



**Tourette's Association
New Zealand**

GOVERNANCE CHARTER

June 2019

Contents

Role of the Association	Page 3
Strategic Focus	Page 3
TANZ History	Page 3
Board Information	Page 4
Board Member Appointments	
Chairperson	
Deputy Chairperson	
Treasurer	
Secretary	
Board Members	
Role and terms of reference of Board sub-committees	
Meeting Cycle	Page 7
Legislative Requirements	Page 7
Staff Information	Page 8
Executive Director	
 TANZ Policy Manual	
Legislative Compliance Policy (p.9)	Privacy Policy (p.21)
Conflict of Interest Policy (p.10)	Media Policy (p.22)
Sensitive Expenditure Policy (p.13)	Health and Safety Policy (p.23)
Fraud Policy (p.15)	Membership Policy (p.24)
Vulnerable Children's Act Policy (p.16)	Events Policy (p.25)
Code of Ethics Policy (p.17)	Board Election Policy (p.26)
Complaint Procedure Policy (p.18)	Employment Policies
	Personnel (p.27)
	Disputes and Personal Grievance (p.28)
 Appendix	
1. Trust Deed	Page 29
2. Strategy	Page 30
3. Current Board Members	Page 31
4. Finance Subcommittee	Page 32
5. Marketing Subcommittee	Page 34

Role of the Association

The Association was established to:

- help and support all those involved with the care, upbringing and education of children and adults with Tourette Syndrome and Tic Disorder;
- help and relieve the stress and difficulties of families affected by Tourette Syndrome through increasing public awareness and understanding the development of Tourette Syndrome
- which includes information on treatments and management as well as a library of books, DVDS, newsletters, articles, workshops and seminars;
- provide members with opportunities for contact with experienced and understanding peers by way of support group meetings and events both regionally and nationally;
- carry on any other exclusively charitable purpose which may seem to the Trust capable of being conveniently carried on in connection with the above purposes or calculated directly or indirectly to advance the purposes of the Trust;
- limit the activities of the Association to Aotearoa/New Zealand.

Strategic Focus

VISION

To support and empower people with Tourette's to feel accepted within the wider community.

VALUES

Inclusiveness: We respect all people, value diversity and are committed to equality.

Voice: We value the voice of our members with Tourette's.

Fun: Providing families and young people with enjoyable experiences

Participation: We recognise the contribution of volunteers and our members.

Community: Working with community to reduce the stigma of people living with Tourette's.

Integrity: TANZ is a credible national voice with transparent practices.

OBJECTIVES

To host a number of gatherings and events for people and families living with Tourette's;

To be the number one resource on all things Tourette's;

To reduce the stigma people with Tourette's face in the community;

Youth Development;

To have Tourette's recognised as a disability in New Zealand;

To establish a facility in Canterbury for individuals and families with Tourette's;

TANZ is a sustainable organisation

TANZ History

The Association was formed in 2013 by Robyn Twemlow of Christchurch in response to receiving the diagnosis that her eldest daughter had Tourette Syndrome. When attempting to obtain information and peer support within the community she found that in fact no support network existed in New Zealand. Being a qualified journalist, she instigated her own investigations into what information was available worldwide on the subject of Tourette Syndrome, what was best practice in assisting those with the neurological disorder and guidelines should the medical and educational sectors in New Zealand be applying in order to effect best practice.

During these investigations she made contact with two other mothers of children with Tourette Syndrome who were also searching for guidance and help. Collectively Robyn Twemlow, Amber Murdoch and Robyn Martinovich registered the Tourette's Association New Zealand (TANZ) in July 2013 and set the wheels in motion for information building and peer support to commence.

In October 2014 the Tourette's Association NZ held its inaugural Camp Twitch, in Hanmer Springs which was attended by children, teenagers and adults with Tourette Syndrome as well as parents, caregivers and siblings. Due to the success, demand and on-going growth of numbers wanting to attend Camp Twitch it has become an annual event.

Board Information

BOARD MEMBER APPOINTMENTS

Board members are elected for a term of two (2) years which may be reviewed and/or renewed on an annual basis at the AGM.

The current board has identified a wide range of skills and knowledge that it believes are necessary for effective governance. They are:

- governance;
- legal;
- investment;
- youth development;
- advertising/marketing;
- public relations/journalism;
- accounting;
- education (school trustees, teachers);
- fundraising;
- charity/not for profit.

The Board may have between three and 10 members.

New/replacement board members are appointed in the following manner:

- nominations are sought from existing trustees of suitable and potentially interested persons in the community;
- nominations are collated along with the skills/experience base of each nominee and are reviewed by the board against skill gaps of the current trustees;
- a short list is prepared and an information pack about TANZ is sent to these nominees;
- these nominees are invited to attend a board meeting to deliver a short verbal presentation of their suitability and desire to become a trustee and to ask any questions regarding TANZ (this presentation may be in person or via a medium such as Skype)
- the trustees in turn have a short period in which to question each nominee should they wish to do so
- a short-listed nominee may be asked to provide referees who may be contacted for validation;
- the board considers the merits of each nomination and makes its decision 'in committee';
- any nominee who is then invited to become a trustee receives a copy of the Trust Deed and is allowed a maximum of 30 days to accept or decline the invitation.

