

**APRIL 2023
TO MARCH 2024
IMPACT REPORT**



PREPARED BY
EMMA MCNALLY
CEO

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Introduction

This financial year, we have made a significant impact and a real difference in helping people with Tourette syndrome live their lives to the fullest.

We spent a fair bit of time formalising our new vision, mission and values statements, which then enabled us to ensure our priorities and goals were really aligned with what our service users wanted and the charity's mission statement and values.

Our Vision

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.

Our Mission

- We will support and empower people living with Tourette syndrome, and their loved ones, through comprehensive advice and support.
- We will campaign to improve services, raise awareness and understanding of Tourette syndrome, and work to eliminate the stigma surrounding it.
- We will assist and promote essential research into Tourette syndrome.

Our Values

These values underpin everything that we do:



Empathy

We approach every person and situation with understanding, kindness, and genuine concern. We listen to our community, to support people with Tourette syndrome and their families in their hour of need.



Eradicate Stigma

We push to break the stigma of Tourette syndrome by educating the public and professionals, to enhance understanding and promote social acceptance of people living with the condition.



Empowering

We empower people with Tourette syndrome to be themselves and reach their full potential.



Equity

We create an environment where people from all backgrounds feel welcome, respected, and valued - creating a level playing field for all our members.



Ethical

We give impartial advice grounded in scientific and research-based evidence and operate with honesty, transparency, and accountability in all our actions.

Our Goals

Our five strategic goals for the year were:

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 established in response to surveys undertaken within the Tourette's community which identified the main obstacle as an overall lack of awareness of Tourette's within all parts of society.

This Year's Accomplishments

Despite working to reduce the stigma surrounding Tourette syndrome (TS), those living with the condition are aware that it is still one of the most **stigmatised** and **misunderstood** of all the neurological conditions, bringing distress to those with the condition as well as their family and friends. In all that we do, we aim to increase **awareness** and bring about **acceptance** for those living with TS, hoping to one day eradicate this stigma and bring true acceptance to those living with it.

Looking back over the past 12 months, we've seen significant growth in engagement and visibility. Reflecting on our journey, we're proud of all we've accomplished—from simply "being there" for those who need us to actively campaigning for improved services and greater awareness of Tourette syndrome. Our reach has certainly expanded, with our message resonating across a wider audience, including teachers, health professionals, employers, public services, and customer-facing industries - ensuring our voice is being heard. Take a look to see how we have achieved our goals this financial year.

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 annual, nationwide awareness campaigns to truly reflect the voices of our community. Sharing accurate information that is not only based on lived experience but also on recent scientific and research-based evidence about Tourette syndrome. Conducting educational training and workshops for both education, workplace and healthcare professionals.



Tourette's Awareness Month

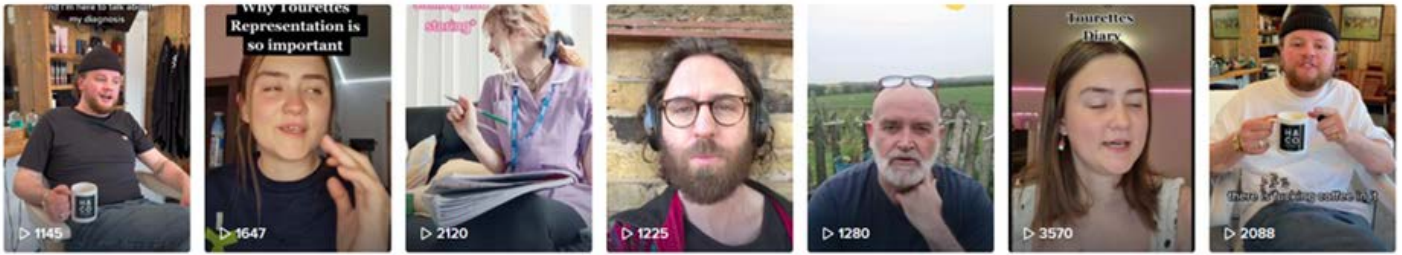
This year, we launched our second nationwide campaign for Tourette's Awareness Month, called *#ItsWhatsMakesMeTic*. The goal was to raise awareness, from the mouths of those who live with it daily. We recruited 5 TS ambassadors, each with a unique story, to share their experiences on TikTok. Our hope was that everyone could relate, in some way, to at least one of the ambassadors. More info on each ambassador [here](#)

The project took the following format:

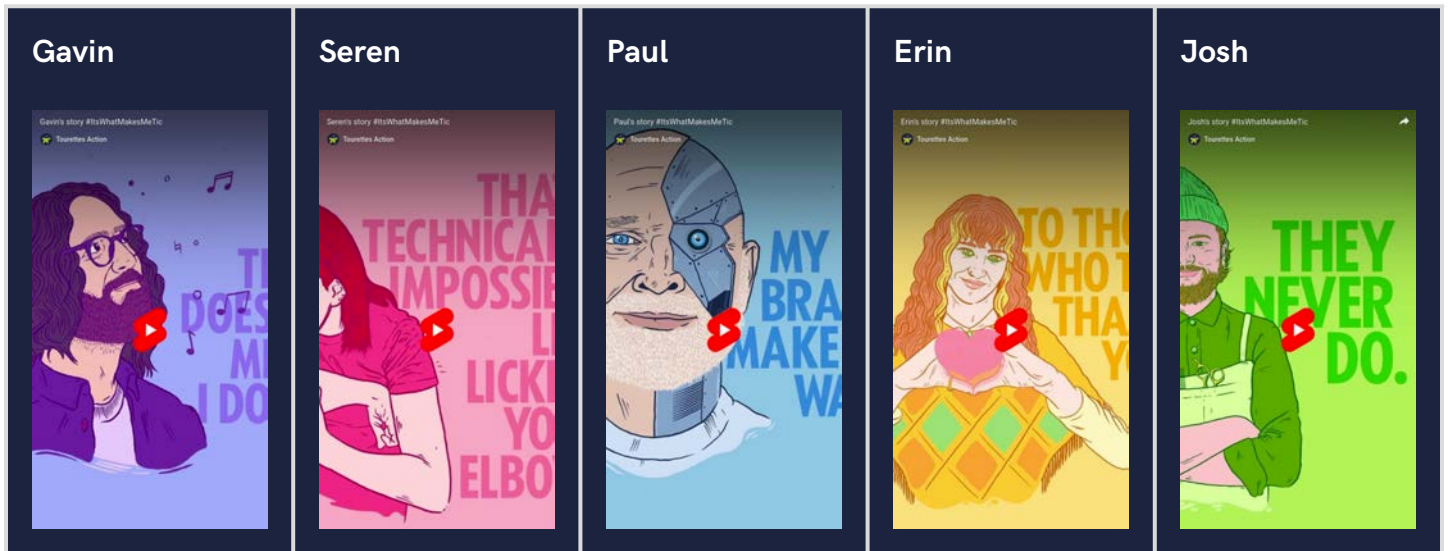
1. A TikTok docuseries where the ambassadors shared their stories of living with TS, showing the true realities of Tourette's whilst educating the public, exploring what TS is and what it isn't and talking about coping mechanisms. These videos aimed to be of benefit to people with TS and also as an educational resource for those looking to learn more, rather than videos of a comedic nature.

2. Poster and animation creation of each ambassador, using their message. We advertised on Facebook and touring digivans to further promote the message.

The docuseries can be found [here](#)



The following animation videos were created:



Each of the ambassadors had their story displayed on a digivan that visited and toured their home town.



The campaign achieved tremendous success, garnering enthusiastic feedback from our community while significantly bolstering growth and involvement across all facets of the charity.

Almost 600 service users joined us in raising awareness



Our social posts on META reached 1.3 million and 1 million on TikTok



Over 40 awareness sessions held in schools



Over 30 media articles in TV, radio and paper



Many buildings turned green on awareness day



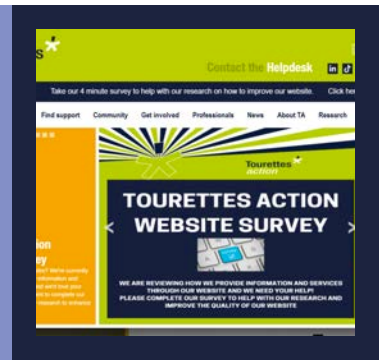
Posters displayed on bus stops, train stations and airports



During awareness month, almost 34,000 people viewed our website to gather information

Website

Our website remains a key information source and is widely recognized as a trusted resource for TS and related conditions. All content is freely downloadable, and we believe access to this information is crucial. Feedback often highlights our site as a "one-stop shop" that has provided valuable, and sometimes the only, information individuals have received.



eLearning

Our free CPD eLearning module, Understanding Tourette syndrome, remains highly popular, particularly among education and health professionals. We're proud to have it as the only Tourette's module on the NHS Learning Hub, as well as being featured on various Local Authority learning systems in both English and Welsh, broadening our reach.

Socials

We promote our website content, research, campaigns, events, and training through social media and our newsletter. As our voice and campaigning efforts grow, so does our engagement, with numbers increasing across all platforms. This financial year we launched our TikTok channel, securing 16,900 followers by year-end, tapping into a new demographic.

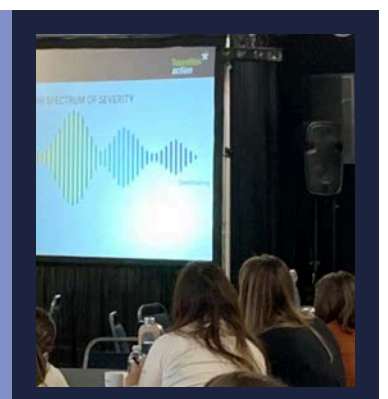


Media

Our awareness raising was further enhanced by the heart-wrenching performance by Lewis Capaldi at Glastonbury. The resulting media discussions led to Tourettes Action being invited to provide commentary, featuring on broadcast, print, and online outlets, it shone a light on Tourette's and for the first time in years, brought a greater understanding. In November, we also appeared on **Children in Need**, where young Shay shared his story, sparking further TV **coverage** and extending our reach.

