



# ANNUAL REPORT 2020

## TOURETTE SCOTLAND

Scottish Charity Number: SC021851



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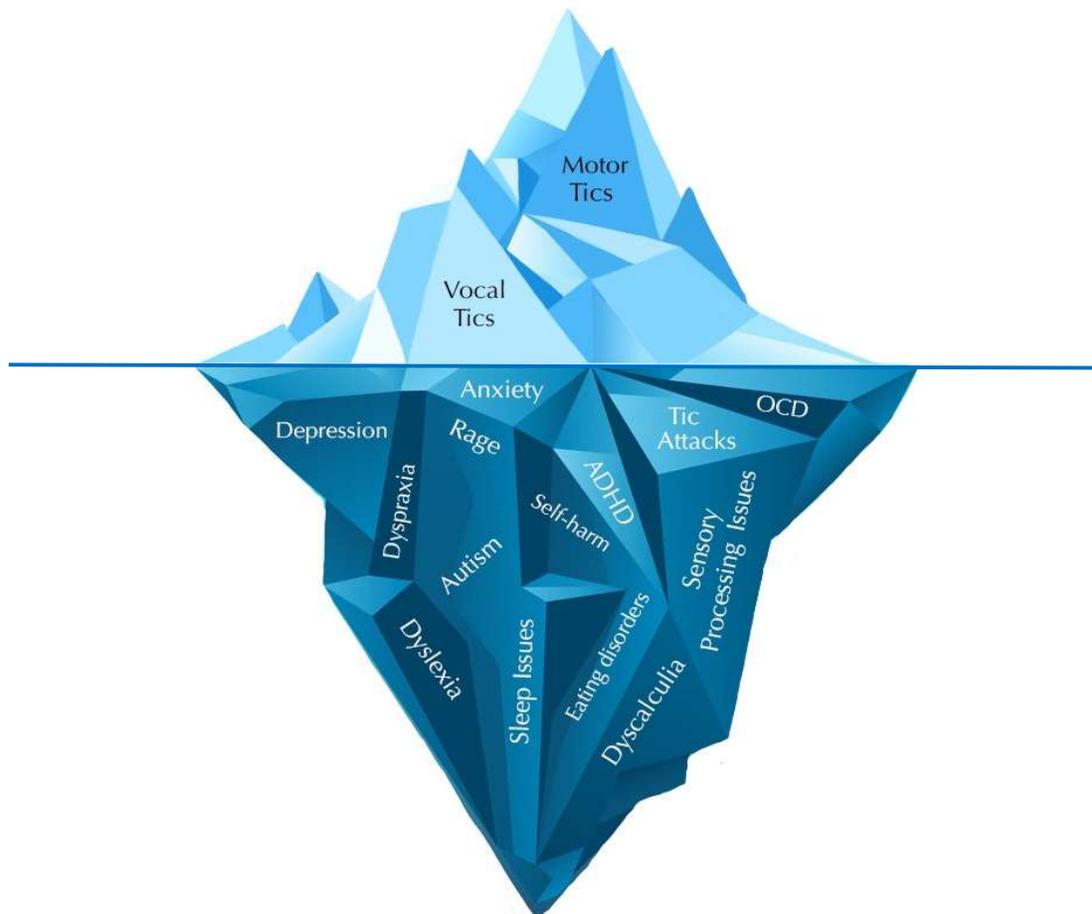


# What is Tourette Syndrome

Tourette Syndrome (TS) is a complex and heredity neurological condition. It is 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 and attention/concentration.

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).

They 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).



All these challenges that people with Tourette Syndrome have to cope with can significantly affect their self-esteem and confidence. This can also lead to feelings of isolation and not belonging within their communities.

## A note from our Chairperson



Welcome to Tourette Scotland's first annual report, where we aim to show all the hard work we have been doing and continue to do with your support.

2020 was a challenging year for everyone and changed our lives like never before. To keep our members safe, we stopped holding all of our regular face-to-face activities and several planned events that we were all looking forward to sadly had to be cancelled. Lockdown meant that many of our members became more isolated than before, and there was a marked increase in the requests for support, as we all had to accept that it was going to take much longer to get back to normal than initially thought.

Covid-19 may have put a spanner in the works, but we are very proud of what we have managed to achieve despite the changes we have had to make. We have risen to the challenge and transformed the way we work to ensure our members still get the support they need, albeit in a slightly different way.

We realised very quickly that we had to embrace technology to keep in touch with our members, and we found that it offered us the opportunity to connect with even more people than before. Our training sessions were very well attended and simpler to arrange due to no travel being involved. We began to hold our support groups and personal outreach sessions online, which has also proved very successful and has helped reduce the isolation felt by some of our members.

We have created and distributed hundreds of face-mask exemption cards and lanyards to help alleviate some of the associated anxiety surrounding the Coronavirus and offer advice and coping strategies to help manage mental health.