CHAIRPERSON

The principal role of the Chair is to ensure the effective management of TANZ's governance process. The chair presides over meetings of the TANZ but does not have a casting vote in the instances of equality of a vote. The Chairperson needs to facilitate effective meeting outcomes, be aware of developmental issues facing the Board, lead and create a safe environment in which members make an optimal contribution and keep the Board focussed on its task.

Specific responsibilities:

- Building an effective team
- Be the key link person between Board and staff
- Serve as ex-officio members of all committees
- Work in partnership with key staff to make sure Board resolutions are carried out.
- Call special meetings if necessary
- Assist key staff in conduction new Board member orientation
- Oversee searches for key staff
- Coordinate key staff annual performance evaluation
- Work with other Board/staff to recruit new Board members
- The chair may be asked to represent TANZ at public meetings in the absence of the Executive Director and issue public statements at the request of the Executive Director when necessary

SECRETARY

The Secretary is the chief administrative officer of the organisation and should be capable of working closely and amicably with the Chairperson. He/she should also have a good eye for detail, be a good organiser and meticulous in keeping records.

Specific responsibilities:

- Attend all Board meetings
- Serve on the Executive Committee
- Maintain all Board records and ensure their accuracy and safety
- Review Board minutes
- Assume responsibilities of the Chairperson in the absence
- Provide notice of meetings of the Board and/or of a committee when such notice is required.

TREASURER

The Treasurer is responsible for the handling of monies - including the payment of tax returns, issuing of receipts and planning budgets. Where tasks are delegated to paid staff, extra care should be taken in certifying the records.

Specific duties:

- Preparation of a budget with Executive Director
- The budget is presented to the first general committee meeting for adoption
- Ensure all activities are in accordance with the financial policy
- If the Treasurer is given authority to pay accounts without committee approval, a list of payments is reported to the next meeting and endorsed.
- At regular Board meetings, the treasurer reports financial results with a brief comparison of how the situation compares with the budget.
- The Treasurer checks monthly bank statements and checks against records

BOARD MEMBER

The Board is the governing body for the Tourette's Association of New Zealand (TANZ). Board Members act in a position of trust for the community and are responsible for the effective governance of the Organisation. Board Members are accountable to members of TANZ, funders, and their legal responsibilities.

Responsibilities:

- In collaboration with other Board Members:
- Sets the vision, mission and values of the Organisation and makes them clear to all members and employee(s) of the Organisation.
- Regularly reviews the values of the Organisation to ensure that what it is attempting to achieve remains both relevant and aligns with the values.
- Communicates with members and stakeholders to ensure that they have input into the determination of direction and goals and to keep them informed about the organisation's performance.
- Ensure the good standing of the organisation within the community.
- Develops policies and structures which ensure that the functions of the Organisation are fulfilled and the service provided is efficient and effective.
- Develops and expand services on the basis of clearly identified needs.
- Assists in developing and maintaining positive relations among the Board, committees, staff members and the community to enhance the organisation's mission.
- Attends and participates in all Board and committee meetings and functions.
- Reviews agendas and supporting materials prior to Board and Committee meetings.
- Stays informed about sub-committee matters, prepares themselves well for meetings and reviews and comments on minutes and reports.
- Ensures the accuracy of monthly meeting contents.
- Sits on at least one sub-committee and participates actively in committee work.
- Volunteers for and willingly accepts and completes assignments on time.
- Is an active participant in the Board's annual evaluation and planning efforts.
- Votes on, where appropriate, policy and other recommendations received from the Board, its standing committees and employees.
- Monitors and develops all Board policies and sets strategic direction for the organisation.
- Ensure adequate resources and their effective management including money, people, facilities and equipment.
- Acts as a good employer of paid and unpaid staff.
- Deals with any complaints laid against the Organisation of staff.
- Defines the Organisation's legal and constitutional framework and its purpose, direction and priorities. Complies with all legal and contractual requirements placed on the Board and seeks legal advice to stay up to date with what these are.
- Assists the Boards in carrying out its fiduciary responsibilities such as reviewing the Organisation's annual financial statements and approving the annual budget.
- Suggests possible nominees to the Board who can make significant contributions to the work of the Board and the Organisation.
- Nominates and elects Board members to officer positions annually or at the resignation of the position holder.
- Continually evaluates own performance as well as the performance of the Board.
- Follows conflict of interest and confidentiality policies.
- Refrains from making special request of the staff or volunteers.
- Adheres to Code of Conduct and organisational policies.

ROLE AND TERMS OF REFERENCE FOR BOARD SUBCOMMITTEES

The Board are responsible for the Association's overall performance in accordance with the relevant sections of its Trust Deed (Appendix 1) and in accordance with the Charitable Trust's Act 1957 and the Trustee Act 1957.

As such it has the following responsibilities:

- setting strategic direction and policy;
- ensuring compliance to the Charitable Trusts Act 1957, the Trustee Act 1957, the Law and any accountability documents that may exist;
- maintaining proper relationships with the Ministry of Education, Ministry of Health, sponsors and the general public;
- recruiting and monitoring an Executive Director;
- monitoring performance of trustees and asset management.

The board has wide ranging powers and these are contained within Clause 6 of the Trust Deed.

