# TOURETTE



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## WHAT IS TOURETTE SYNDROME?

Tourette Syndrome (TS) is a complex and heredity neurological condition. It's neurodiversity at its best. People with TS will present with simple and complex motor, vocal and internal tics. These can be long term, wax and wane, or one-off tics (contextual or environmental tics). The effects can be exhausting, painful, embarrassing and can also affect things such as memory, attention and concentration.

#### IT'S MORE THAN TICS

Tics are only half the challenge.
Neurological experts now
recognise that 80% of people with
TS will also have a diagnosis of
Attention Deficit Hyperactivity
Disorder/Attention Deficit
Disorder (ADHD/ADD), 70% have
Obsessive Compulsive Disorder
(OCD) and 5-15% have Autism
Spectrum Disorder (ASD).

People with TS can also experience difficulties with mental health, eating and sleep disorders, anxiety, sensory processing and specific learning difficulties such as dyslexia, dysgraphia (handwriting) and dyscalculia (maths).



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1 in 100 It's estimated that 1 in 100 people have Tourette Syndrome.

# A MESSAGE FROM OUR CHAIRPERSON

Welcome to Tourette Scotland's annual report, where we aim to show you all the hard work we've been doing, and continue to do, with your support. It's been another fantastic year and it's been a pleasure working with such a brilliant team and supporting our wonderful members.

We've welcomed 176 new members from across the country over the last year, and we've really enjoyed getting to know them through our online channels, open days and face to face groups.

Our increased use of online services continues to allow us to communicate regularly with people living with TS, and their families, in a manner and frequency that we previously never could. Our members based in more geographically remote locations have found this particularly beneficial. We've found that running a combination of online and face-to-face groups has the biggest impact for our members and allows us to support so many more people. We have 2 new face-to-face groups which are developing a core member group and I'm sure they'll continue to grow as the year progresses.

We have some exciting plans for the coming year and we can't wait to share them with you. We are, as always, eternally grateful for the support of our members and funders. Thank you to everyone for your continued support over the last year.

# **Kyla McDonald**Chairperson



Our membership has increased by 176 since this time last year!

## **OUR MISSION**

Tourette Scotland is always inclusive, understanding, and supportive to all. Tourette Syndrome (TS) is a highly complex neurological condition that affects children and adults throughout the world.

Not only do we offer support in the form of outreach, profiles and support groups, we also run fundraising events, awareness sessions and training. We work hard to provide information, support, and acceptance to everyone living with TS and we continue to work towards our four main goals.



We are always learning and looking to improve our knowledge so that we can better support our members. We work with Tourette's charities across the world hoping to learn more about the condition and the variety of ways that it can affect individuals and the people around them.

# TRAINING & AWARENESS

At Tourette Scotland we pride ourselves on providing quality awareness and training sessions for community groups, educational institutes, and employers. We also provide training for our members on additional, relevant topics.

This year we continue to have a high request rate for training. Keeping most sessions on-line helps us keep our running costs down, allows us to reach many more people, spend more time at the end of sessions answering questions and respond more promptly to requests.

We continue to have a small training team who work extremely hard to maintain the quality of the information we provide and to offer regular sessions. This year we have completed sessions with schools, health organisations, colleges and workplaces.



#### **School Awareness Sessions**

We are immensely proud to have delivered 46 training sessions to schools with it being estimated over 400 staff being reached. It has been fantastic to reach so many education staff and hopefully this will have a positive impact on increasing awareness, acceptance and understanding of Tourette's.

We have also provided support and training for 2 different independent therapeutic schools in Scotland to support young people with Tourette's in their schools. It has been a fantastic opportunity to help committed staff to get it right for their young people and it has been a pleasure working so closely with them.



Tourette's was all about, it was clear I didn't!! I have taken away some interesting insights which have made me think about how I interact with my learners



#### **Peer Awareness Sessions**

As well as training staff, we also offer peer awareness sessions. These sessions are individually tailored to the young person so that their classmates or friendship groups at community-based activities can better understand the challenges they face.

In the same period, we have completed five peer awareness sessions. The young people are often involved in the delivery of the sessions, and it empowers them to be open and honest about the challenges they face but also to advocate for themselves. Here is some feedback we received...

"Our head teacher requested a peer awareness session to inform pupils about Tourette's, to support our son who is in P4. He has a dual diagnosis of Tourettes Syndrome and Autism, possibly ADHD and learning delays to come. Out of all these, Tourettes is the one which is either a mystery or completely misunderstood.

We are quite a small school of 109 pupils, so the Head Teacher thought it best that every pupil should take part. The trainer came to say hello to our son, who she knows well, and asked him if he'd be ok if she said she knows him and his sister. He was happy with this. The staff were quite surprised whenthe trainer didn't need the projector for a PowerPoint. She conducted the 45 minute assembly, completely without props or visuals, in a beautifully soft voice, which held the attention of the pupils so well.

The majority of it was pupil led, giving them chance to think of the answers to various questions, before putting their own questions back to the trainer. She had very good questions from all of the year groups, plus I think it may be the record for the least requests for the toilet, says it all really!

The assembly was a week ago today. In that time, our son has been much more confident in school, he went to a weekend long cub camp, where 4 pupils from the school also attended, who then explained about TS to the other Cubs and supported him in many different ways.

The Teachers had had the TS training via zoom 2 years ago, the assembly gave the Teaching Assistants chance to learn more, albeit at a different depth, but all found it extremely helpful.

As a family we can't thank Tourette Scotland enough!"



#### **Higher Education Institutes**

The feedback from the training completed at the Higher Educational institutes reflects the same as teaching staff in schools. Staff at colleges/universities also acknowledged that the information and supports/strategies discussed during the training also support the wider neurodivergent population studying at their institute and not just our members.

For a second year running we were invited to work with a group of final year master's Occupational Therapy students at Queen Margaret University. It was a fantastic opportunity to educate future clinicians about the complexities of living with Tourette syndrome and all the co-existing conditions.

At the request of Northeast Scotland College, we delivered 2 sessions during their winter development day for staff. We received some lovely feedback and enjoyed some thoughtful questions and comments with staff on how they can support young people attending their college.





#### **Voluntary Sector**

In June 2022 we were delighted to support our friends and colleagues at TIC Hull and Yorkshire. TIC is a small charity started by co-founders and fellow mums to children with Tourette's Syndrome, Kim Mitchell, and Beverley Wright.



They took on a massive challenge of organising a 2-day symposium for health and education staff and invited us to deliver sessions on sensory processing and the impact of sensory differences/preferences have for people living with Tourette's. However, the weekend was not stress free for Kim and Bev as their keynote speaker was unable to fly over from America, due to Covid. To help we delivered our Inclusive Classroom session as well. It was a fun filled weekend and the lovely Kim and Bev are now considering doing it all over again!



#### **NHS Training**

We have continued to provide awareness sessions for several NHS Children and Mental Health Services across the country. This year we also joined NHS Lothian's Community Child Health In-service Day sharing our Tourette's Training with Doctors, Health Visitors, School Nurses, and Allied Health Professionals. We embrace supporting our NHS colleagues to improve their knowledge and understanding of Tourette's and more importantly how it affects people living with the condition.

"I had no idea how challenging and complex it is to live with Tourette's. I have new insights on the impact Tourette's has on the person and their family. I found the session engaging, well presented, and sharing the lived experience made it meaningful"





### **Corporate Training**

We were delighted to deliver a Tourette's awareness session to OVO during their neurodiversity awareness week. It was a fun online session where people asked thoughtful questions! We have also worked with another company and a local council to help support staff to gain a better understanding of Tourette's, reasonable adjustments and how to support staff appropriately. The feedback has been positive with our members reporting that they feel better understood, supported and able to work to their potential.



