

Date: 17 October 2019

HREC Project Number: HREC/17/SCHN/227 & ETH17-1967

Research Project Title: Understanding patients' and carers' decision making in Spinal Muscular Atrophy care

Principal Investigator: Associate Professor Michelle Farrar

I am writing to let you know about a new research project that is being led by UNSW Sydney, The University of Sydney Technology and The Sydney Children's Hospital at Randwick, in which you may be interested in participating.

The research is being carried out to learn more about what factors (such as benefits of treatment and cost) are important when making decisions related to treatment for Spinal Muscular Atrophy (SMA), a genetic neuromuscular disorder that leads to muscle weakness and atrophy. In this project we are seeking the views of parents/carers of people with SMA, health care providers and the wider community. We will use this information to improve management and care for people with SMA and their families. We hope around 200 health care professionals will take part.

This research is funded by the Motor Neurone Diseases Research Institute of Australia,

We are inviting you to participate because you are a healthcare professional. We would like you to complete an online survey that will take about 15-20 minutes. The survey will present 8 different hypothetical SMA treatment scenarios (stories). Based on the information provided (such as the benefits of treatment, risks of side effects and cost), you will be asked if you would recommend treatment. Following the treatment scenarios, you will be asked a series of questions about your experiences of completing the survey questions. The third part of the survey will ask general questions such as your age, gender, and educational level. The last part of the survey asks some general questions about your thoughts, feelings and behaviours.

Participation in this project is voluntary; you do not have to take part if you do not want to.

By participating in this study we do not expect there to be any benefit to you or your patients. However, we hope the information from this study will help to improve the management and care for people with SMA and their families in the future.

The main risk of participating in this study is the inconvenience and time to complete the survey and that the scenarios described may be potentially upsetting for some participants. The survey provides a scenario about an infant diagnosed with SMA, describes the symptoms of SMA in infants and asks you to make treatment recommendations for that child. We have been careful to try and ensure that the questions in the survey do not upset you. However, if you are worried about any of the questions, you do not need to answer them. You can also contact Associate Professor Michelle Farrar, the principal investigator, to discuss any questions or concerns you have. If you need immediate support, you may like to contact Lifeline on 13 11 14.

The information collected in this study will be completely anonymous. This means it will not include your name or any other personal information that might identify you. No one, not even the research

team, will be able to identify you or your information. If you take part it will not be possible to withdraw any information you give us. This is because it is anonymous and we do not know who answered the questions in each survey. All information will be stored securely by SurveyEngine who will export and provide the data to the research team (who will store the information on secure servers at the University of Technology Sydney and UNSW Sydney. Only the research team will have access to this information.

The information collected as part of this research study will be stored for 5 years following publication of the project. At the end of the project, it is anticipated that the results of this research project will be published and/or presented in a variety of forums.

You do not need to complete a consent form to take part in this project. If you continue to complete the survey, this means you are giving your consent.

To complete the survey, please click the following link:

<https://chere.surveyengine.com/survey/441/523>

If you have any questions, or would like further information about this project, please email or call the research team on (02) 9382 1549.

Yours sincerely

Associate Professor Michelle Farrar

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If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact the HREC executive officer, Sydney Children's Hospitals Network Human Research Ethics Committee on: (02) 9845 1253 or at SCHN-ethics@health.nsw.gov.au.

The ethical aspects of this research project have been approved by the HREC of The Sydney Children's Hospital Network Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007) – including all updates.