Current board members – see Appendix 3

There may be two standing committees – finance and marketing. The role of each committee would be to advise the board on any issue covered by its term of reference and to investigate any matters referred to it by the board.

Please refer to Appendix 4 and 5 for subcommittee Terms of Reference

Meeting Cycle

Normal meetings of the Board follow a quarterly pattern with the timing of the AGM determined by the timing of the Annual Financial Report which will usually be available within six months from the end of the TANZ's financial year (March 31st).

A marketing committee meeting would normally precede a finance committee by one week and the board meeting would follow the finance committee meeting by one week. The AGM is normally held in September, back-to-back with the September board meeting. Special board meetings may be convened at any stage as long as trustees are given 10 calendar days' notice of such a meeting.

Legislative Requirements

The TANZ applies integrity and diligence in conforming with those Acts of Parliament in the Legislation Requirements Policy that have been identified as pertaining to its operation.

Furthermore, TANZ has two specific policies that demonstrate best practice of governance that it reviews on an annual basis. These policies are:

Sensitive Expenditure Policy;

Fraud Policy

Please refer to TANZ Policy Manual

Staff Information

EXECUTIVE DIRECTOR

The Executive Director is responsible for the successful leadership and management of the organization according to the strategic direction set by the Board of Directors.

Statements of Intent

- To reach out to those living with Tourette's, either as a child, adult or parent/caregiver/ supporter of someone with Tourette's to let them know they are not alone.
- To establish a library of relevant reading materials and other forms of information for parents to better understand Tourette's Syndrome.
- To provide information and guidelines to educators and health care service providers so that the best care and support is available for our children.
- To encourage evidence based best practice in assisting children during formative and tertiary education.
- To increase public awareness and understanding of the nature and cause of Tourette's.
- To ensure that New Zealanders will have a greater acceptance of those with Tourette Syndrome.

TANZ carries out the business of a community organisation in Christchurch and the TANZ Executive Director is employed as an employee of the business. Due to the nature of the organisation all employees are employed on contracts which are subject to funding availability.

Further information on the person specifications of the TANZ Executive Director can be found in the Executive Director Job Description.

Tourette's Association New Zealand Policies

Policy 1: Legislative Compliance Policy

The Trustees of TANZ are obligated to keep aware of changes in legislation that may/will always have an impact upon any aspect of the functions/governance/management of the TANZ's affairs and act accordingly to ensure compliance .

The known Acts of Parliament that impact upon the Association are as follows:

The Trustees Act 1957

Charities Act 1957

Health and Safety in Employment Act 1992

The Human Rights Act 1993

The Privacy Act 1993

Holidays Act 2003

The Employment Relations Act 2000

New Zealand Income Act 2007

The Vulnerable Children's Act 2014

In order to remain abreast of actual changes to any of these pieces of legislation the Trustees may arrange to receive regular briefings from a NZ Law Society approved organisation/individual that currently holds a certificate as 'Barristers and Solicitors'.

Policy to be reviewed every three years

Date last reviewed: June 2019

Next review: June 2022

Policy 2: Conflict of Interest Policy

1. Purpose

It is important for the Tourette's Association New Zealand Trustee's and staff to be aware that both real and apparent conflicts of interest or dualities of interest sometimes occur in the course of conducting the affairs of the Association and that the appearance of conflict can be troublesome even if there is in fact no conflict whatsoever.

Conflicts often occur because the persons associated with the Association could be expected to have, and do in fact generally have, multiple interests and affiliations, and various positions of responsibility within the community.

In these situations, a person will sometimes owe identical duties of loyalty to two or more organisations.

The purpose of the Conflict of Interest policy is to protect TANZ's tax-exempt interest when it is contemplating entering into a transaction or arrangement that might benefit the private interest of an office or board member of the Association or might result in a possible excess benefit transaction.

Each member of the board of directors and staff of the Association have a duty of loyalty to the Association. The duty of loyalty generally requires a board member or staff member to prefer the interests of the Association over the trustee's/staff's interest or the interests of others.

In addition, board members and staff of the Association shall avoid acts of self-dealing which may adversely affect the tax-exempt status of the Association or cause there to arise any sanction or penalty by a government authority.

However, the long-range best interests of the Association do not require termination of all association with persons who may have real or apparent conflicts that are harmless to all individuals or entities involved.

In connection with any actual or possible conflict of interest, an interested person must disclose the existence of the interest and be given the opportunity to disclose all material facts to the Trustees and members of the committees with governing board delegated powers considering the proposed transaction or arrangement.

2. Definitions

2.1 Interested person

Any board member, principal officer, or member of a committee with governing board delegated powers who has a direct or indirect financial interest, as defined below, is an interested person.

2.2 Financial interest

A person has a financial interest if the person has, directly or indirectly, through business, investment or family:

- (a) ownership or investment interest in any entity with which the TANZ has a transaction or arrangement;
- (b) a compensation arrangement with the organisation or with any entity or individual with which the TANZ has a transaction or arrangement;
- (c) a potential ownership or investment interest in, or compensation arrangement with, any entity or individual with which the TANZ is negotiating a transaction or arrangement.

