Tourettes action

IMPACT REPORT:

APRIL 2024 - MARCH 2025

Tourettes Action is the only UK-wide charity dedicated to supporting individuals with Tourette syndrome and their families. Our staff, volunteers and supporters are engaged and energised in driving forward our mission. Everything we do is grounded in our community's needs and informed by the voices of our community and research-based evidence.

2024 - 2025 HIGHLIGHTS

AWARENESS

- 2M+ reached via campaigns
- 64,000 website visitors
- 11,000 newsletter subscribers
- 20 research studies supported

LEARNING & TRAINING

- 2,000 eLearning certificates
- 97 training sessions (delivered to 7,500 people)
- 1,700+ education enquiries
- 271 advocacy sessions
- 170+ employment enquiries
- 2 workshops (delivered to 65 people)

PRACTICAL SUPPORT

- 1,300 TS passports
- 94 ID cards
- 14 webinars (413 people)
- 6 grants given

SUPPORT

- 4,600 helpdesk queries
- 8 residential weekends (700 attendees)
- 147 online groups (671 attendees)
- 7 music workshops + 9 activities

PREPARED BY

EMMA MCNALLY
CEO

We want a world where people with Tourette syndrome are: **accepted**, **supported** and **embraced**. This is a world which enables people with the condition to reach their full potential.

CEO Welcome

Emma McNally

CEO

This past year has been one of both challenge and incredible progress for our Tourette's community. Every day, I am reminded of the strength, resilience and honesty of the people we support — individuals and families who face misunderstanding, inconsistent clinical care and, all too often, stigma. It is their courage that drives every decision we make.

I am deeply proud of what we have achieved together over the last 12 months. Whether we were offering a listening ear, delivering essential information, pushing for better clinical pathways, or raising awareness across schools, workplaces, public services and healthcare — we have worked hard to ensure that no one feels they have to face Tourette syndrome alone. And little by little, we are seeing our voice reach further and resonate louder.

None of this would have been possible without the generosity of our donors, fundraisers, partners, and supporters. Your belief in our mission, especially during such difficult financial times, means so much. Your support has allowed us not only to sustain our work, but to grow it, deepen it, and make a measurable difference in people's lives.

While we celebrate these achievements, we remain clear about the road still ahead. Too many people continue to wait far too long for clinical support. Too many face judgement before understanding. Too many feel their needs are dismissed or misunderstood. This is why our mission must remain bold, focused and unwavering.

Our five strategic goals — empowering people with Tourette syndrome to thrive, raising awareness and challenging stigma, tackling inequality in healthcare, ensuring no one feels isolated, and championing research — will continue to guide everything we do in the year ahead.

I am hopeful. I am determined. And I am incredibly grateful to everyone who stands with us.

Together, we will continue to build a future where every person with Tourette syndrome can live the full, confident and stigma-free life they deserve.

Much Love Emma x

Introduction

Since 1981, Tourettes Action has been committed to supporting everyone living with Tourette syndrome (TS), as well as those navigating the diagnostic journey. While we continue to challenge misconceptions and tackle stigma, TS sadly remains one of the most **misunderstood** and **stigmatised** neurological conditions, often causing significant distress not only for individuals with TS but also for their families and loved ones.

Our Goals

Our five strategic goals remain:

- **To enable people with Tourette syndrome to thrive**
- **To raise awareness of Tourette syndrome and reduce the stigma associated with it**
- **To reduce health inequalities for those living with Tourette syndrome**
- **To ensure that no-one with Tourette syndrome feels alone**
- **To support research into Tourette syndrome**

These goals were shaped by surveys within the Tourette's community, which identified a lack of awareness across all parts of society as the most significant barrier to progress.

We remain dedicated to building a future in which stigma is eliminated entirely and every person with TS feels supported, included, and valued.

2024 / 2025 Achievements

This financial year, we have continued to see meaningful growth in engagement, visibility, and impact. We are incredibly proud of what we have achieved, ranging from delivering direct support to individuals and families, to driving national conversations about the need for improved services and greater public understanding of Tourette syndrome.

Our reach has expanded significantly, with our work resonating across an ever-wider range of audiences, including educators, healthcare professionals, employers, public service providers, and customer-facing industries. This increased visibility has ensured that the voices of those living with TS are heard, their experiences recognised, and their needs more clearly understood.

Take a look at how we have achieved our goals this financial year and the difference your support has helped make possible.

1. To raise awareness of Tourette syndrome and reduce the stigma associated with it

Increase public awareness and understanding about the reality of Tourette syndrome, and what it means to live with it.

How we do this: Delivering nationwide awareness campaigns reflecting our community voice. Sharing accurate information that is not only based on lived experience but also on recent scientific and research-based evidence about Tourette syndrome, through various media. Conducting educational training and workshops for parents, schools, workplaces and healthcare professionals.

Website

Our website received over **64,000** views this financial year

eLearning

Over **2,000** individuals completed our eLearning module to learn more about Tourette syndrome

Newsletter

We had a 20% increase in people signing up to our newsletter, with over **11,000** subscribers at the end of the financial year

Socials

We had an increase in followers and engagement across all platforms. We saw an increase of just over **2,500** followers across our social platforms, with the biggest increase on Instagram and LinkedIn

Training

2 workshops and **97** bespoke online training sessions delivered to over **7,500** individuals

Tourette's Awareness Month

For the third year running, we embarked on a major campaign during Tourette's Awareness Month, which ran from 15th May to 15th June. The campaign was called ***#TourettesHurts*** and its aim was to highlight the impact Tourette's can have on those with the condition and those around them. The campaign wasn't just about raising awareness of Tourette's. It was about challenging misconceptions.

The campaign was informed by the views of members of the community who wanted a campaign which would help people understand the truth of the condition – and just how painful it can be both from a physical and emotional aspect. They wanted to showcase the realities of the condition but to also show that with the right support, and the understanding of the general public, the condition would be that little bit easier to live with.

This project involved designing 5 poster themes and recruiting 5 members of the TS community to appear in the posters. Each of the posters shared a different message about why #TourettesHurts:

Exhaustion	Physical Pain	Lack of Medical Provision	Suppression	Social Exclusion

The powerful poster campaign captured the imagination of the UK public. It was built from compelling headlines and visuals, whilst shining a light on real members of the Tourette's community.

The idea was to dramatize the pain of daily tics by quantifying it with bold language that everyone could understand.

We landed on headlines such as:

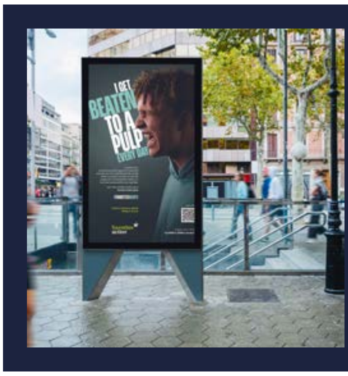
> **"My skin catches fire every day"**

> **"I'm in a car crash every day"**

> **"I get beaten to a pulp every day"**

We photographed the members and put the headlines at an angle, as if colliding with the person, amplifying the sense of discomfort.

