



TOURETTE'S

Association of New Zealand

2024

**SPONSORSHIP
PROPOSAL**

ABOUT TOURETTE SYNDROME



Tourette syndrome (TS) is a neurological disorder characterized by repetitive, involuntary movements and vocalizations known as tics. The severity and types of tics can vary widely among individuals, however, common disadvantages include:

Social Stigma: People with TS often face social stigma and misunderstanding due to their tics. This can negatively affect their self-esteem and mental well-being or vocalizations.

Bullying and Teasing: Tamariki and rangatahi with TS are at a higher risk of being bullied or teased by their peers leading to emotional distress, anxiety, and depression. It is uncomfortable or even painful, especially if they involve repetitive movements or vocalizations.

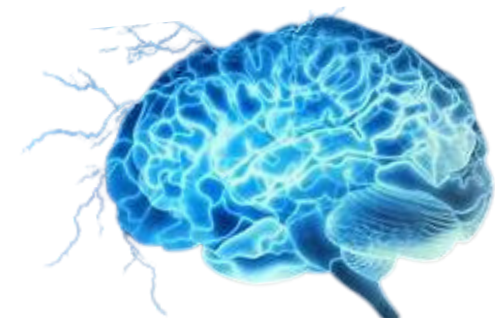
Educational Challenges: Tics can disrupt concentration and learning in school, affecting academic performance and it may require special support to succeed in the classroom.

Social Relationships: Relationships can be challenging for individuals with TS due to their tics. Some people may struggle with forming close bonds or may avoid social situations.

Emotional and Psychological Impact: Living with TS can lead to emotional and psychological challenges, including anxiety, depression and low self-esteem.

Physical Discomfort: Tics can be physically uncomfortable or even painful, especially if they involve repetitive movements or vocalizations.

Exercise



To get a small insight into what it is like to have TS and to try and suppress it, try and hold your breath or keep your eyes open for as long as you can. The longer you do it, the more you want to blink or take a deep breath, and then when you do succumb you want to blink more or breathe heavily to feel better. This is what it is like to suppress tics, while it can be done, it makes the feeling worse and the tics more severe when they return



ABOUT TANZ

Living with Tourette Syndrome (TS), a rare genetic disorder that manifests itself physically and intrusively, can be a challenging experience. Due to the low diagnosis rates, children diagnosed with Tourette Syndrome, along with their families, may feel isolated in small countries like New Zealand. They may be the only ones in their school or town with this condition, which can make it difficult to find support and understanding. Feeling alone is a common theme among families affected by Tourette Syndrome. To address this need for support, the Association was formed in 2013, and became a registered charity in the same year. Since then, it has continued to grow in strength and numbers, providing much-needed support to families affected by Tourette Syndrome.

We want people with TS to receive the practical support and social acceptance they need to help them live their lives to the fullest.

We want people with TS to receive the practical support and social acceptance they need to help them live their lives to the fullest.

HOW WE ACHIEVE THIS:

We raise awareness and **FOSTER SOCIAL ACCEPTANCE** through education and robust social media campaigns.

We **INVEST IN RESEARCH** that will advance scientific understanding, treatment options and care.

We **EDUCATE PROFESSIONALS** to better serve the needs of children, adults and families challenged by Tourette and Tic Disorders.

We **PROVIDE SUPPORT, HOPE AND HELP** through our network across the country. We host virtual and in-person discovery and learning sessions, support groups for a variety of ages, and maintain library resources to raise understanding.

We **EMPOWER THE COMMUNITY** to advocate for the most pressing issues facing the TS community.

MISSION

To help those affected by tics grow up in a world that supports and encourages them to be the best they can be through awareness, connectivity, inclusivity and acceptance

VISION

Together build a tic friendly world.

VALUES

Inclusivity: We are committed to providing equal access to opportunities and resources for people affected by tics.

See also: collaborative, respectful, acceptance.

Empathy: We strive to foster connection and understanding for those we serve and to promote the wonder of people affected by tics.

See also: compassion, understanding, recognition.

Advocacy: We will work to support and enhance the rights of people affected by tics.

See also: represent, champion, advancement.

Integrity: We uphold the highest ethical standards in all our operations and interactions.

See also: excellence, honour, principle.