Compensation includes direct and indirect remuneration as well as gifts or favours that are not insubstantial. A financial interest is not necessarily a conflict of interest. Under Part 3 (Procedures) section 2, a person who has a financial interest may have a conflict of interest only if the appropriate governing board or committee decides that a conflict of interest exists.

3. Procedures

3.1 Duty to disclose

In connection with any actual or possible conflict of interest, an interested person must disclose the existence of the financial interest and be given the opportunity to disclose all material facts to the Trustees and members of committees with governing board delegated powers considering the proposed transaction or arrangement.

3.2 Determining whether a conflict of interest exists

After disclosure of the financial interest and all material facts, and after any discussion with the interested person, he/she shall leave the governing board or committee meeting while the determination of a conflict of interest is discussed and voted upon. The remaining board or committee members shall decide if a conflict of interest exists.

3.3 Procedures for addressing the conflict of interest

(a) an interested person may make a presentation at the governing board or committee meeting but after the presentation he/she shall leave the meeting during the discussion of, and the vote on, the transaction or arrangement involving the possible conflict of interest.

(b) the chairperson of the governing board or committee shall, if appropriate, appoint a disinterested person or committee to investigate alternatives to the proposed transaction or arrangement.

(c) after exercising due diligence, the governing board or committee shall determine whether the Association can obtain with reasonable efforts a more advantageous transaction or arrangement from a person or entity that would not give rise to a conflict of interest.

(d) if a more advantageous transaction or arrangement is not reasonably possible under circumstances not producing a conflict of interest, the governing board or committee shall determine by a majority vote of the disinterested Trustees whether the transaction or arrangement is in the Association's best interest, for its own benefit, and whether it is fair and reasonable. In conformity with the above determination it shall make its decision as to whether to enter into the transaction or arrangement.

3.4 Violations of the conflict of interest policy

(a) if the governing board or committee has reasonable cause to believe a member has failed to disclose actual or possible conflicts of interest, it shall inform the member of the basis for such belief and afford the member an opportunity to explain the alleged failure to disclose;

(b) if, after hearing the member's response and after making further investigation as warranted by the circumstances, the governing board or committee determines the member has failed to disclose an actual or possible conflict of interest, it shall take appropriate disciplinary and corrective action.

4. Records of Procedures

4.1 Minutes

The minutes of the governing board and all committees with board delegated powers shall contain:

(a) the names of the persons who disclosed or otherwise were found to have a financial interest in connection with an actual or possible conflict of interest, the nature of the financial interest, any action taken to determine whether a conflict of interest was present, and the governing boards or committee's decision as to whether a conflict of interest in fact existed.

(b) the names of the persons who were present for discussions and votes relating to the transaction or arrangement, the content of the discussion, including any alternatives to the proposed transaction or arrangement, and a record of any votes taken in connection with the proceedings.

5. Compensation

5.1 Board members

A voting member of the governing board who receives compensation, directly or indirectly, from the Association for services is precluded from voting on matters pertaining to that member's compensation

6. Annual Statements

Each board member, principal officer and member of a committee with governing board delegated powers shall annually sign a statement which affirms such person: **needs to be done**

- (a) has received a copy of the conflicts of interest policy;
- (b) has read and understands the policy;
- (c) has agreed to comply with the policy; and
- (d) understands that the Association is charitable and in order to maintain its tax-exemption it must engage primarily in activities that accomplish one or more of its tax-exempt purposes
- (e) each board member shall list their main employment, any other directorships or board positions they may hold and any trading entities in which the trustee may have a share-holding or any other form of financial benefit interest. This list will be kept confidential to TANZ and will be held by the branch secretary to which the board member belongs.

7. Periodic reviews

To ensure that TANZ operates in a manner consistent with charitable purposes and does not engage in activities that could jeopardise its tax-exempt status, periodic reviews shall be conducted. The periodic reviews shall, at a minimum, include the following subjects:

- (a) whether compensation arrangements and benefits are reasonable, based on competent survey information and the result of arm's length bargaining; and
- (b) whether partnerships, joint ventures and arrangements with management, public relation companies or the like, conform to the Association's written policies, are properly recorded, reflect reasonable investment or payments for goods and services, further charitable purposes and do not result in inurement, impermissible private benefit or in an excess benefit transaction.

Policy to be reviewed every three years

Date last reviewed: 2014

Next review: August 2019

Policy 3: Sensitive Expenditure Policy

1. Definition

TANZ understands “sensitive expenditure” to be any expenditure that confers some private benefit to the individual trustee or staff member that is additional to the business benefit of the expenditure.

2. Basis of policy

2.1 This policy is based on the **principles approach** and recognises the board members’ decision to allow the Executive Director and Treasurer to use the TANZ office, phone and computer for personal and business reasons subject to a zero-marginal regime i.e. all such usage should not incur additional cost for the TANZ over that incurred in the normal operation of the TANZ.

2.2 It also recognises that many common areas of sensitive expenditure e.g. travel, accommodation and hospitality do not occur in the **daily** operation of TANZ.

3. Principles-based approach

The Executive Director has authority to spend up to \$1000 on any capital purchase and no limit for payments to supplier and for professional services providing these are within the budget.

We expect that any spending decision to be made is subject to the following principles:

- has a justifiable TANZ business purpose;
- preserves impartiality;
- is made with integrity;
- is moderate and conservative, having regard to the circumstances;
- is made transparently; and
- is appropriate in all respects.

