**PARTICIPANT INFORMATION SHEET – Parent**

**Exploring the associations between coping, resilience, well-being and glycaemic control in adolescents with type 1 diabetes and their parents.**

**What is the purpose of this research?**

This study aims to explore the relationship between the way that adolescents with type 1 diabetes (T1D) and their parents cope with stress. The study will also investigate the relationship between coping with stress and glycaemic control.

**What will the study tell us?**

If the coping of adolescents with type 1 diabetes mirrors that of their parents, it may be possible to foster adaptive coping by targeting interventions at the parents of very young children. We therefore may be able to improve both the adolescent and parent’s ability to cope with stress and potentially improve long term physical and mental health outcomes for adolescents with type 1 diabetes.

**Is there likely to be a benefit to you?**

We cannot guarantee that you will receive any benefits from this research; however, possible benefits may include an enhanced self-awareness and a positive feeling knowing you contributed to research that could improve outcomes for others in the future.

**Is there likely to be a benefit to other people in the future?**

The outcomes of this study may contribute to the development of interventions to improve the way that adolescents with type 1 diabetes deal with stress. This in turn may have a positive impact on their physical health and mental wellbeing. This project may also lead to the development of positive coping strategies for parents of adolescents and therefore impact on their wellbeing also.

**Why are we doing the study?**

We know that besides the challenges of being an adolescent, youth with T1D need to negotiate an intensive treatment regime. The challenges of adolescence and T1D can lead in some cases to poor mental health. We are undertaking this project to better understand how to prevent and reduce anxiety and mental health issues in adolescents with T1D through improving the way parents cope with stress.

**Who is organising and funding the research?**

This research project is being conducted by Children’s Diabetes Research Centre, which is a joint initiative between the Telethon Kids Institute and the Perth Children’s Hospital and is funded by a Centre for Research Excellence grant funded by the NHMRC and JDRF Australia.

**Who can be involved?**

We would like to invite adolescents between the ages of 12 and 18 years with a T1D diagnosis and their parents to participate in this study.

**Do you have to take part?**

Participation in any research project is voluntary. We will respect your decision whichever choice you make. If you decide to take part and then later have a change of mind, then that is ok and you can withdraw from the study at any stage. If you decide that you will take part in this project, we invite you to sign the form attached. Your decision whether you take part or not take part, or to take part and then withdraw, will not affect your child’s routine treatment, relationship with those treating him or her, or relationship with the Telethon Kids Institute.

**What will you need to do to take part in this study?**

Your participation in this study will involve the completion of online questionnaires. These will either be completed on a tablet device at the time of your child’s regular clinic visit or be emailed to you to complete at a time that is convenient to you. Your child will also be asked to complete online questionnaires. The questions to be completed will relate to how you and your child deal with stress and the level of anxiety you and your child experience in relation to your child’s chronic disease. We expect the questionnaires to take approximately half an hour to complete. The information you and your child provide will be examined in relation to data obtained from your child’s medical records.

**What are the possible risks and/or side effects?**

This is a low-level risk study, meaning that we do not anticipate any risks from being involved in this project. In the unlikely event you become upset or distressed because of participation in the research, we will arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff who are not members of the research project team. This counselling will be provided free of charge. You do not have to answer any questions if not comfortable with answering them.

**What if you want to withdraw from this research?**

You can withdraw your involvement at any point during the project. Withdrawal will not affect your relationship with the researchers or the Telethon Kids Institute or with your child’s clinicians. Information collected up to the point of withdrawal will be deleted from the project if that is your wish.

**Where will the collected information be kept?**

All information collected for this research project will be treated as private and securely stored. All data will be stored in a password-protected database at Telethon Kids Institute which will only be accessed by the project team.

**What about your privacy?**

As soon as the data collected is collated it will be de-identified. That is, names will be removed and the information coded so that no one can associate what has been said with anyone. Any data that is published and/or presented will be provided in such a way that individuals cannot be identified.

**What happens when the project ends?**

Should you wish to be informed about the results of the study a written summary will be provided by the primary investigator. To request a summary, please contact Dr Keely Bebbington on 6319 1766 or email Keely.Bebbington@telethonkids.org.au.

**Who has approved the study?**

The ethical aspects of this research project have been approved by the ***Child and Adolescent Hearth Service (CAHS) Human Research Ethics Committee (HREC)***. This project will be carried out in accordance with the *National Statement on Ethical Conduct in Human Research (2007)* produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies. All the researchers involved in the project have a current Working with Children Check.

**Who do you contact for more information about this study?**

If you would like any more information about this study, please do not hesitate to contact Dr Keely Bebbington at Keely.Bebbington@telethonkids.org.au. She will be happy to answer your questions. You are entitled to retain a copy of any Participant Information Form and/or Participant Consent Form related to this project.

**Who do you contact if you have any concerns about the organisation or running of the study?**

If you have any concerns or complaints about the way we ran this study, you can contact the Executive Director of Medical Services at PCH (Telephone No. (08) 6456 2222). Your concerns will be drawn to the attention of the Ethics Committee who monitor the study.

**What do you do next if you would like to take part in this research?**

If you would like to take part in this research study, please contact Dr Keely Bebbington at Keely.Bebbington@telethonkids.org.au.

**THANK YOU FOR YOUR TIME**