TOURETTE'S

Association of New Zealand

TANZ PRIORITIES

- Online resources/websites
- Social media campaigns
- Media outreach
- Awareness
- Merchandise

Awareness

- Grants Writing
- Diversify Funding Options
- Corporate Sponsorships
- Donations

Financial Stability

Advocacy

- Medical Advisory Committee
- Policy briefings and submissions
- Public Events and Campaigns

Innovation

- Education Program
- Medical Awareness Program
- Pathway to Diagnosis



SPONSORSHIP OPPORTUNITY



SCHOOL KITS

We have designed a specialist course to provide educators with the knowledge and tools to teach a student living with Tourette Syndrome (TS).

There is currently no specialist training available for the estimated 8,000 students living with TS, plus teachers associated with these students. TS in the classroom can be distracting for everyone.

By understanding the condition and learning how to manage students' needs a stronger relationship and positive learning experience can happen.

Our online course covers information about TS, case studies, and videos from those living with TS, along with access to our association. Once completed, we invite the educator, student, and family to a meeting facilitated by TANZ (an adult living with TS) to discuss the student's particular needs, and to come up with a plan for their year.

Our expectations are that this will be a self funded course within 18-24 months. Funds have already been raised to get the program into development.



We are seeking support to fund the staff required to manage this project:

Program Manager

Adult with sibling with TS

Program Administrator

Parent of child living with TS

Facilitators

Adults living with TS

Total Cost required for first year:

\$156,000

SPONSORSHIP OPPORTUNITY



CAMP TWITCH



Every year families/whanau from throughout New Zealand come together at Camp Twitch to meet others just like them,

Those attending range in age from primary school children diagnosed with TS who attend with at least one caregiver to adults living with TS who bring along their families.

We structure activities into groups so that the young adults with TS can be team leaders to the younger children – the children love having an older leader who is just like them. We also encourage siblings to come along to camp and include a team of brothers and sisters in all activities also.

Parents are always grateful when adults with TS come to camp as it gives them a chance to speak to someone about the reality of life with TS and their insight is often more valuable than the information that the health professionals provide.

Camp Twitch is held in the first week of the school holidays between term 3 and 4..

The purpose of the camp is to connect through fun activities, friendship, and group workshops.



We are seeking support to fund the following for our annual camp:

Program Manager / Facilitator: \$12,000

Accommodation for families: \$24,500

Catering: \$19,000

Activities: \$5,700

TOTAL CAMP COSTS: \$61,200

SPONSORSHIP OPPORTUNITY



AWARENESS

Campaigns

We plan to get the attention of New Zealanders this year with an impactful campaign to highlight the stigma, bullying and misunderstanding surrounding Tourette Syndrome. We will also highlight TS Awareness Month

We want to be more than a punchline

Merchandise

New merchandise is available online, with multiple designs and formats available to highlight the spectrum in which TS presents. One of the campaigns was designed by our own community - our best seller!

Advocacy

We are underrepresented and under diagnosed. We are advocating for a change at a systematic level with the government to get greater representation and support for our community.

All of our awareness projects cost significant investment up front and we are seeking support to be able to complete our campaigns and achieve our strategic goals. We request donations to allow us to proceed.

SPONSORSHIP OPPORTUNITY



KEEPING THE LIGHTS ON

Running an association at a basic level costs money. We are a frugally run association who keeps costs down at all times, however, we have big plans, and these plans all cost money, but so does the day to day running of TANZ. An opportunity exists to support our association as a whole, rather than a project basis.



TS community management - We are the main contact for our TS community. We organise regular online meetings with the community which allow for connection and information sharing. We host information sessions, help with localised personal funding for individuals and advocate for our community.

Medcal Advisory Committee - we are organising an advisory committee to assist our community with all medical aspects involved with TS, including, advocacy, diagnosis, medical industry representation.

Website: www.tourettes.org.nz is the first point of contact for anyone who requires information for all things TS related.

Resources: As the only point of contact for our community we strive to continually provide informative resources that help people living with TS to have a greater understanding of their journey. We also have resources for people in the education and medical sectors to help with understanding the condition.

An opportunity exists to fund the day to day running of the Tourette's Association of New Zealand, to be able to change the lives of those living with TS.



CONTACT US

Emma Henderson
General Manager

gm@tourettes.org.nz
021 084 22110

tourettes.org.nz



TOURETTE'S

Association of New Zealand