### Training for our members

We provide high quality training sessions for our members based on what they have identified as their training needs. We provide the following sessions and we've had some great feedback:

- Tourette's awareness session for newly diagnosed members and their families.
- Tourette's and Attention Deficit Hyperactivity Disorder
- Tourette's and Autism Spectrum Disorder
- Tourette's and Sensory Processing Difficulties
- Coping with Anxiety

## **OUTREACH**

Our dedicated outreach team has managed to offer, and complete, an incredible 111 initial Outreach sessions with a further 126 follow-up appointments during the past year. The sessions covered a varied array of needs including Personal Profiles, Tic Attack Plans, help with ADP (Adult Disability Payment) and CDP (Child Disability Payment) applications, and sometimes universal support and advice.



This is a huge increase in the number of people we have managed to reach, and it has only been achievable due to our increased use of digital platforms, a reduction in travel time and the dedication of our volunteers.

We are delighted with how well our digital Outreach is working. However, we acknowledge that there are still challenges to overcome, particularly in terms of digital poverty. We hope to be able to offer a blended approach in the future whereby we can hold face-to-face sessions with those who require it.

66 TThe two outreach workers were very friendly. I felt at ease in expressing my thoughts and feelings and issues I have been dealing with my whole life in relation to my tics and other issues I feel I have. Although I got upset during the conversation, I never felt judged or ashamed and felt reassured by both ladies. I'm feeling heard and supported on this journey to helping myself cope better with things impacting my day-to-day life and look forward to getting more support and finding way in which to cope and help myself progress and understand everything that has troubled me for many years. "

what's going on with my son as he's preparing for high school after summer. They listened to my worries and were reassuring and really understand all of my concerns. We came up with a solid plan going forward to update his profile, offer the high school Tourette's training, planning for benefit support and how to help my son get the most out of his last few months at primary school. They understand the complexities of raising neurodivergent children and were helpful when I spoke about the entire family.

# SENSORY LADDERS

We are really delighted to be able to offer sensory ladders as one of our tools to support the community. We know lots of people with Tourette's have difficulties with sensory processing and sensory overload.

Sensory ladders were created by an occupational therapist called Kathryn Smith, using her expert knowledge of Jean Ayres work on Sensory Integration to develop a way of helping someone with sensory processing difference self-regulate or co-regulate. Each ladder is designed to meet the persons sensory profile and is unique to them. It can be used with children, young people, and adults. Sometimes we can also suggest how to create a self sooth kit or a fidget toolbox to support self-regulation.



#### **TESTIMONIAL...**

"We contacted Tourette Scotland when our son was going through the process of being diagnosed with Tourette Syndrome. We had excellent support from Tourette Scotland from the first time we contacted them. We had mixed emotions and didn't know much about Tourette's but they helped all of us learn what we needed to know, and how to navigate the world. It was all very new to us and scary for us all.

The support worker is an Occupational Therapist and she helped immensely, by firstly putting together a personal profile for him. This helped explain his complexities at school etc. Following on from that, it was clear he needed further support to help him recognise his own feelings and tics, and to help him find ways to manage and to cope. We were given Tourette's Awareness cards which gave us more confidence whilst out and about.

She offered to compile a Sensory Ladder with him, which would help him identify what would help him best in different situations. She did a couple of sessions with me, and then with our son. He quickly identified the theme he wanted for his sensory ladder. This could have been anything at all, and he chose our dog, who he is very close to.

Our support worker worked with him to identify sensory strategies for states of being, he came up with some very apt strategies, such as a cold flannel for his forehead when he is getting overwhelmed, and bouncing on the trampoline at home when he is over energetic, to having earphones and music to help him concentrate.

School was very open to allowing our son to have his actual sensory ladder tool which is in the form of laminated picture cards, with simple explanations of the strategies on a key ring and kept on him at school.

Over time he has used the sensory ladder more when things are tricky for him, for example at times of transition such as before and after the holidays. He has used this now for almost 2 years. I think it has worked because it is so well thought out, and our son has agency over it, as he was the one who had the greatest input. Making the sensory ladder with Tourette Scotland increased his self awareness and confidence. We are very grateful to have had the chance for him to have his sensory ladder, and for all of the help and support."

# PERSONAL STORY BY MELISSA

Our son was diagnosed in 2020 following years of tics. We found Tourette Scotland through a friend and since we have been in touch, they have provided invaluable support in a range of ways.

Our son had been mostly out of school through difficulty integrating into the neurotypical world and Tourette Scotland provided training to his new school and people began to understand his condition better.

Tourette Scotland attended several school meetings and provided advice to the school and other professionals involved in our sons care leading best practice in what seems to be a poorly understood condition in some areas.

They've provided us with outreach calls when we needed help the most and they have been so pivotal in us having direction in where to go, what to do and how to best support our son that I cannot imagine where we would be had they not been there.



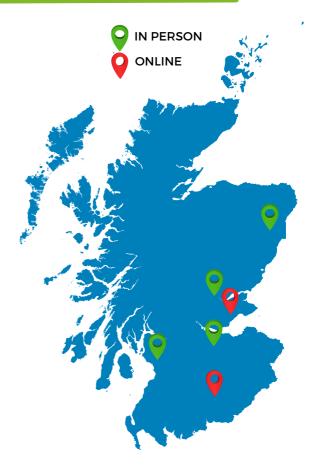
Tourette Scotland have helped our son not feel alone. We have been able to attend local get togethers, group meet ups and even spend a weekend at Fordel Firs which really helped our son feel like he wasn't alone. Our son loves the monthly Kid's Club and even joins in when things are challenging.

The support Tourette Scotland have provided has been invaluable and the people there have always been and continue to be supportive, caring and compassionate never making us feel a burden and are always there when we need them.

# PEER SUPPORT

Scotland is a vast area to cover, but we still believe one of the best coping mechanisms is to meet others living with the same challenges. Feedback from group members tells us that being able to talk to other people and families who are in similar situations makes a huge difference to their quality of life, and their understanding of this complex condition.

The groups support local families in a variety of situations, many of whom are in crisis. Tourette's can be completely overwhelming, especially in the beginning. Group sessions often include awareness sessions to increase the general understanding of Tourette's and its co-existing conditions, a general catch up or targeted activities and outings.



We have continued to offer monthly meetings on a digital platform to ensure we can support those unable to attend our face-to-face groups and open some new groups. For information on any of our groups, please **contact us**. Read on to find out a little more about our groups and activities.



# **GROUP HIGHLIGHTS**

#### THE LOTHIAN'S GROUP IS GROWING!

We now have 2 rooms which means the kids have a great space to play pool, use a Wii and get to know each other independently from their parents/carers. It is a noisy, busy room with lots of laughter and happy faces. Our young adults in the group often support the children in the noisy room and are fantastic role models!

In the quieter room we have coffee and a chat. We are really spoilt by some of our members who turn up every session with home baking! It is well worth a visit just for the baking – and of course the great chat. We can have people in to talk about services that may be beneficial for our members or have in-depth discussions about the latest research for Tourette's. Sometimes it is just a safe place to offload with people who really understand the challenges you face. We are looking forward to planning some day trips and getting out into our local communities.

"I have found the groups, both in person and online as welcoming and friendly safe spaces where there is no judgement of anyone, only support and encouragement are provided. They are a vital part of the service that Tourette Scotland provides."



#### Our member, Jenna, said:

"Since I started going to the Lothians Tourette's group, although it was difficult for me in the beginning, it has done much to help me deal with and understand my condition. I have been given support in terms of understanding and making a tic attack profile, which has helped my school understand how they can help me and giving training to my school prior to me starting there.

As I said, it was difficult for me to go in the beginning due to my anxieties of being around people, but after a while, I have gotten comfortable and friendly with the people there. I enjoy going there every month as it reminds me that I am not alone, and there are others who share the same experiences as me. It is an appreciated backing that I know is there to help me, and that makes me more comfortable when dealing and understanding my tics."

#### THE PERTHSHIRE GROUP

Our Perthshire group was just getting going when the pandemic hit and we were forced to move online. In March this year we started up our face-to-face meetings again. We've also moved to a great new venue, Perth Autism's building in the city centre. We have a great space to use with a pool table, comfy couches for chatting and an area for games and art. It's early days and we're just getting back into the swing of things but we hope to arrange a day out soon and plan some more activities.