The campaign content could not be ignored. The dark backgrounds and angled lighting added drama that threw the real expressions of pain very much into the spotlight. It challenged misconceptions and led to greater understanding of the condition that is, sadly, very much mocked and misunderstood. It gave a voice to people for whom medical provisions and research is lacking, who are ignored, laughed at and often isolated. It's changed preconceptions, and in doing so, it brought about empathy and understanding to those with the condition. Our 5 posters were:

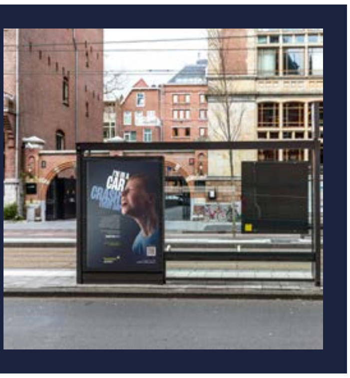


Exhaustion: I get beaten to a pulp every day

Experiencing constant agony from hundreds of involuntary tics every single day feels like a brutal attack on your body. And with over 300,000 people in the UK living with the condition, it's much more widespread than you might think.

Physical Pain: I'm in a car crash every day

Over 90% of people with the condition experience pain daily because of their tics. The relentless discomfort of these involuntary neck and shoulder movements, repeated hundreds of times a day, adds up to what feels like whiplash from a car accident.



Lack of medical provision: I'm crushed by boulders every day

Involuntary tics cause constant pain, but over 50% of people living with the condition have to wait more than a year to see a specialist. And when they do, 60% of patients are diagnosed and discharged in the same appointment, with no ongoing care. That's a heavy load for them and their families.

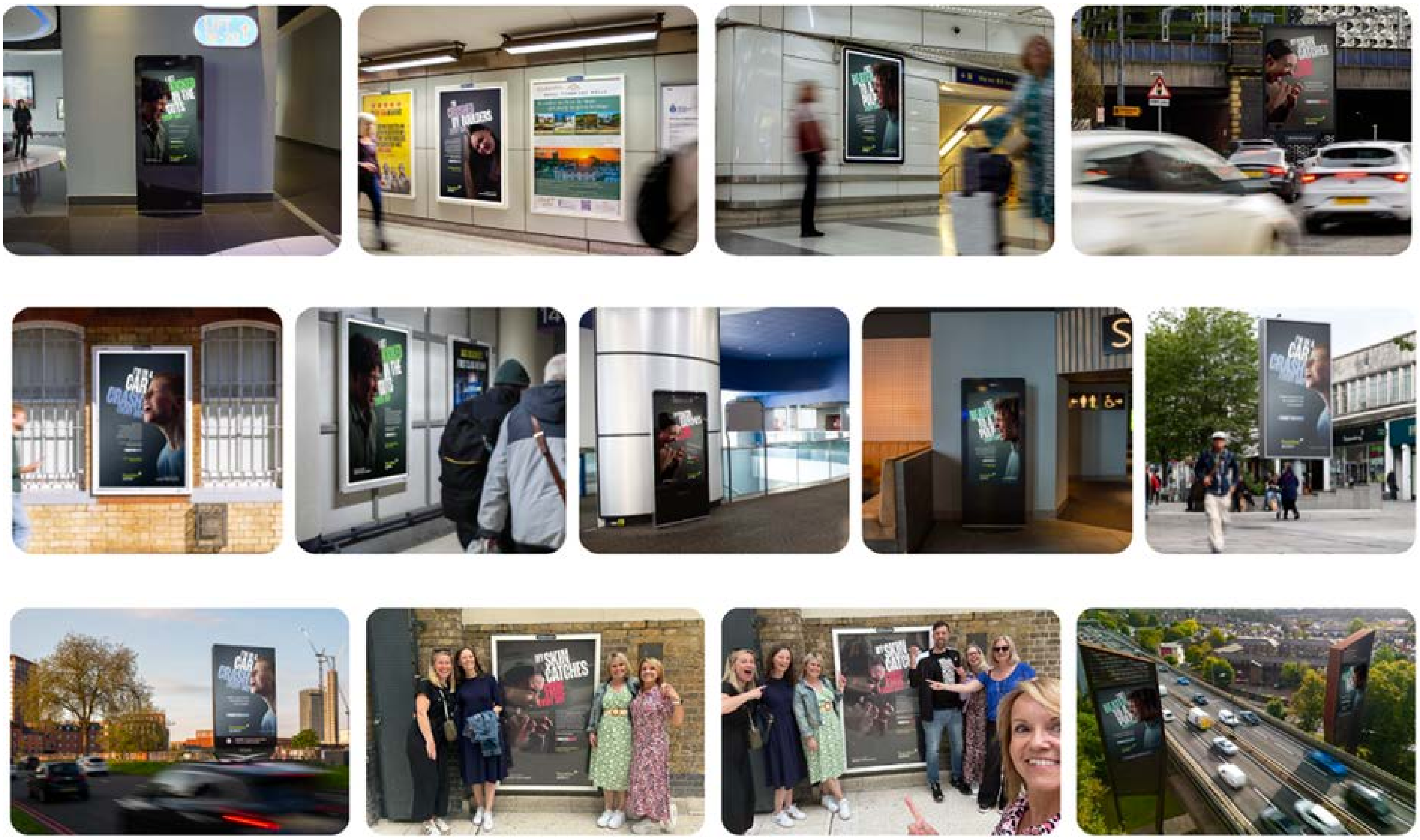
Suppression: My skin catches fire every day

75% of those living with the condition feel compelled to hide it for fear of stigma and discrimination. The effort required to hold back the hundreds of involuntary tics they experience every day can create an agonising build-up of tension that makes it feel like their whole body will combust.

Social Exclusion: I get kicked in the guts every day

Every single day, people with the condition are mocked or excluded because of their involuntary tics. This can cause lasting psychological damage - sadly, those with Tourette's are four times more likely to die by suicide than the general population.

The campaign reached over **2 million views** through paid ads in 82 London train stations during Tourette's Awareness Month. During this time, we also successfully secured significant free advertising space across **89 high-traffic locations**, including Piccadilly Circus, Westfield London, Nelson Street Glasgow, Bond Street Leeds, Snowhill Birmingham, Westminster Towers, Chiswick Towers, Liverpool Towers, Manchester Trinity Way and **76 cinemas** throughout the UK.



We further amplified our message with a video featuring community members and 8 celebrities (Eddie Marsan, Aidy Smith, Daniel Mays, Omid Djalili, Matt Lucas, Sally Hawkins, David Morrissey, Izzy Judd) who each read lines from the poster messaging. The video was viewed over **221,000 times** during the campaign.

Watch it here: https://www.youtube.com/watch?v=_Y8KOC863bs

The campaign was picked up by 12 media outlets, including BBC National News and BBC Breakfast.

During the awareness month we saw a huge amount of engagement from the community, with lots of people supporting us in getting the message out there:

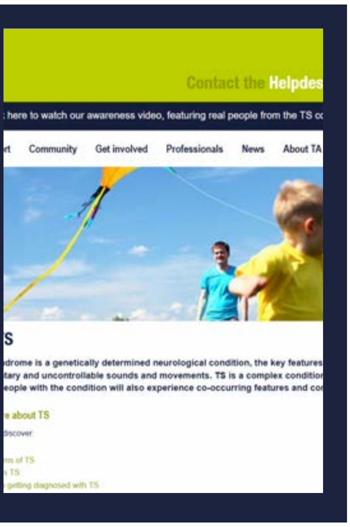
Over 750 service users joined us in raising awareness	Our awareness video was played over 221,000 times	Lots of awareness sessions held in schools and businesses	The campaign was featured on BBC news & BBC this morning	57 buildings turned green on awareness day to show support	Our posters were advertised in 175 high footfall locations
					

Our website saw nearly 13,000 visitors, and social engagement peaked at **1.1 million** — far surpassing typical months.

