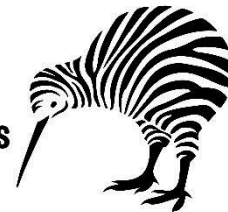


# Constitution of the Ehlers-Danlos Society New Zealand Incorporated

Ehlers-Danlos Syndromes  
New Zealand



## 1. Name

- 1.1 The name of the society is Ehlers-Danlos Society NZ Incorporated.
- 1.2 The Society is constituted by resolution dated 1 April 2018.
- 1.3 Also known as Ehlers-Danlos Syndromes New Zealand (“EDSNZ”).

## 2. Registered Office

- 2.1 The Registered Office of the Society is located at 21a Alexander Avenue, Torbay, Auckland.

## 3. Purposes of the Society

- 3.1 The purposes of the Society are:
  - a. To raise awareness of Ehlers-Danlos Syndromes in New Zealand.
  - b. To facilitate patient support networks.
  - c. To connect patients with clinicians knowledgeable about Ehlers-Danlos Syndromes.
  - d. To provide clinicians with accurate information on Ehlers-Danlos Syndromes.
  - e. To support and conduct related research for advancing understanding and treatment.
  - f. To facilitate international support connections for New Zealand.
  - g. To undertake any activities necessary or advantageous to these purposes.
- 3.2 Pecuniary gain is not a purpose of the Society.

## 4.0 Leadership Team and Committee Members

- 4.1 Leadership Team:
  - a. EDSNZ shall have a Leadership Team comprising the following positions: i. The President; ii. The Secretary; iii. The Treasurer (with Co-Treasurer if applicable).
  - b. The Leadership Team must include at least two individuals.
  - d. Such other Members as the Society shall decide.
- 4.2 Committee Members:
  - a. All Committee Members must be current members of the Society.
  - b. The Committee shall consist of a minimum of three Committee Members.
  - c. Only Members of the Committee may become part of the Leadership Team.

## 5.0 Appointment and Voting of Committee Members

- 5.1 At an EDSNZ Meeting, the Members may decide by majority vote:
  - a. How large the Committee will be;
  - b. Who shall be the Chair/President, Secretary, and Treasurer;
  - c. Whether any Committee Member may hold more than one position as an officer;
  - d. How long each person will be a Committee Member ("the Term").
  - e. If an EDSNZ meeting does not have enough people available for a vote during a meeting, then this vote will move to a post-meeting vote.
- 5.2 Voting Requirements:
  - a. All approvals by the Committee require a minimum of five votes to proceed.
  - b. Decisions shall be made by a majority vote of the Committee Members present at the meeting. In the event of a tie, the Chair/President shall have a casting vote.
- 5.3 If quorum is not met at a meeting, votes may be conducted via post-meeting vote as outlined in Section 5.2 of the constitution.

## 6.0 Cessation of Committee Membership

- 6.1 Persons cease to be Committee Members under the following circumstances:

- a. They resign by giving written notice to the Committee.
- b. They are removed by a majority vote of the Society at a Society Meeting, following a discussion where the Member is given an opportunity to present their case. This applies unless immediate removal is required due to exceptional circumstances affecting the Society's reputation, finances, or ongoing relationships.
- c. Their Term expires.
- d. They have been inactive for more than 6 months, without contact, and are voted out by majority vote.

#### 6.2 Discussion and Immediate Removal:

- a. In ordinary circumstances, a Committee Member facing removal shall have the right to discuss the reasons for potential removal with the Committee before a vote takes place. The Member must be provided with a written notice outlining the reasons for potential removal at least 14 days before the Committee Meeting where the vote will occur.
- b. Immediate Removal: If the Committee determines that there are exceptional circumstances jeopardizing the Society's reputation, finances, or ongoing relationships, the Committee may immediately remove a Committee Member without prior discussion or notice. Such removal must be approved by a majority vote of the Committee present at the meeting where the decision is made.
- c. Following removal, the former Committee Member must, within one month, return all Society documents and property in their possession.

### 7. Nomination of Committee Members

- 7.1 Committee Members may be nominated and elected by majority vote of the Committee.
- 7.2 Nominations and elections for committee positions are not restricted to annual meetings.
- 7.3 Nominations of increasing the responsibility of any officer is voted in with majority vote rules.

### 8. Role of the Committee

- 8.1 The Committee administers, manages, and controls EDSNZ operations.
- 8.2 The Committee manages financial affairs, sets accounting policies, and ensures compliance with rules.
- 8.3 The Committee has all powers of EDSNZ unless restricted by these Rules or Society majority decision.
- 8.4 The Committee shall also operate as a board until our leadership team reaches at least five members or until we implement a formal board to assist with operations. This 'temporary board' will oversee the execution of strategic initiatives, ensure compliance with organizational policies, and provide guidance on operational matters.

### 9. Roles of Committee Members

- 9.1 The Chief Visionary Officer/CEO/President oversees adherence to the Rules, chairs meetings, and reports on Society operations.
- 9.2 The Secretary records minutes, maintains the Register of Members, and manages correspondence.
- 9.3 The Treasurer manages financial records, prepares financial statements, and reports finances to the Committee.
- 9.4 All other Committee members act in the best interests of the Society, undertake tasks as assigned, and support the overall mission and objectives of the organization.