Training

We hosted 3 workshops this year in Wrexham, Swansea and Halton. These aimed to equip attendees with the knowledge to support those with TS at home, in education, and healthcare, reaching 85 parents, 72 health and social care staff, and 21 education professionals. We also facilitated 104 training sessions to 4 community groups, 18 corporate organisations, 15 health teams, and 67 education establishments, up 40% from last year.



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, ethical or cultural background or social status.

How we do this: Bringing our community together to push for improvements and supporting them in lobbying parliament and health campaigning. Belonging to relevant coalitions and steering groups which work together to push for improvements in health provisions, ensuring the voices of our community are heard.

Due to the struggles people face in accessing a timely diagnosis and follow-on care and treatment following a diagnosis, one of the main priorities of the charity has been to campaign for health improvements. We have made significant progress this year in our campaigning efforts but progress with NICE, the government, and the NHS is a slow process, with much more still to be done.

Regional disparities in accessing medical support for TS, still remain, with substantial differences noted across the country. Around 10% of individuals with Tourette's are able to access Behavioural Therapy for Tics through the NHS. Furthermore, outside of London, there are minimal provisions available for those with TS, compounded by the absence of NICE clinical guidelines for the condition.

NICE

National Institute for
Health and Care Excellence

NICE

A key step forward for the TS community is our involvement with the NICE Committee in their technology assessment to look at [Digitally-enabled therapy for chronic tic disorders and Tourette syndrome](#).

Our CEO was accepted as a professional expert and 2 TA board members were accepted as specialist committee members. This combination ensured that the voices of the community are heard and represented in the project.

Members of Parliament

To tackle limited medical support, we've helped the community advocate for change by encouraging them to contact their MP. As a result, 215 individuals used our templates this financial year, leading to 12 questions being raised in Parliament to address these issues.



The NHS logo, consisting of the letters 'NHS' in white on a blue background.

NHS

As campaigning intensifies and more MPs get involved, commissioners are feeling greater pressure to act, with many now considering the implementation of TS services at the local level. We've worked with several Integrated Care Boards (ICBs) as they begin to establish pathways.

Advocacy Groups

We are an active participant in a number of pressure and advocacy groups to broaden our impact and influence including the [Nottingham Steering Group](#), [NDMAG](#) in Wales and the [Neurological Alliance](#). Being involved in these groups ensures the TS community's voice is heard, counted and recognised.



Key results to note:

- The Nottingham Steering Group launched an NIHR (National Institute for Health and Care Research) funded project to develop a service model for children and young people with tics, with our CEO leading the PPI arm to prioritise patient input.
- The group completed an animation to reflect the voices and experiences of people trying to access healthcare for their tics. It is entitled [#TourettesHearUs](#)

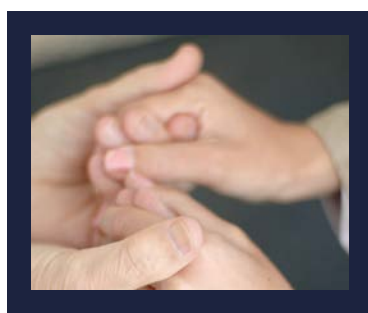
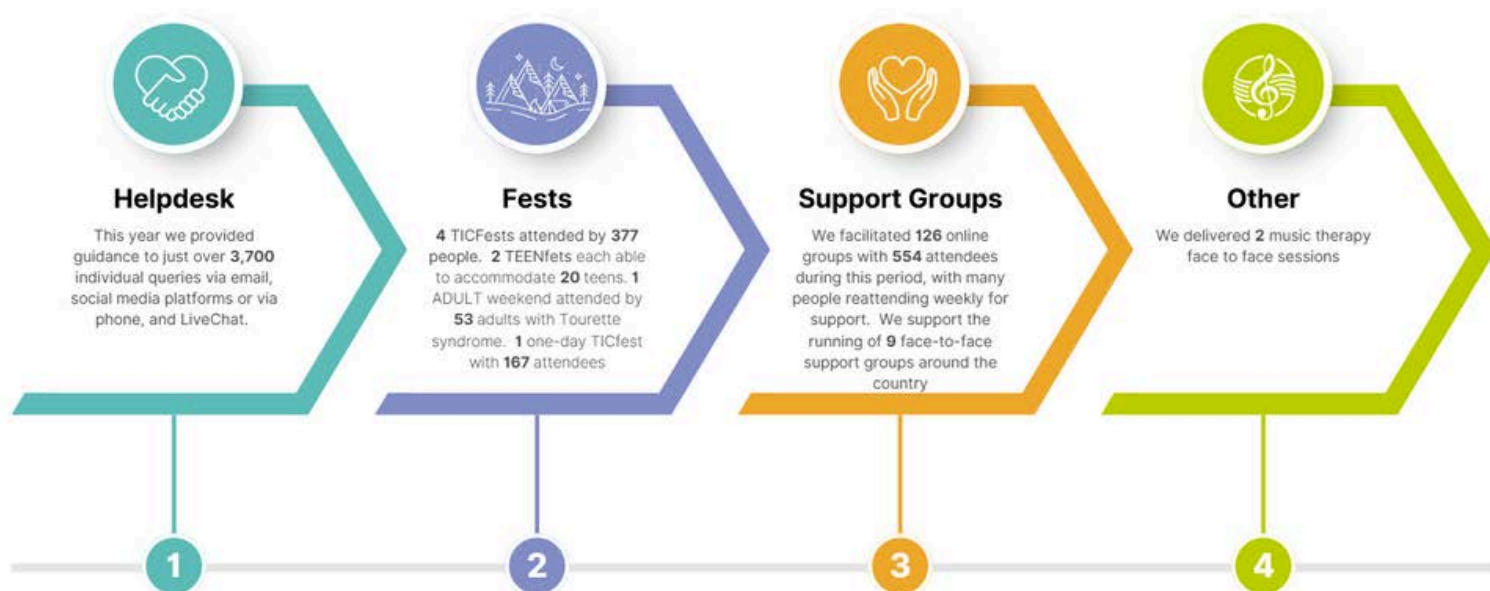