Website

Our website remains a central source of reliable information on Tourette syndrome. All resources are freely downloadable, reinforcing our commitment to open access.

We frequently receive feedback describing the website as a "one-stop shop," providing clear, research-based facts and often being the **only** source of information individuals have received. Our factsheets continue to answer the community's most common questions, empowering people with trusted, evidence-based guidance.



here to watch our awareness video, featuring real people from the TS co

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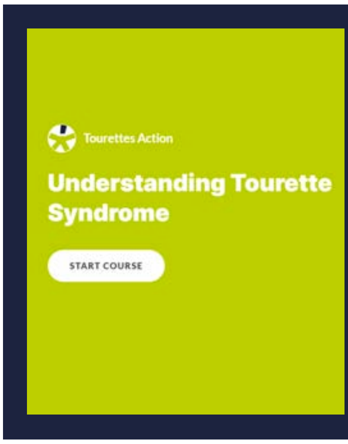


Understanding Tourette Syndrome

eLearning

Our free CPD eLearning module, *Understanding Tourette Syndrome*, continues to be widely used by both the general public and professionals in the education and health sectors. We are proud that it remains the **only** Tourette syndrome training module available on the NHS Learning Hub, and its inclusion on numerous Local Authority learning platforms in both English and Welsh allows us to extend our reach even further.

Socials

We continue to promote our website content, along with research news, fundraising campaigns, events, webinars and training through our social media platforms and our monthly newsletter. Engagement across social platforms has strengthened again this year, particularly on Instagram and LinkedIn.

Training

This year, we delivered two major workshop events: a day-long session in Haywards Heath for parents and carers, and a multi-day workshop in Birmingham for professionals across health, social care and education, as well as families. **100%** of attendees reported they would implement new strategies learned.

Demand for tailored training has remained high this year, and we have continued to provide individual sessions via Zoom throughout the year, including 9 community groups, 15 corporate organisations, 13 health and social care teams, and 60 educational settings.

2. To reduce health inequalities for people living with Tourette syndrome

Campaign so that everyone with Tourette syndrome can have access to an appropriate NHS healthcare provision, regardless of their location, ethnic or cultural background or social status.

How we do this: Supporting community-led lobbying and parliamentary engagement. Participating in coalitions and steering groups to advocate for improved services. Ensuring representation of community voices in health policy discussions.

The ongoing challenges around timely diagnosis, care, and treatment remain a significant concern for our community. As a result, driving improvements in healthcare provision has been one of our key priorities throughout this financial year.

NICE

We've made significant strides in our campaign for health service improvements, with one of the most notable advancements being our involvement with the NICE Committee, which began in 2023.

This year, our CEO and two Tourettes Action board members contributed to the **NICE Early Value Assessment on digital therapies for chronic tic disorders and Tourette syndrome**, ensuring the lived experience of the TS community shaped the process.

As part of this work, we collaborated with NICE to develop and distribute a nationwide survey on healthcare access for those living with TS. The findings were concerning:

1,508 respondents

- **63%** waited over a year for diagnosis
- **23%** waited more than three years
- **13%** waited over five years
- **more than 60%** had never been offered treatment
- Only **17%** received face-to-face behavioural therapy
- **77%** reported pain as a significant issue, yet just **3%** received pain management
- **31%** of those offered CBiT were still waiting over a year for their first appointment
- Nearly **32%** were never assessed for co-occurring conditions

These findings underscore the urgent need for systemic change. Many respondents reported stark regional disparities in access to medical support, highlighting inconsistencies across the country.

To amplify these concerns, we submitted a detailed response to the **NHS 10-Year Change Plan** and formally proposed that **NICE develop clinical guidelines** for the diagnosis and management of Tourette syndrome.

Clinical understanding and interest

Many of our service users continue to report that medical professionals hold outdated views about Tourette syndrome, for example, the misconception that *"you can't have Tourette's if you don't swear."* Challenging these misunderstandings remains a key part of our work.

This year, we expanded our eLearning offer with a new module designed specifically for **GPs and health professionals**, aimed at improving clinical understanding and reducing delays caused by outdated beliefs. We are grateful to Dr Kate Szymankiewicz for her valuable contribution to this resource.

In November, our CEO presented at the National Psychiatry and Intellectual Disability Conference, highlighting the lack of nationwide provision for people with TS. Clinicians expressed strong interest in learning more and in improving access to support across the UK.

Advocacy Groups and Collaboration

This year, we continued to play an active role in several key advocacy and policy groups, including the **Nottingham Tourette's Steering Group**, **NDMAG**, and the **Neurological Alliance**. Our involvement in these groups helps ensure that the needs and voices of the TS community are represented at national and regional levels strengthening our influence.

The Nottingham Tourette's Steering Group NIHR-funded project, launched in November 2023, and continued throughout this financial year. Its aim is to develop a recommended service model for children and young people with tics, and our CEO led the Patient and Public Involvement work to ensure the patient voice shaped the final recommendations.

The Neurological Alliance hosted a parliamentary breakfast which encouraged MPs to be a #NeuroChampion. I attended the event, along with Paul Stevenson. **Paul presented** highlighting the issues the TS community face with gaining a diagnosis.

Advocacy and Parliamentary Engagement

This year, we continued to empower the TS community to advocate for meaningful change by encouraging them to contact their MPs. As a result, **95 individuals** used our templates to reach out, leading to **seven Parliamentary questions** being submitted on Tourette syndrome.