#### THE WEST OF SCOTLAND GROUP

The West of Scotland group returned to face to face meetings in January 2023. We now have between 15 and 20 people attending on a regular basis. A variety of board games and arts and crafts have been going down well with the youngsters, whilst general chit chat or discussion around specific topics goes on between the adults. We've also had a visit from the Family Fund and hope to arrange more activities soon.



#### THE GRAMPIAN GROUP

The Grampian group is back meeting face to face, in Inverurie. We've welcomed individuals and their families from the Grampian area, creating a sense of friendship along the way. Our meetings are very open and we talk about the services we provide and share personal experiences of the daily battle of living with TS. We share advice on how we cope as families and there are some giggles thrown in too. At each meeting, we try to do an activity like making slime, painting pots and planting sunflowers, alongside refreshments and some homebaking from one of our members. The group has really opened doors for the community to meet other people with TS, make friends and, most importantly, realise they aren't alone and have a safe, welcoming space for anyone affected by TS.

#### DREAMNIGHT AT BLAIR DRUMMOND

Tourette Scotland Families and members were delighted to be invited along to Dreamnight at Blairdrummond Safari Park, last June. Dreamnight is a VIP event, especially for terminally ill, disabled and disadvantaged children and their families, as well as those facing life-long conditions.

138 people, of all ages, from Tourette Scotland, made the most of the very welcome opportunity to go along and enjoy all that was on offer.

We all loved seeing the animals, from elephants to ants, and learning all about them.

We had great fun at the fairground, and got a bit over competitive on the dodgems!



Everyone enjoyed the lovely cakes and ice creams, which helped replenish our energy for playing at the adventure playground.

Some were very brave and hunted for dinosaurs!

Best of all, we had a chance to catch up with our old friends, and to make some new ones. The children even got to choose a new friend to take home, an adorable cuddly toy.

We would like to thank the organisers and staff very much, and look forward to doing it all again!











#### THE TIC TIME CLUB

We are delighted by the success of The Tic Time Club! For the past year, some of our youngsters and their siblings have been participating in craft activities via zoom. This is delivered by a few of our creative teenagers and overseen by Gillian and Sarah.



The monthly sessions continue to be extremely popular with some fabulous creations and friendships forming. Our youngsters with Tourette's are the Tic Time Crew and their siblings, the Tic Time Support Crew. We have Tic Time t-shirts available on our website and each new member is sent a goodie bag and membership certificate.





#### SUPPORT FOR TEENAGERS

We are currently putting plans in place to have an activity day in August for our secondary school aged young people.

This will take place at Lochore Meadows Country Park where a wide range of instructor led activities will be on offer, both on land and on the water.

This will give our young people the chance to get together, have fun and to challenge themselves, bolstering relationships, and building confidence. More details will follow in due course.

#### **ADULT ONLINE SUPPORT GROUP**

The adult support group is run once a month online. It is growing in its sense of community and the numbers of people who attend. The group has become very important to many of our members.

#### LINDORES ABBEY DISTILLERY TRIP

This year our adult's group had a fantastic trip to Lindores Abbey Distillery. The Distillery is located on the same site as the Abbey used to stand.

The team at Lindores Abbey made the experience fantastic before we even arrived, they were diligent in their questions and flexible with our requests, they tried so hard to ensure they got it right for us; and they succeeded.



We were welcomed warmly at the distillery and introduced to the staff who would be looking after us. There was no rush or pressure, everyone was relaxed, and we were able to chat casually while we waited for everyone to arrive. Our members were quickly reassured by the professionalism of the staff that there would be no judgement or issues with tics or anything else. The lift made the tour accessible for those who needed it, and we had many opportunities to share any additional requirements during the booking process and during the visit.

"I wanted to say how welcome you've both made me at the groups I've attended online. I've also felt able to connect with the other members of the group so that when I met them in person at the Lindores Distillery trip they didn't seem like strangers."

As I've mentioned before I have found online work meetings quite difficult sometimes & even Zoom meetings with my family as I prefer to speak to people face to face but it doesn't seem to be the case so much with the Tourette Scotland online support meetings where I feel much more at ease & included. I've learnt a lot more about Tourette's & have found the meetings supportive. When someone is feeling low the others try to help with advice. It helps to know that it's not just me that struggles sometimes & that we have highs & lows. You're both very aware of how someone is feeling & will not force anyone to speak if they don't want to. Sometimes I've noticed that people just want to listen.

Hopefully that gives you both an idea of how valuable your work is & how much it's appreciated by myself & others.

Thanks so much."

Our tour guide Dean was knowledgeable and engaging and he took his time to answer all our questions, including some tricky engineering queries. The tour was remarkably interesting and enjoyable with lots to learn.

Some of our members joined in with tasting the whisky and we were pleasantly surprised to be given samples for those who could not try on the night.

The fantastic selection of food was delicious and was served buffet style for our convenience. We were well looked after by Steph and Leigh who were always attentive and friendly, and we were made to feel very welcome.

"Was a fun and enjoyable evening, great to meet some others face to face, the staff at the distillery were very welcoming and hospitable, the food was great as well as the whisky."





"Really great spending time with everyone in person! It was a perfect evening."

"Thank u so much for a lovely time out

guys. I really enjoyed myself and meeting you all, was great."

Everyone spoke of how wonderful it was to meet other adults with Tourette's and make new connections especially in such a lovely setting

We had a wonderful private tour around the distillery followed by an amazing meal. It's such a beautiful place with a fascinating history and wonderful staff who really looked after us.

#### FORDELL FIRS RESIDENTIAL WEEKEND

Meeting with other people who have Tourette's is all too often something that many never experience. Tourette Scotland has welcomed many new members who, until then, had never known anyone else living with the same diagnosis. They often felt alone and isolated with their condition, not knowing who to turn to for support. Tourette Scotland support groups are a great first step to meeting others and it has become clear over the years that activities and outings out-with the groups help create bonds. These activities give members the opportunity to be themselves, feel accepted, relax, and have fun while challenging themselves and stepping out of their comfort zone.

With thanks to funders like the Carnegie Trust and Better Breaks and the group's own fundraising efforts, Tourette Scotland's support Group members have managed to plan and attend an annual weekend camp in Dunfermline, Fife.

The camp is held at Scout Adventures
Fordell Firs and is always an enormous
success. Instructors assist with several
activities over the course of the weekend
including bungee trampoline, archery,
climbing wall and abseiling. They lead
team building activities and host a
fantastic campfire which is always
followed by hot chocolate and
marshmallows.

The instructors are accepting, understanding and compassionate along with being a great laugh. There is always much laughter and encouragement to try new things and take risks!

Members stay in dorm style accommodation and Tourette Scotland Group leaders supply and prepare all food and drinks. Menus are prepared in advance and special dietary needs catered for where possible.





Previous camps have seen family bonds improved with greater understanding of Tourette's and the challenges of living with this condition. Being able to spend time talking with others really helps to facilitate development of coping strategies and building resilience. The children and young people are so supportive of their peers and welcome any new members with open arms which helps increase confidence and wellbeing. Parents have commented several times that their child or young person never leaves their side yet within half an hour of being at the camp they are off having fun. It is a fantastic, powerful, and often a very emotional experience.







In 2022 we doubled our numbers and hosted 66 people over the course of the weekend. Some managed to stay while others opted to spend the day and join in activities, everyone got so much out of the camp. Even though everyone left exhausted, there were lots of requests to do it all again.

Adults with Tourette's are also welcomed and often find themselves relaying their own childhood experiences and coping strategies. This is a significant help to the youngsters and their parents who often can't imagine what lies ahead. The parents/carers always have a wonderful time making new connections and taking part in activities often leading to hilarity. The friendships created here are long lasting and we find that parents/carers reach out to each other and offer support and friendship throughout the year.