3. To ensure that no-one with Tourette syndrome feels alone

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: Providing support to individuals affected by Tourette syndrome by creating opportunities for them to meet and connect with others facing similar challenges through both in-person and online events. This includes facilitating both face-to-face and online support groups, hosting various online and in-person events, organising several annual residential gatherings for families, teenagers, and adults with the condition, and offering access to a help desk for personalised, one-on-one assistance.



Helpdesk

Our helpdesk remains the main source of 1-to-1 support. This year, support requests grew significantly, with demand increasing annually. Support is offered via email, phone, and LiveChat, and is managed by two staff members and a volunteer team, to whom we're very grateful.

Residential Events

This year, we launched our first-ever 1-day TICfest event alongside our usual events. With high demand for our events, the 1-day format helped bridge the gap, offering past participants a chance to reconnect and newcomers a taste of the experience. Of all our services, the fests have the greatest impact on participants, providing a safe, fun space to form friendships, take on challenges, and engage in psychosocial education.



This year we delivered:



The feedback we receive shows how essential these events are for our community.

“I cannot sum up into words what tic fest means to us as a family. It goes above and beyond an adventure weekend for the children. It is a place that has no judgment and even though most of the other people there are complete strangers you get a real sense of community and understanding as we travel on our TS journey.”

— TICfest parent

”

Less Anxious



95% of children attending the TICfest events state they felt **happier** and **less anxious** as they experienced what it is like to be accepted and that they are not the only ones to have Tourette's.

Increased Confidence



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.



Online Support Groups

The need for our online groups has remained high this financial year and as such we continued providing a regular online support offering. A wide range of online groups were held during this period. We offered groups for teens with TS, adults with TS, parents of children with TS, and groups specifically for dads and male role models of those with TS.

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. Having these support groups creates 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.



Music Therapy

We facilitated two courses of music therapy in Reading this financial year, they had a positive impact on those that attended, giving them relief from tics in a safe creative place around like-minded people.

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: Develop and distribute comprehensive resource guides and factsheets that are accessible online. Provide training and advocacy within education and employment. Provide online seminars to keep our community updated on the latest advice from experts.



Educational Support

The demand for information and support for educational support remains as high as ever. Schools continue to experience a high number of pupils experiencing sudden, severe tics, with many also reporting that anxiety from the pandemic is still affecting students, leading to heightened tics in school. Our Education Manager has dedicated significant time assisting teachers and parents in supporting children facing challenges in education.

Advocacy

The range of organisations seeking advice in supporting individuals with Tourette's is expanding. During this period, we've been contacted by children's homes, community centres, wellbeing centres, social services, sports clubs, and behaviour support units. This is great news, as we're now supporting those with TS across a variety of settings, not just education.





Workplace Support

This year, we've seen more requests to support adults with TS in the workplace, leading to several training sessions. The demand for advocacy sessions has also grown, focusing on work access, workplace support, disability rights, and empowering individuals 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 TS passports is another useful resource, which we have had for a number of years now, that enables people with TS to list their support needs. They are a great asset for those in education and the workplace.

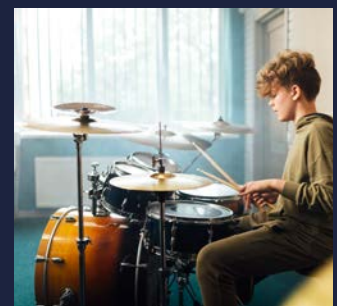


Webinars and Facts

We held a series of informative and educational webinars during this financial year, covering topics such as: Tourette's and employment; How the sensory system can impact on tics; How to support those with Tourette's within school; Sleep issues in those with TS; Functional Tics and their impact; Therapy techniques for tic management. This period we also began work on expanding and updating our factsheet resources that are freely available on our website.

