Activity

**We exist to give hope and support to those living with dystonia. Creating UK and worldwide awareness.**

We are the only national charity dedicated to supporting people with dystonia throughout the UK. During the last year we have continued development of the charity to meet the needs of both members and the wider dystonia community. This has included:

- Providing support and information to the dystonia community
- Developing our website, especially to include a section on Frequently Asked Questions
- Working with partners in the neurological and disability communities so that clinical and support services meet the needs of people living with dystonia
- Developing our 'Reach Out, Reach All' programme with webinars, podcasts and a further episode of Dystonia Animated for children
- Creating mutually beneficial relationships with the major providers of pharmaceuticals and medical devices for the treatment of dystonia
- Enhancing online fundraising and awareness raising
- Ensuring that the voice of the dystonia community is heard as part of policy developments in the NHS and other public services

### Ensuring Dystonia Matters

As the only UK-wide charity representing people living with dystonia, Dystonia UK uses its influence to get the best possible support, care and treatment, and to make their voice heard. Our policy work and medical network are an important part of helping to raise awareness of dystonia at governmental and national level.

- Your Voice was Heard – 8510 people took part in the Neurological Alliance's 'My Neuro Survey' including 753 people living with dystonia.
- The report from the National Neuro Advisory Group on 'Neurology Outcomes' published following our involvement in their 2021 event.
- We responded to the Department of Health and Social Care's consultation on the acquired brain injury strategy.
- Dystonia UK took part in the 'Mind You Listen' campaign with the Neurological Alliance of Scotland focussed on people living with neurological conditions and the one thing they wished people understood about their condition.

## THE DYSTONIA SOCIETY

### Report of the Trustees for the year ended 31 March 2023 (incorporating the Directors' Report)

- We promoted and signed the petition asking UK governments #BackThe1in6 and set up a neuro taskforce – the petition has been supported by over 19,000 people affected by neurological disorders and 100 organisations and was presented to the Department of Health and Social Care in June 2023.
- We participated in a workshop to help form a response with the Neurological Alliance to the Health and Care Select Committee inquiry into Integrated Care Systems autonomy and accountability. Our focus was to highlight less-common conditions like dystonia and make sure these don't get missed in representation.
- We provided feedback to the Neurological Alliance of Scotland for a response to the Mental Health Wellbeing Strategy.
- In response to the 'My Neuro Survey' findings, the Welsh Governments' Neurological Conditions Implementation Group has incorporated the key themes into their priorities and pledged to set up several working groups on improving early diagnosis, service delivery, neuro-rehabilitation and neuro-psychiatry.
- We shared the findings of the 'My Neuro Survey' with over 100 clinicians at the British Neurotoxin Network highlighting the gaps in service for people living with dystonia.
- We co-signed letters with partner charities to the Chancellor on the need for urgent action to support people affected by neurological conditions such as dystonia due to the cost of living crisis.
- A new Optimal Clinical Pathway for Movement Disorders including dystonia has been developed by the National Neurosciences Advisory Group and Association of British Neurologists with input from Dystonia UK and many members of our medical network.
- Our annual Awareness Month in September 2023 continued to raise awareness of Dystonia through a variety of events across the UK from landmark light ups, webinars, podcasts, and picnics.

Raising the voice of the dystonia community is of vital importance. Too often we hear that delays in diagnosis and treatment or support in education and employment are due to a lack of knowledge and understanding of the condition in its many forms. Our members provide valuable support by responding to surveys and giving their personal stories to provide evidence for the need for change. Throughout the year, we have publicised over 15 surveys and policy related events. We are members of more than 10 organisations working together on issues that will improve lives for people living with dystonia.

#### **'Reach Out, Reach All'**

Our programme to improve and modernise the information and advice available for people with dystonia continues to grow and develop. We aim to make information as accessible as possible to people by using a variety of different channels – online, in print and in person.

**Our updated website** has become the primary source of information for people looking for information about dystonia. It provides a platform on which people are able to search for information, see videos and listen to podcasts. The section of 'Frequently Asked Questions' makes it much easier for people looking for information to find exactly what they need. We continue to add information to the website based on new clinical insights and in response to enquiries that people make to us.

**Our webinars** enable people to access up to date information without the need to attend conferences or in-person events. Where people can access these in real time there is also an opportunity to put questions to our experts. They are also available on our website and YouTube channel to view later. Series 2 included topics on sleep and dystonia, mental health issues when living with dystonia, as well as Q&A sessions with medical professionals.

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2023 (incorporating the Directors' Report)

In our **Dystonia Matters Podcasts**, people with dystonia and their families can share their stories in their own words as well as offering useful tips for their listeners. We are now into Season 3 with 14 podcasts in total available on our website. These are publicised both through our social media and e-newsletter with more still to come.

We have continued to develop the acclaimed 'Dystonia Animated' series, a new animation for children about dystonia, treatment in childhood and transitioning to adulthood for both treatment and educational support. Episode 3, 'Sam's Surgery Story', was launched in January 2023 at Alder Hey Children's Hospital in Liverpool and describes the journey to receiving deep brain stimulation (DBS) surgery. All the animations in this series have been sponsored by our pharmaceutical and medical industry partners, the latest being thanks to funding from Boston Scientific.

Work is continuing on new booklets for distribution to clinics as well as supporting our awareness raising activities. Like other clinical information, these are all reviewed by our medical advisers before publication. The first of these has already been issued. The booklets help people living with dystonia at different stages of their journey:

- What Is Dystonia? includes an overview of dystonia symptoms, causes, and the different forms and types of dystonia.
- Just Diagnosed with Dystonia offers practical information for those who have been recently diagnosed including where to find support.
- Treatments For Dystonia provides an overview of the main treatments used to help manage dystonia.

### Raising awareness and fundraising

We continue to be supported by many loyal members and donors along with several charitable trusts and foundations. This support creates a base on which we can build our other fundraising initiatives. Fundraising not only provides the essential funds to enable us to operate but also enables us to increase awareness of dystonia.

Fundraising continues to be challenging for charities like Dystonia UK. Although many of the challenge events that were paused due to coronavirus constrictions have resumed, levels of giving have been affected by the impact of cost of living increases. The small team of staff also limits the amount of direct support that we can give to fundraisers.

Much of our fundraising efforts have been centred on Dystonia Awareness Month in September which we try to give a festival vibe with activities including Dystonia Around the World, the first national Dystonia UK Awards, and the team on tour around the UK to promote our activities.

We held our Dystonia Matters Live 2023 conference in Newcastle in June. High profile events like this are important in bringing together people living with dystonia, clinicians, corporate sponsors and other stakeholders. While many members and supporters are not able to attend in person, they provide material that can be published on our website or in other ways to disseminate information and raise awareness.

### Research

As a small charity, our support of research is often based around patient recruitment, general guidance and support and dissemination activities. We do this to ensure that dystonia research can take place and to ensure that people with dystonia have opportunities to directly contribute to research as patients or by sharing their own experiences. In addition to this, when we have funds available, we will support projects with a financial contribution. We currently hold funds for research into blepharospasm will be reviewing how best to utilise these funds when resources allow.

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2023 (incorporating the Directors' Report)

Every year we endeavour to support a wide range of support studies that focus on different aspects of dystonia, for example treatments, causes, types of dystonia and psychological elements of the condition. Some examples of activities we have supported are:

PRIME-VR2, a research project developing bespoke virtual reality controllers and games for people with dystonia or a hyperkinetic movement disorder that affects their hands and arms. The aim is to understand how well commercial VR controllers and games work for people with dystonia. It is led by the Global Disability Innovation Hub and the UCL Computer Science department.

Following a pilot study which we funded a couple of years ago, a full study is being conducted by Manchester Metropolitan University with a commercial sponsor. This study is developing computer machine-learning aided imaging of neck muscles to enable greater accuracy in targeting the correct muscles for botulinum toxin injections. Dystonia UK is supporting this study by publicising the study to recruit the volunteer patients needed for the project.

We have also awarded a discretionary grant to researchers at UCL for a study on the genetic predictors of efficacy of direct brain stimulation treatment (DBS). Although this can be a highly effective treatment, there is still a wide variability in response, and genetic factors are suspected of playing a role. The aim of this study is thus to evaluate the role of genetics in the efficacy of DBS.

We are also supporting a study investigating the lived experiences of psychological distress in neck dystonia. This study aims to look at the challenges faced by individuals with neck dystonia and to highlight the need for increased psychological support. This study is being conducted by a Doctoral clinical psychologist student at Lancaster University.

### Staff and Trustees

The loyalty and commitment of our staff is greatly appreciated. They are a highly motivated team with dedication to the needs of people with dystonia. We have found that working from home is a viable and efficient way of working as it allows staff to work flexibly. However, we continue to use our office for administration and some meetings.

Senior staff report on a day-to-day basis to the Chair of Trustees, with other trustees being actively involved in supporting our work in responding to enquiries, engaging with strategic partners, supporting groups, fundraising and administration. Without this commitment, given the small number of employed staff, we could not achieve our objectives.

### Future plans

Our aim is to continue building on what we have achieved over the last few years. However, we have limited resources so a priority is to increase income to a level that will enable us to increase our capacity. Meanwhile, we must ensure that our resources are used in the most efficient and effective way to achieve the maximum impact.

Awareness raising and campaigning for change – building on our collaboration with the neurological alliances of England, Scotland, Wales & Northern Ireland and other charities to ensure that the voice of people with dystonia is recognised by health commissioners, providers, government and other agencies.

'Reach Out, Reach All' – ensuring that our resources are relevant and accessible to the whole dystonia community. We will continue producing information in a variety of formats to support people with dystonia. This will include further webinars and podcasts, further printed information for use in hospital clinics as well as responding to enquiries and updating our website with additional information.

## **THE DYSTONIA SOCIETY**

### **Report of the Trustees for the year ended 31 March 2023 (incorporating the Directors' Report)**

Social networks - we will work with group leaders and coordinators so that they can support the charity's work better at a local level. We will continue the development of social media for networking and sharing information.

Research – we will look at ways in which the restricted funds that we have received can support clinicians undertaking research that has the greatest benefit to our community.

#### **Financial Review**

Our financial position for the year ending 31st March 2023 was a deficit of £8,363 compared to a surplus of £30,775 in the previous year. Income was £277,412 (2022: £293,052). Grant income from corporate sources increased but this was offset by lower funding from charitable trusts and lower legacy income. Expenditure of £285,775 (2022 £262,278) was increased due to higher level of activity as well as inflation.

Fundraising continues to be challenging, but the impact that we have achieved from our new initiatives will, we hope, demonstrate the benefit of grants and donations. We will continue to promote the welfare of those living with the impact of dystonia and those who support them. To do this, we need to work to ensure that our income streams enable us to operate at break-even financially without reliance on legacy income. That said, the Charity has benefited from generous legacies in the past and in the next financial year and these are still essential in supporting our work. The trustees and staff have agreed a budget which assumes improvement in fundraising from charitable trusts, foundations and corporate sponsorship as well as the continued support of our many members and supporters, but also a level of legacy income. Nevertheless, they will continue to monitor this income closely and to take action to ensure that reserves are sufficient to ensure that the charity can meet its obligations as they fall due.

#### **Reserves**

The trustees feel it is prudent to maintain the Society's general unrestricted reserves at a level sufficient to cover commitments such as property rental, creditors and other liabilities and to reflect the relative uncertainty of income and potential restrictions on its use. The level of reserves is reviewed monthly in conjunction with the trustees' review of the financial position. The trustees have not designated any of the unrestricted reserves for specific future activities.

The level of unrestricted reserves at 31st March 2023 represented 97% of expenditure in the year (2022: 94%).

Certain grants and donations received by the Society are given for specific projects or initiatives. Funds held in respect of these activities are carried forward if they are unspent or uncommitted. At 31st March 2023, funds of £108,764 were carried forward (2022: £117,732) following receipt of a significant restricted legacy.

#### **Investment Policy**

The Society does not have currently sufficient resources to make long term investments. Surplus funds are held in deposit facilities so that they remain accessible to meet our operational needs.