This year we trialed a parents and carers session with our resident storyteller, Nigel. Nigel led the participants through a variety of questions and helped them to develop their own stories and experiences. Sharing parts of their lives with each other and having others empathise and offer support was an emotional journey with a fantastic outcome. Nigel is working on a new project highlighting the variety of skills a parent or carer needs to have when they have a young person with Tourette's. This will be showcased on our website.

Tourette Scotland aim to support the whole family and not just the person with Tourette's. Whole families are encouraged to attend and join in activities. The weekend camp provides the opportunity for siblings to meet others with Tourette's and other siblings dealing with similar issues. At the end of every camp, Group leaders hand out feedback forms to ensure we are getting it right and see what can be improved upon for the following year.

We are excited to be planning our next visit to Fordell Firs in September 2023 and we are sure it will be another successful trip.

#### THE MAD GROUP

Our MAD Group is not as controversial as it may sound. The "Mum's and Dad's" group was originally started by parents and carers from our Fife group to allow them the space to come together and chat through their experiences. It was and is a safe space to vent or share exciting triumphs since the last meet-up. Having Tourette's and coping with the co-existing challenges is tough, we also acknowledge how difficult this can be for parents and carers at times and so we feel this group is important. It helps parents and carers to remember to take care of themselves too so that they can support their person with Tourette's effectively.



The original MAD group was in-person and involved lunch and a coffee while we set the world to rights. We now meet online monthly to share support with parents and carers across the whole of Scotland. It's pretty much the same except you need to make your own coffee...an added bonus is you can even join in your jammies if you wish!

#### **OPEN DAYS**

After the tremendous success of our open days in Glasgow, Lothians, and Perth, which we spoke about in our last report, we have been busy planning the next wave. We love being able to come into the local communities of our members and spend some time engaging face-to-face.

Our Open Days give families the opportunity to come together and meet other families who are in similar situations as themselves, as well as meeting other people with Tourette's, often for the first time. Feedback tells us that meetings like these can help people accept their diagnosis, increase their knowledge about this complex neurological condition and reduce isolation. They help people realise that they are not alone and that there is hope with the right support.

So far, we have some great venues to visit in Perth, Lothians, and Aberdeen and we hope to secure dates and venues for the West of Scotland and the Scottish Borders soon. We have some fascinating talks on sensory integration and Tourette's lined up with question-and-answer sessions and activities for the kids. The whole family is welcome, and we encourage everyone to attend wherever possible. We are excited to see some fresh faces alongside lots of familiar faces, these events are always a lot of fun.

# PERSONAL STORY BY JENNA

Jerking, flailing, shouting, swearing.

I am not sure what others know about Tourette's Syndrome, but this can't even be considered the tip of this infuriating iceberg. For me, starting from strange impulses to tap the table, to jerking my shoulders upwards, to hour long episodes where I cannot control my constantly moving body, has been a difficult ride. My experience cannot be compared to others like myself, as we have all experienced this differently, but I hope that with what I have to share, it can encourage not only the general people to be more open minded and accepting of this condition, but to tell those with Tourette's to also accept themselves.



My story started in June of 2018, just as we had started the new S2 timetables before the school year ended. I am unsure if it was this change that triggered the following events, but after four and a half years of having this condition, I can confirm that stress and anxiety makes it so much worse. I don't know when exactly it started though, June is simply when things began to get concerning. At first, it was only a strong desire to tap things – I could ignore it. But soon enough, this turned into larger actions that I couldn't control, such as throwing things, hitting, and jerking my head and shoulders.

I was afraid and confused - this had never happened to me before and the physical and mental discomfort I experienced when I abstained from following these impulses became a sensation I began to fear. All I can think to compare it to is a strange force whispering in my ear to do these things, or as if something had decided to possess me and was forcibly trying to take control. Even now, if I were to ignore or suppress the tics, an ungodly and painful sensation is felt in my back as if something were being forcefully contained. However, the tics must eventually come out, so similar to when you hold a ball under the water, the deeper you push it under, the more forceful its impact when it finally reaches the surface.

Our knowledge of Tourette's is limited, not because there is no research into it, but because the condition is in a part of the brain that we can't easily study or access. Though, it is thought to be a combination of the basal ganglia, the frontal lobe, the cortex and various neurotransmitters (such as dopamine, serotonin and norepinephrine). We also don't know the cause for Tourette's but, again, it is though that it is a hereditary gene, with a 50-50 chance of it being passed down to offspring. It has been observed, however, that boys are 3x more likely to display symptoms of Tourette's and that the estimated number of individuals with Tourette's is probably double that of what has been diagnosed.

As I previously stated, we don't know much about Tourette's, or, generally, tic disorders, but that shouldn't stop us from spreading awareness of it. I have read and listened to many stories of bullying due to having this condition, and I myself am not exempt from those stories. I was often bullied throughout Primary, mostly just teasing and exclusion. But when I entered S1, light physical bullying began as well. This caused for low self-esteem and insecurities, so when I first started having motor tics, the eventual bullying contributed to my receding from society and isolation that had already started to manifest due to my own fears and lack of understanding to what was happening to me.

I was often called out in front of crowds and told to "stop doing that" and "why can't you just stop" while I was being stared and laughed at. Others would also get my attention and perform their small-minded imitation of Tourette's – by swearing and doing rude hand gestures. Mentioning this, I want to bring up a term special for this kind of tic – it is called Coprolalia; a tic that makes the individual say profanities and rude words. I also have this type of tic; however, I will state that it is only 10% of people with Tourette's that will have this tic. I find it ironic that this is the only impression some people have of Tourette's. Sadly, the response from others towards my tics is not a rare occurrence. It is what often happens and is why most individuals with Tourette's suffer from depression and anxiety. You will also see people who isolate themselves, not being able to go to school or even outside. I was also like this, begging to be home schooled and barely leaving the house out of fear and discomfort.

But personally, I feel that all the things I have previously mentioned aren't as bad as what we call "Tic attacks". These are episodes of basically a tic explosion, where you constantly tic for a period of time, unable to control your body at all. Everyone experiences tic attacks differently, but for me, it is a nightmare. As previously mentioned, I experience long periods (up to an hour or two) of constant tics throughout my entire body. I cannot control my body and I cannot control when this happens. It is a difficult thing to describe, but I feel the frustration may be similar to walking through a door, only to end up in the same hallway, in a constant loop, wanting to escape so desperately, but unable to. No matter if I am mentally or physically exhausted, I can't stop. But what destroys me the most is that my tics are particularly destructive and violent in terms of harming both myself and others. I am constantly hitting, kicking, moving. I am constantly screaming vulgarities and dangerous statements, and to top it all off, they try desperately to physically harm me by banging my head against any hard object, biting, and scratching. Lately, it has gotten to the point of my tics attempting to bite others as well.

These things are and have been incredibly difficult to handle, and although I want to get across how damaging this condition is, I also want to show the funny side of it all. It is a personal preference that my tics are treated with jest. My way of coping is by seeing the funny side of it all. I have really frequent tics I like to call "conversational tics". Basically, my tics react to what is happening or is said around me, such as stating the obvious when someone mentions something, or vehemently insisting or denying something absolutely ridiculous. They have also attached 'nicknames' to various people, such as family members and familiar teachers. Though, I will mention that most of these are pejoratives, of which my mother gets slandered the most. In turn, the teachers and people around me react and converse with my tics as well, laughing ALONG with me, and not AT me. And I find this the most comforting way to handle my tics.

I really am truly happy that I decided to come back to school, and that I have been surrounded by support and care. I have also been lucky enough to have a mother that doesn't bat an eye at the amount of insults hurled her way, and the violent episodes she experiences at least once a day. I say I am lucky, and I am, because despite the difficulties I've experienced, I am still supported. Many others do not get this, and for some, their own families don't even believe they really are suffering from this condition. To others, it may seem like silly movements and sounds done for attention, but it is truly tiring, taxing, and tenacious in taking control. It is physically and mentally painful, and can be horrendous to deal with during intense periods.

