

SUDI Nationwide Study

increasing understanding of Sudden Unexpected Death in Infancy

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WELCOME

*Tēnā koutou katoa, nau mai,
 haere mai*

Kia ora and welcome to the first edition of the **SUDI Nationwide Study** newsletter, designed to provide you with regular updates on the progress of the study.¹

INTRODUCTION

The 3-year study follows research from 20 years ago which continues to inform the practice that putting babies to sleep on their backs, with their faces clear, saves lives. Since the original study, the numbers of SUDI have reduced from 250 per year to 60 nationwide. About half of these infants are Māori.²

STUDY QUICK FACTS

The study:

- Looks at the impact of co-sleeping with baby and whether co-sleeping can occur safely
- Overall goal is to reduce the SUDI rate further
- Funded by Health Research Council
- Led by Prof. Ed Mitchell, University of Auckland
- Has the authorisation of Judge A. N. MacLean, Chief Coroner
- Will involve more than 400 whānau including those that experience SUDI (Case) and those with living babies (Control, or Comparison)
- Uses a specially-trained SUDI Liaison team.

CASE GROUP

In this project, a SUDI death is when a baby aged 1 year or less has died unexpectedly, though not accidentally, e.g. in a motor vehicle accident. There are two components to information gathered from whānau in the Case group. The first is the collection of information for the coroner, called the initial dataset. The second is the collection of research data for the University of Auckland. Separate guidelines exist for both components.

MEETING WHĀNAU

After receiving authorisation from police, a SUDI Liaison will make contact whānau and arrange to meet. Extended family are often involved with the interview, either as other caregivers of the baby or as kaitiaki (guardian) for the mother or parents. Re-telling events around baby's death is extremely difficult and mother (and other caregivers) will need as much support as possible. Police interviews will have already occurred and SUDI Liaison staff take care not to compound the grief and pressure on whānau during this time. A good rapport with whānau is essential to creating an environment where whānau feel able to tell their story.

Kia noho kotahi ai tātou mo te kaupapa nunui nei, e whakaora ana i ngā mokopuna e haere mai nei i ngā rā e heke mai nei³

The SUDI Liaison helps notify organisations outside of Police and Coronial processes, e.g. GP or well child/ tamariki ora provider.

Footnotes:

1. SUDI - Sudden Unexpected Death in Infancy
2. NZMJ 4 November 2011, Vol 124 No 1345; ISSN 1175 8716
 Page 12: <http://journal.nzma.org.nz/journal/124-1345/4930/>
3. Cases Information Sheet – Feb12 v1.0

INITIAL DATASETS

The 'initial dataset' is collected for the coroner that has jurisdiction of the SUDI case. This does not require consent of whānau; however, if a meeting cannot be arranged, this is communicated back to the coroner. He or she will then advise how to proceed. If possible, a set of physical or 'objective' measures is also collected. These include the use of a cloth, sand-filled doll which the SUDI Liaison uses to clarify with whānau things like baby's positioning at bedtime. The full initial dataset is sent to the coroner and forensic pathologist for their consideration.

CASE RESEARCH

Separate to the initial dataset, whānau are invited to participate in the research. This is voluntary and subject to Health Research Council and Ethics Committee rules. Greater detail is collected for the study compared to the initial dataset, including clinical, environmental and social information relating to baby. The research information is provided to the University of Auckland.

6-WEEK ENGAGEMENT

The SUDI Liaison works with whānau for up to 6 weeks after the SUDI. Most of the time, collection of the initial dataset and research is completed within two weeks. During the 6-week period, whānau use the SUDI Liaison as an extra contact person for information on coronial processes. At 6 weeks, the SUDI Liaison meets with coronial services to provide a thorough handover. The SUDI Liaison makes final contact with whānau to bid farewell and update them on their key contact in coronial services.

COMPARISON GROUP

The Comparison group includes whānau that have met the study criteria and agreed to participate in the study. Whānau are interviewed at home and objective measures are obtained. Responses from these whānau will be analysed and compared to those in the Case group. Over 3 years, 500 whānau will be invited to participate.

SUDI LIAISON TEAM

The SUDI Liaison team, each of whom has a clinical health background, liaise with whānau involved in the study. Melanie MacFarlane, project manager, is based in Auckland and assisted in the top half of the North Island by Shelley Jonas and Rebecca Passi. The lower North Island is covered by Jazz Heer and the South Island by Elaine McLardy.



The SUDI Liaison Team, from left; Melanie MacFarlane, Elaine McLardy, Rebecca Passi, Shelley Jonas and Jazz Heer

RECRUITMENT OPPORTUNITY

Sadly, Jazz Heer will be leaving in February – a great loss for the team. If you or anyone you know is interested in this opportunity and wants to find out more, further information is available from Melanie MacFarlane.

KEY LINKAGES

The SUDI Liaison team work closely with NZ Police in accessing and engaging with whānau in the Case group. Iwi Liaison Officers have provided invaluable support, as has Victim Support. Whānau Ora networks and health and social services have been linked in to whānau through the study. DHBs link with the project in a number of the ways, such as identifying whānau for the Comparison group, or providing additional support at hospital mortuaries via Māori liaison and support teams.

KOHA

We are extremely grateful for the generosity of our sponsors who enable us to provide whānau with a small koha in appreciation of their time and/or acknowledgment of their grief. Special thanks to Heinz Watties, Moffats Flowers Christchurch and SANDS Manukau. If your organisation would like to contribute in some way, please let us know.

FINAL WORDS

There is no simple answer, SUDI is a complex tragedy. With your help, understanding and proactive support you will be assisting whānau and contributing to a valuable body of information. This information will increase current knowledge enabling Coroners, policy makers and health professionals to give informed advice that will lead to the prevention of infant deaths in the future.

*Ngā mihi nui ki a koutou katoa
mo to koutou manaaki,*

*Meri Kirihimete me ngā mihi o te
Tau Hou!*