Subject to the authority levels specified above, it is expected that the Executive Director will observe these principles in all areas of sensitive expenditure.

4. Policy

The following table sets out the policy for each category of sensitive expenditure.

Area of expenditure	Relevance	Policy
TRAVEL & ACCOMMODATION		
Air travel (NZ)	R	Approval over \$500 needed
Meals & accommodation	R	Approval over \$500 needed
Motor Vehicles	R	Approval over \$500 needed
Tipping	NR	Requires prior board approval
Other travel	NR	Requires prior board approval
ENTERTAINMENT & HOSPITALITY		
Hospitality (suppliers/sponsors etc)	R	Actual & real costs reimbursed
GOODS & SERVICES		
Sale of surplus assets	NR	Requires prior board approval
Loyalty reward scheme benefits	NR	Requires prior board approval
Private use of entity assets	R	Approved as per 5.2.1
Entity use of private assets	NR	Requires prior board approval

Private use of entity's suppliers	R	Approved as per 5.2.1
STAFF SUPPORT & WELFARE		
Clothes & grooming	NR	Requires prior board approval
Care of dependants	NR	Requires prior board approval
Farewells & retirements	R	Requires prior chair approval
OTHER TYPES OF EXPENDITURE		
Donations/grants	NR	Requires prior board approval
Communications technology	R	Approved as per 5.2.1

Policy to be reviewed every three years
Date last reviewed: 2014
Next review: October 2019

Policy 4: Fraud Policy

The current operating environment of the TANZ with one and half full-time employees, reporting directly to the Board of Trustees, is a low-risk one with respect to fraud.

The current controls in place to mitigate the risk of fraud are:

- assigned authority of two trustees to authorise internet banking payments with a maximum daily limit of \$30k (two trustees plus Treasurer to have signatory rights); (\$30k because Camp Twitch invoice is generally around \$25K)
- requirement for counter-signatory or authoriser to sight relevant statements or tax invoices prior to approval;
- regular reporting to the Executive Director and/or Finance Committee of income and expenditure reconciled against the bank statements;
- annual financial statements audited by an accredited accountant each year.

In the event that the Finance Committee detects or suspects that fraudulent activity may have or be taking place it will report directly to the Chair of the Board of Directors setting out the evidence and this will be discussed at a Special Meeting of Trustees called by the Chair within 14 days of receiving the report.

In assessing the evidence provided by the Finance Committee, the Board of Directors will observe the following principles:

- every individual suspected of committing fraud will be treated in the same manner and if this includes one or more trustees they will be excluded from the Special meeting;
- every effort will be made to gather sufficient and reliable evidence to support a prosecution and every case of suspected fraud, supported by evidence, will be referred to the appropriate law enforcement agency with a view to prosecution;
- recovery of lost money or other property will be pursued wherever possible and practical;
- all employees and trustees will be made aware of their responsibilities under this policy.

Policy to be reviewed every three years

Date last reviewed: 2014

Next review: December 2019

Policy 5: Child Protection Policy

1. Safety Checking Children's Workers

The health and safety of young people with Tourette Syndrome is the core value of the Tourette's Association New Zealand.

Occasionally full-time and voluntary workers may be required to work directly with children. While in most instances a parent or caregiver is generally present, the following policy shall be upheld to ensure that all interaction with children is conducted in a safe and best practice manner.

The Vulnerable Children Act 2014 requires safety checking of people employed or engaged in work that involves working with vulnerable children as part of a specified organization providing regulated services in order to reduce the risk of harm to children in support of the Government priorities for improving the wellbeing of vulnerable children.

A children's worker is one providing a regulated service in a specified organization, as defined under the Vulnerable Children's Act 2014, and must undergo specific safety checks prior to employment

Positions that have been identified as requiring the safety check in accordance with the Act, including that of management, will have this requirement included in the job description and recruitment process and complete a full safety check.

The requirements of the safety check include:

- Identity verification;
- New Zealand Police Vetting
- The Criminal Records (Clean Slate) Act 2004
- Reference Check
- Interview
- Work history
- A risk assessment

All children's workers must undergo a safety check prior to being employed and a children's worker position should not in any circumstances be offered to an applicant until all the requirements of the safety check have been met.

Once appointed, the safety check will need to be repeated ever three years. This periodic check must require the person to confirm whether, since the last safety check, their name has changed or is different from any original documentation supplied; requires a renewed police vetting process and any information that may be relevant to an assessment of the person, including a risk assessment of the person.

Managers undertaking safety checks of children's workers must retain the information pertaining to the employee. The Secretary of the Board will retain information pertaining to management staff.

Policy to be reviewed every three years
Date last reviewed: 2014
Next review: February 2020

Policy 6: Code of Ethics Policy

The Code of Ethics serves to:

- indicate what is expected by clients of the Tourette's Association New Zealand and the TANZ's paid and unpaid workers, as well as members of the Board of Directors;
- show agreed standards of responsible practice on which the TANZ's services are based;
- establish a basis for making complaints and the consideration of these;
- give protection to the rights and interests of paid and unpaid workers.