Small Support Grants

Due to the ongoing support of a very generous benefactor, we continue to offer small grants for items, which help people to manage their TS. During this period we issued grants for things such as a desk, a computer chair, a VR headset and a digital drum kit, all of which helped the individuals manage their symptoms of Tourette's.



5. To support research into Tourette syndrome



Informed by the views of our community, we will assist and promote research that examines the causes, the treatments, and the impact of Tourette syndrome, with a view to improving the lives of people with the condition.

How we do this: Facilitating researchers in their studies and provide insights into the lived experience of Tourette syndrome. Developing community-defined priorities for research. Where possible, funding research into Tourette syndrome. Disseminating findings of research in accessible formats to the community and stakeholders.

Our 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.

This financial year we supported 7 researchers in their studies, promoting their studies on our website and social media to engage participants, helping to provide insights into the lived experience of Tourette's. The promoted studies were:

- Experiences of a functional tics diagnosis in adolescents, and their caregivers
- Exploring the nature of anxiety in children and adolescents with and without Tic disorder
- Evaluating healthcare professionals' experiences of assessing and treating tics in children and young people in the UK
- Tourette syndrome and self-stigma - A research study examining internalisation, social support, self-esteem, and quality of life
- SATURN - Stimulant medication for ADHD and Tics - Understanding Response versus Non-stimulants- Welsh Government's Neurodivergence and Learning Disability Team Research
- Understanding the expression of everyday vocal and motor tics in adults

We continue to support the project led by Professor Stephen Jackson at Nottingham University to develop a wrist-worn device providing an imperceptible electrical stimulation that can have the effect of significantly reducing tics in the wearer and are excited about the results following the trials of the prototype device.

Leadership and Governance



Emma McNally

CEO

"Each step we take is inspired by the positive change we hope to create. By staying true to our values and determined in our mission, we believe that together, as a community, we are stronger and more determined to make a lasting impact. Together, we are building a brighter future for us all"

Since 1981, when I was only 4 years old, Tourettes Action was born with the aim of supporting people living with, or waiting for a diagnosis for Tourette's. That aim remains today - to support those with TS.