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2023 (incorporating the Directors' Report)

### Structure, Governance and Management

The Society is a company limited by guarantee and is registered with the Charity Commission (Number 1062595) and with the Office of the Scottish Charity Regulator (SC042127). It is constituted by its Memorandum and Articles of Association. In the event of the insolvency of the Society, members can be asked to pay a maximum of £10 towards any unpaid debt.

Control of The Dystonia Society is vested in the trustees, each of whom is a member of the Society. All decisions are made by the board of trustees, and at the present time no sub-committees are in operation.

Existing trustees encourage potential trustees to stand for election to maintain an appropriate balance of skills and experience. Where specific skills are needed the recruitment of potential trustees may be expanded to look beyond the current membership. Where there are more candidates than vacancies, trustees are elected by the members at an AGM or by a postal ballot. Trustees serve for a three-year term and then stand for re-election. A minimum of a third of the trustees stand for re-election each year. If less than a third of the trustees are due for re-election, then those nearest to the expiry of their term stand for re-election. Trustees serve for a maximum of three terms. A trustee may be appointed by the Board if a vacancy becomes available during the financial year and the trustee would then stand for re-election at the year end. The maximum number of trustees is twelve and the minimum is three. We aim to give new trustees a programme of induction and training. Further training is available when required and relevant.

### Risk

The trustees identify and review the major risks to which the Society is exposed and have established appropriate systems to anticipate further risks that may arise. The trustees consider that implementation of agreed actions and procedures will significantly reduce the probability and impact of these risks.

The most recent review identified the key risk to be its ability to achieve sufficient fundraising and therefore maintain financial sustainability. However, it was recognised that this will be mitigated by significant legacy income in the next financial year. The Society undertakes careful monitoring of its projected cash flows and levels of reserves so that it can meet its financial duties.

### Public Benefit

The trustees have referred to the Charity Commission's guidance on public benefit, and the guidance "Meeting the Charity Test" published by the Office of the Scottish Charity Regulator, when reviewing their aims and objectives, and planning the Society's future activity.

## THE DYSTONIA SOCIETY

### Report of the Trustees for the year ended 31 March 2023 (incorporating the Directors' Report)

#### Statement of trustees' responsibilities

The trustees (who are also directors of the Society 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 (UK Generally Accepted Accounting Practice (UK GAAP)).

Company law requires the trustees to prepare financial statements for each financial year. Under that law the trustees have elected to prepare the financial statements in accordance with UK GAAP. Under company law, the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and of the surplus or deficit of the charitable company for that period. In preparing those financial statements, the trustees are required to

- Select suitable accounting policies and then apply them consistently
- Observe the methods and principles in the Statement of Recommended Practice "Accounting and Reporting by Charities"
- 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 business

The trustees are responsible for keeping adequate accounting records which are sufficient to show and explain the charitable company's transactions and which 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, the Charities Accounts (Scotland) Regulations 2006 and the charity's constitution. 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 information of which the charitable company's independent examiner is unaware
- The trustees have taken all steps that they ought to have taken to make themselves aware of any relevant information and to establish that the independent examiner 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.

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2023 (incorporating the Directors' Report)

### Small company exemption

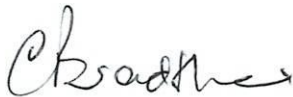
This report has been prepared in accordance with the special provisions for small companies under Section 15 of the Companies Act 2006.

### Thanks

We are very grateful indeed to the Society's staff team, volunteers, donors and fundraisers, to the charitable trusts and corporate partners that have given grant funding, and to clinicians and other professionals who have attended meetings or provided advice and guidance during the year, donating their time and expertise. Their support is very much appreciated.

### Approval

This report was approved by the Board of Trustees on 8 December 2023 and signed on its behalf by



Chris Bradshaw

Chair of Trustees

## **Independent Examiner's Report to the trustees of The Dystonia Society ('the Company')**

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 March 2023.

### **Responsibilities and basis of report**

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under the Charities Act 2011, s145 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under s145(5)(b) of the 2011 Act.

### **Independent examiner's statement**

Since the Company's gross income exceeded £250,000 your examiner must be a member of a body listed in s145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am member of the Institute of Chartered Accountants in England and Wales, which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that:

- (1) accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
- (2) the accounts do not accord with those records; or
- (3) the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair view which is not a matter considered as part of an independent examination; or
- (4) the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



Michael A Williams ACA.  
Chartered Accountant  
30 Retford Drive  
Sutton Coldfield  
West Midlands  
B76 1DG

8<sup>th</sup> December 2023

**THE DYSTONIA SOCIETY**

**Statement of financial activities for the year ended 31 March 2023**

	Notes	Restricted funds £	General funds £	Total 2022/23 £	Restricted funds £	General funds £	Total 2021/22 £
<b>Income from</b>							
Donations and subscriptions		423	136,571	136,994	670	142,364	143,034
Grants	14	47,000	33,274	80,274	20,000	44,800	64,800
Legacies and in memoriam gifts		-323	57,950	57,627	66,488	16,055	82,543
<b>Total donations, subscriptions, grants and legacies</b>	<b>3</b>	<b>47,100</b>	<b>227,795</b>	<b>274,895</b>	<b>87,158</b>	<b>203,219</b>	<b>290,377</b>
Other trading activities		0	1,134	1,134	0	2,644	2,644
Investments		0	1,383	1,383	0	31	31
<b>Total income</b>		<b>47,100</b>	<b>230,312</b>	<b>277,412</b>	<b>87,158</b>	<b>205,895</b>	<b>293,052</b>
<b>Expenditure on</b>							
Raising funds	4	0	50,961	50,961	0	54,210	54,210
Charitable activities	4,14	56,068	178,746	234,814	26,167	181,901	208,068
<b>Total expenditure</b>		<b>56,068</b>	<b>229,707</b>	<b>285,775</b>	<b>26,167</b>	<b>236,111</b>	<b>262,278</b>
<b>Net income/(expenditure)</b>	<b>4</b>	<b>-8,968</b>	<b>605</b>	<b>-8,363</b>	<b>60,991</b>	<b>-30,217</b>	<b>30,774</b>
Transfers between funds		0	0	0	0	0	0
<b>Net movement in funds</b>		<b>-8,968</b>	<b>605</b>	<b>-8,363</b>	<b>60,991</b>	<b>-30,217</b>	<b>30,774</b>
<b>Reconciliation of funds</b>							
Total funds brought forward		117,732	221,849	339,581	56,741	252,066	308,807
<b>Total funds carried forward</b>	<b>12</b>	<b>108,764</b>	<b>222,454</b>	<b>331,218</b>	<b>117,732</b>	<b>221,849</b>	<b>339,580</b>

# THE DYSTONIA SOCIETY

## Balance sheet at 31 March 2023

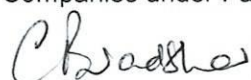
	Notes	31 March 2023	31 March 2022
		£	£
<b>Non-current assets</b>			
Tangible fixed assets	7	0	0
Investment in subsidiary company	7	1	1
<b>Current assets</b>			
Debtors	8	46,479	17,526
Cash at bank and in hand	9	306,082	341,905
		<b>352,561</b>	<b>359,431</b>
<b>Creditors: amounts falling due within one year</b>	10	<b>-21,344</b>	<b>-19,851</b>
<b>Net current assets</b>		<b>331,217</b>	<b>339,580</b>
<b>Net assets</b>		<b>331,218</b>	<b>339,581</b>
<b>Represented by</b>			
General funds		221,849	252,066
I&E		605	-30,216
Designated funds		0	0
<b>Total unrestricted funds</b>		<b>222,454</b>	<b>221,849</b>
Restricted funds	14	108,764	117,732
<b>Total funds</b>	12	<b>331,218</b>	<b>339,581</b>

The Trustees are satisfied that the Charitable Company is entitled to exemption from the provisions of the Companies Act 2006 (the Act) relating to the audit of the financial statements for the year by virtue of section 477, and that no member or members have requested an audit pursuant to section 476 of the Act.

The Trustees acknowledge their responsibilities for

- (i) ensuring that the charitable company keeps adequate accounting records which comply with section 386 of the Act, and
- (ii) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of the financial year and of its results for the financial year in accordance with the requirements of sections 394 and 395, and which otherwise comply with the requirements of the Act relating to financial statements, so far as applicable to the charitable company.

These financial statements have been prepared in accordance with the special provisions for Small Companies under Part 15 of the Companies Act 2006.



Chris Bradshaw  
Chair



Robert Semple  
Treasurer

Company Registration Number: 03309777

The notes on pages 14 to 20 form part of these financial statements

# THE DYSTONIA SOCIETY

## Statement of cash flows for the year ended 31 March 2023

	2023	2022
	£	£
<b>Net income/(expenditure) as per the statement of financial activities</b>	<b>-8,363</b>	<b>30,774</b>
Adjustments for		
Depreciation charges	0	0
Interest from investments	-1,383	-31
(Increase)/decrease in debtors	-28,953	17,252
Increase/(decrease) in creditors	1,493	-14,012
<b>Net cash generated /(used) in operating activities</b>	<b>-37,206</b>	<b>33,983</b>
<b>Cash flows from investing activities</b>		
Interest from investments	1,383	31
Purchase of equipment	0	0
<b>Net cash provided by/(used in) investing activities</b>	<b>1,383</b>	<b>31</b>
<b>Net increase/(decrease) in cash and cash equivalents</b>	<b>-35,823</b>	<b>34,014</b>
Cash and cash equivalents at the beginning of the year	341,905	307,891
<b>Cash and cash equivalents at the end of the year</b>	<b>306,082</b>	<b>341,905</b>
<b>Check total</b>	<b>306,082</b>	<b>341,905</b>

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2023

### 1 Accounting policies

#### a) Basis of preparation of financial statements

- 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) (effective 1 January 2015), the Companies Act 2006 and the Charities and Trustees Investment (Scotland) Act 2005.
- The Charity constitutes a public benefit entity as defined by FRS 102.
- The accounts include the balances and transactions of 30 of the Society's support groups.
- The preparation of the financial accounts requires the Society's management to make reasonable and prudent judgements, estimates and assumptions that affect the amounts reported for assets and liabilities as at the balance sheet date and the amounts reported for income and expenses during the year. These judgements are detailed in these accounting policies.

#### b) Income

Income is received by way of grants, donations and subscriptions. The income from fundraising ventures is shown gross in the period in which the event occurs, with the associated costs included in costs of raising funds. From time to time the Society receives donations of goods and services in kind and where there is a measurable material value to the Society, which can be ascertained with reliability, they are included as both income and expenditure. Equipment given for use by the Society is included as a donation at estimated value when received. Legacy income is included in the period in which it is received, or, if earlier, the period in which the Society receives confirmation of entitlement and amount. If there is uncertainty as to the amount and timing of payment, the legacy is not recognised as income, but disclosed as a contingent asset.

Subscriptions are included in the accounts in the year in which they are received.

Revenue grants are credited to incoming resources on the date they are received or when they are receivable, unless they relate to a specific period, in which case they are deferred.

#### c) Expenditure

Expenditure is recognised on an accruals basis and includes VAT which the charity cannot recover.

Direct expenditure on charitable activities is allocated to the Society's objectives in five streams of work.

Support costs are allocated to each of the charitable activities (and to the associated restricted funds) based on staff salary costs.

Costs of raising funds relate to expenditure incurred in approaching and facilitating people and organisations to contribute financially to the Society's work.

Grants payable are accounted for when paid or when the Society has, by communicating a commitment, created a valid expectation that it will make future payments.

Those costs shown as governance relate to the management of the Society's assets, organisational administration and compliance with constitutional and statutory requirements.

#### d) Pension contributions

The Society makes contributions to defined contribution personal pension schemes held by employees. Contributions are a percentage of gross salary and are charged to the same restricted or unrestricted funds, and in same the accounting periods, as the related salary costs.

#### e) Tangible fixed assets

Items of equipment are capitalised if their cost exceeds £1,000 and if they have an expected useful life of more than two years. Depreciation is then charged at a uniform rate over that life.

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2023

### f) Operating leases

Rentals applicable to operating leases where substantially all the benefits and risks of ownership remain with the lessor are reflected in the Statement of Financial Activities on a straight-line basis over the period of the lease.

