



**UNIVERSITY OF  
CANBERRA**

AUSTRALIA'S CAPITAL UNIVERSITY

## **Questionnaire Information Sheet**

This research projects aims to determine the kinds of needs (e.g., practical, emotional, social) that carers of children with neuromuscular conditions experience at various stages of the illness.

### **What is this research about?**

In advocating for the needs of their children, parents/carers report that accessing appropriate care is a complex, ongoing and stressful task. Research indicates that carers and parents of children with neuromuscular conditions have a higher risk of emotional distress and reduced quality of life.

To help provide appropriate services, it is important to develop a better understanding of the specific needs of carers. In addition, it is important to understand how these needs may change at various stages of throughout the illness and may impact of carer wellbeing.

### **What will I have to do?**

If you are happy to participate in this study, please click on the link in the email which will take you to the online survey. The survey itself contains some questions about yourself and your child, your needs, and the impact on you of caring for your child. It takes ten to fifteen minutes to complete and all the responses are completely anonymous. There are no right or wrong answers, what matters most is that you answer honestly, because your experiences are important to understanding how to better address the needs of carers of children with neuromuscular conditions. Also, if you know of other carers who might like to participate in this study, please forward this email.

### **Are there any risks?**

This research is not anticipated to cause you any distress or anxiety. However, if you experience some upset from participating in this study, it is strongly advised that you contact your Muscular Dystrophy Queensland Case Worker. Alternatively, you may wish to call Lifeline on 13 11 14 for anonymous and confidential telephone counselling.

Participation is voluntary.

Participation is completely voluntary, and you may withdraw from the questionnaire at any time. Your responses are anonymous, and all results reported from this study will be based on group trends only.

### **Reporting of Results**

The results of this project will form the basis of a Masters' thesis being conducted by Ms Sharon Dawson, University of Canberra and may form the basis of a publication in an academic journal. The results will also be reported to Muscular Dystrophy Queensland.

### **What will be the benefits of this study?**

Although you may not personally receive any direct benefit from participating in this study, it is hoped that the results will be able to inform Muscular Dystrophy Queensland about service needs. Such information will provide the basis for advocacy for direct service provision.

### **Will I hear about the results of this research?**

Feedback about the results of the study will be provided to you via Muscular Dystrophy Queensland.

### **Who has approved this research?**

This study has been approved by the human research Ethics Committee at the University of Canberra. Should you have any concerns regarding the ethics of this research please contact the Ethics and Compliance Officer at the University of Canberra tel 02 6201 5870

For further information concerning the details of this study, please free to contact me ([sldawson@bigpond.com](mailto:sldawson@bigpond.com)) or my research supervisor, Assistant Professor Vikki Knott ([Vikki.Knott@canberra.edu.au](mailto:Vikki.Knott@canberra.edu.au)).

### **Independent Complaints Procedure**

1. As a participant or potential participant in research, you will have received written information about the research project. If you have questions or problems which are not answered in the information you have been given, you should consult the researcher or (if the researcher is a student) the research supervisor. For this project, the appropriate person is:

**Name:** D. Vikki Knott

**Contact Details:** Faculty of Health  
University of Canberra  
Ph: 02 6201 2157

2, If you wish to discuss with an independent person a complaint relating to:

- conduct of the project, or
- your rights as a participant, or
- University policy on research involving human participants,

**Please Contact:**

**Ethics and Compliance Officer**

Telephone (02) 6201 5870

Room 1 D116

UNIVERSITY OF CANBERRA ACT 2601