



Rules of Tuberous Sclerosis Complex New Zealand

1.0 The Society

- 1.1 The name will be Tuberous Sclerosis Complex New Zealand (TSCNZ)
- 1.2 The Society was formally established on 3rd April 2014

2.0 Registered Office

- 2.1 Tuberous Sclerosis Complex New Zealand, 11 Riverlea Drive, Katikati 3129

3.0 Purpose of the Society

- 3.1 The purposes of the society is to:
 - (a) Provide a community and network for those people and families who are, or have been affected by Tuberous Sclerosis Complex.
 - (b) Communicate medical and scientific information about Tuberous Sclerosis Complex to the public.
 - (c) Advance and promote medical knowledge, understanding and education on Tuberous Sclerosis Complex.
 - (d) Help ensure best practice management and care for TSC affected people in New Zealand.
 - (e) To initiate, facilitate, co-ordinate and encourage scientific research activity in Tuberous Sclerosis Complex.
 - (f) Be established, respected and maintained with charitable purpose in all aspects of business operation.

MANAGEMENT OF THE SOCIETY

4.0 Managing Committee

- 4.1 The Society shall have a Management Committee comprising of the following elected/appointed persons:
 - (a) The President

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- (b) The Secretary
- (c) The Treasurer
- (d) Membership Officer
- (e) Such Management Committee members so decided by the Society

5.0 Appointment of Management Committee members

5.1 At an Annual General Committee, the members may decide by majority vote:

- (a) How large the Management Committee will be. There will be a minimum of 3 people.
- (b) Who will hold the positions of President, Secretary and Treasurer, and the members of the Management Committee.
- (c) Whether a person may hold more than one elected position
- (d) The "Term" of each officer will be one year. Office holders may be re-elected.

6.0 Cessation of Management Committee membership

6.1 Persons cease to be Management Committee members when:

- (a) They resign by written notice to the Secretary
- (b) They are removed by majority vote at a General / Special General meeting of the Society or,
- (c) Their 'Appointed Term' expires.

7.0 Nomination of Management Committee members

7.1 Nominations for Management Committee members shall be made in writing prior to the Annual General Meeting.

7.2 All retiring Management Committee members shall be eligible for re-election

7.3 Should vacancies occur between Annual General Meetings then the Management Committee may appoint a member to fill that vacancy until the next Annual General Meeting.

8.0 Role of Management Committee

8.1 The role of the Management Committee is to:

- (a) Administer, manage and control the Society
- (b) Advance the purposes of the Society and the use of financial resource to achieve these purposes.
- (c) Manage the Society's financial affairs in a 'Not for Profit' manner and present a financial statement to the Annual General Meeting
- (d) Set accounting policies in line with accepted accounting procedures.

- (e) Ensure the Society's rules are followed at all times and determine how complaints are to be dealt with within the Society.
 - (f) Set times, frequencies and agendas for all meetings
 - (g) Set membership fees for all persons within the Society including levies and / or subscriptions
 - (h) Develop policies of the Society.
- 8.2 All decisions of the Management Committee shall be by majority vote. In the event of a tied vote, the President shall have the casting vote.
- 8.3 Decisions of the Management Committee shall bind the Society, unless the Management Committee's power is limited by these rules, or by a vote at a General Meeting of the Society.

9.0 Roles of Management Committee members

9.1 All Management Committee members are expected to:

- (a) Participate in Management Committee meetings
- (b) Maintain knowledge of the society and personal commitment to its goals and objectives.

9.2 The President is responsible for:

- (a) Ensuring that the Rules of the Society are followed;
- (b) Convening meetings and ensuring that a quorum is present;
- (c) Chairing the meetings, deciding who may speak, and when;
- (d) Overseeing the operation of the Society
- (e) Providing a report on the operation of the Society at each Annual General Meeting

9.3 The Secretary is responsible for:

- (a) Ensuring meetings are effectively organised and minuted.
 - Liaising with the President to plan meetings, receiving Agenda items from Committee members, and circulating Agendas.
 - Taking minutes, circulating minutes within 30 days from the time of the meeting), checking that agreed actions are carried out.
- (b) Maintaining effective records and administration.
 - Holding an accurate record of all documents for the Society, including minutes and reports
- (c) Communication and correspondence.
 - Responding to, and filing of official Management Committee correspondence received and sent.
 - Keeping a record of all of the Society's publications.
- (d) Upholding legal requirements
 - Acting as custodian for the society's governing documents

- Ensuring charity law requirements are met, such as checking quorum is present at meetings, ensuring elections are in line with stipulated procedures.
- Submissions to the Charities Commission - notification of rule changes, update officers, and file annual returns, following approval by the Committee.