### g) Fund accounting

Restricted funds are to be used for specific purposes as stated by the donor. Expenditure which meets these criteria is charged to the fund.

Designated funds are unrestricted funds earmarked by the trustees for specific purposes.

Unrestricted funds are donations and other incoming resources receivable or generated for charitable purposes, in line with the objects of the Society, but not restricted to any specific activity.

### h) Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

## 2 Income and expenditure account

A separate income and expenditure account has not been prepared as the figures comprising net income for the year shown in the Statement of Financial Activities give the information required under the Companies Act 2006, together with details of other recognised gains and losses.



# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2023

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# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2023

<b>5 Staff costs</b>	<b>2023</b>	<b>2022</b>
	<b>£</b>	<b>£</b>
Salaries and wages	133,537	138,856
Social security costs	8,957	9,121
Pension contributions	7,100	6,018
	<b>149,594</b>	<b>153,995</b>
Staff employed under service contracts	-	-
Other employment and training costs	-	-
<b>Total employment and training costs</b>	<b>149,594</b>	<b>153,995</b>

The average number of employees during the year was 4.1 (2022: 4.1) of whom 3.1 were full-time. The full-time equivalent was 3.9. (2022: 3.9), No employee earned more than £60,000 during the year (2022: nil).

The Society contributes to defined contribution personal pension schemes. The assets of these schemes are held separately from those of the Society in independently administered funds. At 31<sup>st</sup> March 2023, the Society owed £827 (2022: £983) to these pension schemes.

### 6 Trustees' remuneration and expenses

The trustees received no remuneration for their services (2022: nil). Two trustees (2022: none) were reimbursed £249 for travel expenses and other costs (2022: nil).

<b>7 Non-current assets</b>		
Office equipment and fixtures		<b>£</b>
Cost at 1 April 2022		22,317
Additions		-
<b>Cost at 31 March 2023</b>		<b>22,317</b>
Depreciation at 1 April 2022		22,317
Charge for the year		-
<b>Depreciation at 31 March 2023</b>		<b>22,317</b>
Net book value at 1 April 2022		-
<b>Net book value at 31 March 2023</b>		<b>-</b>

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2023

<b>8</b>	<b>Debtors</b>			
		<b>2023</b>	<b>2022</b>	
		£	£	
	Prepayments	10,087	10,028	
	Other debtors and accrued income	36,392	7,498	
		<b>46,479</b>	<b>17,526</b>	
<b>9</b>	<b>Cash at bank and in hand</b>			
		<b>2023</b>	<b>2022</b>	
		£	£	
	Bank investment accounts	187,354	186,078	
	Other bank and building society accounts	117,039	153,679	
	Petty cash and groups	1,689	2,148	
		<b>306,082</b>	<b>341,905</b>	
<b>10</b>	<b>Creditors: Amounts falling due within one year</b>			
		<b>2023</b>	<b>2022</b>	
		£	£	
	Taxation and social security costs	3,122	3,406	
	Other creditors	12,426	13,403	
	Accruals	5,796	3,042	
		<b>21,344</b>	<b>19,851</b>	
<b>11</b>	<b>Commitments under operating leases</b>			
		<b>2023</b>	<b>2022</b>	
		£	£	
	Office Lease + Service Charge	21,690	14,363	
<b>12</b>	<b>Analysis of net assets between funds</b>			
		<b>Restricted</b>	<b>General</b>	<b>Total</b>
		<b>funds</b>	<b>funds</b>	<b>funds</b>
		£	£	£
	Fixed assets	-	1	1
	Current assets	108,764	243,797	352,561
	Creditors	-	21,344	-21,344
		<b>108,764</b>	<b>222,454</b>	<b>331,218</b>

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended

### 31 March 2023

#### 13. Contingent liabilities

No contingent liabilities exist as of 31<sup>st</sup> March 2023 and the date of this Annual Report & Accounts.

<b>14</b>	<b>Activity on restricted funds</b>	<b>Opening balance</b>	<b>Income</b>	<b>Transfers</b>	<b>Expenditure</b>	<b>Closing balance</b>
		<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>
	Awareness and best practice	3,000	-	-	-	3,000
	Information and support	33,144	47,423	-	-56,068	24,499
	Research	81,588	- 323	-	0	81,265
		<b>117,732</b>	<b>47,100</b>	<b>0</b>	<b>-56,068</b>	<b>108,764</b>

#### 15 Related party transactions

There have been no related party transactions in the year ending 31st March 2023 (prior year nil).

**THE DYSTONIA SOCIETY**

England & Wales - Charity number 1062595

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# Accounts

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**THE DYSTONIA SOCIETY**

**Report of the Trustees for the year ended 31 March 2022  
(incorporating the Directors' Report)**

**THE DYSTONIA SOCIETY**

**A company limited by guarantee  
Financial Statements  
31 March 2022**

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2022 (incorporating the Directors' Report)

<b>Contents</b>	<b>Page</b>
Reference and administrative information	2
Report of the trustees	3 - 10
Independent examiner's report	11
Statement of financial activities	12
Balance sheet	13
Statement of cash flows	14
Notes to the financial statements	15 - 20

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2022 (incorporating the Directors' Report)

### Reference and administrative information

#### Patron

Tully Kearney

#### Trustees and Directors

Daniel Berry	
Christopher Bradshaw	Chair
Timothy Gannicliffe	
Nick Morgan	From 1 <sup>st</sup> March 2021
Penny Ritchie Calder MBE	
Andrew Russell	From 1 <sup>st</sup> March 2021
Robert Semple	From 1 <sup>st</sup> March 2021
Ian Silvester	Resigned 14 <sup>th</sup> January 2022
Katie Wells	From 1 <sup>st</sup> March 2021
James Wishart	
Andy Young	Resigned 20 <sup>th</sup> June 2021

#### Secretary

Roger Edmonds FCA

#### Medical Advisers

Prof. Mark Edwards  
Mr. Daniel Ezra  
Ms. Lucy Hicklin  
Dr Jean-Pierre Lin  
Dr. Marie-Helene Marion  
Dr. Kathryn Peall  
Prof. Tom Warner

#### Registered Office

3<sup>rd</sup> Floor  
89 Albert Embankment  
London  
SE1 7TP

#### Independent Examiner

Michael Williams ACA  
30 Retford Drive  
Sutton Coldfield  
B76 1DG

#### Bankers

CAF Bank  
Kings Hill  
West Malling  
Kent ME19 4TA

Bank of Scotland  
14/16 Cockspur Street  
London SW1Y 5BL

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2022 (incorporating the Directors' Report)

The trustees, who are also the directors of the company, submit their report and the financial statements of The Dystonia Society ("the Society") for the year ended 31 March 2022 on the basis of the accounting policies set out in Note 1 to the financial statements, and comply with the requirements of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial reporting Standard in the UK and Republic of Ireland (FRS102) (effective 1 January 2015) (Charities SORP, FRS102). The reference and administrative information on the previous page forms part of this report.

### Principal Objective

The Society was established to promote the welfare of people who living with any form of the neurological movement disorder known as dystonia. The Society aims to do this by providing information and support, promoting awareness of the disorder and by supporting research. It does this on a national level and through its network of local support groups.

### Review of Activity

## **We exist to give hope and support to those living with dystonia. Creating UK and worldwide awareness.**

Under our operating name of Dystonia UK, we are the only national charity dedicated to supporting people with dystonia throughout the UK. During the last year and in spite of the continuing impact that the Covid-19 pandemic had on our activities, we have made significant progress in developing the charity to meet the needs of both members and the wider dystonia community. This has included:

- Providing support and information to the dystonia community
- Developing our website, especially to include a section on Frequently Asked Questions
- Working with partners to ensure that clinical services meet the needs of people living with dystonia
- Developing our Reach Out Reach All programme with webinars, podcasts and a further episode of Dystonia Animated for children
- Creating mutually beneficial partnerships with the major providers of pharmaceuticals and medical devices for the treatment of dystonia
- Enhancing online fundraising and awareness raising
- Ensuring that the voice of the dystonia community is heard as part of policy developments in the NHS

### Covid-19 pandemic

The pandemic has directly affected the way in which we can operate as a charity for a second year. Events have been postponed as they were either not allowed by restrictions or not safe for people with dystonia. These restrictions continued to have an impact on our fundraising as challenge events such as marathons were cancelled and the many smaller activities within groups could not take place.

Our staff continue to work from home most of the time. Virtual meetings using Zoom are the norm, both within the staff team and with our partner organisations. Trustee meetings also take place using Zoom.

### Ensuring Dystonia Matters

As the only UK-wide charity representing people living with dystonia, Dystonia UK uses its influence to get the best possible support, care and treatment, and to make their voice heard. Our policy work and

## THE DYSTONIA SOCIETY

### Report of the Trustees for the year ended 31 March 2022 (incorporating the Directors' Report)

medical network are an important part of helping to raise awareness of dystonia at governmental and national level. Some of the key work in which we have been involved is summarised below:

- British Paediatric Neurology Association training survey launched to gather insights into the impact of paediatric consultant neurologists.
- 'NeuroLifeNow' findings, included experiences of people with dystonia, was shared with ministers at the Department of Health and Social Care. 'NeuroLifeNow' is a social research platform owned by The Brain & Spine Foundation in collaboration with the Neurological Alliance. Early data was also presented to nearly 100 health and care professionals and NHS managers working in neurological services and shared with the NHS England and NHS Improvement outpatient and neuroscience transformation teams.
- We ensured the updated 'Suspected Neurological Conditions Quality Standard' published by NICE (The National Institute for Health and Care Excellence) featured the recognition of dystonia symptoms.
- National Voices 'Unlocking the digital front door – keys to inclusive healthcare' report launched featured case studies from people with dystonia.
- The Neurological Alliance's 'Clearing the backlog caused by the pandemic' report was published after consultation with Dystonia UK and input from our medical advisers.
- We presented to around 100 clinicians, many of whom specialise in movement disorders, at the British Neurotoxin Network's annual meeting, highlighting the feedback that we receive from people about issues with injection clinics and access to treatment.
- The Neurological Alliance of Scotland report on virtual consultations featured feedback from Dystonia UK.
- We participate in the organisation of the Neurological Alliance's 'My Neuro Survey', the UK's largest survey of people living with neurological conditions. We will analyse information from the hundreds of people living with dystonia to shape our policy work in the future.
- We provided evidence for the report 'Building the foundations for change: The impact of the Welsh Government's Neurological Delivery Plan – A cross-party Group on Neurological Conditions Inquiry'.
- Dystonia UK provided examples of how people living with dystonia experience integration in health and social care with the Department of Health and Social Care and No.10 policy unit.
- We continue to be involved in development work with the National Neuro Advisory Group for a new movement disorder optimum clinical pathway.
- We have provided input to the Disability Benefits Consortium legal challenge against the Department for Work and Pensions regarding discrimination against disabled people during the pandemic and also responses to 'Shaping Future Support: The Health and Disability Green Paper'.

Raising the voice of the dystonia community is of vital importance. Too often we hear that delays in diagnosis and treatment or support in education and employment are due to a lack of knowledge and understanding of the condition in its many forms. Our members provide valuable support by responding to surveys and giving their personal stories to provide evidence for the need for change.

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2022 (incorporating the Directors' Report)

### Reach Out Reach All

Our programme to improve and modernise the information and advice available for people with dystonia continues to grow and develop. We aim to make information as accessible as possible to people by using a variety of different channels – online, in print and in person.

**Our updated website** has become the primary source of information for people looking for information about dystonia. It provides a platform on which people are able to search for information, see videos and listen to podcasts. During the year we have added a section of Frequently Asked Questions. Since they launched in July 2021 there have been over 6,800 views of our FAQs. The top three most viewed questions are: What should I do if I think I have dystonia? Who can I talk to for support? and Can I drive with dystonia?