We have welcomed an influx of new members from across the country and have enjoyed getting to know them through our online resources. We will continue to offer online services in the future; however, we know that sometimes a face-to-face chat is better, and we cannot wait to do that again.

We gained some fantastic new committee members and are taking full advantage of their skills to take the charity forward and improve our services and availability across the country. Planning for the future in the current environment is difficult, but we have still managed to develop some exciting plans for the coming year, which we cannot wait to share with you.

We are eternally grateful for the support of our members and funders, and we thank you all from the bottom of our hearts.

**Kyla McDonald**

Chairperson, Tourette Scotland



## Our Mission

Tourette Scotland is a national charity that prides itself on being open, understanding and supportive. Tourette Syndrome is a highly complex neurological condition that affects children and adults throughout the world. We offer up to date and informative training for teachers, peers, families and organisations hoping to learn more about the condition and the variety of ways that it can affect individuals and the people around them.

We run fundraising events, awareness sessions, training and support groups for adults and families. We also network with other Tourette support charities across the world. We are working to provide information, support and acceptance to everyone living with Tourette Syndrome. We welcome everyone, young and old and hope to change the way people look at Tourette's by dispelling the myths and creating understanding around this condition.

Since our relaunch in 2018, we have been updating and developing our services. There have been many changes and challenges along the way, but the outcomes have been very successful and positive. Not only can our members see the difference, but they can feel it too. Please feel free to get in touch and help us raise awareness, acceptance and understanding for people with Tourette's.

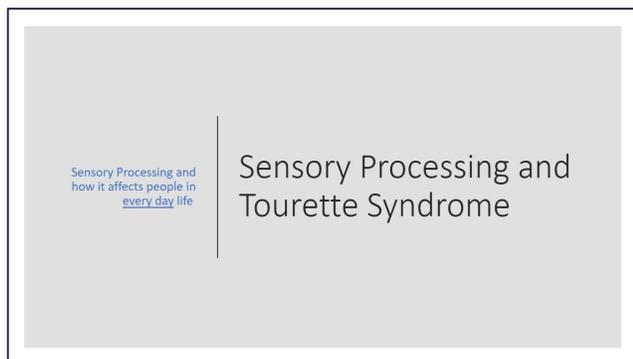
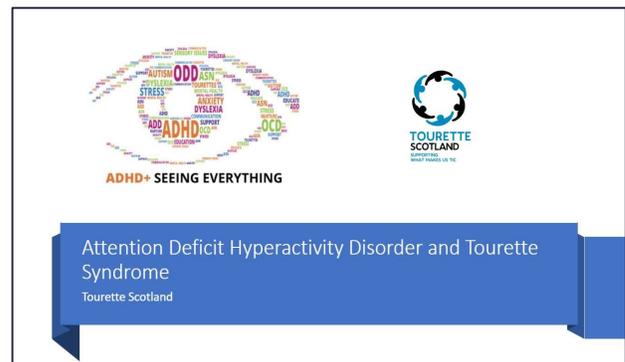


# Our Work

## Training and Awareness

At Tourette Scotland, we pride ourselves on providing quality awareness and training sessions for community groups, educational institutes, and employers. We also offer training for our members on additional and relevant topics. Our training sessions are free, but we welcome donations to support our work.

Over the past year, we have substantially developed this critical part of our work. We have had to adapt our training methods due to the restrictions around Covid-19, but we have found that offering training on a digital platform has enabled us to reach far more people than we usually would, and plan to use this approach more in the future.



## Schools Awareness sessions

Prior to the pandemic we were training at the rate of one to two schools per week in response to newly diagnosed young people. This is a slight increase on previous years which averaged one per week. June 2019-September 2020 we trained at 24 schools with over 200 staff being reached. Since the Covid-19 restrictions have halted our face-to-face sessions, we have been offering virtual training sessions and the demand for these sessions are now increasing since the start of the new academic year. We are reviewing how we move forward post lockdown and how to use technology to develop our reach further and wider. The feedback we have received from schools continues to be excellent.

## Peer Awareness sessions

We offer peer awareness sessions which are tailored to the young person so that their classmates or friendship groups at community-based activities understand their challenges. In the same period of time we have completed 12 peer awareness sessions. The young people are often involved in the delivery of the session and it empowers them to be open and honest about the challenges they face but also to advocate for themselves. Here are a couple of comments from young people who have been part of our Peer Awareness sessions:

*"I don't have to hold my tics in anymore and I am much happier in class", Robyn, aged 10*

*"My friends don't stare and whisper now. They help me", Jack, aged 6.*

Feedback from educators:

*"Better awareness of the impact of TS."*

*"Great presentation, well presented."*

*"Extremely informative."*

*"Thought provoking."*

*"Much deeper understanding."*

*"Loved the personal stories."*

*"Interesting and helpful."*

*"Better awareness of the signs to look for in the classroom."*

*"Dispelled the myths of TS."*

## Higher Education Institutes

The feedback from the training completed at 2 Higher Educational Institutes reflects the same as teaching staff in schools. Staff at colleges/universities also acknowledged that the information, supports and strategies discussed during the training also support the wider neurodiverse population studying at their institute.

