

18 June 2013

Dr Daphne J. Rickson  
Te Koki, The New Zealand School of Music  
Mt Cook Campus, Music Therapy Department  
P.O. Box 2332  
Wellington 6140

Dear Dr Rickson

Re:	<b>Ethics ref:</b>	<b>13/NTA/74</b>
	Study title:	Developing sustainable programmes to support the well-being of young people with intellectual disability transitioning to adulthood: Learning from a collaborative music therapy process

I am pleased to advise that this application has been approved by the Northern A Health and Disability Ethics Committee. This decision was made through the HDEC-Full Review pathway.

The main issues considered by the HDEC in giving approval were as follows.

- The committee noted that the participants in this study are also the researchers, which differs from the usual paradigm.
- Anticipated risks of working with this vulnerable population
- Would researchers be confident that having a consent form is the right approach
- The notion of consent would get in the way of what researchers intend to do. Suggestion was made to remove the word 'consent' from the forms and replacing it with 'agree to take part'.
- Would researchers have the ability to manage any incidents that arise
- Is a process in place to deal with the potential issue of disclosure
- Why is joint ownership of the research considered to be problematic
- Will the researchers publish information to non-medical stakeholders as maintaining confidentiality would need to be considered
- Consultation with Maori to ensure Maori participants' needs are met
- The committee would think about reviewing representation from participants themselves should any issues arise.

#### Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Northern A Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at *any* locality in New Zealand, all relevant regulatory approvals must be obtained.
2. Before the study commences at *any* locality in New Zealand, it must be registered in a WHO-approved clinical trials registry (such as the Australia New Zealand Clinical Trials Registry, [www.anzctr.org.au](http://www.anzctr.org.au)).
3. Before the study commences at a *given* locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

After HDEC review

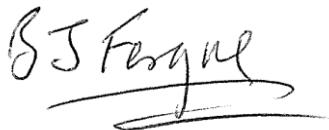
Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on [www.ethics.health.govt.nz](http://www.ethics.health.govt.nz)) for HDEC requirements relating to amendments and other post-approval processes.

Participant access to ACC

The Northern A Health and Disability Ethics Committee is satisfied that your study is not a clinical trial that is to be conducted principally for the benefit of the manufacturer or distributor of the medicine or item being trialled. Participants injured as a result of treatment received as part of your study may therefore be eligible for publicly-funded compensation through the Accident Compensation Corporation (ACC).

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,



Dr Brian Fergus  
Chairperson  
Northern A Health and Disability Ethics Committee

Encl: appendix A: documents submitted  
appendix B: statement of compliance and list of members

**Appendix A**  
**Documents submitted**

<i>Document</i>	<i>Version</i>	<i>Date</i>
CV for CI: CV, Daphne Joan Rickson	1	03 April 2013
Protocol: Music therapy with young people with ID	2	28 March 2013
Evidence of scientific review: Evidence of Peer Review by College of Health PVC and Executive Committee	1	03 April 2013
Application		24 May 2013
PIS/CF- Parent/Guardian	1	
PIS/CF – Young Person		23 March 2013
PIS/CF - Caregiver		23 March 2013
PIS/CF		23 March 2013
PIS/CF		23 March 2013

## Appendix B Statement of compliance and list of members

### Statement of compliance

The Northern A Health and Disability Ethics Committee:

- is constituted in accordance with its Terms of Reference
- operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
- is registered (number 00008714) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

### List of members

<i>Name</i>	<i>Category</i>	<i>Appointed</i>	<i>Term Expires</i>	<i>Present on 11/06/2013?</i>	<i>Declaration of interest?</i>
Dr Brian Fergus	Lay (consumer/community perspectives)	01/07/2012	01/07/2015	Yes	No
Ms Susan Buckland	Lay (consumer/community perspectives)	01/07/2012	01/07/2015	Yes	No
Ms Shamim Chagani	Non-lay (health/disability service provision)	01/07/2012	01/07/2014	Yes	No
Mr Kerry Hiini	Lay (consumer/community perspectives)	01/07/2012	01/07/2014	Yes	No
Assoc Prof Wayne Miles	Non-lay (intervention studies), Non-lay (health/disability service provision)	01/07/2012	01/07/2013	Yes	No
Dr Etuate Saafi	Non-lay (intervention studies)	01/07/2012	01/07/2014	Yes	No
Ms Michele Stanton	Lay (the law)	01/07/2012	01/07/2014	Yes	No

<http://www.ethics.health.govt.nz>