There needs to be more support for people with Tourette's Syndrome, and more awareness and acceptance from the people too. Just like any other condition, sincerity and care should be given instead of judgement and mockery. I earnestly implore that you look into Tourette's a bit more, for, despite the difficulties, it is quite an interesting condition to know about, and further understanding will bring more awareness to the difficulties we face and how real this condition is.

# THE GANNOCHY TRUST

For the last 3 years we have been incredibly lucky and grateful to have received funding from the Gannochy Trust. The Gannochy Trust was founded in 1937 by Scottish businessman and philanthropist Arthur Kinmond Bell, known as A.K. Bell. His unique approach to philanthropy has matured into a legacy that has improved the quality of life of many thousands of people, not only in Perth but all over Scotland.



With the support from Gannochy we have been able to grow the charity to include lots of services in response to our members' requests. Please read on to see how the money Gannochy granted us has impacted the growth of Tourette Scotland.

#### **TRAINING**

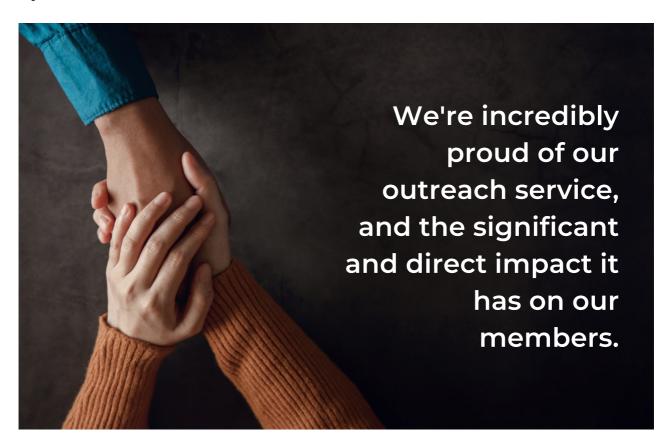
As we have now come to the end of the three-year funding, we are taking the opportunity to reflect on what we have achieved since the funding began. When the current committee took over the charity in 2018, the previous training sessions were approximately once or twice a year, using outdated materials. We reviewed, updated, and sought feedback from our community to provide a training resource that reflected the up-to-date evidence around Tourette Syndrome. We also felt that the previous training lacked the "lived experience" which is vital in helping people understand the complexities of Tourette Syndrome. So, we have developed a robust training package that provides people with a blend of information, and we have had some fantastic feedback about the training and its delivery.

In 3 years, we have gone from training one or two schools a year in 2018 to providing on average one or two training sessions per week including schools, universities, workplaces, health professionals, public awareness, and third sector organisations. Our reach has been phenomenal, and we are being sought to speak at Conferences within the UK. It has been hard to gauge the true numbers of people reached with training due to digital delivery, but we believe it is now in excess of a thousand people, which can only benefit our Tourette's Community.

#### **OUTREACH**

When we took over the charity in 2018 our understanding was that there was very little outreach support being offered. We did find a record of telephone requests for assistance but as the charity had no outreach workers, we believe members were only sent information packages including lots of outdated information leaflets.

With the money from Gannochy we have been able to provide an outreach service which has grown year on year for the last three years. We have three volunteer outreach workers, and we cover outreach 2-3 days a week. On an average week we will complete three to four outreach sessions supporting adults and families with Tourette Syndrome.



In the last three years, we have also developed a range of follow-up services including personal profiles, tic attack plans, benefit supports, supports for occupational health or school meetings, and development of sensory ladders. On an average week we offer three to four follow-up sessions as well. The outreach service takes up most of our volunteers' time. We're incredibly proud of our outreach service and the significant and direct impact it has on our members.

#### PEER SUPPORT

When we took over the charity in 2018 there was one functioning support group in Fife. Over the last three years, with the assistance from Gannochy's funding, we have provided support groups across the country, some of which are now face to face and some that remain online.

We now have 4 face-to-face groups, Lothian, West of Scotland, Grampian, and Perth. We also provide a Scotland-wide online support group which is open to all. As part of the development of our Peer Support we now have an adult support group, a parent and carer support group and a children's club online as well.

Each group also has a corresponding private Facebook group which we monitor and regularly offer support and advice using this medium.



#### **WEBSITE**

In the last three years, we have significantly benefited from our upgraded website which was managed in house by two of our committee members. We had an independent review of our website to look at accessibility and content and we're delighted to receive extremely positive feedback on both content/accessibility and design.



None of our achievements would have been possible without the amazing support from The Gannochy Trust and we are delighted to have been in receipt of the funding.

# **OUR VOLUNTEERS**

Currently we have volunteers working in outreach, training, storytelling, and creative activity projects. These projects would be much more limited without their support and dedication to raising awareness and supporting others with Tourette's.

We were lucky to retain Elaine Smurthwaite when she stepped down from the committee four years ago. Elaine has 3 wonderful children who all have Tourette's and a complex mixture of the coexisting conditions. Elaine helps with training, profiles and outreach, benefit forms and is an integral part of the team.

We were thrilled to see our Occupational Therapy student Katie also came back on board as a volunteer after successfully qualifying and getting her first job as an Occupational Therapist. Katie offers an evening session for outreach and profiles.



**Elaine Smurthwaite** 



Iona McDonald



Joel Smurthwaite



**Nigel Ashworth** 



**David Macpherson** 



**Ross Macpherson** 

We have two of our young ambassadors, Joel Smurthwaite, and Iona McDonald, supporting our training for schools. The feedback they get for sharing their lived experience of Tourette's is fantastic and they are always asked lots of questions by teachers and parents alike.

Nigel Ashworth has very kindly donated his time and expertise for our story writing group, the fantastic Living with You script reading, and he has more recently been working on a new podcast project. It will be fantastic to see more of our communities Tourette stories brought to life.

David Macpherson is known as our "tea and coffee" man and does such a lot for us during our open days and events, keeping everyone fed and watered.

Ross Macpherson, Nia Duncan, and Abi McDonald support our popular monthly online kid's activity sessions which are organised and planned by committee members Gillian and Sarah.

We asked some of our volunteers some questions about their voluntary work with us, here's what they said...



NIA DUNCAN

When did you start volunteering with Tourette Scotland? 2020 I think.

What sparked your interest in supporting the work of the charity? Seeing the support they offer people and their families made me interested in supporting their work

What does your role involve? I help out at the kid's club

What do you personally gain from supporting the charity?

I get to meet lots of people like me and do fun things like occasional nerf wars

**Do you feel supported when working with Tourette Scotland?** Yes

**Would you recommend volunteering with Tourette Scotland?**Definitely



ABI MCDONALD

When did you start volunteering with Tourette Scotland? Around 2020 I think.

What sparked your interest in supporting the work of the charity?

To help get kids more involved with crafts and meet others with

Tourette's

#### What does your role involve?

and supportive.

I help to run the kids club with Sarah Nia and Ross we think of crafts and activities to show the kids how to do and to get them creating fun stuff.

What do you personally gain from supporting the charity?

I gain more confidence and experience working with children I'm able to communicate more and give clearer instructions

Do you feel supported when working with Tourette Scotland?

Totally, if I'm not free to help them they are absolutely understanding

Would you recommend volunteering with Tourette Scotland? Yes, they are supportive and kind they are always super helpful if I need anything.



**KATIE LYONS** 

When did you start volunteering with Tourette Scotland? May 2021

What sparked your interest in supporting the work of the charity? The kind, caring and nurturing people and members I met while on work experience with the charity in 2021. The people who use our services and the people who run our services our some of the most genuine, courteous and selfless people I have had the good fortune of meeting, I enjoyed my time so much I refused to leave ©.

#### What does your role involve?

I provide outreach support, advice and strategies, school profiles and TS awareness training sessions as required. I keep up to date with current evidence and research to ensure a comprehensive understanding of the many strengths and needs of the people I support.