## Voluntary Sector

We have been asked to provide training to teams that run the Looked After and Accommodated Children services (LAAC), as well as adoption/fostering services as word-of-mouth feedback has proved extremely positive. This is currently in the process of being rescheduled due to Covid-19 restrictions.

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## NHS Training

We provided an awareness session for NHS Lanarkshire Child and Adolescent Mental Health Team. The purpose of this session was to primarily develop the understanding and awareness of the Occupational Therapy Team but included many of the multi-disciplinary team. This is some of the feedback we received:

*"As occupational therapists, we are interested in all aspects of people's lives and to hear how Tourette's impacts all aspects of daily life for them and their family members has been eye-opening and will inform our practice further."*

*"Learning about the huge variety of tics and how they can affect the individual and their family, education and social inclusion, as well as the personal experiences has been an invaluable learning opportunity."*

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## 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

*"Really interesting and I didn't realise how complex Tourette's is."*

*"I have a better understanding of why my child has meltdowns and what I can do to try and help."*

# Corporate Training

## OVO Energy

We carried out an initial awareness session with one small team in the summer of 2020, in order to support one of our members. Their feedback was invaluable in helping us to develop our training presentation, 'Tourette Syndrome: Neurodiversity at its best'. In October we presented that training session to some of the high-level management team at SSE/OVO Energy. This was to support the development work that they are undertaking to become a recognised neurodiverse employer. The training session was recorded and is now available to several thousand OVO staff on their internal training platform.

## Civil Service

We were part of the Civil Service's "Let's Celebrate Neurodiversity" event, as part of their 2020 Year of Inclusion. The event ran from 10-13 November 2020 and we were delighted to open the event with the first presentation, 'Tourette Syndrome: Neurodiversity at its best'. This session was recorded and is now available to the wider civil service.

*"I've learned that this is an extremely complex problem with many layers and for me, it is quite possible to not know that someone suffers with it. I have a much better understanding of the less obvious symptoms now and how to make sure that anyone in the workplace is cared for appropriately and in a supportive manner."*

*"Thanks for such an open, honest, and informative session."*

*"Informative and dispelled the myths of Tourette's."*

*"Thank you. So much I didn't know. I really learned a lot."*

*"I had no idea Tourette Syndrome was so complex but fantastic to hear the about skills people with Tourette's can bring to a team."*

*"I've learned a lot about the impact tics can have on people and how people try to hide them and the further impacts this can have. Was great to hear relevant, relatable experiences and how we can improve things in the workplace."*

We look forward to carrying out more workplace training in the coming year.



## Outreach

Our Outreach service gives our members a safe space to talk through the challenges they face and ask questions about Tourette's and any co-existing conditions. These sessions can be a gateway to further support services if required.

We were initially quiet during the first few months of lockdown. However, we managed to offer and complete 37 initial Outreach sessions with a further 44 follow up appointments during June 2020 – February 2021. The sessions covered various needs, including Personal Profiles, Tic Attack Plans, help with PIP and DLA applications, and sometimes general support and advice. This is a considerable 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 and a reduction in travel time.

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. As Covid-19 is better managed and lockdown restrictions ease, we hope to offer a blended approach whereby we can hold face-to-face sessions with those who require it.

Here are some comments from families who have received support from our outreach workers:

From an adult who had never spoken to anyone else about their Tourette's:

*"It's a relief to speak to people who really get it, don't judge and truly understand."*

From a family attending a tribunal for DLA:

*"Just wanted to let you know that I'm just out the tribunal. It went in our favour and \*my child has been awarded middle rate care and low-rate mobility and is being backdated. I can't thank you enough for your letter of support."*

From a family who needed a letter to support a housing application:

*"Thank you so much, that is absolutely amazing. Thank you so much from the bottom of my heart."*

## Personal Story...



My name is Ross, and I am 19 years old. At the age of 9, I was diagnosed with Tourette's Syndrome. Coping mechanisms are a key part of managing Tourette's, and I have developed many over the years, my most effective being focusing on my artwork. Some of the art I have done includes modular origami models, drawing, sewing, and painting.

The starting point for my campaigning was when I started high school, and somebody realised I had Tourette's but was confused, as they had never heard me swearing. That was when I knew something had to be done, as it is one of the most misrepresented conditions in the world.

At this point, I decided to sell some of my work at different craft fayres and events, as well as doing commissions. By doing this, I raised a four-figure sum of money which I donated to Tourette Scotland. This charity was chosen as they are the only charity in Scotland that support Tourette sufferers and their families. I thought it would be good to give something back in return after the support that my family and I received.

Through selling, I have also managed to raise awareness of Tourette Syndrome by opening up conversation with potential customers. I also visited local primary schools to teach origami as well as in my own high school and let young people know that, no matter what barriers are thrown in their way, if they believe in themselves, then anything is possible! Tourette Scotland also recognised my efforts and awarded me with the position of Youth Ambassador, which shows me as a positive role model for other young people with Tourette's.