9.4 The Treasurer is responsible for:

- (a) Managing the Society's review of and action related to the Society's financial responsibilities
- (b) Working with the President and the Secretary to ensure that appropriate financial reports are made available to the Management Committee on a timely basis
- (c) Presenting the annual budget to the Management Committee for approval
- (d) Overseeing the operation of the society's bank accounts to the satisfaction of the Management Committee

9.5 The Membership Officer is responsible for:

- (a) Maintaining the Register of the Society's membership
- (b) Ensuring that all member details are kept up to date
- (c) Sending out membership packs
- (d) Regular mailouts to members of Newsletter and Reach Out Magazine

10.0 Management Committee Meetings

10.1 Management Committee meetings may be held via video, telephone conference, email or other formats as the Management Committee may decide.

10.2 A quorum of three Management Committee members must be available for a meeting to commence.

- a. In the event that a quorum is not available the chair may adjourn the meeting for a period of time to allow absent members to become present.
- b. If a quorum is still not available after the prescribed time has elapsed then the meeting shall be dissolved and a future date / time set.
- c. All business shall be carried over until the next meeting.

10.3 If the President is unavailable to chair the meeting then another person may act in that capacity provided 10.2 is met.

10.4 All decisions made by the Management Committee must be by majority vote.

10.5 Only members present at a specific Management Committee meeting shall be eligible to vote at the specific Management Committee meeting.

10.6 The Management Committee will agree a procedure for running of meetings by email

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11.0 Society Membership

11.1 Types of members

- a. Membership may consist of different classes of membership as decided by the Society at a General Meeting of the Society.
- b. Members have the rights and responsibilities as laid out within these rules.

12.0 Admission of members

12.1 To become a member, an Applicant for membership must:

- (a) Meet the requirements of the Society as determined by the Management Committee.

The criteria for membership includes, but is not limited to the following:

- i. Anyone diagnosed with Tuberous Sclerosis Complex.
 - ii. Partners and extended family of those diagnosed with Tuberous Sclerosis Complex.
 - iii. Health Professionals involved in the treatment of Tuberous Sclerosis Complex.
- (b) The Management Committee shall have full control over selection and/or refusal, of any applicant, as it sees fit or necessary.

A member will be classified only a member once they have registered with the Society and when applicable has paid their annual fees. The Committee will determine an annual fee for membership at the AGM. This fee may be set to \$0.

13.0 The Register of members

- 13.1 The Membership Officer shall keep a full and comprehensive record of all members called the "Register" containing names, communication numbers / email address and the dates they became members or ceased to be members.
- 13.2 Members are responsible for notifying the Membership Officer of any /all changes to information given.
- 13.3 The privacy of members will be respected and applicable privacy legislation will be complied with.

14.0 Cessation of membership

- 14.1 Any member may resign in writing to the Membership Officer
- 14.2 Membership may be terminated by a vote at a Management Committee of the Society if a member does not uphold clause 15.1 of these rules

15.0 Obligations of members

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- 15.1 All members shall promote the purpose of the Society and do nothing to bring disrepute to the Society or any member of the Society

MONEY AND OTHER ASSETS OF THE SOCIETY

16.0 Provision against Pecuniary Profit

- 16.1 Any income, benefit, or advantage must be used to advance the charitable purposes of the group.
- 16.2 No member of the group, or anyone associated with a member, is allowed to take part in, or influence any decision made by the group in respect of payments to, or on behalf of, the member or associated person of any income, benefit, or advantage.
- 16.3 Any payments made to a member of the group, or person associated with a member, must be for goods or services that advance the charitable purpose and must be reasonable and relative to payments that would be made between unrelated parties.

17.0 Joining fees, subscriptions and Levies

- 17.1 The Annual Subscription shall be determined annually by the Management Committee and approved at the Society's AGM. This fee may be set to \$0.

18.0 Additional Powers

- 18.1 The Society may employ people for the purpose of the Society.
- 18.2 The Treasurer in conjunction with a person delegated by the Management Committee may manage income and expenditure, and operate bank accounts for Society purposes.
- 18.3 The Society may fundraise to achieve the purposes of the Society.
- 18.4 The Society will have the same powers as if they were the beneficial owner of the Society's Fund; and
- 18.5 The Society's powers will not be limited or restricted by any principle of construction or rule of law or statutory power of provision except to the extent that is obligatory.

19.0 Financial year

- 19.1 The financial year of the Society begins on the 1st of April every year and ends on the 31st March every year.

20.0 Assurance on the Financial Statements

- 20.1 The Management Committee shall appoint an independent party with relevant experience to inspect the financial statements of the Society annually.
- 20.2 The Management Committee is responsible to provide the independent party with all documents so required, and
- 20.3 Reasonable access to Committee members from whom the independent party may require to obtain documentation.

