

TRAGADY

Trans Tasman **R**esponse **A**gainst sudden **D**eath in the **Y**oung

Executive summary November 28th 2005.

Who we are

TRAGADY is a multidisciplinary group of people whose core aim is the reduction of sudden death in the young, principally by understanding the molecular, genetic and pathological basis of a number of cardiovascular disorders. The group is based in New Zealand and Australia, and has collaborations with other groups and individuals with a common interest from all over the world. The group comprises mostly health professionals, research scientists, and others from a variety of backgrounds, and includes patient groups and individuals personally affected by inherited conditions causing sudden death.

Aims.

The core aim is the reduction of sudden unexpected or unexplained death in the young (SUDY). We aim to achieve this using a number of different strategies, which include, but are not necessarily restricted to:

1. Highlighting the importance and significance of sudden death in the young as a significant public health issue.
2. Facilitating data collection and audit of SUDY.
3. Defining, and enabling best practice in the investigation of SUDY.
4. Facilitating the clinical and molecular investigation of families for possible inherited heart and other diseases following a SUDY.
5. Conducting or facilitating studies to improve our understanding of sudden death in neonates, children, and young adults.
6. Education of health and legal professionals, administrators and politicians and the general public in issues related to SUDY and to inherited sudden death syndromes.
7. Facilitating multicentre coordinated high quality research into sudden death syndromes.
8. Securing adequate funding from a variety of sources, e.g. peer-reviewed funding, government support and financial support from commercial and philanthropic organisations, to facilitate the above aims.
9. Ensure the information acquired is used to develop treatment strategies for individuals and families to prevent further sudden death in the young.

Membership, Infrastructure and leadership.

This is an organisation, whose members may belong to other significant organisations involved in health care, research or family support groups or other groups. The chairperson is currently Dr Jon Skinner, paediatric cardiologist from Auckland., and chair of the Cardiac Inherited Diseases Group, New Zealand. The vice chairperson is Associate Professor Chris Semsarian, molecular cardiologist and head

of the Agnes Ginges Molecular Cardiology Centre, Sydney, Australia. The infrastructure is currently informal and based on good-will and collaboration of individuals united by the group's aims. Membership criteria are in development.

Important decisions are made by consensus at a meeting of the group. The meetings are be minuted, and the minutes are approved formally at each subsequent meeting.

Affiliations

The group is independent, without direct responsibility to any other organisation.

However, affiliations exist with:

1. The Australia and New Zealand Children's Heart Research Centre, who have provided a seeding grant to help establish this group, and currently administer funding.
2. The Cardiac Society of Australia and New Zealand, via the genetics working group, currently chaired by Chris Semsarian.
3. SADS Australia (Sudden Arrhythmic Death Syndromes group), who have representatives within this group.

Some members of this group belong to the Royal Australasian College of Physicians, the Royal College of Pathologist of Australasia, the Human Genetics Society of Australasia, SIDS and KIDS, and also scientific bodies. These individuals may be bound by their professional codes of ethics and conduct, but TRAGADY is not directly responsible to any of these organisations. Where it is relevant, active collaboration with these bodies, and others, may be sought to achieve the aims of the group.

Financial support

Financial support to sustain the organisation, and to achieve the aims of the group, will be sought from a variety of sources including charitable funds, research bodies, philanthropic sources, government, professional societies and colleges.

Information for prospective donors

Funds donated are used by this group to achieve the group's aims. Funds are administered by the Australia and New Zealand Children's Heart Research Centre, or Cure Kids who have charitable status and independent auditing. Donations can be made through either organisation but should include advice that funds are directed to TRAGADY. <http://www.curekids.org.nz/donations.htm>