**Our webinars** enable people to access up to date information without the need to attend conferences or in-person events. Where people can access these in real time there is also an opportunity to put questions to our experts. They are also available on our website and YouTube channel to view later. We have now hosted seven webinars in our Reach Out Reach All series:

- Dystonia During The Pandemic with Dr Marie-Helene Marion
- Taking Control Of Your Dystonia – A Physiotherapy Focus with Richmond Stace and Sally Glover
- Your Questions Answered: 2 sessions with Prof Mark Edwards
- Understanding Personal Independence Payments with Janet Ireland from The Brain Charity
- Your Questions Answered: Dr Tom Gilbertson live from Dundee as part of Dystonia Awareness Month
- Your Questions Answered – A kids, carers and families edition with Dr Dan Lumsden and Mr John Ellenbogen

And some fun sessions – our Strictly Specials with John Whaite and Fun Fitness Special led by Tennis No Boundaries

In our **Dystonia Matters Podcasts**, people with dystonia and their families can share their stories in their own words as well as offering useful tips for their listeners. There are now 6 podcasts in the series:

- Episode 1: Faces Of The Dystonia Community – Louise, Katie and Andy
- Episode 2: Working With Dystonia – Gemma and Nick
- Episode 3: Parents and carers – Sylvia, Neil and Julie
- Episode 4: Fundraising brings communities together – Tim, Bethany and DK
- Episode 5: Awareness raising – Karl, Sarah, Graham and Carol
- Episode 6: Dystonia and mental health – Lucy and Dylan

We are continuing to develop the acclaimed Dystonia Animated series, a new animation for children about dystonia, treatment in childhood and transitioning to adulthood for both treatment and educational support.

- Episode 1: Dani Explains Dystonia was launched at our online conference Dystonia Matters Digital: For Kids, Carers & Families in March 2021.
- Episode 2: Charlie at the Children's Hospital was launched in Liverpool as part of Dystonia Awareness Month in September 2021.

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2022 (incorporating the Directors' Report)

Dystonia Animated relies entirely on the support of grants to fund production costs. The first two episodes have been funded by grants from the Coronavirus Community Support Fund (distributed by the National Lottery Community Fund), and from our industry supporters Merz, Boston Scientific and IPSEN. It is great to have the pharmaceutical and medical device companies supporting the dystonia community in this way.

Brand new booklets have been developed for distribution to clinics as well as supporting our awareness raising activities. Like other clinical information, these are all reviewed by our medical advisers before publication. The first of these has already been issued. The booklets help people living with dystonia at different stages of their journey:

- "What Is Dystonia" includes an overview of dystonia symptoms, causes, and the different forms and types of dystonia.
- "Just Diagnosed with Dystonia" offers practical information for those who have been recently diagnosed including where to find support.
- "Treatments For Dystonia" provides an overview of the main treatments used to help manage dystonia.

### Fundraising

We continue to be supported by many loyal members and donors along with several charitable trusts and foundations. This support creates a base on which we can build our other fundraising initiatives. Fundraising not only provides the essential funds to enable us to operate but also enables us to increase awareness of dystonia.

Over the last year, many activities were still restricted due to Covid-19. However, some events were possible including a cycle ride from Land's End to John O'Groats, the Great North Run, London and Belfast Marathons, and a fantastic swim from Gosport to Ryde on the Isle of Wight by the Solent Dolphins. Our own community events have been developed to provide fundraising opportunities throughout the year from 'Picnic and Play' in late spring, 'Dystonia Around The World' in summer, and 'One4all' in the winter.

### Research

Although no new research funding has been granted this year, we have received a significant legacy for research into blepharospasm. During the next year, we will be reviewing how best to utilise these funds.

In addition to financial support, we also highlight research activities for which clinicians and academics are recruiting patients. such as a virtual reality project at UCL, and we are supporting a service study by neurologists on the effects of the lockdown and delays in injection cycles on patients. This is an observation study using established survey forms coordinated by the Walton Centre in Liverpool.

### Staff and Trustees

The loyalty and commitment of our staff is greatly appreciated. They are a highly motivated team with dedication to the needs of people with dystonia. Due to the on-going Covid-19 restrictions during the year, everyone has continued working from home.

Senior staff report on a day to day basis to the Chair of Trustees, with other trustees being actively involved in supporting our work in responding to enquiries, engaging with strategic partners, supporting groups, fundraising and administration. Without this commitment, given the small number of employed staff, we could not achieve our objectives.

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2022 (incorporating the Directors' Report)

### Plans for the coming year

Our aim to continue building on what we have achieved over the last two years.

Awareness raising and lobbying for change – building on our collaboration with the neurological alliances and other charities to ensure that the voice of people with dystonia is recognised by health commissioners, providers, government and other agencies. This is especially important changes take place in the structure of the NHS in England with the development of Integrated Care Systems and Primary Care Networks.

Reach Out Reach All – ensuring that our resources are relevant and accessible to the whole dystonia community. We will continue producing information in a variety of formats to support people with dystonia. This will include further webinars and podcasts, new animations aimed at children with dystonia, further information leaflets for use in hospital clinics as well as responding to enquiries, and updating our website with additional information.

Social networks - we will work with group leaders and coordinators so that they can support the charity's work better at a local level. We will continue the development of social media for networking and sharing information.

Research - we aim to make a call for a new research proposal into blepharospasm using the restricted legacy that has been received.

### Financial Review

Our financial position for the year ending 31st March 2022 was a surplus of £30,774 compared to a surplus of £111,875 in the previous year. Income was £293,052 (2021: £421,975). Reduced income was mainly due to lower legacy income and the grant from the National Lottery Community Fund (NLCF) in 2021 not being repeated. The latter also led to lower expenditure of £262,278 (2020 £310,100).

Fundraising continues to be challenging, but the impact that we have achieved from our new initiatives will, we hope, demonstrate the benefit of grants and donations. We will continue to promote the welfare of those living with the impact of dystonia and those who support them. To do this, we need to ensure our income streams enable us to operate at break-even financially without reliance on legacy income and the trustees have agreed a budget on this basis which depends on improvement in fundraising from charitable trusts, foundations and corporate sponsorship as well as the continued support of our many members and supporters. Trustees consider that increased income is realistically attainable as it is less than was achieved historically. Nevertheless, they will continue to monitor this income closely and to take action to ensure that reserves are sufficient to ensure that the charity can meet its obligations as they fall due.

### Reserves

The trustees feel it is prudent to maintain the Society's general unrestricted reserves at a level sufficient to cover commitments such as property rental, creditors and other liabilities and to reflect the relative uncertainty of income and potential restrictions on its use. The level of reserves is reviewed monthly in conjunction with the trustees' review of the financial position. The trustees have not designated any of the unrestricted reserves for specific future activities.

## **THE DYSTONIA SOCIETY**

### **Report of the Trustees for the year ended 31 March 2022 (incorporating the Directors' Report)**

The level of unrestricted reserves at 31st March 2022 represented 94% of expenditure in the year (2021 104%). We would expect reserves to continue to reduce unless further significant legacy income were to be received.

Certain grants and donations received by the Society are given for specific projects or initiatives. Funds held in respect of these activities are carried forward if they are unspent or uncommitted. At 31st March 2022, funds of £117,733 were carried forward (2021: £56,741) following receipt of a significant restricted legacy.

#### **Investment Policy**

The Society does not have sufficient resources to make long term investments. Surplus funds are held in deposit facilities however interest rates on such facilities are currently very low.

#### **Structure, Governance and Management**

The Society is a company limited by guarantee and is registered with the Charity Commission (Number 1062595) and with the Office of the Scottish Charity Regulator (SC042127). It is constituted by its Memorandum and Articles of Association. In the event of the insolvency of the Society, members can be asked to pay a maximum of £10 towards any unpaid debt.

Control of The Dystonia Society is vested in the trustees, each of whom is a member of the Society. All decisions are made by the board of trustees, and at the present time no sub-committees are in operation.

Existing trustees encourage potential trustees to stand for election to maintain an appropriate balance of skills and experience. Where specific skills are needed the recruitment of potential trustees may be expanded to look beyond the current membership. Where there are more candidates than vacancies, trustees are elected by the members at an AGM or by a postal ballot. Trustees serve for a three-year term and then stand for re-election. A minimum of a third of the trustees stand for re-election each year. If less than a third of the trustees are due for re-election, then those nearest to the expiry of their term stand for re-election. Trustees serve for a maximum of three terms. A trustee may be appointed by the Board if a vacancy becomes available during the financial year and the trustee would then stand for re-election at the year end. The maximum number of trustees is twelve and the minimum is three. We aim to give new trustees a programme of induction and training. Further training is available when required and relevant.

#### **Risk**

The trustees identify and review the major risks to which the Society is exposed and have established appropriate systems to anticipate further risks that may arise. The trustees consider that implementation of agreed actions and procedures will significantly reduce the probability and impact of these risks.

The most recent review identified the key risk to be its ability to achieve sufficient fundraising in light of the Covid-19 pandemic and therefore maintain financial sustainability. The Society undertakes careful monitoring of its projected cash flows and levels of reserves so that it can meet its financial duties.

#### **Public Benefit**

The trustees have referred to the Charity Commission's guidance on public benefit, and the guidance "Meeting the Charity Test" published by the Office of the Scottish Charity Regulator, when reviewing their aims and objectives, and planning the Society's future activity.

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2022 (incorporating the Directors' Report)

### Statement of trustees' responsibilities

The trustees (who are also directors of the Society 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 (UK Generally Accepted Accounting Practice (UK GAAP)).

Company law requires the trustees to prepare financial statements for each financial year. Under that law the trustees have elected to prepare the financial statements in accordance with UK GAAP. Under company law, the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and of the surplus or deficit of the charitable company for that period. In preparing those financial statements, the trustees are required to

- Select suitable accounting policies and then apply them consistently
- Observe the methods and principles in the Statement of Recommended Practice "Accounting and Reporting by Charities"
- 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 business

The trustees are responsible for keeping adequate accounting records which are sufficient to show and explain the charitable company's transactions and which 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, the Charities Accounts (Scotland) Regulations 2006 and the charity's constitution. 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 information of which the charitable company's independent examiner is unaware
- The trustees have taken all steps that they ought to have taken to make themselves aware of any relevant information and to establish that the independent 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.

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2022 (incorporating the Directors' Report)

### Small company exemption

This report has been prepared in accordance with the special provisions for small companies under Section 15 of the Companies Act 2006.

### Thanks

HRH Princess Alexandra discontinued many of her patronages during the year, including that of The Dystonia Society. We appreciate the support that she has given over many years and wish her well for the future.

We are very grateful indeed to the Society's staff team, volunteers, donors and fundraisers, to the charitable trusts, corporate partners that have given grant funding, and to clinicians and other professionals who have attended meetings during the year, donating their time and expertise. Their support is very much appreciated by our members.

### Approval

This report was approved by the Board of Trustees on 4<sup>th</sup> August 2022 and signed on its behalf by



Chris Bradshaw

Chair of Trustees

## THE DYSTONIA SOCIETY

# Independent Examiner's Report to the trustees of The Dystonia Society ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 March 2022.

### Responsibilities and basis of report

As the charity's trustees of the Company (who are also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited for this year under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

### Independent examiner's statement

The Company's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of the Institute of Chartered Accountants in England and Wales (ICAEW).