Tourette's awareness is so important, as it helps bring acceptance and understanding within the local and wider communities and give sufferers a sense of belonging. We need to spread the word that there is more to it than just people swearing all the time, that it affects so many people worldwide, and that we are so much more than what everyone thinks, and from how the media portray us.



## Peer Support

Scotland is a vast area to cover, but we continue to believe that one of the best coping mechanisms available 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 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.

Covid-19 prevented us from holding our various local support groups in person, but we have continued to offer monthly meetings on a digital platform. Although online sessions do not allow us to hold the same activities or games for the kids, they have been crucial in preventing further isolation due to lockdown. Read on to find out a little more about our groups.



## Upcoming Groups

Tourette Scotland are continuing to strive towards opening more support groups across the country. In progress now, we have Moray, Inverness, and the Borders. These groups already have an online presence that will be built upon and developed over the coming months.

There is a need for support and a rise in awareness in several areas across the country. With the help of its members, Tourette Scotland aims to fulfil this need and reach even more people reducing isolation and raising understanding and awareness.

For more information about these groups, please email [kyla@tourettescotland.org](mailto:kyla@tourettescotland.org)

## The Fife Group

The Fife group was started in Dunfermline in 2008 by Michelle, Stevie, Susan and Kenny; all of whom were parents of kids with Tourette's. They recognised that there was no support in their local area and together they started the group with support from the committee of Tourette Scotland. Initially only a few families attended. Before long, the group had grown dramatically, and it soon became (and still is) the most attended group in Scotland.

The Fife group is now based in Cardenden with great attendance by its members who describe the group as their 'Tourette's family'. Along with monthly support groups they also enjoy several annual events, including a trip to Lochore Meadows for Kayaking and a BBQ; a residential weekend at Fordell Firs and members regularly team up to make the most of fundraising events. Fundraising has been an integral part of the Fife group with members organising and undertaking a variety of sponsored events including, The Kilt Walk, half marathons, raffles, bag packing and personal challenges.

When unrestricted by Covid-19, the Fife Group meets on the third Thursday of each month to chat and discuss any issues they have encountered. There is always a friendly ear and a cuppa - occasionally cakes too! The group support the whole family as Tourette's can have an impact on everyone; siblings, children and grandparents are welcome. Activities are available for the children and young people: arts and crafts are usually a big hit, biscuit decorating and games nights often feature.

At present virtual support groups are available via Zoom so that members can still connect to support each other especially in these unprecedented and uncertain times.

For more information on this group please contact [kyla@tourettescotland.org](mailto:kyla@tourettescotland.org)

## Personal Story...

"Tourette syndrome, well it has made me who I am. It has been a pain and annoying, but I have learnt how to deal with Tourette's. In primary 5 I had a tic where I would suck on my lip and I got a big blister, it was painful, but my super Mum came up with the idea of a water ice pole and it helped a lot. It has helped to know my two big brothers have Tourette's as well and that they have gone through the same things as me.



So, I have a dancing tic which everybody thinks is good, which it is, I love it. My friends have really helped me cope in school plus they are all good fun. But my mum and dad are like real life superheroes, they never cease to amaze me.

So, Tourette's has made me different from everyone but that is a good thing."

Robyn

## The Grampian Group

The Grampian Group was relaunched in 2018 and is currently based in Aberdeen. The group is run by Lyndsay Hay and supported by Melissa Doyle.

The Grampian group meets on the 4th Tuesday of every month at Ferryhill Community Centre when unrestricted by Covid-19. At the group you'll find a warm and friendly welcome that supports members to feel comfortable and able to develop friendships with each other. They enjoy catching up on the previous month and sharing their tips for surviving the month ahead.

The Grampian group holds monthly meetings, organises days out, trips to football matches and other events. Everyone is welcome, families, adults and professionals.

For more information on this group please email [info@tourettescotland.org](mailto:info@tourettescotland.org)

## The Lothian's Group

The Lothian's group is based in West Lothian and has now been running for 2 years. It was started by Sarah McClory and Kyla McDonald to cover Edinburgh and the Lothians and has seen a steady increase in attendance by members both online and in person.

The Lothian's group usually meets in Uphall Community Centre on the second Tuesday of every month when unrestricted by Covid-19. At the group you'll find a warm and friendly welcome that supports members to feel comfortable and able to develop friendships with each other. They enjoy catching up on the previous month and sharing their tips for surviving the month ahead.

The Lothians has regular attendance by adults with Tourette Syndrome who are always happy to share their experiences of living with Tourette's through both adulthood and childhood. Not only is it a good opportunity for them to share but they are also a great source of support for other members at an earlier stage in their journey. Activities and games are provided for the group's children and young people including arts and crafts, various games, puzzles and gardening.