CONDUCT OF MEETINGS

21.0 Society Meetings

- 21.1 A Society Meeting is either an Annual General Meeting or a Special General Meeting.
- 21.2 The Annual General Meeting shall be held once per year and not later than 5 months after the end of the financial year.
- 21.3 A Special General Meeting may be called by the Committee following 10% of the Society members submitting a written request to the Secretary. The Management Committee may call a Special General Meeting when 10% of the Management Committee members have submitted a written request to the Secretary.
- 21.4 The Secretary shall, for both types of Society meetings:
 - (a) Give all Society members 28 days notice of the meeting date in writing and a summary of business to be conducted.
 - (b) Additionally, the Secretary will provide at the meeting:
 - (i) A copy of the chairperson report on the Society's operations and of the financial statements – as approved by the Management Committee.
 - (ii) Notice of any Motions and the Management Committee's recommendation(s) about those recommendations.
- 21.5 All Society members may attend and vote at Society meetings. No Society meeting may be held unless at least 5 people attend.
- 21.6 All Society meetings shall be chaired by the President or substituted by the Secretary or to another Management Committee member in the absence or inability of the chairperson to conduct the meeting. The substituted person shall have the casting vote if required.
- 21.7 On any given motion the chairperson shall in good faith determine whether to vote by:
 - (i) Voices
 - (ii) A show of hands; or
 - (iii) Secret ballot.
- 21.9 The business of an Annual General Meeting shall be:

Jim Egan
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- (a) Receiving any minutes from previous Society meetings.
- (b) The Chairperson's report on the Society's business
- (c) The Treasurer's report on the finances of the Society and annual financial statements
- (d) Election of Management Committee Members
- (e) Motions to be considered
- (f) General business.

21.10 The Chairperson or nominee may adjourn the meeting if necessary.

21.11 Meetings may be adjourned for a given time to enable a quorum of at least 5 people to be established or in extreme cases remain adjourned for a future day / time / place so determined by the Chairperson.

21.12 In the event that no quorum is possible the chairperson shall dissolve all business left unfinished at the adjourned meeting.

22 Motions at Society meetings

22.1 Any Society member may request that a motion be voted on at any Society meeting, by giving written notice to the Secretary at least 14 days before that meeting.

The member may also provide supporting documentation in support of the motion but it will remain the discretion of the Management Committee whether or not the Society will vote on the motion.

However, if the member's motion is signed by at least 10% of the eligible members:

- (a) It must be voted upon at the Society meeting chosen by the member; and
- (b) The Secretary must give the information supporting the motion to all members at least 7 days prior to the Society meeting taking place.
- (c) If the secretary fails to do this then the member has the right to raise the motion again at the following Society meeting.

DOCUMENTATION

23 Signing of documents

23.1 Documents requiring signatures shall be signed by at least two appropriate members of the Management Committee or delegate. This includes the signatures required for the operation of the bank account.

CHANGES

24 Changes to the Rules

24.1 The Society may alter or replace the rules at a Society Meeting by a resolution passed by two-thirds majority of those members present and voting.

- 24.2 Any proposal to change the rules shall be advised to all members for comment / approval with full explanations as to the reasons for the change(s) within 28 days.
- 24.3 When a Rule Change has been approved by a Society Meeting. No change will take place until the Secretary has filed the changes to the Charities Commission.

WINDING UP

25 Winding up the Society

25.1 If the Society is wound up:

- a) If a decision is made to wind up or dissolve the society and any property remains after the settlement of the society's debts and liabilities, that property must be used to further a charitable purpose or purposes as defined in section 5(1) of the Charities Act 2005. A decision regarding the distribution of property will be made by the Management Committee.

DEFINITIONS

26 Definitions

26.1 In these Rules:

- a) "Majority vote" means a vote made by more than half of the members present and who are entitled to vote.
- b) "Money or other Assets" means any real or personal property or funds owned or controlled by the Society.
- c) "Society meeting" means any Annual General Meeting or Special General Meeting but not a Management Committee Meeting.
- d) "Written Notice" means communication by post or electronic, or advertising or a combination of these methods.
- e) It is assumed that:
 - i) When masculine is used, the feminine is included
 - ii) Where the singular is used, plural forms of the noun are also inferred
 - iii) Headings are a matter of reference and not part of the rules.
- f) Matters not covered by these Rules shall be decided upon by the Committee.

27 Signatories

President: Helen Willacy *HNWillacy*

Secretary: Frances Morton *FMorton*

Treasurer: Julianne Managh *JManagh*

Dated: *7/9/22*

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HNW*