I have completed my examination. I confirm that no material matter has come to my attention which gives me cause to believe that:

- accounting records were not kept in accordance with section 386 of the 2006 Act; or
- the accounts do not accord with such records; or
- the accounts do not comply with the relevant accounting requirements under section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair view which is not a matter considered as part of an independent examination; or
- the accounts have not been prepared in accordance with the Charities SORP (FRS102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

*Michael A Williams*

Michael A Williams  
Chartered Accountant  
30 Retford Drive  
Sutton Coldfield  
West Midlands  
B76 1DG

Date: *21 December 2022*

**THE DYSTONIA SOCIETY**

**Statement of financial activities for the year ended 31 March 2022**

	Notes	Restricted funds	General funds	Total 2021/22	Restricted funds	General funds	Total 2020/21
		£	£	£	£	£	£
<b>Income from</b>							
Donations and subscriptions		670	142,364	143,034	565	133,988	134,553
Grants	15	20,000	44,800	64,800	80,500	42,894	123,394
Legacies and in memoriam gifts		66,488	16,055	82,543	355	161,458	161,813
<b>Total donations, subscriptions, grants and legacies</b>	<b>3</b>	<b>87,158</b>	<b>203,219</b>	<b>290,377</b>	<b>81,420</b>	<b>338,340</b>	<b>419,761</b>
Other trading activities		0	2,644	2,644	0	2,167	2,167
Investments		0	31	31	0	48	48
<b>Total income</b>		<b>87,158</b>	<b>205,894</b>	<b>293,052</b>	<b>81,420</b>	<b>340,555</b>	<b>421,975</b>
<b>Expenditure on</b>							
Raising funds	5	0	54,210	54,210	0	53,896	53,896
Charitable activities	3, 15	26,167	181,901	208,068	67,866	188,338	256,204
<b>Total expenditure</b>		<b>26,167</b>	<b>236,111</b>	<b>262,278</b>	<b>67,866</b>	<b>242,234</b>	<b>310,100</b>
<b>Net income/(expenditure)</b>	<b>7</b>	<b>60,991</b>	<b>-30,217</b>	<b>30,774</b>	<b>13,554</b>	<b>98,321</b>	<b>111,875</b>
Transfers between funds		0	0	0	-684	684	0
<b>Net movement in funds</b>		<b>60,991</b>	<b>-30,217</b>	<b>30,774</b>	<b>12,870</b>	<b>99,005</b>	<b>111,875</b>
<b>Reconciliation of funds</b>							
Total funds brought forward		56,741	252,066	308,807	43,871	153,061	196,932
<b>Total funds carried forward</b>	<b>14</b>	<b>117,732</b>	<b>221,849</b>	<b>339,581</b>	<b>56,741</b>	<b>252,066</b>	<b>308,807</b>

# THE DYSTONIA SOCIETY

## Balance sheet at 31 March 2022

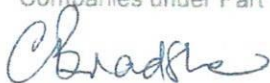
	Notes	31 March 2022 £	31 March 2021 £
<b>Non-current assets</b>			
Tangible fixed assets	8	0	0
Investment in subsidiary company	8	1	1
<b>Current assets</b>			
Debtors	9	17,526	34,778
Cash at bank and in hand	10	341,905	307,891
		<u>359,431</u>	<u>342,669</u>
<b>Creditors: amounts falling due within one year</b>	11	<u>-19,851</u>	<u>-33,863</u>
<b>Net current assets</b>		<u>339,580</u>	<u>308,806</u>
<b>Net assets</b>		<u><b>339,581</b></u>	<u><b>308,807</b></u>
<b>Represented by</b>			
General funds		252,066	153,061
I&E		-30,217	99,005
Designated funds	15	0	0
<b>Total unrestricted funds</b>		<u><b>221,849</b></u>	<u><b>252,066</b></u>
Restricted funds	15	117,732	56,741
<b>Total funds</b>	13	<u><b>339,581</b></u>	<u><b>308,807</b></u>

The Trustees are satisfied that the Charitable Company is entitled to exemption from the provisions of the Companies Act 2006 (the Act) relating to the audit of the financial statements for the year by virtue of section 477, and that no member or members have requested an audit pursuant to section 476 of the Act.

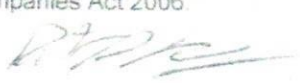
The Trustees acknowledge their responsibilities for

- (i) ensuring that the charitable company keeps adequate accounting records which comply with section 386 of the Act, and
- (ii) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of the financial year and of its results for the financial year in accordance with the requirements of sections 394 and 395, and which otherwise comply with the requirements of the Act relating to financial statements, so far as applicable to the charitable company.

These financial statements have been prepared in accordance with the special provisions for Small Companies under Part 15 of the Companies Act 2006.




Chris Bradshaw  
Chair



Robert Semple  
Trustee

# THE DYSTONIA SOCIETY

## Statement of cash flows for the year ended 31 March 2022

	2022 	2021
	£	£
<b>Net income/(expenditure) as per the statement of financial activities</b>	<b>30,774</b>	<b>111,875</b>
Adjustments for		
Depreciation charges	0	1,146
Interest from investments	-31	-48
(Increase)/decrease in debtors	17,252	-29,799
Increase/(decrease) in creditors	-14,012	6,974
<b>Net cash generated /(used) in operating activities</b>	<b>33,983</b>	<b>90,148</b>
<b>Cash flows from investing activities</b>		
Interest from investments	31	48
Purchase of equipment	0	0
<b>Net cash provided by/(used in) investing activities</b>	<b>31</b>	<b>48</b>
<b>Net increase/(decrease) in cash and cash equivalents</b>	<b>34,014</b>	<b>90,196</b>
Cash and cash equivalents at the beginning of the year	307,891	217,695
<b>Cash and cash equivalents at the end of the year</b>	<b>341,905</b>	<b>307,891</b>
<b>Check total</b>	<b>341,905</b>	<b>307,891</b>

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2022

### 1 Accounting policies

#### a) Basis of preparation of financial statements

- 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) (effective 1 January 2015), the Companies Act 2006 and the Charities and Trustees Investment (Scotland) Act 2005.
- The Charity constitutes a public benefit entity as defined by FRS 102.
- The accounts include the balances and transactions of 30 of the Society's support groups.
- The preparation of the financial accounts requires the Society's management to make reasonable and prudent judgements, estimates and assumptions that affect the amounts reported for assets and liabilities as at the balance sheet date and the amounts reported for income and expenses during the year. These judgements are detailed in these accounting policies.

#### b) Income

Income is received by way of grants, donations and subscriptions. The income from fundraising ventures is shown gross in the period in which the event occurs, with the associated costs included in costs of raising funds. From time to time the Society receives donations of goods and services in kind and where there is a measurable material value to the Society, which can be ascertained with reliability, they are included as both income and expenditure. Equipment given for use by the Society is included as a donation at estimated value when received.

Legacy income is included in the period in which it is received, or, if earlier, the period in which the Society receives confirmation of entitlement and amount. If there is uncertainty as to the amount and timing of payment, the legacy is not recognised as income, but disclosed as a contingent asset.

Subscriptions are included in the accounts in the year in which they are received.

Revenue grants are credited to incoming resources on the date they are received or when they are receivable, unless they relate to a specific period, in which case they are deferred.

#### c) Expenditure

Expenditure is recognised on an accruals basis and includes VAT which the charity cannot recover.

Direct expenditure on charitable activities is allocated to the Society's objectives in five streams of work.

Support costs are allocated to each of the charitable activities (and to the associated restricted funds) based on staff salary costs.

Costs of raising funds relate to expenditure incurred in approaching and facilitating people and organisations to contribute financially to the Society's work.

Grants payable are accounted for when paid or when the Society has, by communicating a commitment, created a valid expectation that it will make future payments.

Those costs shown as governance relate to the management of the Society's assets, organisational administration and compliance with constitutional and statutory requirements.

#### d) Pension contributions

The Society makes contributions to defined contribution personal pension schemes held by employees. Contributions are a percentage of gross salary and are charged to the same restricted or unrestricted funds, and in same the accounting periods, as the related salary costs.

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2022

### e) **Tangible fixed assets**

Items of equipment are capitalised if their cost exceeds £1,000 and if they have an expected useful life of more than two years. Depreciation is then charged at a uniform rate over that life.

### f) **Operating leases**

Rentals applicable to operating leases where substantially all the benefits and risks of ownership remain with the lessor are reflected in the Statement of Financial Activities on a straight-line basis over the period of the lease.

### g) **Fund accounting**

Restricted funds are to be used for specific purposes as stated by the donor. Expenditure which meets these criteria is charged to the fund.

Designated funds are unrestricted funds earmarked by the trustees for specific purposes. Unrestricted funds are donations and other incoming resources receivable or generated for charitable purposes, in line with the objects of the Society, but not restricted to any specific activity.

### h) **Financial instruments**

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

## 2 **Income and expenditure account**

A separate income and expenditure account has not been prepared as the figures comprising net income for the year shown in the Statement of Financial Activities give the information required under the Companies Act 2006, together with details of other recognised gains and losses.

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2022

### Analysis of income and expenditure by charitable activity

	2022		2021	
	Income £	Expenditure £	Income £	Expenditure £
Awareness and best practice		42,436	0	60,121
Support and information				
Research	20,670	151,503	81,420	173,997
	66,488	0	0	6,451
<b>Restricted Income and Expenditure on Charitable Activities</b>	<b>87,158</b>	<b>193,939</b>	<b>81,420</b>	<b>240,569</b>
Unrestricted Income	205,894		340,555	
Fundraising Expenditure		68,339		69,531
<b>Total Income and Expenditure</b>	<b>293,052</b>	<b>262,278</b>	<b>421,975</b>	<b>310,100</b>

Income is analysed according to restrictions imposed by donors and funders.

### Net incoming resources

	2022 £	2021 £
Net incoming resources are stated after charging		
Operating lease - land and buildings	21,230	21,976
Independent examiner's fees	1,500	1,500

### Total resources expended

	Support costs £	Awareness & best practice £	Information & support £	Research £	Fundraising £	Total £
<b>Year to March 2022</b>						
Employment and training						
Premises and general overheads	16,828	30,147	70,296	-	39,188	156,459
Printing and communications	33,119	76	-	-	-	33,195
Independent examination and accountancy	-	2,451	3,513	-	-	5,964
Conferences, meetings and travel	2,640	-	-	-	-	2,640
Direct project costs	1,638	-	-	-	-	1,638
Fundraising and prize draw expenses	-	557	45,999	-	-	46,556
Grants awarded/(recovered)	-	432	373	-	15,022	15,827
Apportioned support costs	-	-	-	-	-	-
<b>Total</b>	<b>54,225</b>	<b>8,773</b>	<b>31,322</b>	<b>-</b>	<b>14,129</b>	<b>0</b>
		<b>42,436</b>	<b>151,503</b>	<b>-</b>	<b>68,339</b>	<b>262,278</b>
<b>Year to March 2021</b>						
Employment and training						
Premises and general overheads	28,269	40,954	61,031	-	35,940	166,194
Printing and communications	39,355	-	-	-	-	39,355
Independent examination and accountancy	-	4,895	2,664	-	-	7,559
Conferences, meetings and travel	1,867	-	-	-	-	1,867
Direct project costs	241	-	-	-	-	241
Fundraising and prize draw expenses	-	753	71,176	-	-	71,929
Grants awarded/(recovered)	-	-	-	-	17,956	17,956
Apportioned support costs	-	-	-	5,000	-	5,000
<b>Total</b>	<b>69,732</b>	<b>13,519</b>	<b>39,127</b>	<b>1,451</b>	<b>15,635</b>	<b>-</b>
		<b>60,121</b>	<b>173,998</b>	<b>6,451</b>	<b>69,531</b>	<b>310,100</b>

## THE DYSTONIA SOCIETY

### Notes to the financial statements for the year ended

31 March 2022

6	Staff costs	2022	2021
		£	£
	Salaries and wages	138,856	140,424
	Social security costs	9,121	9,833
	Pension contributions	6,018	7,370
		<b>153,995</b>	<b>157,627</b>
	Staff employed under service contracts	-	-
	Other employment and training costs	-	59
	<b>Total employment and training costs</b>	<b>153,995</b>	<b>157,686</b>

The average number of employees during the year was 4.1 (2021: 4.2) of whom 3.2 were full-time. The full-time equivalent was 3.9 (2021: 3.7), No employee earned more than £60,000 during the year (2021: nil). The total of employee benefits paid to key management personnel in respect of their key management activities was £17,000 (2021: £17,000).

The Society contributes to defined contribution personal pension schemes. The assets of these schemes are held separately from those of the Society in independently administered funds. At 31<sup>st</sup> March 2022, the Society owed £983 (2021: £962) to these pension schemes.

#### 7 Trustees' remuneration and expenses

The trustees received no remuneration for their services (2021: nil). No trustees (2021: nil) were reimbursed for travel expenses and other costs (2021: nil).