Along with the monthly meetings the group have enjoyed a boat trip to Inchcolm Island on the "Maid of the Forth" which is docked in South Queensferry. Further trips to the Five Sisters Zoo in Polbeth and Mini golf have had to be postponed due to the current restrictions, but they hope to reorganise as soon as possible.

Support groups still run monthly but are currently online via Zoom and have proved essential, especially for those members who are most isolated. The online groups have been well attended and have lifted the spirits of those joining regularly.

For more information on this group please email [kyla@tourettescotland.org](mailto:kyla@tourettescotland.org)

Some pictures from our groups' events...



## The Perthshire Group

The Perthshire Group was only launched late in 2019 and is based in Perth. The group is run by Lauren Reid and Elaine Smurthwaite.

The Perth group usually meets on the 1st Thursday of every month at The Letham Centre when unrestricted by Covid-19. At the group you'll find a warm and friendly welcome that supports members to feel comfortable and able to develop friendships with each other.

The group was just starting to grow when Covid-19 hit but had held a few meetings which included awareness training, a games night and a trip to the pantomime. The group was due to take part in an outdoor activity day at Willowgate Activity Centre, but this had to be postponed due to the pandemic. We look forward to rearranging that as soon as restrictions allow.

Support groups are currently offered online via Skype or Zoom on the second Thursday of the month.

Everyone is welcome, families, adults and professionals.

For more information on this group please email [lauren.reid@tourettescotland.org](mailto:lauren.reid@tourettescotland.org)

## The West of Scotland Group

Tourette Scotland's West of Scotland Support Group covers a massive area and was relaunched in April 2018 after a change in leadership. The group has grown steadily since then with huge increases in online interaction and uptake in services like outreach and personalised profiles.

The group at this time has nowhere to call home unfortunately but this will hopefully be remedied soon. When unrestricted by Covid-19 the group meets on the first Thursday of the month on Argyle Street in the café within Waterstones. The group is quite well attended by both adults with Tourette's and parents of children with Tourette's. It is usually a general chat and catch up with any queries or ideas taken back to the committee for discussion.

The West of Scotland group had several activities planned to include- adventure golf and an Open Day but unfortunately these events had to be cancelled due to the lockdown. Tourette Scotland aims to have these events and more back on the calendar at the earliest opportunity.

Support groups are currently offered online via Skype or Zoom on the first Thursday of the month and are very well attended.

For more information on this group please email [kyla@tourettescotland.org](mailto:kyla@tourettescotland.org)

## 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 significant 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 allow members to be themselves, feel accepted, relax, and have fun while challenging themselves and stepping out of their comfort zone.

Thanks to funders like the Carnegie Trust and Better Breaks and the group's own fundraising efforts, Tourette Scotland's Fife support Group has 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 throughout 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 with special dietary needs catered for where possible. Previous camps have seen family bonds improved with a greater understanding of Tourette's and the challenges of living with this condition. Being able to talk with others really helps to facilitate the 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 very emotional experience.

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 cannot 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.

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 allows siblings to meet others with Tourette's and other siblings dealing with similar issues. Group leaders hand out feedback forms to ensure we are getting it right and any improvements for the following year at the end of every camp.

## Personal Story...

I remember the Dr telling mum I had TS and then mum telling me I had it. Then mum explained what it is. TS causes my brain to make me move parts of my body involuntarily.

It makes me: snap my wrists, crack my toes, roll my neck, move my arms as if I'm lifting weights, blink and frown a lot, tense my stomach (which is a blessing in disguise because it gives you a slight six pack), knock my knees, it's loud which I like, but it's the feeling of the knees knocking together too, tense my calves (which if I have a tic attack can give me cramps), bite the inside of my lip (but I can't tell if it's a habit or a tic), scrape my tongue from my teeth to the back of the roof of my mouth as the sound satisfies the tic.



I find it hard going to sleep as it feels like trying to fall asleep whilst wiggling your toes constantly. I have sensory issues like kicking the side of the kitchen table when eating. I like the feeling and sound of it.

Lawrie

## Our Volunteers

During 2020 we saw our volunteer numbers grow. Our first volunteer was the amazing Elaine Smurthwaite, a mum of 3 young people with Tourette's. Elaine has supported both our outreach service and training. Her knowledge and insight to family life and the day-to-day challenges has helped numerous families at the start of their journey of living with Tourette's. We are also very lucky to have two wonderful young people with Tourette's to support our training sessions, Iona and Joel. This has added massive value to the training we offer. Sharing their personal experiences has been incredibly brave, and it has had a huge impact for people who are at the start of their Tourette's journey and with education staff so that they understand the full impact of going to school every day with a complex neurological condition.

