



**Tourette Support NI
Chairperson's Report
For the Year End March 2024**

Public benefit

The direct benefit flowing from our purposes is that parents no longer feel isolated. They will be able to communicate with other families and experts in the field and will have an opportunity to participate in activities for both parents and children. This will develop skills both within the family, the group, and the wider community. The benefits will be demonstrated through the feedback received from members, the parent carers, the children and the wider community. The benefits will also be demonstrated through the publicity that the group can attract and through the numbers attending the activities which are to be laid on for them. There is no harm arising from our purposes. The Charity beneficiaries are children who have Tourette Syndrome, their parents and carers, the wider community who will gain knowledge of the Syndrome, and professionals working in this field. There is no private benefit flowing from our purposes.

In setting out our objectives and planning our activities our trustees have given serious consideration to the Charities Commission general guidance on public benefit.

Achievements and Performance

Tourette's Support has supported families over the past 2/3 years. During COVID families needed more support with more families contacting Tourette's Support NI Facebook Page and joining the What's App group.

During COVID the group organised more online zoom meetings for parents to chat to members of the committee about their concerns. Meet up sessions took place in Antrim, Cookstown, Belfast, Donaghadee and Portavogie.

ASDA Cookstown Community Representative launched their store as the first store to be Tourette's friendly in Northern Ireland. Staff were trained on how to manage customers with Tics and Tourette's.

Sarah Sharpe from Tictock Therapy facilitated training sessions for parents and one to one consultations. The group are negotiating training content, availability and prices for a major Conference in October 2023.

Hillsborough Castle has been in talks with the Committee about the group using their facilities for days out. The group are looking forward to arranging events.

The group organised trips to the Pantomime in Derry, Dublin Zoo, pottery classes

The group has been working hard behind the scenes contacting the Education Authority and the Health Authority. Many thanks go to Cllr Ian Milne and Emma Sheerin MLA who have supported the group since it started. Ian and Emma organised for the group to make links and give a presentation to Mid Ulster District Council, Education Authority officials and organised the group to attend the ASD All Party Group in Stormont. The group sent a letter to the Minister of Health to ask why there was no current statistics about Tourette's in Northern Ireland.

- The Deputy Minister Michelle O'Neill met with the group in July 2021
- Met with All Party Group Autism in Stormont in March 2023 with the hope of setting up an All-Party Group for Tourette's. This to be revisited again with the support of Emma Sheerin
- Members of Tourette's Support have been featured on UTV Live and BBC Northern Ireland News
- Had several meetings with Mid Ulster Council – raising awareness about Tourette's
- Met with Educational Authority Personnel – informing them of real-life stories from Tourette's families.
- Tourette's Support group gave a presentation about Tourette's in the Long Gallery in Stormont to professionals, MLA's in May 2023
- Members of Tourette's Support took part in Belfast Marathon in May 2023
- First major 3-day conference was a success which was held in October 2023 in Walsh's Hotel Maghera with guest speaker Sarah Sharp from Ticktock Therapy. Families, health and educational professionals attended the event.
- Tourette's Support NI became a community partner with Hillsborough Castle and Gardens. Training was facilitated by Louise Smith.
- To date we have 70 families on the What's App Group.

Tourette's Support Committee are very proud of the work that has taken place since the group started. It is sometimes challenging and overwhelming especially for parents who are dealing with their own family problems- issues with their own

child/children who have Tourette's. Tourette's as we know is a lifetime challenge and Tourette's Support will keep going and keep knocking on doors, keep in touch with local government, Education Authority and the Health Authority to get the voices of these young people heard.

We would like to take this opportunity to thank everyone who has helped in any way over the past 3 years. Your time and support are deeply appreciated. For those who fundraised for the group in whatever way we are eternally grateful for your kind effort and support.

Tourette's Support is stronger now than ever and the group will continue to support their members in whatever way then can.

Going Concern Policy

The Trustees are confident that they will have sufficient funding and unrestricted income so that the activities of the Charity can continue for the next 12 months and beyond. The accounts have therefore been prepared on a going concern basis.