### 10. Committee Meetings

- 10.1 Meetings may be held via video, telephone, or other formats as decided by the Committee.
- 10.2 Quorum requires at least three Committee Members present.
- 10.3 Decisions are by majority vote (by at least 4 people); Chair/President has a casting vote in case of tie.
- 10.4 Offline voting procedures are outlined in Section 5.2 of the constitution.

## **11. Types of Members**

- 11.1 Membership may include individual diagnosed and undiagnosed, family, affiliate, support, and professional classes.
- 11.2 Members have rights and responsibilities as per these Rules.

## **12. Admission of Members**

- 12.1 Applicants with a current Ehlers-Danlos diagnosis or related disorders may apply for membership.
- 12.2 Membership applications are reviewed by the Committee.

## **13. Register of Members**

- 13.1 The Secretary maintains a Register of Members with updated contact details.
- 13.2 Members must inform the Secretary of any changes to their contact information.

## **14. Cessation of Membership**

- 14.1 Members may resign by written notice to the Secretary.
- 14.2 Membership may be terminated as outlined in Section 6 of the constitution.

## **15. Obligations of Members**

- 15.1 Members shall promote Society purposes and uphold its reputation.

## **16. Use of Money and Other Assets**

- 16.1 Society funds and assets must be used for Society purposes as outlined in section 3 and approved by the Committee or Society majority vote.

## **17. Joining Fees, Subscriptions, and Levies**

- 17.1 No compulsory fees are required, but donations are appreciated.

## **18. Additional Powers**

- 18.1 The Society may employ staff, invest, and borrow money with Society approval.

## **19. Financial Year**

- 19.1 The financial year runs from 1 April to 31 March, and the AGM must be completed before 30 September at the latest.

## **20. Assurance on Financial Statements**

- 20.1 Financial statements may be reviewed or audited upon request by 5% of Members.

## **21. Society Meetings**

- 21.1 Meetings include Annual General Meetings and Special General Meetings.
- 21.2 Annual General Meetings are held within five months of the financial year-end.
- 21.3 Special General Meetings may be called by the Committee or on request by 10% of Members.
- 21.4 Meeting procedures and notices are outlined in Section 21 of the constitution.

## **22. Motions at Society Meetings**

- 22.1 Members may propose motions for consideration at Society Meetings as outlined in Section 22.
- 22.2 Committee may also propose motions to be voted on.

## **23. Common Seal**

- 23.1 The Committee oversees the use of the common seal as required.

## **24. Altering the Rules**

- 24.1 Rules may be altered by a two-thirds majority vote at a Society Meeting.

## **25. Media and Communications**

- Respectful Communication: Maintain professionalism, adhere to platform rules, be respectful and kind. Bullying is not tolerated.
- Privacy and Confidentiality: Do not share Personal Health Information (PHI).

- Appropriate Use: Separate personal and professional accounts. Official accounts should be managed by designated personnel
- Content Guidelines: Share credible information and avoid posting PHI or unauthorized medical advice
- Crisis Communication: Use social media to provide accurate information during crises.
- Training and Reviews: Regularly train on policies and review them to stay current

## **26. Bylaws**

26.1 The Committee may establish and amend bylaws not conflicting with these Rules or legal provisions.

## **27. Winding Up**

27.1 If the Society is wound up:

- a. The Society's debts, costs and liabilities shall be paid;
- b. Surplus Money and Other Assets of the Society may be disposed of:
  - i. By resolution; or
  - ii. According to the provisions in the Incorporated Societies Act 1908; but
- c. No distribution may be made to any Member;
- d. The surplus Money and Other Assets shall be distributed to: a Charitable cause, to be decided by majority.

## **28. Definitions and Miscellaneous Matters**

28.1 In these Rules:

- a. "Majority vote" means a vote made by more than half of the Members who are present at a Meeting and who are entitled to vote and voting at that Meeting upon a resolution put to that Meeting.
- b. "Money or Other Assets" means any real or personal property or any interest therein, owned or controlled to any extent by the Society.
- c. "Society Meeting" means any Annual General Meeting, or any Special General Meeting, but not a Committee Meeting.
- d. "Use Money or Other Assets" means to use, handle, invest, transfer, give, apply, expend, dispose of, or in any other way deal with, Money or Other Assets.
- e. "Written Notice" means communication by post, electronic means (including email, and website posting), or advertisement in periodicals, or a combination of these methods.
- f. It is assumed that
  - i. Where a 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 a part of the rules
- g. Matters not covered in these rules shall be decided upon by the Committee.
- h. "EDS" stands for Ehlers Danlos Syndromes. This also includes Hypermobility Syndrome Disorder or 'HSD'
- i. 'Related disorders' relates to associated medical problems or manifestations
- j. 'The Term' relates to discussions at the beginning of a committee member joining the team, and/or throughout their team membership