We would not be able to deliver the outreach and training that we currently offer without their invaluable support. Here are some of the comments from our members about their contribution to the training and outreach:

*"I can't tell you how inspiring it is to hear Joel speaking about his experiences of living with Tourette's as part of the excellent training session tonight. He's an inspiration to listen too."*

*"Hearing from Iona just out of education is really useful in helping us consider the challenges our young people face every day."*

*"Having a Mum who understand the challenges of coming to terms with a Tourette's diagnosis within the family helped me feel less alone, less useless and that there is hope."*

## Personal Story...

My Tourette's journey started when I was 4, on my very first day of primary 1. My teacher noticed that I was blinking excessively. My tics developed over the rest of my childhood to facial grimacing, eye-rolling, sniffing, grunting, etc. The vast majority of my school life was miserable. I was painfully shy, and my tics were the perfect target for anyone wanting to have a go. I was bullied right up until around 5th year at secondary school, both verbally (mimicking, name-calling, being left out) and physically.



What made it more difficult was the lack of a diagnosis. The psychologist I was sent to diagnosed 'nervous twitches' that would go away if I tried hard enough! She even tried to hypnotise me (and my fellow ticcors will understand that when someone tells us to lie still, it's like a green light for our tics to go crazy).

I was finally diagnosed when I was 21/22, and it was a relief. To have a name for it and some validation that I hadn't 'not tried hard enough to stop them'.

By this point in my life, I had finished college and was working. People had, for the most part, grown up and stopped taking the mickey so much. As soon as I was diagnosed, I went into research mode, and that's where I found Tourette Scotland. I went along to their Spring meeting, found the courage to talk to people. Over the years, I have met some of the best people, and I mean the BEST! Being around people like me was everything. Just being able to tell someone about a particular symptom and for them to say, "oh, I do that too" was amazing.

As I've gotten older, I've found that my tics have lessened in their volume, but they have become much more violent. At the end of 2018, I was forced to have spinal surgery due to the neck jerking I've done for years, rupturing a disc in my neck. I still consider myself lucky. I have a very supportive family and some wonderful friends, and a good job. Unfortunately, many of my fellow ticcors have it much worse and are isolated and very much misunderstood. Tourette's isn't just tics. More often than not, it's an amalgamation of several different conditions - it's rare to have just one, the most common being OCD, ADHD, Dyspraxia, ASD, and Dyslexia. So many people suffer because it is such a complex condition and so misunderstood.

So please, take the time to learn about it, and when you see it used as a punchline on TV, take a moment and think about it before laughing. Not so much for me anymore, but for all those kids who still have to go to school every day.

Lauren Reid  
Trustee, Tourette Scotland

## Testimonial

Hi,

I want to take the time to thank you all so very much. In January \*my son was diagnosed with Tourette's and I was blind on how to best help and support him, I was given advice from his Dr to contact Tourette Scotland.

At first, I was extremely nervous I didn't have a clue about Tourette's except of the experiences through \*my son. I contacted Tourette Scotland and was welcomed instantly with open arms; we were offered an outreach appointment and we found out so much information and were forwarded some information to read at our leisure. At the zoom session we were offered a profile meeting as I was extremely on edge about \*my son transitioning to high school, we arranged a meeting very promptly and I had so much reassurance and myself and \*my son are now finding each day easier without the dread hanging over our heads. I asked for some help to fill out a DLA form and again there was another meeting made promptly.

I cannot thank Tourette Scotland enough for all their help and support and for welcoming us in with open arms. We are only at the beginning of our journey but without the support and assistance of you all myself and \*my son would be lost. You all do an incredible job and if I'm ever lost for answers, I always know I can turn to you.

Kind Regards

\*name removed for privacy.

## 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.



### Lyndsay Hay - Secretary

Lyndsay is our brilliant secretary and lives up in Aberdeen. She was instrumental in starting our Grampian support group and is one of our trainers, delivering training to schools in the Grampian region. Lyndsay is also Mum to a son with Tourette's and other co-existing conditions. Lyndsay is currently on a short break from the committee.



### Derek Miller - Treasurer

Derek is very shy, so we've written this for him and chosen the logo to save his blushes! Derek is currently 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!



### Sarah McClory – Vice-chairperson

I have been volunteering with Tourette Scotland for 4 years. 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. In my day job I am an Occupational Therapist, so I bring many of my skills to the work I do with the charity.



### Lauren Reid – Trustee

Hi, I'm Lauren and I have Tourette's myself, along with some of the co-existing 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 just 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.



### CJ Lambe – Trustee

I'm Cheralynne Lambe, CJ for short. I am the wife and Mum of two people with Tourette's. My husband has had tics since he was 4 years old, diagnosed at 14 and is a Paramedic for the Scottish Ambulance Service. We have two children, Amber and Kristian. Kristian has had tics since he was 4 1/2 and we are in the process of getting him diagnosed.

# Our supporters

We are blessed to have had so many people support us over the last few years.

To all of our members and friends who have taken part in fundraising events, we would like to take the opportunity to say a great big **THANK YOU**.

We would also like to say a huge **THANK YOU** to the organisations below – your support has been invaluable.