8	Non-current assets	
	Office equipment and fixtures	
		£
	Cost at 1 April 2021	22,317
	Additions	-
	<b>Cost at 31 March 2022</b>	<b>22,317</b>
	Depreciation at 1 April 2021	22,317
	Charge for the year	
	<b>Depreciation at 31 March 2022</b>	<b>22,317</b>
	Net book value at 1 April 2021	-
	<b>Net book value at 31 March 2021</b>	<b>-</b>
	<b>Investment in subsidiary</b>	
	Investment in Dystonia UK Ltd	1

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended

### 31 March 2022

<b>9</b>	<b>Debtors</b>			
			<b>2022</b>	<b>2021</b>
			£	£
	Prepayments		10,028	9,498
	Other debtors and accrued income		7,498	23,952
			<b>17,526</b>	<b>33,450</b>
<b>10</b>	<b>Cash at bank and in hand</b>			
			<b>2021</b>	<b>2021</b>
			£	£
	Bank investment accounts		186,078	226,046
	Other bank and building society accounts		153,679	79,493
	Petty cash and groups		2,148	2,352
			<b>341,905</b>	<b>307,891</b>
<b>11</b>	<b>Creditors: Amounts falling due within one year</b>			
			<b>2021</b>	<b>2021</b>
			£	£
	Taxation and social security costs		3,406	3,811
	Other creditors		13,403	18,407
	Accruals		3,042	11,645
			<b>19,851</b>	<b>33,863</b>
<b>12</b>	<b>Commitments under operating leases</b>			
			<b>2021</b>	<b>2021</b>
			£	£
			14,363	33,176
<b>13</b>	<b>Analysis of net assets between funds</b>			
		<b>Restricted</b>	<b>General</b>	<b>Total</b>
		<b>funds</b>	<b>funds</b>	<b>funds</b>
		£	£	£
	Fixed assets	-	1	1
	Current assets	117,732	241,699	359,431
	Creditors	-	19,851	-19,851
		<b>117,732</b>	<b>221,849</b>	<b>339,581</b>

#### 14. Contingent liabilities

No contingent liabilities exist as of 31<sup>st</sup> March 2022 and the date of this Annual Report & Accounts.

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended

31 March 2022

15	Activity on restricted funds	Opening balance	Income	Transfers	Expenditure	Closing balance
		£	£	£	£	£
	Awareness and best practice	3,000	-	-	0	3,000
	Information and support	38,640	20,670	-	-26,167	33,144
	Research	15,100	66,488	-	0	81,588
		<b>56,740</b>	<b>87,158</b>	<b>0</b>	<b>-26,167</b>	<b>117,731</b>

### 16 Related party transactions

There have been no related party transactions in the year ending 31<sup>st</sup> March 2022 (prior year nil).

**THE DYSTONIA SOCIETY**

England & Wales - Charity number 1062595

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# Accounts

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**THE DYSTONIA SOCIETY**

**Report of the Trustees for the year ended 31 March 2021  
(incorporating the Directors' Report)**

**THE DYSTONIA SOCIETY**

**A company limited by guarantee  
Financial Statements  
31 March 2021**

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2021 (incorporating the Directors' Report)

<b>Contents</b>	<b>Page</b>
Reference and administrative information	2
Report of the trustees	3 - 10
Independent examiner's report	11
Statement of financial activities	12
Balance sheet	13
Statement of cash flows	14
Notes to the financial statements	15 - 20

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2021 (incorporating the Directors' Report)

### Reference and administrative information

#### Royal Patron

HRH Princess Alexandra

#### Patron

Tully Kearney

#### Trustees and Directors

Daniel Berry	Chair
Christopher Bradshaw	
Timothy Gannicliffe	From 1 <sup>st</sup> March 2021
Nick Morgan	
Penny Ritchie Calder MBE	From 1 <sup>st</sup> March 2021
Andrew Russell	From 1 <sup>st</sup> March 2021
Robert Semple	From 14 <sup>th</sup> Jan 2021
Ian Silvester	From 1 <sup>st</sup> March 2021
Katie Wells	
James Wishart	
Andy Young	Vice-chair

#### Secretary

Roger Edmonds FCA

#### Medical Advisers

Prof. Mark Edwards  
Mr Daniel Ezra  
Ms Lucy Hicklin  
Dr Jean-Pierre Lin  
Dr. Marie-Helene Marion  
Dr. Kathryn Peall  
Prof. Tom Warner

#### Registered Office

3<sup>rd</sup> Floor  
89 Albert Embankment  
London  
SE1 7TP

#### Independent Examiner

Michael Williams ACA  
30 Retford Drive  
Sutton Coldfield  
B76 1DG

#### Bankers

CAF Bank  
Kings Hill  
West Malling  
Kent ME19 4TA

Bank of Scotland  
14/16 Cockspur Street  
London SW1Y 5BL

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2021 (incorporating the Directors' Report)

The trustees, who are also the directors of the company, submit their report and the financial statements of The Dystonia Society ("the Society") for the year ended 31 March 2021 on the basis of the accounting policies set out in Note 1 to the financial statements, and comply with the requirements of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial reporting Standard in the UK and Republic of Ireland (FRS102) (effective 1 January 2015) (Charities SORP, FRS102). The reference and administrative information on the previous page forms part of this report.

### Principal Objective

The Society was established to promote the welfare of people who are affected by any form of the neurological movement disorder known as dystonia. The Society aims to do this by providing information and support, promoting awareness of the disorder and by supporting research. It does this on a national level and through its network of local support groups.

### Review of Activity

**We exist to give hope and support to those living with dystonia. Creating UK and worldwide awareness.**

Under our new operating name of Dystonia UK, we are the only national charity dedicated to supporting people with dystonia throughout the UK. During the last year and in spite of the impact that the Covid-19 pandemic has had on our activities, we have made significant progress in developing the charity to meet the needs of both members and the wider dystonia community. This has included:

- Providing support and information to the dystonia community about the impact of Covid-19
- Relaunching our website with more accessible information
- Working with partners to ensure that clinical services restart as quickly as possible
- Developing our Reach Out Reach All programme with webinars, podcasts and online conferences
- Creating mutually beneficial partnerships with the major providers of pharmaceuticals and medical devices for the treatment of dystonia
- Enhancing online fundraising and awareness raising
- Ensuring that the voice of the dystonia community is heard as part of policy developments in the NHS

We are now in a strong position to ensure the growth and development of the charity to meet the needs of everyone affected by dystonia in the future.

### Covid-19 pandemic

The impact of Covid-19 began in March 2020 with the first national lockdown. For people with dystonia, the effect of the pandemic was enormous. As the NHS responded to the emergency, neurology clinics were cancelled or moved to telephone consultations. Many specialist neurology staff were redeployed in hospitals and injection clinics were postponed for several months. Access to primary care was restricted and will inevitably have resulted in even longer delays to diagnosis and treatment. The restrictions imposed on people generally have exacerbated the isolation and mental health consequences for the dystonia community.

Our heartfelt thanks go to everyone in the NHS, care workers and key workers who have shown such fantastic dedication and support to people during these very difficult times. We extend our sympathy to everyone in the dystonia community, the NHS and other sectors who have lost loved ones.

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2021 (incorporating the Directors' Report)

Our medical advisers responded quickly to provide guidance and reassurance to the dystonia community about the implications of Covid-19 on their health and treatment. We were able to make information from The Association of British Neurologists available through our website. Dr Marie-Helene Marion gave a webinar on Dystonia During The Pandemic with advice for people whose Botulinum Neurotoxin injections were being delayed.

All our staff were required to work from home, and this has continued throughout the year. Fortunately, our core information systems are available online and we were able to adapt our operational procedures quickly. Virtual meetings using Zoom became the norm, both within the staff team and with our partner organisations. Trustee meetings also took place using Zoom.

The pandemic has directly affected the way in which we can operate as a charity. Many events that we were planning were put on hold as they were either not allowed by restrictions or not safe for people with dystonia. These restrictions also had an impact on our fundraising as challenge events such as marathons were cancelled and the many smaller activities within groups could not take place.

### Website relaunch

We relaunched our website in July 2020. The improved layout and accessibility of the new website have been widely welcomed. This now provides a platform on which people will be able to search for information, see videos and listen to podcasts. The internet is the place where most people now search for information. We will continue to add content in response to the many enquiries that people make.

But we know that online information is not the preferred choice or accessible to many members. Dystonia Matters will continue to be published regularly. Last year we also issued a special Letter From The Chair including the advice we had about Covid-19 as well as general updates on our activities.

### Restarting clinical services after lockdown

After the first lockdown, we worked with the British Neurotoxin Network on its plans for restarting injection clinics. Trustees have joined a number of web-conferences with clinicians in order to ensure that the voice of the dystonia community is fully considered including issues with travel, the need for carers to support patients, and lack of access to digital communications.

We worked with the Neurological Alliance (in England) in promoting its survey about the impact of the pandemic and in producing its Neuro Restart report. People with dystonia were one of the largest neurological patient groups that responded to the survey ensuring that their concerns, such as virtual appointments replacing face to face meetings with clinicians, were recognised. We also contributed to the Neurological Alliance of Scotland's report Neurological Voices: Living Through Lockdown.

### Reach Out Reach All

This is our programme to improve and modernise the information and advice available for people with dystonia, for example new videos and other content that is easily accessed and shared on social media. Such a programme is highly attractive when seeking funding. During the year we received funding from the National Lottery Community Fund and from several of the manufacturers of Botulinum Neurotoxin and Deep Brain Stimulation equipment to further this campaign. The programme has included:

#### Lockdown Unlocked

- Tully Kierney, Gemma-Louise Stevenson and Tegan Vincent-Cooke talking about living with dystonia and the impact of the pandemic in a series of video shorts

## **THE DYSTONIA SOCIETY**

### **Report of the Trustees for the year ended 31 March 2021 (incorporating the Directors' Report)**

#### Dystonia Matters Webinars:

- Dystonia During The Pandemic with Dr Marie-Helene Marion
- Taking Control Of Your Dystonia – A Physiotherapy Focus with Richmond Stace and Sally Glover
- Answering Your Questions with Prof Mark Edwards
- Understanding Personal Independence Payments with Janet Ireland from The Brain Charity

#### Dystonia Matters Podcasts

- Episode 1: Faces Of The Dystonia Community – Louise, Katie and Andy
- Episode 2: Working With Dystonia – Gemma and Nick

#### Online conferences

- Dystonia Matters Digital was our first ever online conference. Over two days at the end of Dystonia Awareness Month in September 2020 its four sessions were: Campaigning for Change, Mental Health Matters, The Future Of Neurology and Knowing Your Rights
- Dystonia Matters Digital: For Kids, Carers & Families in March 2021 covered the launch of Dani Explains Dystonia, a new animation for children about dystonia, treatment in childhood and transitioning to adulthood for both treatment and educational support.

#### **Working with pharmaceutical and medical device businesses**

Over the last year, we have strengthened our relationships with these key corporate organisations. Their support to our work through grants has enabled us to take forward much of our Reach Out Reach All programme. In addition, we bring the voices of people living with dystonia to inform their research and development programmes.

#### **Fundraising and awareness raising**

We continue to be supported by many loyal members and donors along with a several charitable trusts and foundations. This support creates a base on which we can build our other fundraising initiatives.

This year, many of the events that would normally promote awareness of dystonia alongside fundraising have been cancelled due to the pandemic. We have switched our fundraising to online activities where we can. The 2.6 Challenge, a national initiative to replace the London Marathon, gave us a significant start.

We created our own challenge event – Dystonia Around The World – which both raised awareness about dystonia and generated over £14,000 in donations. This introduced a lot of new supporters to us, and we look forward to their continued help as Covid-19 restrictions are lifted.

We continue to build and expand our presence on social media to support people as well as to raise awareness. During Dystonia Awareness Month, one infographic that we produced saw over 5,000 reactions and had a reach of over 50,000.

#### **Working for improved services**

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2021 (incorporating the Directors' Report)

Raising the voice of the dystonia community is of vital importance. Too often we hear that delays in diagnosis and treatment or support in education and employment are due to a lack of knowledge and understanding of the condition in its many forms.

We have increased our involvement in the work of the various neurological alliances in England, Wales, Scotland and Northern Ireland and have ensured that dystonia is recognised equally with other major neurological conditions in the overarching work to lobby for improved services. Our members provide valuable support by responding to surveys and giving their personal stories to provide evidence for the need for change. Representatives from all four countries neurological alliances took part in our Dystonia Matters Digital conference.

