



Cardiac Inherited
Disease Group
New Zealand
www.cidg.org

*He aha te mea nui o te ao?
He tangata! He tangata! He tangata!*

When a young person dies suddenly Looking for answers Cardiac Inherited Disease Registry N.Z. Sudden Unexplained Death in the Young (SUDY)

Cardiac Inherited Disease
Registry
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INFORMATION FOR FAMILIES *He whakamāramatanga mo ngā whānau*

You may be reading this information because a loved one, a child, partner or parent has died suddenly and without any warning.

Mehemea e pānui ana koe i tēnei whakamāramatanga, kua ohomate tō pēpi, hoa, tama/ kōtiro, teina/tuakana, tūngane/tuahine, matua/whaea rānei.

The question that you will be asking - is WHY? Why did this happen?

Sudden unexplained and unexpected deaths, in otherwise healthy young people are tragic occurrences. Apart from the question why, families and friends often express thoughts that they should have noticed something; or that something was about to happen. Thoughts and feelings like these are expressed commonly and are a natural reaction to the sudden trauma this tragedy has created in your family.

The Cardiac inherited Disease Group (CIDG) is a New Zealand National Network of clinicians and scientists committed to reducing sudden unexpected death in young people. We have been working with families like yours to try to find a cause of death. With all this experience we can say even before we meet that it is very unlikely that anything you said or did would have changed the course of events. But you deserve the opportunity to meet professionals who have some chance of answering your questions, and that is what we are here for.

It has become increasingly apparent that it is vital to register all cases of young sudden death and to actively investigate the living family members to both assist in finding a diagnosis and to prevent further tragedies.

CIDG helps in the following ways:

E whakakaha ana matou ki te awhina atu I a koutou penei enei whakahaerenga:

- By helping you understand coronial and pathology reports that you may have seen, or have not yet seen, and what genetic tests or other tests may be outstanding.
- By investigating each case and describing conditions that may have been responsible and targeting family screening appropriately with the aim of preventing further tragedies.
- By providing up to date information for families and arranging heart tests and genetic tests on family members where appropriate.
- By gathering incidence statistics on sudden death in young people in New Zealand population to inform future health service provision.
- By providing diagnostic summary reports to the coroner and pathologist.
- By registering all cases of unexplained sudden death and offering ongoing research if no definite answers come from the initial tests.

What does the process of investigating the family involve? *He aha nga whakaritenga aromatawaii te whanau?*

1) Screening family members:

Tirotironga whanau:

Each first degree family member of the deceased (parents, brothers and sisters, children) is seen by a specialist as near as possible to where they live, and they are offered the appropriate heart screening tests. In addition a careful medical and family history is taken to look for other possibly affected family members.

Sometimes family members may be reluctant to come forward for screening because of the grief process. CIDG staff are happy to assist family members when they are ready to come forward. Details such as name, date of birth, and address are necessary in order for referrals to be made on their behalf throughout New Zealand, and sometimes overseas.

Heart tests that may be performed are all pain-free and include a resting ECG (electrocardiogram), which provides information about the electrical excitation of the heart. Additional tests may include an Exercise test which looks at ECG activity whilst the person walks on a treadmill, an Echocardiogram (heart scan) that looks at the structure and function of the heart (using ultrasound), and cardiac MRI (magnetic resonance scan).

If a genetic diagnosis has been made in the family then genetic testing may also be available to other family members. This is provided in addition to heart tests and with appropriate genetic counselling for each family member who wishes to have the test. It involves taking a small sample of blood.

2) Obtaining a family history:

He whiwhinga whakapapa:

It is essential that a thorough family history is taken. This includes information from the mother's and the father's sides of the family going back as many generations as possible (grandparent information is very useful if available). The history of previous events in the family may be very important in helping to understand what may be happening now.

3) Investigating the medical history of your loved one:

He whiwhinga i te hitori hauora mo te whanaunga kua mate:

The past medical history of your loved one is also very important. It may provide valuable clues to clinicians. Of particular interest is whether or not the deceased individual had experienced previous collapses, faints or seizures and whether medications or supplements; or drugs or special diets were being taken or if other lifestyle changes were occurring at the time. Childhood injuries, illnesses, febrile seizures and or events such as seizures or epilepsy, and near drowning events may provide important medical history.

4) What can you do now?

He aha too mahi inaianei?

To register your family member, please sign and return the associated registration consent forms to The Cardiac Inherited Diseases Registry co-ordinator. Please also read the General Cardiac Inherited Disease Registry information sheet in conjunction with this form (*General Information sheet should be supplied together with this information sheet*).

If you have any other questions you would like to ask, please do not hesitate to contact the registry co-ordinator and/or discuss your queries with your specialist. Pulling together all this information may take two or more appointments, as well as referring relatives for specific clinical testing, and undertaking specialist review of all the information.

Mehemea he patai ano kei a koe, kua e whakama ki te whakapa ki te rehitā, te kaituitui, ki te whiriwhiri au awangawanga ki to takuta-matua ranei.

Links to further Information:

Skylight: www.skylight.org.nz Skylight is dedicated to providing assistance and information for grieving children of all ages.

Cardiac Inherited Disease Website: www.cidg.org for further information.

Cardiac Risk in the Young: UK. www.cry.org.uk this is a lay group that has done outstanding work in recognition of inherited heart disease in the UK.

Other Resources: Book

Coping with Grief by Mal and Dianne McKissock: (Palliative Care and Bereavement Education Consultant. Published by ABC books for the Australian Broadcasting Corporation GPO Box 9994 Sydney 2001 (ISBN 978 0 7333 0438 5)

Health Advocacy Information

If you have any queries or concerns regarding your rights as a participant in the Cardiac Inherited disease registry you can contact an independent Health and Disability Advocate. This is a free service provided under the Health & Disability Act; through the offices of the Health and Disability Commissioner.

Telephone (NZ wide): 0800 555 050

Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT) Email: advocacy@hdc.org.nz

Cardiac Inherited Disease Registry Ethical Review and Approval:

The N.Z Cardiac Inherited Disease Registry has received Ethical Approval from the N.Z. Multi-centre Ethics Committee: AKX/02/00/107

Glossary

Sudden unexplained death is defined as a death that occurs within an hour of a symptom which may be a sudden collapse. It has been given a number of different acronyms such as: SIDs (Sudden Infant Death Syndrome) SUDY (Sudden Unexplained Death in the Young), SUNDs (Sudden Unexplained Nocturnal Death Syndrome), SUDEP (Sudden Unexplained Death in Epilepsy), SADS, (Sudden Arrhythmic death syndrome), and SUDs (Sudden Unexplained Death Syndrome).

What is the most important thing in the world? It is people! It is people! It is people!