# Tourette Scotland

## Financial Statements & Accounts

for the Year Ended 31 August 2020



## Reference and Administrative Details

<b>Chairperson:</b>	Kyla McDonald
<b>Trustees:</b>	Derek Miller, Treasurer Sarah McClory, Vice-chair Lauren Reid Gillian Macpherson Melissa Doyle Cheralynne Lamb
<b>Secretary:</b>	Lyndsay Hay
<b>Principle Office:</b>	Inveralmond Business Centre Auld Bond Road Perth PH1 3FX
<b>Charity Registration Number:</b>	SC021851
<b>Independent Examiner:</b>	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 financial statements of the charity for the year ended 31 August 2020.

The financial statements 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 Republic of Ireland (FRS 102) (effective 1 January 2019).

## Treasurer's Report

The financial results for the year are set out in pages 30 to 39

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 to grow the charity, and have been dedicating their time to do so.

In terms of any financial impact as result of Covid-19, the charity has not been massively affected by this. A process has been in place over the past couple of years to move towards a remote working system. The head office in Perth was closed and all administrative work has been dealt with remotely by trustees located around Scotland. We have also received excellent support from our funders and all financial commitments from them have not been impacted by Covid-19.

The main financial impact has been on sponsored fund-raising events such as marathon runs, kilt walks etc. Due to lockdown restrictions our members, who have done some fantastic work in this area over many years, have been unable to do so recently.

However, we have seen a growth over the past year in regular monthly gift-aid donations from our members and these have actually increased throughout the Covid-19 period. Overall, the trustees are satisfied with the current financial position of the charity.

## 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 principal financial 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 credit-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 2020.

## **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

	Note	Unrestricted £	Restricted £	Total 2020 £	Total 2019 £
<b>Income and Endowments from:</b>					
Donations and legacies	2	4,695	-	4,695	8,647
Charitable activities	3	3,448	24,557	28,005	998
<b>Total Income</b>		<b>8,143</b>	<b>24,557</b>	<b>32,700</b>	<b>9,645</b>
<b>Expenditure on:</b>					
Raising funds	4	(678)	-	(678)	(797)
Charitable activities	5, 6	(1,264)	(6,215)	(7,479)	(19,641)
<b>Total Expenditure</b>		<b>(1,942)</b>	<b>(6,215)</b>	<b>(8,157)</b>	<b>(20,438)</b>
Net movement in funds		6,201	18,342	24,543	(10,793)
<b>Reconciliation of funds</b>					
Total funds brought forward		3,641	-	3,641	14,434
Total funds carried forward	15	9,842	18,342	28,184	3,641

All of the charity's activities derive from continuing operations during the above two periods.

The funds breakdown for 2019 is shown in note 15.

## Balance Sheet as at 31 August 2020

	Note	2020 £	2019 £
<b>Fixed assets</b>			
Tangible assets	11	-	176
<b>Current assets</b>			
Debtors	12	287	101
Cash at bank and in hand	13	27,897	7,787
		28,184	7,888
<b>Creditors: Amounts falling due within one year</b>	14	-	(4,423)
<b>Net current assets</b>		28,184	3,465
<b>Net assets</b>		28,184	3,641
<b>Funds of the charity:</b>			
<b>Restricted income funds</b>			
Restricted funds		18,342	-
<b>Unrestricted income funds</b>			
Unrestricted funds		9,842	3,641
<b>Total funds</b>	15	28,184	3,641

# Notes to the Financial Statements for the Year Ended 31 August 2020

## 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' 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
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' 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

	Unrestricted funds General £	Total 2020 £	Total 2019 £
<b>Donations and legacies;</b>			
Donations from individuals	4,162	4,162	8,156
Gift aid reclaimed	533	533	491
	<b>4,695</b>	<b>4,695</b>	<b>8,647</b>

## 3. Income from charitable activities

	Unrestricted funds General £	Restricted funds £	Total 2020 £	Total 2019 £
Fundraising	3,448	-	3,448	453
Membership Fees	-	-	-	81
DVDs, books, bands etc.	-	-	-	464
Grants	-	24,557	24,557	-
	<b>3,448</b>	<b>24,557</b>	<b>28,005</b>	<b>998</b>

The following grants were received:

The Gannochy Trust - £10,000 (2019 - £nil)  
 The National Lottery - £10,000 (2019 - £nil)  
 Better Breaks - £2,557 (2019 - £nil)  
 Carnegie Trust - £1,500 (2019 - £nil)  
 Groundwork UK - £500 (2019 - £nil)

## 4. Expenditure on raising funds

### a) Costs of trading activities

	Direct costs £	Total 2020 £	Total 2019 £
Costs of trading activities	678	678	797

## 5. Expenditure on charitable activities

	Unrestricted funds General £	Restricted funds £	Total 2020 £	Total 2019 £
Direct costs	1,684	5,472	7,156	16,787
Allocated support costs	484	743	1,227	695
Governance costs	(904)	-	(904)	2,159
	<b>1,264</b>	<b>6,215</b>	<b>7,479</b>	<b>19,641</b>