Where appropriate we provide comments and evidence to NICE (the National Institute for Health and Care Excellence) on clinical guidelines. This year, we ensured that dystonia was specifically recognised in their quality standard for suspected neurological disorders, especially concerning the frequently mentioned misdiagnosis of dystonia as either a musculoskeletal or psychological condition. This increases the awareness of dystonia, especially in primary care, as well as providing vital evidence that services are improving.

### Research

We contributed funding towards the Queen's Square Brain Bank at the UCL Institute for Neurology. This work, led by Professor Tom Warner, will enable significant research to be undertaken into the causes and possible treatments for dystonia. The Queen's Square Brain Bank collects, curates and studies brain tissue for research into many neurological conditions including dystonia. This can help identify mechanisms that affect the brain and lead to dystonic movement.

We have also allocated research funding to UCL to help complete a large ongoing study looking at the predictors of long-term efficacy of deep brain stimulation in the management of dystonia. Part of this 3-year research project involves genotyping the participants for novel genetic causes of dystonia.

We are supporting research by neurologists on the effects of the lockdown and delays in injection cycles on patients. This is an observation study using established survey forms coordinated by the Walton Centre in Liverpool.

### Staff and Trustees

The loyalty and commitment of our staff is very much appreciated. They are a strong team with great spirit and focus on the needs of people with dystonia. Due to the Covid-19 restrictions, everyone has worked from home throughout the year including new staff who have joined the team.

Senior staff report on a day to day basis to the Chair of Trustees, with other trustees being actively involved in supporting our work in responding to enquiries, engaging with strategic partners, supporting groups, fundraising and administration. Without this commitment, given the reduced numbers of employed staff, we could not achieve our objectives.

We have expanded our board of trustees to ensure continuity as the charity grows and develops. During the year, we welcomed Nick Morgan, Andrew Russell, Robert Semple, Ian Silvester and Katie Wells. There are currently eleven trustees of which five have a diagnosis of dystonia and three have direct family experience of dystonia. The remaining three, while not having previous experience of dystonia, have been involved in charities for people with other neurological conditions or disabilities.

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2021 (incorporating the Directors' Report)

### Plans for the coming year

In spite of the setback presented by the Covid-19 pandemic, we aim to move forward and build on the new groundwork that we have done this year.

Awareness raising and lobbying for change – building on our collaboration with the neurological alliances and other charities to ensure that the voice of people with dystonia is recognised by health commissioners, providers, government and other agencies. This is especially important as health services recover from the impact of Covid-19.

Reach Out Reach All – ensuring that our resources are relevant and accessible to the whole dystonia community. We will continue producing information in a variety of formats to support people with dystonia. This will include further webinars and podcasts, new animations aimed at children with dystonia, refreshing our information leaflets for use in hospital clinics as well as responding to enquiries, and updating our website with additional information including a section on Frequently Asked Questions.

Social networks - we will work with group leaders and coordinators so that they can support the charity's work better at a local level. We hope that groups will be able to meet in person as soon as it is safe to do so, especially enabling members to share their lived experience of dystonia. We will continue the development of social media for networking and sharing information.

Research - we hope to establish sufficient funds to make a call for a new research proposal into dystonia.

### Financial Review

Our financial position for the year ending 31st March 2020 was a deficit of £111,875 compared to a deficit of £50,709 in the previous year. Income was £421,975 (2020: £221,737). Increased income was mainly due to legacy income and grants especially from the National Lottery Community Fund (NLCF) and medical companies, offset by reduced community fundraising as a consequence of these activities being reduced due to Covid-19 restrictions. Expenditure was £310,100 (2020 £272,446). Increased expenditure was mainly due to the activities funded by the NLCF and medical companies.

With increased legacy and grant income, the Society was able to increase staffing slightly during the year. Fundraising continues to be challenging, but the impact that we have achieved from our new initiatives will, we hope, demonstrate the benefit of grants and donations. We will continue to promote the welfare of those living with the impact of dystonia and those who support them. To do this, we need to ensure our income streams enable us to operate at break-even financially without reliance on legacy income and the trustees have agreed a budget on this basis which depends on improvement in fundraising from charitable trusts, foundations and corporate sponsorship as well as the continued support of our many members and supporters. Trustees consider that increased income is realistically attainable as it is less than was achieved historically. Nevertheless, they will continue to monitor this income closely and to take action to ensure that reserves are sufficient to ensure that the charity can meet its obligations as they fall due.

### Reserves

The trustees feel it is prudent to maintain the Society's general unrestricted reserves at a level sufficient to cover commitments such as property rental, creditors and other liabilities and to reflect the relative uncertainty of income and potential restrictions on its use. The level of reserves is reviewed monthly in conjunction with the trustees' review of the financial position. The trustees have not designated any of the unrestricted reserves for specific future activities.

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2021 (incorporating the Directors' Report)

The level of unrestricted reserves at 31st March 2021 represented 104% of expenditure in the year (2020 65%) due to the receipt of a substantial legacy. We would expect reserves to return to normal levels unless further significant legacy income were to be received.

Certain grants and donations received by the Society are given for specific projects or initiatives. Funds held in respect of these activities are carried forward if they are unspent or uncommitted. At 31st March 2020, funds of £56,741 were carried forward (2020: £43,871).

### Investment Policy

The Society does not have sufficient resources to make long term investments. Surplus funds are held in deposit facilities however interest rates on such facilities are currently very low.

### Structure, Governance and Management

The Society is a company limited by guarantee and is registered with the Charity Commission (Number 1062595) and with the Office of the Scottish Charity Regulator (SC042127). It is constituted by its Memorandum and Articles of Association. In the event of the insolvency of the Society, members can be asked to pay a maximum of £10 towards any unpaid debt.

Control of The Dystonia Society is vested in the trustees, each of whom is a member of the Society. All decisions are made by the board of trustees and, at the present time, no sub-committees are in operation.

Existing trustees encourage potential trustees to stand for election to maintain an appropriate balance of skills and experience. Where specific skills are needed the recruitment of potential trustees may be expanded to look beyond the current membership. Where there are more candidates than vacancies, trustees are elected by the members at an AGM or by a postal ballot. Trustees serve for a three-year term and then stand for re-election. A minimum of a third of the trustees stand for re-election each year. If less than a third of the trustees are due for re-election then those nearest to the expiry of their term stand for re-election. Trustees serve for a maximum of three terms. A trustee may be appointed by the Board if a vacancy becomes available during the financial year and the trustee would then stand for re-election at the year end. The maximum number of trustees is twelve and the minimum is three. We aim to give new trustees a programme of induction and training. Further training is available when required and relevant.

### Risk

The trustees identify and review the major risks to which the Society is exposed and have established appropriate systems to anticipate further risks that may arise. The trustees consider that implementation of agreed actions and procedures will significantly reduce the probability and impact of these risks.

The most recent review identified the key risk to be its ability to achieve sufficient fundraising in light of the Covid-19 pandemic and therefore maintain financial sustainability. The Society undertakes careful monitoring of its projected cash flows and levels of reserves so that it can meet its financial duties.

### Public Benefit

The trustees have referred to the Charity Commission's guidance on public benefit, and the guidance "Meeting the Charity Test" published by the Office of the Scottish Charity Regulator, when reviewing their aims and objectives, and planning the Society's future activity.

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2021 (incorporating the Directors' Report)

### Statement of trustees' responsibilities

The trustees (who are also directors of the Society 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 (UK Generally Accepted Accounting Practice (UK GAAP)).

Company law requires the trustees to prepare financial statements for each financial year. Under that law the trustees have elected to prepare the financial statements in accordance with UK GAAP. Under company law, the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and of the surplus or deficit of the charitable company for that period. In preparing those financial statements, the trustees are required to

- Select suitable accounting policies and then apply them consistently
- Observe the methods and principles in the Statement of Recommended Practice "Accounting and Reporting by Charities"
- 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 business

The trustees are responsible for keeping adequate accounting records which are sufficient to show and explain the charitable company's transactions and which 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, the Charities Accounts (Scotland) Regulations 2006 and the charity's constitution. 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 information of which the charitable company's independent examiner is unaware
- The trustees have taken all steps that they ought to have taken to make themselves aware of any relevant information and to establish that the independent 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.

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2021 (incorporating the Directors' Report)

### Small company exemption

This report has been prepared in accordance with the special provisions for small companies under Section 15 of the Companies Act 2006.

### Thanks

We are very grateful indeed to the Society's staff team, volunteers, donors and fundraisers, to the charitable trusts, corporate partners and the National Lottery Coronavirus Recovery Fund that have given grant funding, and to clinicians and other professionals who have attended meetings during the year, donating their time and expertise. Their support is very much appreciated by our members.

### Approval

This report was approved by the Board of Trustees on 10<sup>th</sup> June 2021 and signed on its behalf by



Chris Bradshaw

Chair of Trustees

# THE DYSTONIA SOCIETY

## Report of the Trustees for the year ended 31 March 2021 (incorporating the Directors' Report)

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Chris Bradshaw

Chair of Trustees

# THE DYSTONIA SOCIETY

## Independent Examiner's Report to the trustees of The Dystonia Society ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 March 2021.

### Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

### Independent examiner's statement

Since the Company's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales (ICAEW), which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities [applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)].

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Michael A Williams  
Chartered Accountant  
30 Retford Drive  
Sutton Coldfield  
West Midlands  
B76 1DG  
Date:

**THE DYSTONIA SOCIETY**  
**Statement of financial activities for the year ended 31 March 2021**

	Notes	Restricted funds	General funds	Total 2020/21	Restricted funds	General funds	Total 2019/20
		£	£	£	£	£	£
<b>Income from</b>							
Donations and subscriptions	15	565	133,988	134,553	14,117	139,724	153,841
Grants		80,500	42,894	123,394	17,281	35,696	52,977
Legacies and in memoriam gifts		355	161,458	161,813	0	11,918	11,918
<b>Total donations, subscriptions, grants and legacies</b>	<b>3</b>	<b>81,420</b>	<b>338,340</b>	<b>419,761</b>	<b>31,398</b>	<b>187,338</b>	<b>218,736</b>
Other trading activities		0	2,167	2,167	0	2,857	2,857
Investments		0	48	48	0	144	144
<b>Total income</b>		<b>81,420</b>	<b>340,555</b>	<b>421,975</b>	<b>31,398</b>	<b>190,339</b>	<b>221,737</b>
<b>Expenditure on</b>							
Raising funds	5	0	53,896	53,896	0	63,567	63,567
Charitable activities	3, 15	67,866	188,338	256,204	37,787	171,092	208,879
<b>Total expenditure</b>		<b>67,866</b>	<b>242,234</b>	<b>310,100</b>	<b>37,787</b>	<b>234,659</b>	<b>272,446</b>
<b>Net income/(expenditure)</b>	<b>7</b>	<b>13,554</b>	<b>98,321</b>	<b>111,875</b>	<b>-6,390</b>	<b>-44,320</b>	<b>-50,709</b>
Transfers between funds		-684	684	0	-3,818	3,818	0
<b>Net movement in funds</b>		<b>12,870</b>	<b>99,005</b>	<b>111,875</b>	<b>-10,208</b>	<b>-40,501</b>	<b>-50,709</b>
<b>Reconciliation of funds</b>							
Total funds brought forward		43,871	153,061	196,932	54,079	193,562	247,641
<b>Total funds carried forward</b>	<b>14</b>	<b>56,741</b>	<b>252,066</b>	<b>308,807</b>	<b>43,871</b>	<b>153,061</b>	<b>196,932</b>
<b>Unrestricted reserves % of expenditure</b>			<b>104.1%</b>			<b>65.2%</b>	

# THE DYSTONIA SOCIETY

## Balance sheet at 31 March 2021

	Notes	31 March 2021	31 March 2020
		£	£
<b>Non-current assets</b>			
Tangible fixed assets	8	0	1,147
Investment in subsidiary company	8	1	1
<b>Current assets</b>			
Debtors	9	34,779	4,980
Cash at bank and in hand	10	307,891	217,695
		<b>342,670</b>	<b>222,675</b>
<b>Creditors: amounts falling due within one year</b>	11	-33,864	-26,890
<b>Net current assets</b>		<b>308,807</b>	<b>195,785</b>
<b>Net assets</b>		<b>308,808</b>	<b>196,932</b>
<b>Represented by</b>			
General funds		153,745	193,562
I&E 2020/21		98,321	-40,501
Designated funds	15	0	0
<b>Total unrestricted funds</b>		<b>252,066</b>	<b>153,061</b>
Restricted funds	15	56,741	43,871
<b>Total funds</b>	13	<b>308,807</b>	<b>196,932</b>

The Trustees are satisfied that the Charitable Company is entitled to exemption from the provisions of the Companies Act 2006 (the Act) relating to the audit of the financial statements for the year by virtue of section 477, and that no member or members have requested an audit pursuant to section 476 of the Act.