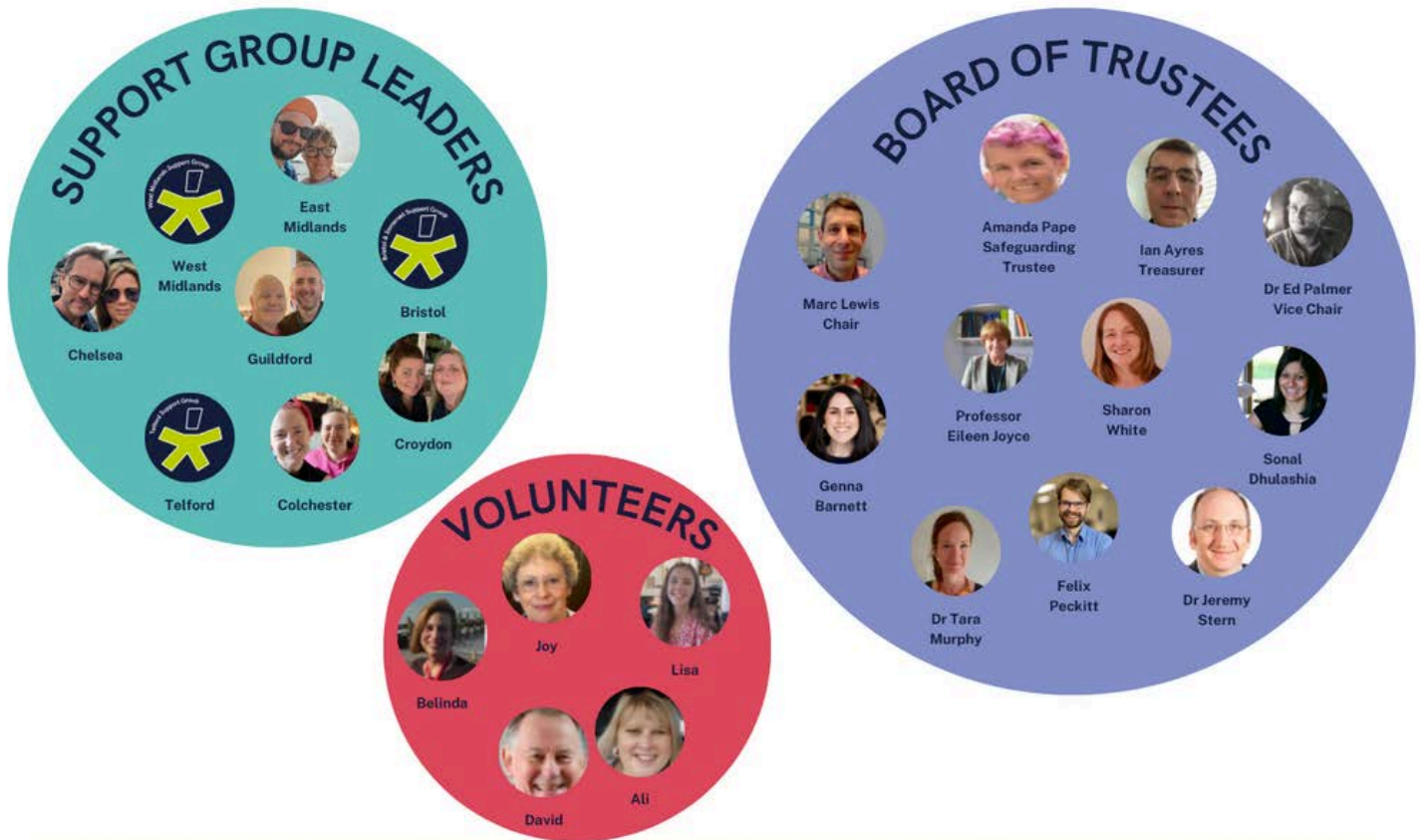
Our People

Although we remain a small national charity with a dedicated team of **16**, working **325.5** hours a week, supported by a fantastic group of volunteers, we have achieved a great deal. Making an impact is an essential aspect of being in the charity sector, and that is only possible with the help of our wonderful volunteers and staff that keep the charity running.

A breakdown of our full, part time, freelance and casual staff



A breakdown of our Board of trustees and volunteers



Structure, Governance and Management

Tourettes 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)

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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

TA's annual research funding programme remained suspended this financial year due to an unforeseen downturn in funding and as yet has not been restarted.

Safeguarding and Services

The subcommittee oversees the quality and effectiveness of TA's services, ensuring activities are appropriate and meets the needs of service users and that any new initiatives are established with appropriate checks and safeguards. It also monitors and ensures compliance with TA's policies.

Financial Performance

Maximising Donations

Someone once said to me:

“

Fundraising is NOT about money - money is the *by-product* of everything you do.

No one *gives* money to charity.

As Jim Langley would say - *people give through you NOT to you.*

Donors give because they believe in your mission and vision.

And they believe in your organisation.

Every penny you spend is because someone asks someone else to believe in you - and they did!

”

This really rang true for me, if we deliver a good service, if we support our service users to the best of our ability, they will then in return want to give something back to support us. At the charity 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.

This financial year, yet again, our amazing fundraisers came out in full force. Our fundraising activities included: The London Marathon, the Virtual Marathon, LLHM, Move for Tourette's, Facebook birthday fundraisers and this year we held a new campaign in October called *Tea for Tourette's*, raising both funds and boosting awareness of the condition.

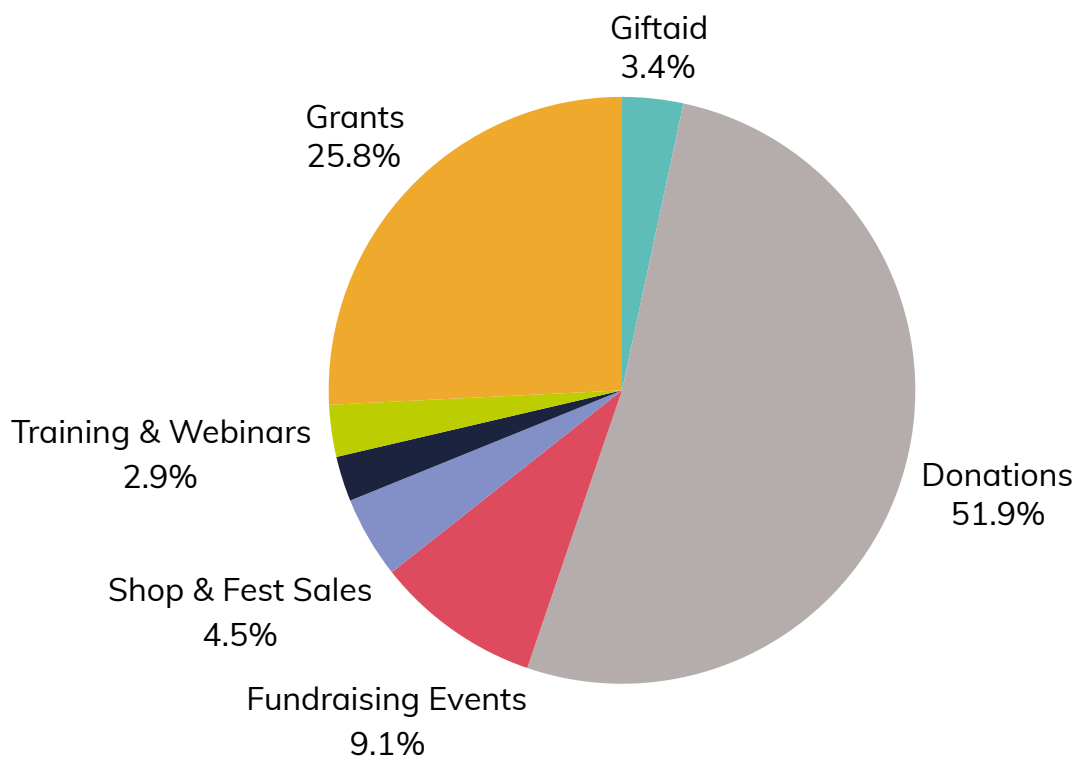


We are very grateful to all of our fundraisers and regular donors who continue to support us with financial contributions, even during these times of economic pressures. We are especially grateful for a substantial multi-year donation from the Hofmeyr family, which has enabled us both to increase the scope and impact of our campaigning as well as substantially expand and improve our offering of weekend residential events.