1. TANZ workers will respect the client's right to privacy and preserve the confidentiality of information obtained during the course of their work. The keeping of confidences is a primary obligation. Non-identifying information should be used in presenting statistics for reports to the Board, government organisations and funders. TANZ workers will inform clients of the limits of confidentiality.

2. No TANZ worker or Board member shall enter into a relationship with a member of the Association – needs to be broadened

Policy to be reviewed every three years

Date last reviewed: 2014

Next review: April 2020

Policy 7: Complaints Policy

Complaints/privacy/confidentiality

Complaints that come through could contain sensitive information and be very personal – board members that are involved with handling the complaint need to adhere to strict privacy and confidentiality – the complaints and contents will not be shared between members of the association or any other people associated with TANZ i.e. film crews, sponsors etc.

Complaints procedures

The aim of this procedure is to:

- investigate complaints thoroughly and in accord with the principles of natural justice. Where a complaint is well-founded, take appropriate steps to address the concerns raised, and where relevant, prevent a recurrence whilst maintaining a high standard of professionalism;
- in applying this procedure, the principles of fairness, common sense and courtesy to both the worker and the complainant will be observed at all times;
- this procedure will be invoked following a formal complaint against a TANZ worker, whether paid or volunteer. Such complaints may come from clients or others from inside or outside of the organisation;
- this procedure aims to initiate, where appropriate a positive environment within the TANZ and to ensure standards and work performance are met. Respect and confidentiality for the process, the complainant and the worker need to be maintained.

1. Making a complaint

Complaints must be in writing addressed to the chair of the Board of Trustees and must be signed. The first step for the person making the complaint is to raise or discuss the matter with the person they wish to complain about (where this is possible).

For complaints by a TANZ worker about another TANZ worker, counter complaints will not be considered until the completion of the investigation of the initial complaint.

Resignation of the TANZ worker will not prevent the complaint being investigated.

When a TANZ worker receives a formal complaint about a breach of the Code of Ethics by her/himself or another worker, from anyone, they will immediately refer the complaint to the Board.

2. Receipt of the complaint

The Board will ensure that the worker is informed at the first available opportunity of the complaint against them. Within seven days of receiving the complaint the Board will appoint an appropriate person to investigate. This person may be a committee member and/or from the community. They will be called the investigator.

3. The complaint process

3.1. The Board will appoint a contact person, also within seven days of receiving the complaint, satisfactory to the complainant who will:

- i. ensure that the complainant understands the Code of Ethics and Complaints procedure;
- ii. offer to act as the complainant's support person if so desired;
- iii. act as the ongoing contact person between the complainant and the process.

3.2. The investigator will write a letter to the complainant to:

- i. acknowledge receipt of the complaint;
- ii. ask what steps have already been taken;
- iii. include a copy of the Code of Ethics and Complaints Procedure;
- iv. inform them of their rights to have a support person of their own choice and any time in dealing with the Complaints Procedure.

3.3. The investigator will meet with the complainant to ensure that the complainant is fully aware of all the matters and processes involved with the TANZ complaint procedure. This meeting is fully documented and signed by the complainant before the investigator can take further action.

3.4. The investigator will keep an accurate written record of all stages of the complaints procedure. The investigator will report to the Board on their findings and recommend an appropriate course of action.

3.5. The Board, in consultation with the Investigator, may require that the worker discontinue working within the area(s) of concern during the consideration of the complaint.

3.6. On completion of each stage of the procedure the investigator will write a letter to the complainant and the Committee informing them of the progress to date.

3.7. If the complaint is about issues that can be suitably addressed in supervision, the investigator may request the worker to take the issues to an approved external supervisor. In such circumstances written assurance will be sought from both the worker and the supervisor that the issues are being satisfactorily addressed.

3.8. If the complaint cannot be addressed, or cannot be resolved to the complainant's satisfaction in supervision, the investigator will take all possible steps to find a satisfactory solution by consulting with the complainant and their support person, the worker and their support person, the worker's supervisor, and any other people appropriate to the situation. They can mediate or call on an outside mediator if this is appropriate. They can recommend resolutions to the Board such as:

- i. that they believe the complaint to be unfounded and that no further action is required;
- ii. a change in policy or procedure;
- iii. ongoing training or a different kind of supervision for the worker, or for all TANZ staff;
- iv. a change in the kind of work that the worker undertakes within the organisation; and/or
- v. the termination of the worker's employment.

4. Complaints subcommittee

4.1. If the complaint cannot be satisfactorily resolved at this level within two months, the Board will refer to the Complaints Subcommittee should there be one. This committee must consist of a lawyer, a mediator and two other specialist persons as may be appropriate to the nature of the case, from outside its own membership.

4.2. The complaints subcommittee will review the steps taken so far and engage in whatever consultation is necessary to resolve the issue. The process is not an adversarial one but one in which the best outcome for all concerned is being sought.

4.3. If the complaints subcommittee is unable to resolve the issue to the complainant's satisfaction, the matter will be referred back to the Board.

4.4. A worker concerned has a right of review of any decision made by the investigator and/or the complaints subcommittee. The decision of the board shall be final.