#### What do you personally gain from supporting the charity?

The charity helps me keep up to date with my skills as a children and young peoples occupational therapist. It broadens my understanding of the many strengths and complex situations people living with TS face in everyday life and the resilience required to live well in today's society where understanding and reasonable adjustments are not commonplace across education and workplace settings. It also gives me a sense of fulfillment and joy when meeting the many interesting and diverse people who share their story with me.

#### Do you feel supported when working with Tourette Scotland?

Yes, there are always several team members available to feedback too and answer any questions I may have. They are quite the supportive bunch.

#### **Would you recommend volunteering with Tourette Scotland?**

Absolutely, I couldn't recommend them highly enough. The opportunity to be part of a hardworking and dedicated team who always strive to do their best to help others and leave no stone unturned in the process.



# OCCUPATIONAL THERAPY PLACEMENT

We were delighted to have another master's Occupational Therapy student from Queen Margaret University with us for a 10-week placement this year. We are sure many of you will have met her while she was here on placement. This is what Grainne had to say about her placement and the impact it had on her personally and professionally...



As a student Occupational Therapist, I was a little daunted with having my final placement mostly online. I'm happy to say that I quickly found out that I had absolutely nothing to worry about! An online service is a really good fit for this organisation and online or in person I was continuously impressed by the people I was lucky enough to interact with. This organization runs a variety of services ensuring I also got loads of face-to-face time with the Scottish Tourettic community. I saw first-hand the role that this charity plays in promoting inclusion and awareness as to how a condition like Tourette's can affect lived experiences for the person and their family and friends.

"Everything was considered a learning opportunity, and it really drove home to me that no two people with Tourette's are the same or present the same. By listening to people's stories, I gained a deeper understanding of the challenges and difficulties that people living with Tourette's face on a daily basis."



Throughout this placement it was clear to me how Occupational Therapists played a vital role in supporting individuals who come in contact with the charity, and how our role adapts to the specific needs and goals of the person and organisation. I can wholeheartedly say that I was welcomed into every outreach, profile build, awareness session and support group that was put in place. Everything was considered a learning opportunity, and it really drove home to me that no two people with Tourette's are the same or present the same. By listening to people's stories, I gained a deeper understanding of the challenges and difficulties that people living with Tourette's face on a daily basis.

I also can't speak highly enough of the TS committee, nothing was too much trouble for them in relation to support and guidance and talk about a wealth of knowledge – nothing fazed them or came as a surprise. They constantly reiterated to me that there was no way anybody could possibly know every single thing about all aspects of living with this condition. And if they didn't know, they were going to try and find out!

Elaine, Sarah and Kyla are a fantastic team, who really care about their extended Tourettic family. They have a way of explaining things that helps to put people at ease (myself included), I've witnessed many incidences where their knowledge and caring natures has been invaluable to the people who have come in contact with the TS service.



Besides all the expertise, guidance and support that Tourette's Scotland gave me, they also gave me agency and autonomy over a project on 'ADHD in Women' which I presented as part of a FB event in my final week (I'm happy to report that people actually showed up to this and told me they learned something!) Along with this I can safely say that I learned more about neurological diversities in this placement than any classroom or book could tell me.

Working with Tourette's Scotland provided me with a unique and rewarding experience as a student Occupational Therapist. I was able to develop my practical skills and knowledge, while feeling like I helping to make a positive impact on the lives of individuals and families affected by Tourette's Syndrome. I am extremely grateful for the opportunity to have worked with such a dedicated and passionate team and Tourettic family and look forward to continuing to support this organisation in the future.

## **TESTIMONIALS**

#### **ALAN MORTON**

Tourette Scotland have been invaluable to us as a family. When you receive a diagnosis of Tourette's, there's no support from the NHS, we were very fortunate that during a hospital stay with one of my children we saw a poster about charities on the neurology ward, which is how we found out about Tourette Scotland. Since then, they have supported us with whole school training after years of disability discrimination and gaslighting from teachers to our son.



There has now been a shift in attitude within the school, our boy has done peer awareness sessions for his class with support from Tourette Scotland. As well as 2 school assemblies. It's amazing to see children who were once taught that it's acceptable to laugh at him and be confrontational to him, now accept him and ignore his tics, or even laugh with him about his turkey noise, they are embracing him and none of this would have been possible without TS. He's even reached celebrity status with the younger year groups and kids have approached him after hearing him ticcing in the supermarket, super excited and proclaiming "I knew it was you! I heard you in the shop!".

#### **HOLLY SMITH**

My son was diagnosed with Tourettes in January <u>2020</u> and it was a very uncertain time for him and our family as we had little knowledge on the subject. I reached out to Tourette Scotland when we were at crisis point as my son's tics had become alarming and the GP had no advice.

Although the pandemic had just come into full swing Kyla immediately responded and arranged an outreach video call which was so helpful and reassuring. She and a colleague talked with me about Tourettes and offered ongoing support through their Facebook page, video calls and emails and eventually when restrictions allowed my son and I were able to attend open days where we met people in person and had time to chat and share stories, my son had such a good time and felt relaxed, they make it really a fun day for the kids and the information talks for the adults are so useful. My son's primary school were very pleased to receive the training Tourette Scotland gave them, every member of staff found it useful and it definitely made things easier for my son and me, as they were so supportive and informed.

I've had a few different outreach calls and support in the years that have followed, advice I really could not have gotten elsewhere as it takes people with lived experience to really help with these things.

My son is a little bit older now, growing fast and about to start High school, he feels nervous at this new phase but having Sarah help him update his profile was very reassuring for him. Sarah took the time to go at his pace, listening to all of his concerns, fears and hopes about going to a new school and they came up with a useful up to date profile to show his new teachers and support for learning staff. I honestly don't think I would have had the strength or knowledge to explain to the teaching staff how Tourettes affects my son and how they could help him settle in on my own.

The high school have arranged the formal training Tourette Scotland offer and this is so reassuring to my son and I, it feels like he will be starting on the best possible terms and the staff will understand exactly what Tourettes is and how they can support him.

I received three video outreach calls recently to support me with filling in an application for Child Disability Payment and Sarah and Kyla were so thorough and helpful as these forms are quite intimidating. I feel a lot more confident about the details and information to share to help my son's application be successful.

I feel very lucky to have found Tourette Scotland when I did as I know they are always available to help and understand the complexities and difficulties that come with the condition, there are times when we have felt at crisis point and they always respond with compassion and practical thoughtful support.

# MEET THE COMMITTEE



# KYLA MCDONALD CHAIRPERSON

I have four awesome kids and one crazy dog. I have Tourette's as do two of my kids. I joined the Fife support group after my youngest son was diagnosed and it made a massive difference to us. We went from being terrified and lost to feeling like part of a new family. This involvement helped me grow in knowledge, understanding, and confidence in all things Tourette's and I loved being a part of it all.



SARAH MCCLORY VICE-CHAIRPERSON

I love volunteering with Tourette Scotland. It's a charity close to my heart as I have 3 family members with Tourette's. My niece and nephews have taught me so much and I am immensely proud of them and their achievements. It's been very exciting watching the charity grow and see firsthand the impact of the work we do. I look forward to a fantastic and productive year ahead.



CAROL GILMOUR SECRETARY

My name is Carol and I'm a mum, foster carer and also an artist. I came across Tourette Scotland after 'googling' Tourette's whilst my youngest child was in the process of getting their diagnosis. The help and support given then, and since, by Tourette Scotland has been truly invaluable to our child and to our whole family. I wanted to do something to help the charity and volunteered last year to be elected to the committee as secretary.



# DEREK MILLER TREASURER

Derek is our treasurer and has been a trustee of the charity since 2012. He is a whizz with a spreadsheet, with a great eye for the details! He is also an expert in all things Rubik's Cube! His current record for solving it is 12.13 SECONDS!



# LAUREN REID TRUSTEE

I have Tourette's myself, along with some of the coexisting conditions. I wasn't diagnosed until I was almost 22. After growing up feeling so different, it was a relief to have a name for it and I set about learning what I could. That's how I found Tourette Scotland, it was amazing to meet other people like me and it was genuinely like gaining a second family. I'm really proud of the work we do and love being a part of it.