The Trustees acknowledge their responsibilities for

- (i) ensuring that the charitable company keeps adequate accounting records which comply with section 386 of the Act, and
- (ii) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of the financial year and of its results for the financial year in accordance with the requirements of sections 394 and 395, and which otherwise comply with the requirements of the Act relating to financial statements, so far as applicable to the charitable company.

These financial statements have been prepared in accordance with the special provisions for Small Companies under Part 15 of the Companies Act 2006.

Chris Bradshaw  
Chair

Andy Young  
Vice-chair

Company Registration Number: 03309777

The notes on pages 14 to 20 form part of these financial statements.

# THE DYSTONIA SOCIETY

## Statement of cash flows for the year ended 31 March 2021

	2020/21	2019/20
	£	£
<b>Net income/(expenditure) as per the statement of financial activities</b>	<b>111,875</b>	<b>-50,709</b>
Adjustments for		
Depreciation charges	1,146	2,583
Interest from investments	-48	-144
(Increase)/decrease in debtors	-29,799	17,096
Increase/(decrease) in creditors	6,973	-11,045
<b>Net cash generated /(used) in operating activities</b>	<b>90,149</b>	<b>-42,219</b>
<b>Cash flows from investing activities</b>		
Interest from investments	48	144
Purchase of equipment	0	0
<b>Net cash provided by/(used in) investing activities</b>	<b>48</b>	<b>144</b>
<b>Net increase/(decrease) in cash and cash equivalents</b>	<b>90,196</b>	<b>-42,075</b>
Cash and cash equivalents at the beginning of the year	217,696	259,771
<b>Cash and cash equivalents at the end of the year</b>	<b>307,892</b>	<b>217,696</b>

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2021

### 1 Accounting policies

#### a) Basis of preparation of financial statements

- 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) (effective 1 January 2015), the Companies Act 2006 and the Charities and Trustees Investment (Scotland) Act 2005.
- The Charity constitutes a public benefit entity as defined by FRS 102.
- The accounts include the balances and transactions of 30 of the Society's support groups.
- The preparation of the financial accounts requires the Society's management to make reasonable and prudent judgements, estimates and assumptions that affect the amounts reported for assets and liabilities as at the balance sheet date and the amounts reported for income and expenses during the year. These judgements are detailed in these accounting policies.

#### b) Income

Income is received by way of grants, donations and subscriptions. The income from fundraising ventures is shown gross in the period in which the event occurs, with the associated costs included in costs of raising funds. From time to time the Society receives donations of goods and services in kind and where there is a measurable material value to the Society, which can be ascertained with reliability, they are included as both income and expenditure. Equipment given for use by the Society is included as a donation at estimated value when received.

Legacy income is included in the period in which it is received, or, if earlier, the period in which the Society receives confirmation of entitlement and amount. If there is uncertainty as to the amount and timing of payment, the legacy is not recognised as income, but disclosed as a contingent asset.

Subscriptions are included in the accounts in the year in which they are received.

Revenue grants are credited to incoming resources on the date they are received or when they are receivable, unless they relate to a specific period, in which case they are deferred.

#### c) Expenditure

Expenditure is recognised on an accruals basis and includes VAT which the charity cannot recover.

Direct expenditure on charitable activities is allocated to the Society's objectives in five streams of work.

Support costs are allocated to each of the charitable activities (and to the associated restricted funds) based on staff salary costs.

Costs of raising funds relate to expenditure incurred in approaching and facilitating people and organisations to contribute financially to the Society's work.

Grants payable are accounted for when paid or when the Society has, by communicating a commitment, created a valid expectation that it will make future payments.

Those costs shown as governance relate to the management of the Society's assets, organisational administration and compliance with constitutional and statutory requirements.

#### d) Pension contributions

The Society makes contributions to defined contribution personal pension schemes held by employees. Contributions are a percentage of gross salary and are charged to the same restricted or unrestricted funds, and in same the accounting periods, as the related salary costs.

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2021

### e) **Tangible fixed assets**

Items of equipment are capitalised if their cost exceeds £1,000 and if they have an expected useful life of more than two years. Depreciation is then charged at a uniform rate over that life.

### f) **Operating leases**

Rentals applicable to operating leases where substantially all the benefits and risks of ownership remain with the lessor are reflected in the Statement of Financial Activities on a straight-line basis over the period of the lease.

### g) **Fund accounting**

Restricted funds are to be used for specific purposes as stated by the donor. Expenditure which meets these criteria is charged to the fund.

Designated funds are unrestricted funds earmarked by the trustees for specific purposes.

Unrestricted funds are donations and other incoming resources receivable or generated for charitable purposes, in line with the objects of the Society, but not restricted to any specific activity.

### h) **Financial instruments**

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

## 2 **Income and expenditure account**

A separate income and expenditure account has not been prepared as the figures comprising net income for the year shown in the Statement of Financial Activities give the information required under the Companies Act 2006, together with details of other recognised gains and losses.

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2021

3 Analysis of income and expenditure by charitable activity						
	2021		2020			
	Income	Expenditure	Income	Expenditure		
	£	£	£	£		
Awareness and best practice	0	-60,121	0	97,442		
Support and information	81,420	-173,997	29,113	67,003		
Research	0	-6,451	2,285	18,785		
	<b>81,420</b>	<b>-240,569</b>	<b>31,398</b>	<b>183,230</b>		
Income is analysed according to restrictions imposed by donors and funders.						
4 Net incoming resources						
			2021	2,020		
			£	£		
Net incoming resources are stated after charging						
Operating lease - land and buildings			21,976	22,043		
Independent examiner's fees			1,500	1,500		
5 Total resources expended						
	Support costs	Awareness & best practice	Information & support	Research	Fundraising	Total
	£	£	£	£	£	£
Year to March 2021						
Employment and training	28269	40954	61031	0	35940	166194
Premises and general overheads	39355	0	0	0	0	39355
Printing and communications	0	4895	2664	0	0	7559
Independent examination and accountancy	1867	0	0	0	0	1867
Conferences, meetings and travel	241	0	0	0	0	241
Direct project costs	0	753	71176	0	0	71929
Fundraising and prize draw expenses	0	0	0	0	17956	17956
Grants awarded/(recovered)	0	0	0	5000	0	5000
Apportioned support costs	-69732	13519	39127	1451	15635	0
<b>Total</b>	<b>0</b>	<b>60121</b>	<b>173997</b>	<b>6451</b>	<b>69531</b>	<b>310100</b>
Year to March 2020						
Employment and training	24825	50419	34669	0	39050	148963
Premises and general overheads	44657	0	0	0	0	44657
Printing and communications	0	17024	2664	0	0	19688
Independent examination and accountancy	2900	0	0	0	0	2900
Conferences, meetings and travel	5944	0	0	0	0	5944
Direct project costs	0	1985	10408	0	0	12392
Fundraising and prize draw expenses	0	0	0	0	24517	24517
Grants awarded/(recovered)	0	0	0	13384	0	13384
Apportioned support costs	-78325	28014	19263	5400	25649	0
<b>Total</b>	<b>0</b>	<b>97,442</b>	<b>67,003</b>	<b>18,785</b>	<b>89,216</b>	<b>272,446</b>
			2021	2020		
			£	£		
Support costs include governance costs of			1,800	7,188		
Grants awarded included						
To individuals			0	0		
To organisations			5,000	13,385		

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2021

6 Staff costs	2020/21	2019/20
	£	£
Salaries and wages	140,424	122,619
Social security costs	9,833	9,250
Pension contributions	7,370	5,589
	<b>157,627</b>	<b>137,458</b>
Staff employed under service contracts	0	0
Other employment and training costs	59	784
Total employment and training costs	<b>157,686</b>	<b>138,242</b>

The average number of employees during the year was 4.2 (2020: 3.8) of whom 3.2 were full-time. The full-time equivalent was 3.7 (2020: 3.2). No employee earned more than £60,000 during the year (2020: nil). The total of employee benefits paid to key management personnel was £85,000 (2020: £19,875 for the Chief Executive for part of the year only).

The Society contributes to defined contribution personal pension schemes. The assets of these schemes are held separately from those of the Society in independently administered funds. At 31<sup>st</sup> March 2021, the Society owed £962 (2020: £635) to these pension schemes.

### 7 Trustees' remuneration and expenses

The trustees received no remuneration for their services (2020: nil). No trustees (2020: two) were reimbursed for travel expenses and other costs (2020: £2,657).

8 Non-current assets	
Office equipment and fixtures	£
Cost at 1 April 2020	22317
Additions	0
<b>Cost at 31 March 2021</b>	<b>22317</b>
Depreciation at 1 April 2020	21171
Charge for the year	0
<b>Depreciation at 31 March 2020</b>	<b>21171</b>
Net book value at 1 April 2020	1146
<b>Net book value at 31 March 2021</b>	<b>1146</b>
<b>Investment in subsidiary</b>	
Investment in Dystonia UK Ltd	1

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended 31 March 2021

<b>9</b>	<b>Debtors</b>			
			<b>2021</b>	<b>2020</b>
			£	£
	Prepayments		9498	4,980
	Other debtors and accrued income		23952	0
			<b>33,450</b>	<b>4,980</b>
<b>10</b>	<b>Cash at bank and in hand</b>			
			<b>2021</b>	<b>2020</b>
			£	£
	Bank investment accounts		226046	95,999
	Other bank and building society accounts		79493	118,880
	Petty cash and groups		2352	2,816
			<b>307,891</b>	<b>217,695</b>
<b>11</b>	<b>Creditors: Amounts falling due within one year</b>			
			<b>2021</b>	<b>2020</b>
			£	£
	Taxation and social security costs		3811	3,555
	Other creditors		18407	13,785
	Accruals		11645	9,550
			<b>33,864</b>	<b>26,890</b>
<b>12</b>	<b>Commitments under operating leases</b>			
			<b>2021</b>	<b>2020</b>
			£	£
			33176	54900
<b>13</b>	<b>Analysis of net assets between funds</b>			
		<b>Restricted</b>	<b>General</b>	<b>Total</b>
		<b>funds</b>	<b>funds</b>	<b>funds</b>
		£	£	£
	Fixed assets	0	1	1
	Current assets	64,622	278,048	342,670
	Creditors	-7,881	-25,983	-33,864
		<b>56,741</b>	<b>252,066</b>	<b>308,808</b>

#### 14. Contingent liabilities

The Society has received a claim from a former employee as a result of their redundancy. The claim is being rigorously defended. At the date of this report the amount cannot be quantified.

# THE DYSTONIA SOCIETY

## Notes to the financial statements for the year ended

31 March 2021

15	Activity on restricted funds	Opening balance	Income	Transfers	Expenditure	Closing balance
		£	£	£	£	£
	Awareness and best practice	3,000	0	0	0	3,000
	Information and support	25,770	81,420	-684	-67,866	38,640
	Research	15,100	0	0	0	15,100
		<b>43,870</b>	<b>81,420</b>	<b>-684</b>	<b>-67,866</b>	<b>56,740</b>

### 16 Related party transactions

The Chair is a governor of Queen Alexandra College (a registered charity). No transactions occurred in the year to 31<sup>st</sup> March 2021 (2020: the Society paid QAC £1,089 in respect of the hire of a conference facilities and catering for its General Meeting in October 2019).