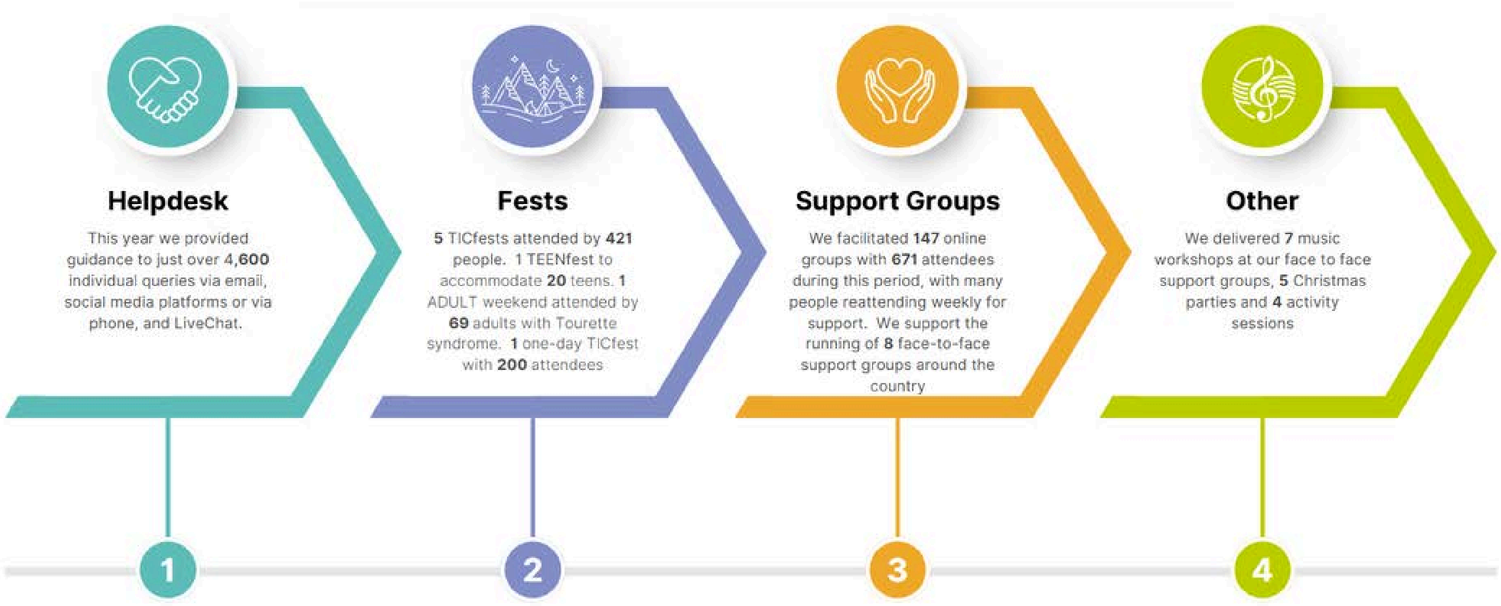
As more MPs engage with these issues, commissioners are increasingly recognising the need for action. Several Integrated Care Boards (ICBs) have begun exploring the development of local Tourette's pathways, and we have supported this work by advising on current best practice.

In April 2024, our CEO attended Parliament alongside charity representatives and advocates for the reading of Matt Hancock's *Neurodivergent Conditions Screening Bill*. While highlighting the importance of early diagnosis, she also stressed the critical need for robust treatment pathways to support children following a diagnosis.

3. To ensure that no-one with Tourette syndrome feels alone

Build a network of support for people with Tourette syndrome and their families, ensuring that no one living with, or affected by the condition, feels alone.

How we do this: Facilitating online and in person support groups. Organising residential events for families, teenagers, and adults with TS. Providing personalised assistance through our helpdesk.



1

Helpdesk

This year we provided guidance to just over **4,600** individual queries via email, social media platforms or via phone, and LiveChat.

2

Fests

5 TICfests attended by **421** people. 1 TEENfest to accommodate **20** teens. **1** ADULT weekend attended by **69** adults with Tourette syndrome. **1** one-day TICfest with **200** attendees

3

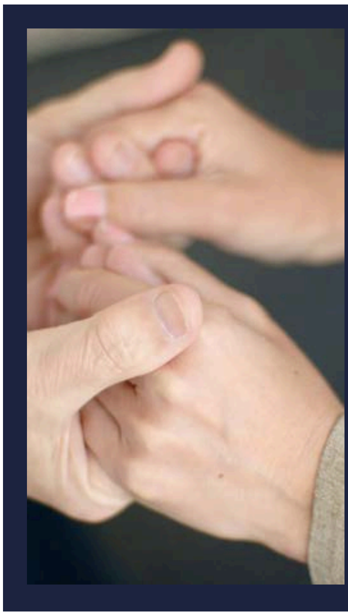
Support Groups

We facilitated **147** online groups with **671** attendees during this period, with many people reattending weekly for support. We support the running of **8** face-to-face support groups around the country

4

Other

We delivered **7** music workshops at our face to face support groups, **5** Christmas parties and **4** activity sessions



Helpdesk

Our helpdesk remains our main method of personal one to one support, providing personalised support and guidance to people with TS and those supporting them. This financial year we saw a notable increase in the complexity of queries received, often resulting from the lack of medical provision. Many people told us they felt we were their only source of hope – having spent years seeking a diagnosis or having been discharged from medical services without ongoing support.

The Helpdesk is run by 2 members of Tourettes Action staff and supported by a dedicated group of volunteers. We are deeply grateful to our volunteers for their time, compassion, and invaluable contributions.

Residential Events

Our Fests deliver the greatest positive impact of all our events. They create a safe space where participants have fun, build friendships, and take on both exciting challenges and calmer activities supported by psychoeducation. The concept is simple, but the effect is profound. For many, it's one of the few places where they truly feel they belong.

TICfest | **5**

Residential weekends for children with Tourette syndrome and family members. These were held in Somerset, Derbyshire, Newcastle, South Wales and Norfolk

ADULT Weekend | **1**

Hosted in the Midlands for adults with Tourette syndrome.

1 | **TEENfest**

Residential weekends for teenagers with Tourette syndrome. This weekend was hosted in Dorset

1 | **1-Day TICfest**

Delivered in November in Watford, enabling anyone from the Tourette's community to come together for a day to learn and share, feel accepted and part of a wider community.

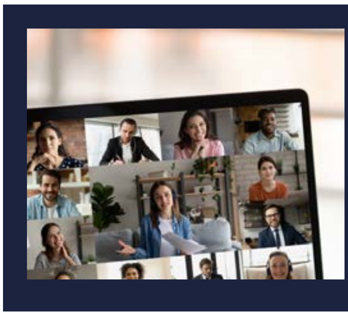
> The feedback we receive shows how essential these events are:
>
> ***"I was blown away - what an experience TICfest was for our whole family. We came with my daughter and her 2 younger brothers and even for them it was a fantastic weekend. My daughter has never had an opportunity before this event to meet other children with Tourette's and similar struggles to her. This weekend made us feel like we had our daughter back, we haven't seen or heard her laugh and smile like she did at this weekend for a long time. The staff are all amazing and we were made to feel welcome from the moment we arrived. Her confidence was sky high after the event, she made new friends who she has kept in contact with. From this event we will have lifelong memories of us being able to enjoy family time and having fun without any worries. This is not something we regularly get to do now."*** TICfest parent

Happier and Less Anxious, Increased Confidence, Less Isolated and Alone

87% of children attending the TICfest events state they felt **happier** and **less anxious** as they experienced what its like to be accepted and that they are not the only ones to have TS.

84% stated that their **confidence has increased** since attending and they now felt more able to talk and explain to people about their condition and will have a better understanding of it themselves.

89% said they were able to make friends with people who understand them, helping them to feel **less isolated and alone**.



Online Support Groups

Demand for our online groups has remained high this financial year, so we continued to offer regular virtual support. We delivered a wide range of sessions, including groups for teens and adults with TS, parents, dads and male role models, as well as family groups.

Less Alone and Gained a Support Network

91% of people who attended the online groups said that since attending the group they felt **more supported** and **less on their own.**

84.5% said the group had given them and their family a network of support that they can now call on for **support** to help them cope in challenging times.

Face-to-Face Support Groups

This year we have put substantial effort into growing our national network of face-to-face support groups that are facilitated by a wonderful group of dedicated volunteers. These groups make a significant positive impact on the Tourette syndrome community giving a platform for individuals with TS, their families, and caregivers to connect, share experiences, offer mutual support, and foster a sense of belonging and understanding.

Less Alone, More Confident, Gained a Support Network

89% of people attending the face-to-face groups said that since attending the group they felt more **supported** and **less alone.**

78% said they felt more **confident** about their future than before they joined the group.