# GILLIAN MACPHERSON TRUSTEE

I'm Gillian, from Glasgow. I'm married to David and have a son, Ross. Ross was diagnosed with Tourette's at age 9 and since then, Tourette Scotland has been, at times, a lifeline! I am a Support for Learning Worker and find it challenging but rewarding. I recently stepped down as a Boy's Brigade Leader after 30 years. I love travelling, all things Disney, and a good blether!



MELISSA DOYLE TRUSTEE

I got involved with Tourette Scotland through a recommendation by a friend. Our son suffers from a wide array of tics and Tourette Scotland has provided invaluable support for both him and us. When I'm not working, we enjoy walks in the hills, cycling and caring for animals.

## **FUNDRAISING**

We want to give a **HUGE** shout out to everyone who has donated or fundraised for us over the last year!

We have seen Kiltwalker's, runner's, walker's, quizzers, a head shaver and more! By supporting Tourette Scotland you've helped us raise even more awareness of Tourette's and Tics. This coming year, we are exploring more options to support those who wish to raise money for Tourette Scotland so keep your eyes peeled.

We wouldn't be here without the support our our wonderful members, so a very big and heartfelt...





## **OUR SUPPORTERS**

We've been lucky to have been supported by so many people and organisations over the past year.

We'd like to say a huge **THANK YOU** to all of our members and friends who have taken part in fundraising events, donated, volunteered at our open days, and generally supported us in any way, however small.

We'd also like to say **THANK YOU** to the organisations below - your support has been invaluable to us.

















































## **TOURETTE SCOTLAND**

# Financial Statement & Accounts

for the Year Ended 31 August 2022



## Reference and Administrative Details

Chairperson: Kyla McDonald

**Trustees:** Sarah McClory (Vice-Chairperson)

**Derek Miller (Treasurer)** 

**Lauren Reid** 

**Gillian Macpherson** 

Melissa Doyle

**Principle Office:** Inveralmond Business Centre

**Auld Bond Road** 

Perth PH1 3FX

**Charity Registration No.:** SC021851

**Independent Examiner:** Alexander J Fyfe M.A.A.T., C.A., DCha.

**Morris & Young** 

**Chartered Accountants** 

**6 Atholl Crescent** 

Perth PH1 5JN

## **Trustees' Report**

The trustees present the annual report together with the financial statements of the charity for the year ended 31 August 2022.

The financial statement have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with applicable law and the Statement of Recommended Practice, "Accounting and Reporting by Charities", applicable to Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Replublic of Ireland (FRS 102) (effective 1 January 2019).

## Treasurer's Report

The financial results for the year are set out on the following pages.

The surplus for the year has been allocated in full to the general reserve.

The trustees aim to keep at least enough within the General Reserve to keep the charity going for a period of three months in the event of no income being generated, and as such consider the reserves to be satisfactory. The Trustees have been considering their options going forward and recognise the need to bring in further grants and donations and have been dedicating their time to do so.

The charity was not massively impacted financially as a result of Covid-19. As with many other organisations our activities were greatly restricted over this perios but have now largely returned to normal. We have been able to reconvene some of our core activities such as monthly community group meetings and open days.

We also received excellent support from our funders throughout the Covid period and financial commitments were honoured. The main financial impact over that period was on sponsored events such as marathon runs and walks. However, we are already startig to see an upturn in these activities with events such as the annual Kiltwalks.

We currently have over 500 registered members of the charity via our website. This has in turn lead to a further increase in the number of monthly gift-aid donations we are receiving from supporters. A massive thank you goes out from all the board to everyone who has contributed to the charity. This has been absolutely key to our long-term stability and is greatly appreciated by everyone. Overall the trustees are satisfied with the charity's current financial position.

## Structure, governance and management

#### **Recruitment and appointment of trustees**

The trustees are as stated on the administration page. The trustees are volunteers and they administer the society. New trustees are trained by the existing trustees as to their legal obligations under charity law, the Scottish Charity Regulator's guidance on trustees' duties, the decision making duties and the recent financial performance and plans for the future of the charity.

#### **Organisational structure**

Tourette Scotland is a registered charity. The Association is a charitable unincorporated association and the purpose and administration arrangements are set out in our constitution.

## **Financial instruments**

#### **Objectives and policies**

The charity's activities expose it to a number of financial risks including credit risk, cash flow risk and liquidity risk.

#### Cash flow risk

The trustees are conscious of the aim to retain sufficient cash resources to meet the immediate requirements of the charity.

#### **Credit risk**

The charity's principle assets are bank balances.

The charity has no significant concentration of credit risk.

The credit risk on liquid funds is limited because the counterparties are banks with high creedit-ratings assigned by international credit-rating agencies.

#### **Liquidity risk**

In order to maintain liquidity to ensure that sufficient funds are available for ongoing operations and future developments, the Charity's liquid funds are kept in a combination of bank accounts to enable it to service its everyday financial needs.

## Statement of Trustees' Responsibilities

The trustees are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with the United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) and applicable law and regulations.

The law applicable to charities requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources of the charity for that period. In preparing these financial statements, the trustees are required to:

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

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

## Independent Examiner's Report to the trustees of Tourette Scotland

I report on the accounts of the charity for the year ended 31 August 2022.

#### Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts in accordance with the terms of the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006. The charity's trustees consider that the audit requirement of Regulation 10(1)(a) to (c) of the 2006 Accounts Regulations does not apply. It is my responsibility to examine the accounts as required under Section 44(1)(c) of the Act and to state whether particular matters have come to my attention.

#### **Basis of independent examiner's report**

My examination was carried out in accordance with Regulation 11 of the Charities Accounts (Scotland) Regulations 2006. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently I do not express an audit opinion on the view given by the accounts.

#### Independent examiner's statement

In connection with my examination, no matter has come to my attention:

- (1) which gives me reasonable cause to believe that in any material respect the requirements:
  - to keep accounting records in accordance with Section 44(1)(a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations; and
  - to prepare accounts which accord with the accounting records and comply with Regulation 8 of the 2006 Accounts Regulations

have not been met; or

(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Alexander J Fyfe M.A.A.T., C.A., DCha.
Institute of Chartered Accountants of Scotland
Morris & Young Chartered Accountants
6 Atholl Crescent
PERTH
PH1 5JN

## Statement of Financial Activities for the Year Ended 31 August 2020

Income & Endowments from:	Note	Unrestricted £	Restricted £	Total 2022 £	Total 2021 £
Donations and legacies	2	13,933		13,933	7,232
Charitable activites	3	325	8,000	8,325	12,062
Total Income		14,258	8,000	22,258	19,294
Expenditure on:					
Raising funds	4	(338)	(2,186)	(2,524)	(2,120)
Charitable activities	5	(547)	(14,228)	(14,775)	(7,543)
Total Expenditure		(885)	(16,414)	(17,299)	(9,663)
Net movement in funds		13,373	-8,414	4,959	9,631
Reconciliation of funds:					
Total funds brought forward		17,479	20,336	37,815	28,184
Total funds carried forward	12	30,852	11,922	42,774	37,815

All of the charity's activities derive from continuing operations during the above two periods. The funds breakdown for 2021 is shown in note 12.

## Balance Sheet as at 31 August 2021

		2022	2021
Fixed assets:	Note	£	£
Tangible assets	9	1,466	1,012
Current assets:			
Stocks		304	-
Debtors	10	104	633
Cash at bank and in hand	11	41,006	36,170
		41,414	36,803
Total assets less current liabilities		-106	-
Net current assets		41,308	36,803
Net assets		42,774	36,803
Funds of the charity:			
Restricted income funds			
Restricted funds		11,922	20,336
Unrestricted income funds			
Unrestricted funds		30,852	17,479
Total funds	12	42,774	37,815

## Notes to the Financial Statements for the Year Ended 31 August 2022

## 1) Accounting policies

#### **Statement of compliance**

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 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006 (as amended).

