



Growing kāpo up Māori: Accessing paediatric ophthalmology services

**Dr. Nancy Higgins, Dr. Hazel Phillips, Dr. Graham
Wilson & Karen Stobbs**

Summary:

This nationwide research project is about how kāpo (blind or vision impaired) Māori children and young adults, with their whānau, are accessing ophthalmology services and about kāpo Māori children and young adults, themselves. We will do this by talking to whānau and by establishing a paediatric vision database. We want to know how many kāpo Māori children and young adults are in New Zealand, about their eye problems and health, and, find out if anything is a barrier for them or their whānau when seeking an eye specialist or a diagnosis. Māori and Pākehā researchers will be working together with a research advisory committee from Ngāti Kāpo O Aotearoa in this project.

This study is funded by the Health Research Council and will run for two years. It is being conducted by Ngāti Kāpo O Aotearoa, alongside the Ophthalmology Department at the Tairāwhiti District Health Board and the Ministry of Education's Blind and Low Vision Education Network New Zealand (BLENNZ), which is a nationwide school and part of the Ministry of Education's educational system. Ngāti Kāpo O Aotearoa, which is hosting the project, is a national .4

that represents kāpo Māori and their whānau. Ngāti Kāpo O Aotearoa's mission is to improve the quality of life, advocate for, and provide peer support to kāpo Māori and their whānau.

The researchers for this project include: Dr. Nancy Higgins (Pākehā) and Dr. Hazel Phillips (Ngāti Mūtunga), who both can be contacted through Ngāti Kāpo O Aotearoa on 0800-770-990; Karen Stobbs from BLENNZ, who can be contacted on 03-375-4334; and Dr. Graham Wilson (Paediatric Ophthalmologist, Tairāwhiti District Health Board), who can be contacted on 06- 869-0500.

We are hoping to talk to whānau of kāpo Māori children and kāpo Māori from the ages of 16 to 21 about participating in this project.

Background: There are no in-depth published studies about kāpo Māori children in New Zealand, although there has been some general research about blind people and about Māori with a disability. (Bevan Brown, 1989; Collins & Hickey, 2006; Higgins, 2001, 2004, 2005; Phillips, 2005) There is one 2003 HRC partially funded ophthalmological study, which was led by Dr. C. Hope and found a New Zealand gene that has resulted in stationary night blindness in children in one Māori whānau (Hope et al, 2003). This project has been developed by Ngāti Kāpo O Aotearoa in response to researcher discussions with Dr. C. Hope and initial findings from the

HRC funded 2007-2009 *Growing up kāpo Māori: Whānau, identity, cultural well-being and health* study about the lived experiences of kāpo Māori and their whānau. In this 2007-2009 study, it has been found that 26% percent of the 174 kāpo Māori under the age of 22, who are registered with the Royal New Zealand Foundation of the Blind (RNZFB), don't have a recorded visual diagnosis and 16% don't have a visual diagnosis that fitted into the RNZFB's extensive diagnosis categories. Thus, the causes of vision impairment in 42% of kāpo Māori children within the RNZFB are unknown.

Similarly, the Blind and Low Vision Education Network NZ (BLENNZ) does not have complete overall information about the causes of vision impairment in Māori children on its roll. There is no national paediatric vision database, which can provide accurate epidemiology information. Overseas, researchers have begun to use the World Health Organisation's (WHO) standard reporting protocol so that international comparisons can be made and early intervention can be undertaken (Algaratnam et al, 2002; Rogers, 1995; Resnikoff & Pararajasegaram, 2001). Also, the 2007-2009 project's initial qualitative results indicated that whānau of kāpo Māori children were not easily accessing ophthalmology services because of cultural issues. Without a diagnosis, kāpo Māori children may not access appropriate education or medical support services. (Gilbert & Foster, 2001; Thompson & Kaufman, 2003)

Aim: The aim is to establish a paediatric vision impairment database based on WHO standard reporting protocols, by exploring, identifying, and addressing the barriers to accessing ophthalmological services that whānau of kāpo Māori children encounter.

Design & Participants: This research is positioned as a Māori development research project, and as in the 2007-2009 *Growing up kāpo Māori* study, Māori and Pakeha researchers from multiple perspectives will work together, through a research management committee from Ngāti Kāpo o Aotearoa, to plan, interpret, and disseminate the results of this research. It has already been agreed that the whānau of kāpo Māori children (n≈244) on the roll of BLENNZ will be ask to participate in this project. Fieldnotes from qualitative in-depth hui/interviews about accessing ophthalmologic services, will be undertaken by whānau community researchers from Ngāti Kāpo. A demographic questionnaire will also be completed. Participants' ophthalmologic records will be reviewed by a paediatric ophthalmologic researcher, and vision diagnosis data will be entered into a paediatric database. Participants will be supported by whānau community researchers to obtain an accurate visual diagnosis if necessary. Fieldnotes and questionnaires will be analysed in research and research management team hui, and by using SPSS and Nvivo software packages as appropriate. Dissemination of the research results will be through a variety of media (e.g. Braille, print, electronic, audio, publications, presentations, and hui) to ensure that reporting back to participants is conducted widely and appropriately.

Dr. Nancy Higgins (nancy@kāpomaori.com), Ngati Kāpo o Aotearoa (NZ), 510
Market St., Hastings, NZ