Policy to be reviewed every three years

Date last reviewed: 2014

Next review: June 2020

Policy 8: Privacy Policy

Unless a board member is a parent of a child with Tourette Syndrome, or an individual living with Tourette Syndrome, there is no need for Board Members to be given access to the closed private Facebook groups of parents and adults members of the Association. Information shared in this group is very personal and highly sensitive.

The trustees who are all parents of young people with Tourette Syndrome monitor this group and share a duty of care to report any concerning comments or behaviour.

The privacy of employees and members is of high importance to the TANZ. TANZ will at all times comply with the Privacy Act 1993.

Procedures

- Personal information collected by TANZ must be for a necessary and lawful purpose connected with TANZ activities. We gather personal information from multiple sources including membership details, complaints files, camp registration and any written communication to TANZ (including electronic and paper).
- Personal information must be collected directly from the individual concerned unless there are reasonable grounds for collecting that information from another source. Reasonable grounds are as specified in the Privacy Act.
- Personal information is to be collected only with the knowledge and written informed consent of the individual concerned, unless there are reasonable grounds for not doing so. This means all processes that involve collection of information (for example surveys etc.) will contain a privacy summary for participants.
- Personal information shall not be collected by TANZ by means which are unlawful, unfair, or an unreasonable intrusion upon that individual's personal affairs.
- TANZ is committed to ensuring your information is secure. In order to prevent unauthorised access or disclosure we will use suitable physical, electronic and managerial procedures to safeguard and secure any information collected including locked filing cabinets and password protection.
- The individual is entitled to seek access to the personal information held by TANZ and advise of any potential inaccuracy. There are some exceptions to this right set out in the Privacy Act. If an access/correction request is received TANZ will ask the individual to verify their identity and specify what information they require.
- TANZ will take reasonable steps to ensure information is accurate, up to date, complete, and not misleading.
- Personal information will not be kept for longer than necessary. Membership details will be deleted on termination of membership. Complaints details will be held indefinitely.

- Personal information gained will not be used for any purpose other than that for which it is obtained. We generally use information collected to help us manage or enhance our support and communication to members.
- TANZ will not disclose personal information to anyone other than the individual concerned unless:
 - Disclosure is for a purpose for which the information is obtained
 - Source of information is publicly available
 - Disclosure is authorised by the individual concerned
 - Disclosure is necessary to prevent or lessen a serious and imminent threat to public health and safety, or the individual's life and health
 - Disclosure will not identify the individual
- It is our policy to send emails (including newsletters, job advertisements and other sector related notices) to all those on our database that you have elected to receive. We will remove any person from any mailing list upon the person's request.
- Our website will comply with the provisions of the Privacy Act. It may contain links to other websites.
- Where there a Privacy Breach received by TANZ there are four key steps to be followed when responding to a breach or suspected breach:
 - Breach containment and preliminary assessment;
 - Evaluation of the risks associated with the breach;
 - Notification to those affected by the breach; and
 - Prevention of future breaches.

*Policy to be reviewed every three years
Date last reviewed: June 2019
Next review: June 2022*

Policy 9: Media Policy

Board members should not engage with children under the age of 18 years old on social media nor email etc etc

Somehow word it so that future Exec Directors also have to comply with the above as well as friendships with parents and children however at this stage my involvement as founder and the “parent” figure of the Association deems to necessary for me to interact with all ages of the Association but need to future proof this.

Policy to be reviewed every three years

Date last reviewed: Non-existent

Next review: August 2019

Policy 10: Health and Safety Policy

*Policy to be reviewed every three years
Date last reviewed: Non-existent
Next review: October 2019*

Policy 11: Membership Policy

Honorary membership and lifetime membership to recognise services of founding members and trustees and their children e.g. Amber Murdoch, Rhys and Gwynne Murdoch (with TS) and Connor Murdoch; Robyn Martinovich and her daughter Taylor Martinovich; Robyn Twemlow and Analise Twemlow.

Responding to and managing situations that involve escalated behaviour of TANZ members at TANZ events such as camp – possibly not the place to have this?

- Step by step response management
 - Response hierarchy – who is in charge, who delegates next steps etc to avoid confusion, incorrect handling of possibly sensitive and potentially unsafe information/behaviour.
 - Strict confidentiality around who is involved and who is told about the event
 - Possible statement prepared for any parents etc that may ask what happened and how it was handled – one factual statement that is used by everyone involved to anyone that needs further information – may be important in some instances for parents to know that everyone is safe and that the situation has been handled etc.
-

Policy to be reviewed every three years

Date last reviewed: Non-existent

Next review: December 2019

Policy 12: Events Policy

*Policy to be reviewed every three years
Date last reviewed: Non-existent
Next review: February 2020*

Policy 13: Board Election Policy

*Policy to be reviewed every three years
Date last reviewed: Non-existent
Next review: April 2020*

Policy 14: Personnel Policy

*Policy to be reviewed every three years
Date last reviewed: Non-existent
Next review: June 2020*

Policy 14: Disputes and Personal Grievance Policy

*Policy to be reviewed every three years
Date last reviewed: Non-existent
Next review: August 2020*

Appendix 1: Trust Deed

Appendix 2: Strategy

Tourette's Association of New Zealand Draft Strategy

VISION

To support and empower people with Tourette's to feel accepted within the wider community.

VALUES

Inclusiveness

We respect all people, value diversity and are committed to equality.