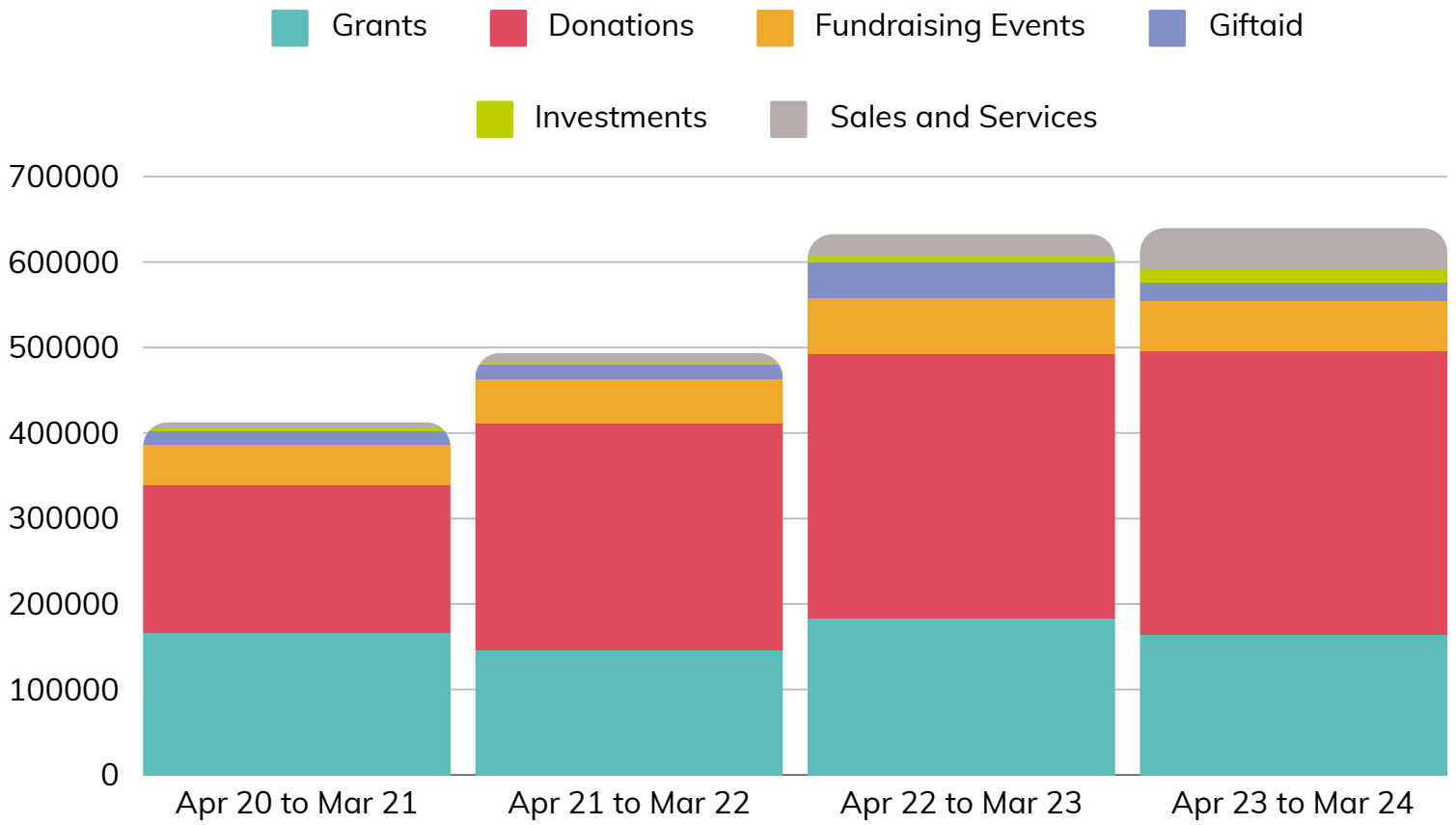
The majority of our charity funds come from grants, many of which are restricted to specific projects. During the year, we received grants and donations from a variety of trusts and funders including BBC Children in Need, The National Lottery Community Fund - RC England Wide, The National Lottery Community Fund - Awards for All Wales, Sir Jules Thorn, Michael Cornish Charitable Trust, Anton Jurgens Charitable Trust, Masonic Charitable Foundation and the Angus Lawson Memorial Trust.