89% said they felt the group had given them and their family a **network of support** that they can now call on for support to help them cope in challenging times.

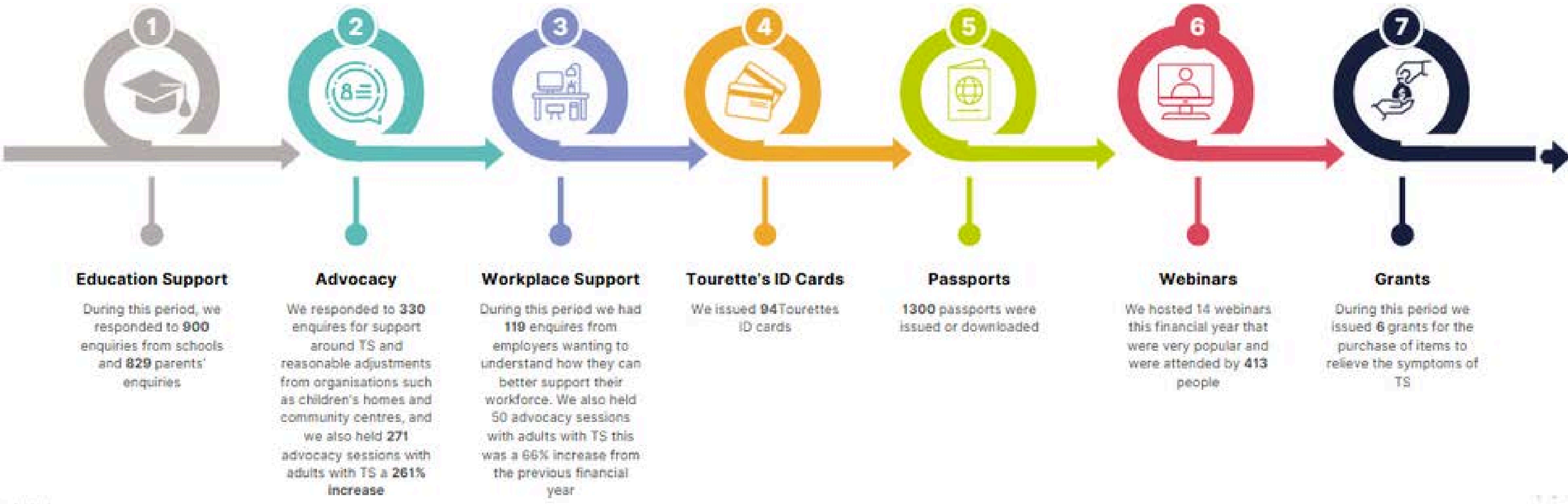
Group Workshops and Activities

During this period, we facilitated 16 activity sessions at our face-to-face groups. These sessions ranged from music workshops, beatboxing, animal therapy, laser tag and wild science. Feedback from the group members was positive, feeling these activities give them the chance to bond.

4. To enable people with Tourette syndrome to thrive

Provide accessible support, advice and training, to individuals and their families, and professionals, helping people living with the condition to flourish at home, in education and in employment.

How we do this: Developing and distributing resource guides and factsheets online. Advocating for those with Tourette syndrome in educational and workplace settings. Hosting online and in-person seminars featuring expert advice.



Education Support

During this period, we responded to **900** enquiries from schools and **829** parents' enquiries

Advocacy

We responded to **330** enquires for support around TS and reasonable adjustments from organisations such as children's homes and community centres, and we also held **271** advocacy sessions with adults with TS a **261% increase**

Workplace Support

During this period we had **119** enquires from employers wanting to understand how they can better support their workforce. We also held 50 advocacy sessions with adults with TS this was a 66% increase from the previous financial year

Tourette's ID Cards

We issued **94**Tourettes ID cards

Passports

1300 passports were issued or downloaded

Webinars

We hosted 14 webinars this financial year that were very popular and were attended by **413** people

Grants

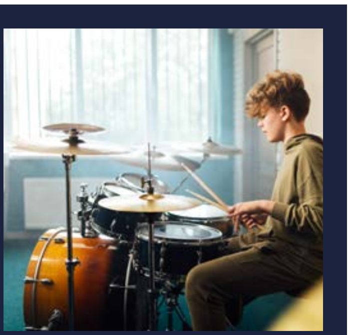
During this period we issued **6** grants for the purchase of items to relieve the symptoms of TS

Educational Support

The need for information and support in schools is as high as ever. Our Education Manager has spent many hours equipping teachers and parents with the knowledge and strategies they need to support children with TS effectively in education.

Small Support Grants

Due to the ongoing support of a very generous benefactor, we continue to be able to offer small grants for items, which help people to manage their TS. During this period we issued grants for things such as a supporting bed and mattress, Rubik's Cubes, a tablet, a sofa bed, a shower rail and shower equipment, and a Polyphonic Analogue Synthesizer, all of which helped the individuals manage their symptoms of TS.



Workplace Advocacy and Support

This year, we received an increasing number of requests for support from adults with TS in the workplace. We've worked closely with employers seeking to better understand how to support staff with Tourette's, helping to create more inclusive and informed working environments.

We've also delivered 1-to-1 advocacy sessions for adults with TS, covering Access to Work, workplace adjustments, and disability rights, equipping them with the knowledge and confidence to advocate for themselves.

Supporting Documents

Our Tourette's ID cards are still very popular. Users often tell us that the cards give them confidence to go out and travel alone - the card can explain their condition, when they are not able to.

The TS passport is another useful document enabling people with TS to list their support needs in education and the workplace.

Tourettes action

For more information call:
0300 777 8427
www.tourettes-action.org.uk

Name: Your Name

This person has
Tourette Syndrome.

Please seek advice if you are dealing with or assisting them and are uncertain about any aspects of the condition.

Webinars and Facts

We held a series of informative and educational webinars during this financial year, covering topics such as: Managing transition and change, The Neupulse Device, Autism in Girls, Educational Support, Employment, Sleep, Anxiety & TS, Evidence Based Treatments, FND, Anxiety.

This period we also continued to expand and update our factsheet resources that are freely available on our website.

New Strategies, More Informed, More Empowered and Confident

73% of people said they would implement **new strategies** learned from the webinar.

78% said they felt more **informed** about TS, its impact and tic management following the webinar.

71% felt more **empowered** and **confident** to seek support or make choices about their health or their family member's health following the webinar.

Advocacy

This period we have continued to receive requests for support around TS from children's homes, community centres, wellbeing centres, social services, sports clubs and behaviour support units.

5. To support research into Tourette syndrome

Promote and assist research into the causes, treatments, and the impact of Tourette syndrome, with a view to improving the lives of people with the condition.

How we do this: Collaborating with researchers and sharing community insights. Developing community-defined research priorities. Disseminating research findings in accessible formats to the TS community.

This financial year brought a notable rise in research activity around Tourette syndrome. We supported 20 researchers in their studies, promoting their projects across our website and social media to reach participants and deepen understanding of the lived experience of Tourette's.