	Activity undertaken directly £	Activity support costs £	Total 2020 £	Total 2019 £
Service user activities	2,101	-	2,101	3,429
Travel expenses	1,801	-	1,801	4,099
Rent and water rates	-	-	-	6,199
Premises hire	532	-	532	375
Professional fees	-	-	-	923
Subscriptions	974	-	974	366
Subsistence	979	-	979	1,073
Insurance	769	-	769	875
Misc. and admin expenses	-	1,227	1,227	143
	<b>7,156</b>	<b>1,227</b>	<b>8,383</b>	<b>17,482</b>

## 6. Analysis of governance and support costs

### Charitable activities expenditure

	Basic of allocation	Unrestricted funds General £	Restricted funds £	Total 2020 £	Total 2019 £
Printing, stationery and postage	actual	177	743	920	184
Telephony and internet	actual	73	-	73	511
Sundry expenses	actual	234	-	234	-
		<b>484</b>	<b>743</b>	<b>1,227</b>	<b>695</b>

### Governance costs

	Unrestricted funds General £	Total 2020 £	Total 2019 £
Independent examiner fees			
Examination of the financial statements	(1,080)	(1,080)	2,100
Depreciation, amortisation and other similar costs	176	176	59
	<b>(904)</b>	<b>(904)</b>	<b>2,159</b>

## 7. Net incoming/outgoing resources

Net incoming/(outgoing) resources for the year include:

	2020 £	2019 £
Loss on disposal of fixed assets held for the charity's own use	176	-
Depreciation of fixed assets	-	59

## 8. Trustee's remuneration and expenses

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

### **Kyla McDonald**

£1,258 (2019: £2,264) of expenses were reimbursed to Kyla McDonald during the year.  
Travel expenses, activity expenses.

### **Lyndsay Hay**

£35 (2019: £50) of expenses were reimbursed to Lyndsay Hay during the year.  
Travel expenses.

### **Elaine Smurthwaite**

£264 (2019: £889) of expenses were reimbursed to Elaine Smurthwaite during the year.  
Travel expenses.

### **Lauren Reid**

£67 (2019: £78) of expenses were reimbursed to Lauren Reid during the year.  
Travel expenses and activity expenses.

### **Sarah McClory**

£1,178 (2019: £Nil) of expenses were reimbursed to Sarah McClory 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.

## 9. Independent examiner's remuneration

	2020 £	2019 £
Examination of the financial statements	(1,080)	2,100

## 10. Taxation

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

## 11. Tangible fixed assets

	Furniture and equipment £	Total £
<b>Cost</b>		
At 1 September 2019	4,577	4,577
Disposals	(4,577)	(4,577)
At 31 August 2020	-	-
<b>Depreciation</b>		
At 1 September 2019	4,401	4,401
Eliminated on disposals	(4,401)	(4,401)
At 31 August 2020	-	-
<b>Net book value</b>		
At 31 August 2020	-	-
At 31 August 2019	176	176

## 12. Debtors

	2020 £	2019 £
Other Debtors	287	101

## 13. Cash and cash equivalents

	2020 £	2019 £
Cash on hand	-	13
Cash at bank	27,897	7,774
	27,897	7,787

## 14. Creditors: amounts falling due within one year

	2020 £	2019 £
Other creditors	-	1,142
Accruals	-	3,281
	-	4,423

## 15. Funds

	Balance at 1 September 2019 £	Incoming Resources £	Resources Expended £	Balance at 31 August 2020 £
<b>Unrestricted funds</b>				
<b>General</b>				
General	3,641	8,143	(1,942)	9,842
<b>Restricted funds</b>				
TOPS Program Fund	-	10,000	-	10,000
Fordell Firs Annual Camp Fund	-	4,057	(1,638)	2,419
Covid Assistance Fund	-	500	(83)	417
Project Support Fund	-	10,000	(4,494)	5,506
<b>Total restricted funds</b>	-	24,557	(6,215)	18,342
<b>Total funds</b>	3,641	32,700	(8,157)	28,184

	Balance at 1 September 2018 £	Incoming Resources £	Resources Expended £	Balance at 31 August 2019 £
<b>Unrestricted funds</b>				
<b>General</b>				
General	14,434	9,645	(20,438)	3,641

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-19 Assistance Fund** represents monies advanced from Groundwork UK to be used for the Fife Group to assist members through Covid-19. 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.

## 16. Analysis of net assets between funds

	<b>Unrestricted funds General £</b>	<b>Restricted funds £</b>	<b>Total funds 2020 £</b>
Current assets	9,842	18,342	28,184

	<b>Unrestricted funds General £</b>	<b>Restricted funds £</b>	<b>Total funds 2019 £</b>
Tangible fixed assets	176	-	176
Current assets	7,888	-	7,888
Current liabilities	(4,423)	-	(4,423)
Total net assets	3,641	-	3,641

## 17. Related party transactions

There were no related party transactions in the year.