Participation

We recognise the contribution of volunteers and our members.

Voice

We value the voice of our members with Tourette's.

Community

Working with community to reduce the stigma of people living with Tourette's.

Fun

Providing families and young people with enjoyable experiences.

Integrity

TANZ is a credible national voice with transparent practices.

OBJECTIVES

To host a number of gatherings and events for people and families living with Tourette's

To be the number one resource on all things Tourette's

To reduce the stigma people with Tourette's face in the community

Youth Development

To have Tourette's recognised as a disability in New Zealand

To establish a facility in Canterbury for individuals and families with Tourette's

TANZ is a sustainable organisation

Appendix 3: Current Board Members

Current Board members as of Sept 2018

MEMBER	DATE APPOINTED	TERM ENDS
Tayla Reid – chair	Sept 2018	Sept 2020
Di Harwood – deputy chair	Sept 2018	Sept 2020
Rinea Robson – secretary	Sept 2018	Sept 2020
Lauren Smith (re-elected)	Sept 2018	Sept 2020
Chad Blair	Sept 2018	Sept 2020
Andrew Norton	Sept 2018	Sept 2020

Board members can be re-elected for two more terms of two-years but then must retire unless unable to be replaced. Retirement of trustees may be staggered to maintain continuity of knowledge and systems.

Current position holders

Executive Director	Robyn Twemlow
Chairperson	Tayla Reece
Deputy Chairperson	Di Harwood
Secretary	Rinea Robson
Treasurer	Rinea Robson

Appendix 4: Finance Subcommittee

Terms of Reference

The Finance Committee could be a standing committee of the Association with delegated responsibilities and authorities as set out below.

Purpose

The purpose of the Finance Committee is to monitor the finance and investments of the Association and to make recommendations to the Trustees.

Responsibilities

The Finance Committee is responsible for monitoring the financial and investment welfare of the Association.

Specific responsibilities include:

- monitor financial operations and results;
- oversee the preparation and accuracy of annual budget;
- ensure timely, accurate and useful financial information is presented to the trustees;
- receive annual accounts and make recommendations to the board members regarding their content and presentation;
- receive reports from any appointed investment manager and monitor performance of any investment portfolio;
- recommend budgets, financial and investment decisions to the trustees for approval or other required action;
- develop and recommend to the board members appropriate policies to guide the financial and investment affairs of the Association;
- arrange for and maintain **adequate insurance cover** for the Association. **Don't have this?**

Membership

The Finance Committee shall comprise not less than three trustees appointed by the board.

The chair of the Finance Committee shall be elected by the members of the Finance Committee.

The board's chairperson is an ex officio member of the finance committee.

The Executive Director will attend Finance Committee meetings.

Meetings

The Finance Committee shall meet at least four times each year.

A quorum shall be two members of the committee.

Reasonable notice of meetings and business to be conducted shall be given to all trustees.

Any trustee is entitled to attend meetings of the Finance Committee.

The committee may invite such persons as it considers necessary to provide appropriate information and advice.

Any member of the Finance Committee or the Executive Director may request a special meeting having given 10-days notice.

Minutes of all meetings shall be kept and shall be circulated to all Trustees.

Reporting

Agendas and minutes of all TANZ committee meetings shall be circulated to all board members and shall be retained by the Association. Minutes will be included in the next set of Board papers for noting. After each meeting the Committee chair shall report any of the committee's recommendations to the Board.

Authority

The Finance Committee has no delegated authority.

Approval of the Board must be obtained before committing to any expenditure.

The Board may delegate to the Finance Committee such matters as it sees fit.

Recommendations of the Finance Committee must take into account the impact on all other aspects of the TANZ's activities.

Appendix 4: Marketing Subcommittee

Terms of Reference

The Marketing Committee could be a standing committee of the Association with delegated responsibilities and authorities as set out below.

Objectives

The objectives of the Marketing Committee are to assist and advise the Executive Director to promote and market TANZ and its activities to stakeholders and potential funders and partners; and to assist the Executive Director to develop annual marketing and fundraising plans as appropriate and to monitor progress against targets on behalf of, and reporting to, the **board of directors**.

Membership

The Marketing Committee shall comprise not less than **two board members appointed** by the board. The Executive Director will attend the Marketing Committee meetings. The board's chair may attend ex officio. – **again we don't have this committee at present**

Meetings

A quorum shall be two members of the committee.

The committee may have in attendance such other persons including external advisors as it considers necessary to provide appropriate information and advice.

All board members shall be entitled to attend Committee meetings after giving prior notice to the committee chair.

Reasonable notice of meetings and business to be conducted shall be given to the members of the committee and other members of the board.

The committee shall hold at least three meetings each year.

Any member of the Committee or the Executive Director may request a special meeting having given 10-days notice.

Minutes of all meetings shall be kept and shall be kept by TANZ secretary.

Reporting

Agendas and minutes of all committee meetings shall be circulated to all **board members** and shall be retained by the Association. Minutes will be included in the next set of Board papers for noting. After each meeting the Committee chair shall report any of the committee's recommendations to the Board.

Authority

The Committee must seek approval of the Board before committing to any expenditure or engaging the service or advice of any external advisors.

The Board may delegate to the Committee such matters as it sees fit.