The promoted studies included:

- From Trauma to Tics: A Qualitative Exploration of Later-Onset Tourette syndrome in Adults
- Investigating the Experiences of Phonic Tics and Involuntary Vocalisation Behaviour in Adults with Tic Disorders
- How do animals benefit individuals with Tourette syndrome?
- Developmental characterization of explosive outbursts in youths with Tourette syndrome
- Are there benefits to using physiotherapeutic methods to decrease tic severity and pain levels for individuals with Tourette syndrome?
- The relationship between parental stress, stigma, resilience, and social support
- Optimising Therapy for Neurodivergent Adults: Reasonable Adjustments and Special interests and their interplay in therapy and quality of life
- Coping Strategies, Stress, and Sleep: Evaluating Their Relationships and Influence on Tic Severity in Children with Tourette syndrome (TS)
- Exploring the **EXP**eriences of **A**ccessing services and understanding **N**eurodevelopmental **D**isorders for ethnic minorities in England (EXPAND)
- Research for the Development of a Script dealing with Tourette syndrome
- Functional Tic-Like Behaviours: Towards an Understanding of Young People’s Experiences
- Self-stigma in Parents of Young People with Functional Neurological Disorders or Asthma.
- Professionals experiences of working with functional tic disorder
- Help improve access to healthcare for young people with neurodevelopmental disorders

- Designing an online intervention to improve GPs knowledge of tic disorders
- Lived Experience of TS - Exploring the success of pharmacological vs art-based intervention
- Sleep Traits in Tourette syndrome
- Exploring the urge to tic in TS

Our funded research support programme remains suspended for new applications due to lack of funding, but we continue to support and monitor progress on research projects previously committed, disseminating findings to our community.

There are several long-term projects we've supported that are now delivering exciting results:

Neupulse

The wrist-worn device developed under the leadership of Professor Stephen Jackson, which provides an electrical stimulation that can have the effect of significantly reducing tics in the wearer, is now progressing toward market launch.

ORBIT (Online Remote Behavioural Treatment for Tics)

Led by Professor Chris Hollis, is being developed into a scalable, patient-ready digital tool for delivery across the NHS.

Leadership and Governance

Emma McNally

CEO

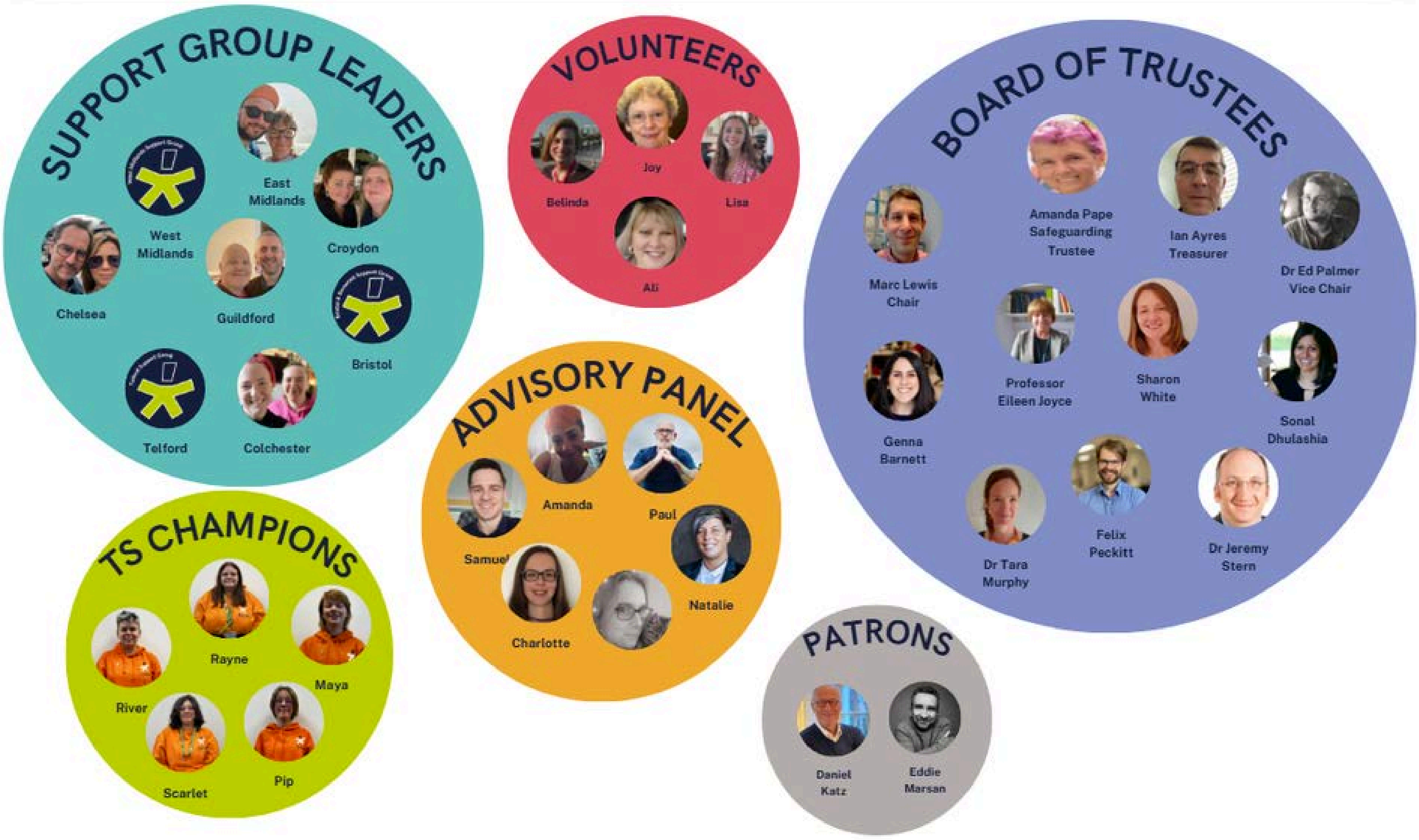
> "Every action we take is guided by our commitment to creating meaningful, positive change. By staying anchored in our values and focused on our mission, we continue to grow stronger as a community. Together, we're shaping a future that is brighter, more inclusive, and filled with lasting impact."

Tourettes Action was founded in 1981, when I was only four years old, with a clear and simple purpose: to support individuals living with Tourette syndrome and those searching for a diagnosis. Today, that purpose remains unchanged.

Our People

Although we remain a small national charity we have achieved a great deal this year. Our dedicated team of 16, many of whom are part-time, along with our fantastic volunteers, are the heartbeat of our charity. Their passion, commitment and hard work are what drive our impact and bring our mission to life each and every day.

A breakdown of our Board of trustees and volunteers



Structure, Governance and Management

Tourette syndrome (UK) Association trading as Tourettes Action, ('the charity' or 'TA'), is a company limited by guarantee and as such is governed by its Memorandum and Articles. It was incorporated on 23 May 1991.

The charity is governed by the Trustee Board, which sets the strategy of the charity, ensures compliance with its charitable objectives, approves the business plan and budget annually and monitors the ongoing operational and financial performance of the charity.

As a charity, we ensure that we have prudent financial and risk management, seeking to preserve and enhance the strength of the charity, whilst safeguarding our people, our community and the enduring reputation of the charity. We also have strict budget and financial management and ensure that all areas of risk, including but not limited to safeguarding, and compliance and technology, are effectively managed through our risk register and through appropriate maintenance and monitoring of policies and procedures.