#### **Basis of preparation**

Tourette Scotland meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes. The financial statements are presented in sterling (£) and are rounded to the nearest £1.

#### **Going concern**

The trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern.

#### **Income and endowments**

Voluntary income including donations, gifts, legacies and grants that provide core funding or are of a general nature is recognised when the charity has entitlement to the income, it is probable that the income will be received, and the amount can be measured with sufficient reliability.

#### **Donations and legacies**

Donations and legacies are recognised on a receivable basis when receipt is probable, and the amount can be reliably measured.

#### **Grants receivable**

Income from charitable activities includes grant funding subject to specific performance conditions. Grant income included in this category provides funding to support programme activities and is recognised where there is entitlement, probability of receipt and the amount can be measured with sufficient reliability.

#### **Expenditure**

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings, they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

#### **Raising funds**

These are costs incurred in attracting voluntary income and those incurred in trading activities that raise funds.

#### **Charitable Activities**

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

#### **Support costs**

Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, for example, allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

#### **Governance costs**

These include the costs attributable to the charity's compliance with constitutional and statutory requirements, including audit, strategic management and trustees's meetings and reimbursed expenses.

#### **Taxation**

The charity is considered to pass the tests set out in Paragraph 1 Schedule 6 of the Finance Act 2010 and therefore it meets the definition of a charitable company for UK corporation tax purposes. Accordingly, the charity is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 of the Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

#### **Tangible fixed assets**

Individual fixed assets costing £100 or more are initially recorded at cost, less any subsequent accumulated depreciation and subsequent accumulated impairment losses.

#### **Depreciation and amortisation**

Depreciation is provided on tangible fixed assets so as to write off the cost or valuation, less any estimated residual value, over their expected useful economic life as follows:

Asset class Depreciation method and rate

Computer Equipment 25% reducing balance Fixtures and fittings 25% reducing balance Equipment 33% straight line

#### **Cash and cash equivalents**

Cash and cash equivalents comprise cash on hand and call deposits, and other short-term highly liquid investments that are readily convertible to a known amount of cash and are subject to an insignificant risk of change in value.

#### **Fund structure**

Unrestricted income funds are general funds that are available for use at the trustees's discretion in furtherance of the objectives of the charity. Restricted income funds are those donated for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

#### **Financial instruments**

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

## 2) Income from donations and legacies

Donations and legacies:

Donations from individuals Gift Aid reclaimed

Total

Unrestricted funds General £	Total 2022 £	Total 2021 £
12,827 1,106	12,827 1,106	6,435 797
13,933	13,933	7,232

### 3) Income from charitable activities

Fundraising Grants

Total

Unrestricted funds General £	Restricted funds £	Total 2022 £	Total 2021 £
325 -	- 8,000	325 8,000	1,062 11,000
325	8,000	8,325	12,062

The following grants were received:

The Gannochy Trust - £8,000 (2021 - £9,000)

Voluntary Arts - £nil (2021 - £2,000)

## 4) Expenditure on raising funds

### a) Costs of generating donations and legacies

Unrestricted funds General £ E E E E Total 2022 Total 2021 £ £

Cost of raising funds

## 5) Expenditure on charitable activities

Service user activities
Subscriptions
Insurance
Travel & subsistence
Telephone
Printing, postage & stationery
Professional fees
Sundry expenses
Depreciation, amortisation and
other similar costs

Unrestricted funds General £	Restricted funds £	Total 2022 £	Total 2021 £
546	5,825	6,371	3,530
-	1,996	1,996	1,011
-	888	888	786
-	2,744	2,744	-
-	87	87	65
-	1,584	1,584	1,154
-	420	420	630
1	195	196	30
-	489	489	337
547	14,228	14,775	7,543

## 6) Net incoming / outgoing resources

Total

Net incoming resources for the year include:

Depreciation of fixed assets

Total 2022 £	Total 2021 £
488	337

#### 7) Trustees remuneration and expenses

During the year the charity made the following transactions with trustees:

#### **Kyla McDonald**

£631 (2021: £NIL) of expenses were reimbursed to Kyla McDonald during the year. Travel expenses and activity expenses.

#### **Lyndsay Hay**

£325 (2021: £NIL) of expenses were reimbursed to Lyndsay Hay during the year. Travel expenses.

#### **Elaine Smurthwaite**

£121 (2021: £NIL) of expenses were reimbursed to Elaine Smurthwaite during the year. Travel expenses.

#### **Lauren Reid**

£96 (2021: £NIL) of expenses were reimbursed to Lauren Reid during the year. Travel expenses and activity expenses.

#### **Sarah McClory**

£779 (2021: £357) of expenses were reimbursed to Sarah McClory during the year. Travel expenses and activity expenses.

#### **Gillian Macpherson**

£708 (2021: £77) of expenses were reimbursed to Gillian Macpherson during the year. Travel expenses and activity expenses.

No trustees, nor any persons connected with them, have received any remuneration from the charity during the year.

#### 8) Taxation

The charity is a registered charity and is therefore exempt from taxation.

## 9) Tangible fixed assets

Cost

At 1 September 2021 Additions At 31 August 2022

Depreciation

At 1 September 2021 Charge for the year At 31 August 2022

Net book value

At 31 August 2022 At 31 August 2021

Furniture & equipment £	Total £
1,349	1,349
942	942
2,291	2,291
337	337
488	488
825	825
1,466	1,466
1,012	1,012

## 10) Debtors

Other debtors

Total 2022	Total 2021
£	£
104	633

## 11) Cash and cash equivalents

Cash at bank

Total 2022	Total 2021
£	£
41,006	36,170

#### 12) Funds

IZ/I GIIGS				
,	Balance at 1 September 2021 £	Incoming resources £	Resources expended £	Balance at 31 August 2022 £
Unrestricted funds				
General	17,479	14,258	(885)	30,852
Restricted funds				
TOPS Program Fund	10,000	-	(4,377)	5,623
Fordell Firs Annual Camp Fund	2,419	-	(2,419)	-
Covid Assistance Fund	417	-	(417)	-
Project Support Fund	7,500	8,000	(9,201)	6,299
Total restricted funds	20,336	8,000	(16,414)	11,922
Total funds	37,815	22,258	17,299	42,774

Unrestricted funds
General
Restricted funds
TOPS Program Fund
Fordell Firs Annual Camp Fund
Covid Assistance Fund
Project Support Fund
Total restricted funds
Total funds

Balance at 1 September 2020 £	Incoming resources £	Resources expended £	Balance at 31 August 2021 £
9,842	8,294	(657)	17,479
10,000	-	-	10,000
2,419 417	-	- (0.006)	2,419 417
5,506 18,342	11,000 11,000	(9,006) (9,006)	7,500 20,336
28,184	19,294	(9,663)	37,815

The specific purposes for which the funds are to be applied are as follows:

The TOPS Program Fund represents monies advanced from the National Lottery to be used for our training, outreach and peer support (TOPS) program. The monies are restricted in that they can only be used for the purposes set out.

Fordell Firs Annual Camp Fund represents monies from Better Breaks and the Carnegie Trust to be used for the Fife's Group annual camp trip to Fordell Firs. The monies are restricted in that they can only be used for the purposes set out.

Covid Assistance Fund represents monies advanced from Groundwork UK to be used for the Fife Group to assist members through Covid. The monies are restricted in that they can only be used for the purposes set out.

The Project Support Fund represents monies advanced from The Gannochy Trust to be used for training, outreach, website and general running and support costs. The monies are restricted in that they can only be used for the purposes set out.

## 13) Analysis of net assets between funds

Tangible fixed assets Current assets Current liabilities

Total net assets

Unrestricted funds General £	Restricted funds £	Total funds 2022 £
-	1466	1466
30,852	10,562	41,414
-	(106)	(106)
30,852	11,922	42,774

Tangible fixed assets Current assets Total net assets

Unrestricted funds General £	Restricted funds £	Total funds 2021 £
-	1012	1012
17,479	19,324	36,803
17,479	20,336	37,815