Breakdown in charity income for Apr 23 - Mar 24

A little over half of the charity income was via donations this financial year, for this we are very grateful, especially during this tough economic climate

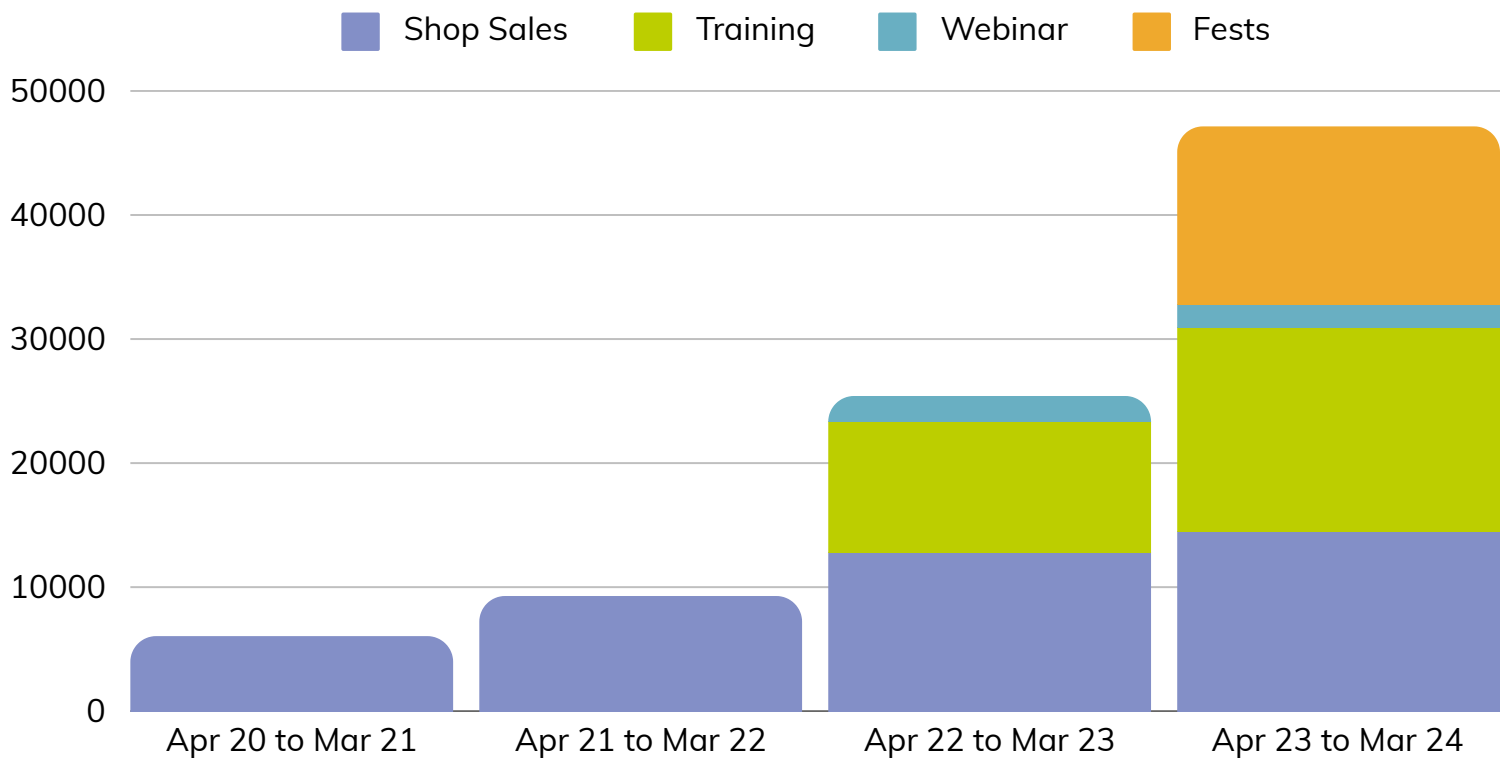


Charity income: grants, donations, fundraising, Giftaid, interest, sales & services for last 4 years



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

Charity income from sales, training, fest and webinar sales for last 4 years



Future Plans

We have achieved lots this financial year, none of which would have been possible without your invaluable support, for this I am extremely grateful. There is, however, still much work to be done in securing transformative clinical support that is accessible when needed and free from social stigma, so that our community can truly live their lives to the fullest. And as such our 5 strategic goals, outlined above, will remain the same and at the forefront of all that we do this coming year.

We have lots of ideas and projects in the pipeline, namely:

- building on our previous years' awareness campaigns to reach a larger audience, whilst also ensuring that we involve the community in this
- developing a new website making it easier to navigate, search and access for our users, and enabling us to provide new services and content in the future
- delivering numerous fest events across the UK, in many new areas, enabling us to reach new people
- expanding our educational workshops and training events throughout the UK to educate and promote understanding
- growing the breadth of training sessions TA offers

Reach Out

Registered Address: Tourettes Action, The Meads Business Centre, 19 Kingsmead, Farnborough, Hampshire, GU14 7SR

Email: help@tourettes-action.org.uk

Website: www.tourettes-action.org.uk

Reg Charity no: 1003317

Company registered in England and Wales number 2613993