The board maintains three sub-committees:

- Finance and General Purposes (F&GP)
- Research (RSC)
- Safeguarding and Services (S&S)

Finance and General Purposes

The F&GP assists the CEO with budget preparation, financial performance monitoring through monthly management accounts, and publication of statutory accounts. Also supporting in areas like HR, staffing, premises, administration, and oversight of operational risks.

Research

The Research Committee comprises clinicians and lay members. The committee ensures TA's support and advice is evidence-based and they oversee all research-related activities and support.

Safeguarding and Services

The subcommittee oversees the quality and effectiveness of TA's services, ensuring activities are appropriate and meet the needs of service users. It also monitors and ensures compliance with TA's Safeguarding and other related policies.

Financial Performance

Maximising Donations

Someone once said to me:

> **Fundraising isn't really about money — the money is simply the outcome of everything you do for people.**
>
> **People don't give to a charity; they give through it.**
>
> **They give because they believe in your mission, in the difference you make for people with Tourette syndrome, and in the support you deliver every single day.**

This really rang true for me. When we provide **meaningful support**, when we **show up** for our community and offer the services they need, people naturally want to give something back. Their generosity is a reflection of the trust they place in us and the value they see in our work.

At Tourettes Action we work extremely hard to support our service users and in return, our service users work really hard in supporting us - through their fundraising efforts - for this we are very grateful.

And yet again this financial year our incredible fundraisers showed unwavering commitment and energy. Highlights from this year's fundraising activities included participation in the London, Manchester, and Hamburg Marathons, the Bristol Half Marathon, Tough Mudder, the London Landmarks Half Marathon (LLHM), Move for Tourettes, Facebook birthday fundraisers, and our Tea for Tourette's events.

We were also fortunate to welcome two new charity partners, LSP and GS1UK who pledged to support Tourettes Action this financial year. Their support has significantly strengthened our efforts to raise awareness of both the condition and the charity's mission.

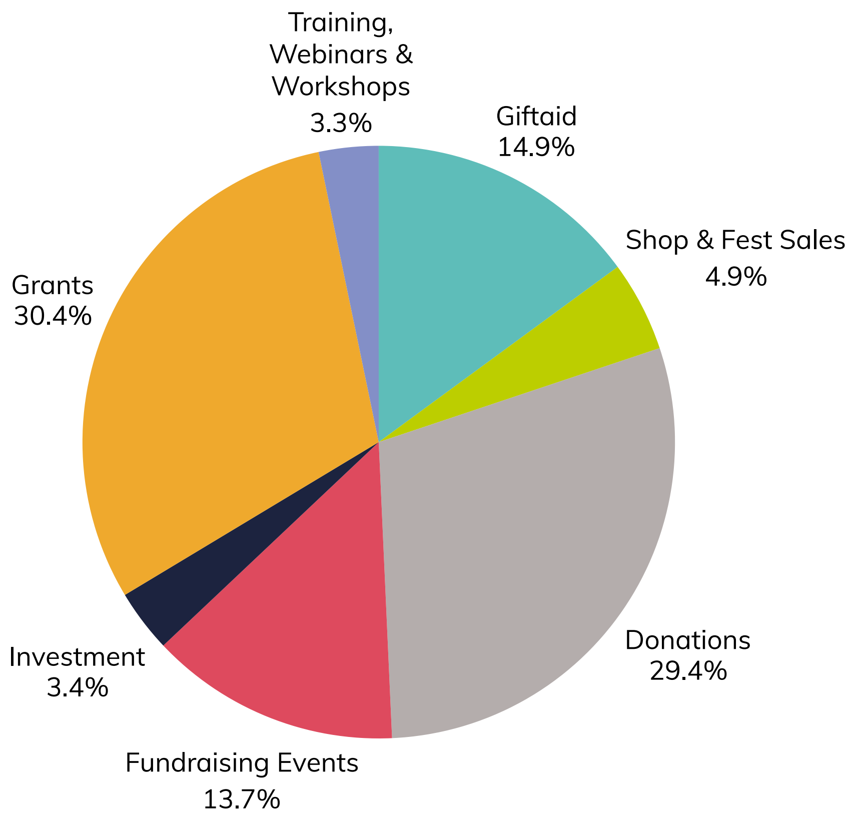
We are very grateful to all of our fundraisers and regular donors who continue to support us with financial contributions, even during these times of economic pressures.

The majority of our charity funds come from grants, many of which are restricted to specific projects. During the year, we received grants and donations from a variety of trusts and funders including BBC Children in Need, The National Lottery Community Fund - RC England Wide, The National Lottery Community Fund - Awards for All England, the Angus Lawson Memorial Trust, D'Oyly Carte Charitable Trust, Marsh Charitable Trust, Forvis Mazars Foundation UK, De Brye Charitable Trust, Hospital Saturday Fund, RSA Match funding, Miller Homes, Florence Turner Trust and CHK Foundation.

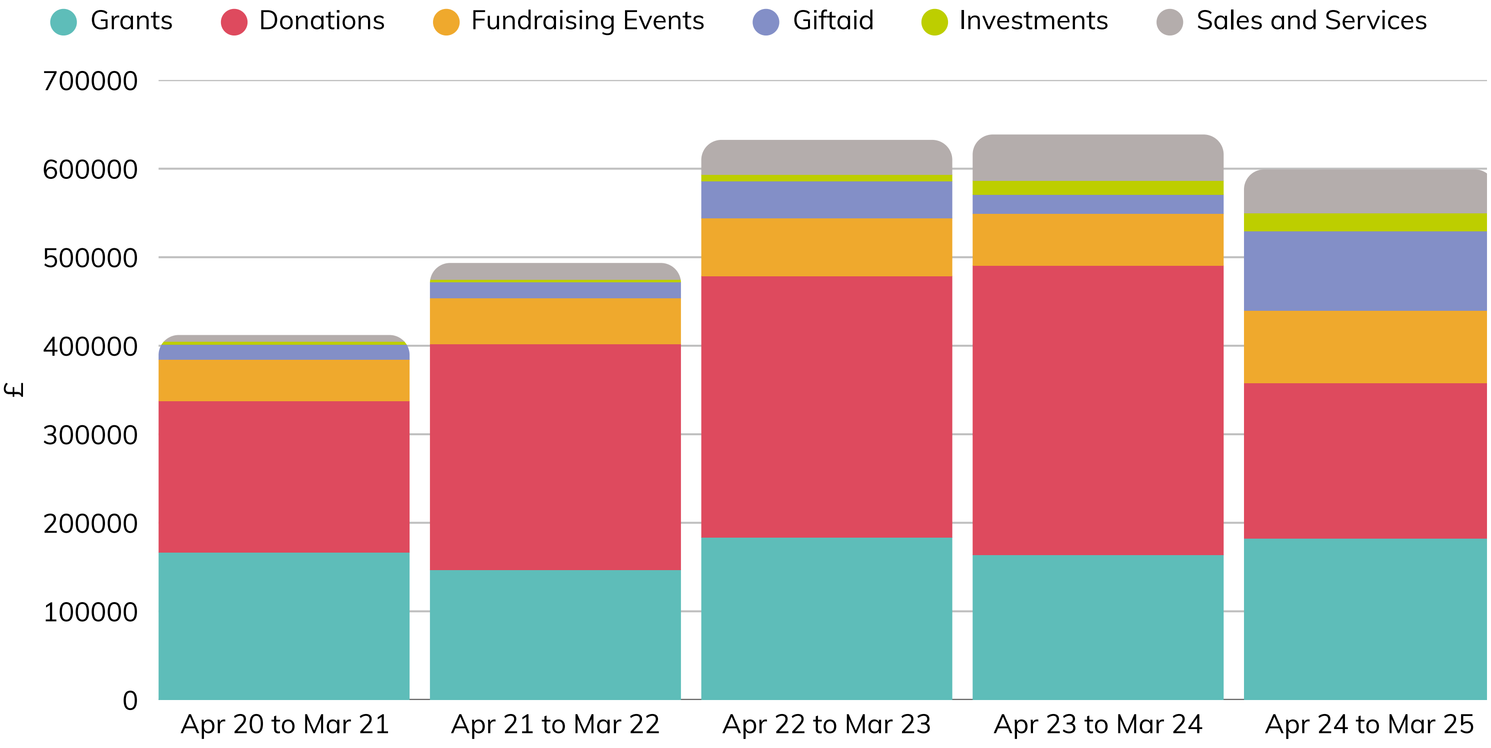
This year for the first time we took part in The BIG Give Christmas Challenge, which enabled us to double our donations during one week in December. The funds raised during this campaign will fund the running of our Helpdesk.

Breakdown in charity income for Apr 24 - Mar 25

In previous years, donations accounted for just over half of our total income, making us heavily dependent on a single funding source. We are now working to develop a broader range of income sources to ensure we are not overly reliant on any individual donor or funding source, giving us greater long-term financial stability.

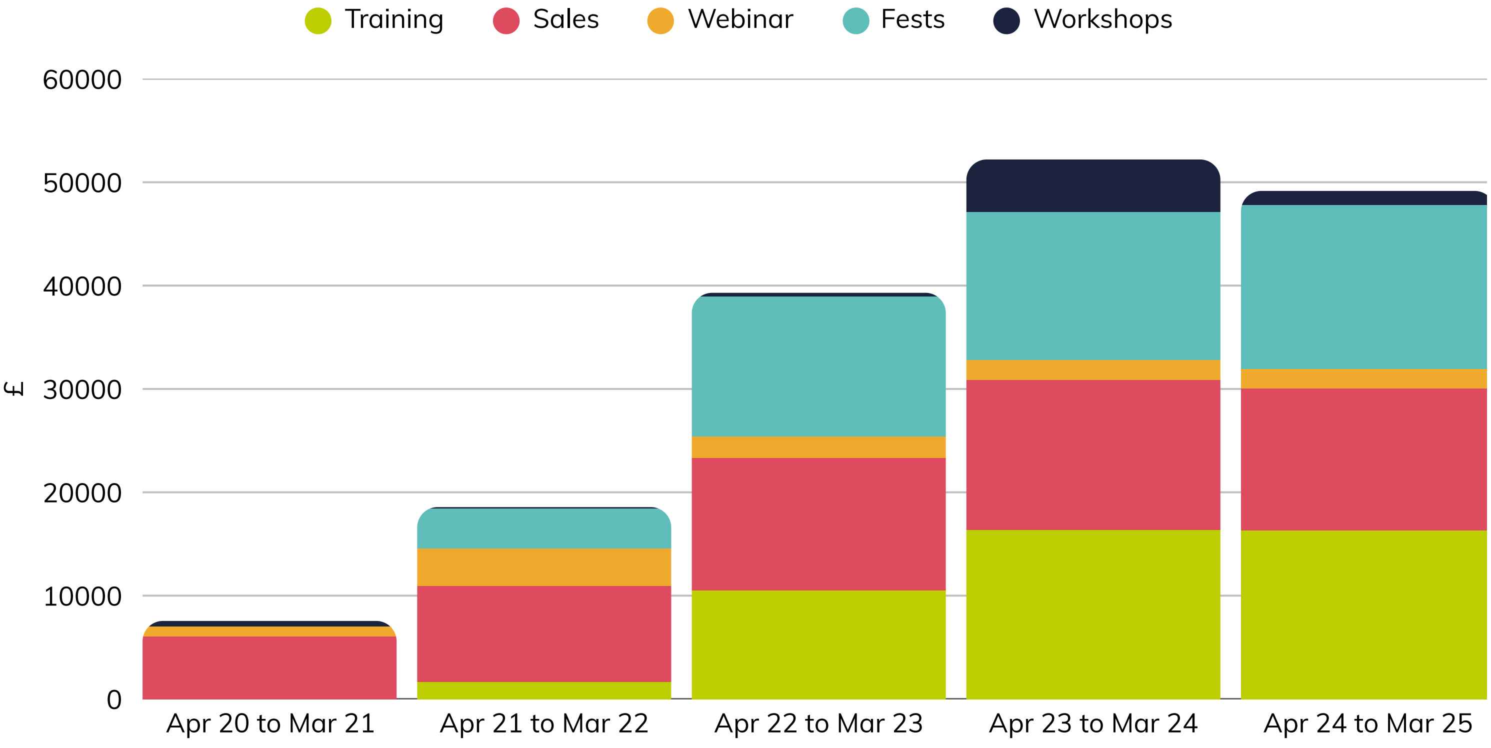


Charity income: grants, donations, fundraising, Giftaid, interest, sales & services for last 5 years



Over the past few years, our *'Sales and Services'* income from our training, shop sales, webinars, workshops and fest events, along with our fundraising campaigns, have started to provide a steady stream of revenue for the charity, increasing year on year.

Charity income from sales, training, workshop, fest and webinar sales for last 5 years



Future Plans

As we reflect on the past year, I am immensely proud of all that we have achieved together. From simply *being there* for individuals and families at moments of real need, to amplifying the voice of our community across education, healthcare, workplaces and public services—we have taken meaningful steps forward. None of this progress would have been possible without the unwavering generosity of our donors, fundraisers, partners and supporters. Your commitment, especially during such challenging economic times, means more than words can express.

And yet, we know our work is far from finished.

Too many people with Tourette syndrome still struggle to access timely, specialist clinical support. Too many still face misunderstanding, stigma, or a lack of recognition in the systems designed to help them. Our mission remains clear: to create a future where every person with Tourette syndrome can live freely, confidently and without barriers.

With that in mind, our five strategic goals will continue to guide everything we do in the coming year. We remain focused on:

- enabling people with Tourette syndrome to thrive
- raising awareness and reducing stigma
- tackling health inequalities
- ensuring no one ever feels alone
- supporting vital research

Awareness will be key, and so will driving forward long-overdue improvements in health services.

We are hoping it will be a big year for the Tourette's community as it will see:

I Swear

The release of the I Swear film, which is based on the true life story of campaigner John Davidson MBE.

New Digital Therapies

Digital therapies such as ORBIT and the wearable device from Neupulse getting closer to delivery and release

We will continue to push for change, build partnerships, support research, and stand alongside every person and family affected by Tourette syndrome. With your continued support, I truly believe the year ahead can be our most transformative yet.

#TogetherWeAreStronger

Together, we can create the future our community deserves

Reach Out

Contact Us

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Reg Charity no: 1003317

Company registered in England and Wales number 2613993

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https://www.youtube.com/user/UKTourettesAction