PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

SIBS-ONLINE: An online support program for siblings and parents who have a family member with a serious condition

Young sibling participants

Study Title	The feasibility and acceptability of SIBS-ONLINE for siblings and parents of someone with a serious neurological condition: A pilot study	
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You are invited to participate in a research study to assess an online program to support siblings and parents of individuals with a developmental and epileptic encephalopathy (DEE). DEEs are conditions which cause epilepsy and impacts on learning. They can include specific conditions such as:

- Dravet Syndrome
- Lennox-Gastaut Syndrome
- West Syndrome or infantile spasms
- SCN1A or SCN2A-related DEE

This information sheet tells you about the study. It will help you choose if you want to join or not.

1. What is this study about?

We are researchers at the University of New South Wales. Research shows siblings of individuals with a DEE can experience emotional, psychological, social and schooling impacts. Some siblings report that they are left out of important conversations with their parents and want more information about their brother or sister's illness.

This research study aims to assess an online program, **SIBS-ONLINE**, which was developed to:

A) Connect you with other siblings to share your experiences
B) Help you learn how to ask your parents questions and teach your parents how to answer
C) Provide a space for you to reflect on what you need and how your parents can help

This is the first study to assess SIBS-ONLINE for adolescent siblings and parents of patients with a DEE in Australia. SIBS-ONLINE is not yet offered in everyday care, but we hope that the results of this study will encourage this. We hope that it will connect you with other siblings who understand your difficulties and joys and help you feel supported and understood.

The results of this study will be used by Maddison Smith as part of a PhD program. We can do this study with support from a Research Fund from the Australian Government.

2. Why have I been invited to this study?

You are invited to take part in this study because you are:

- Between 12 and 18 years old
- Currently living with a brother or sister who has been diagnosed with a developmental and epileptic encephalopathy (DEE) (e.g., Dravet Syndrome, Lennox-Gastaut Syndrome, West Syndrome, SCN1A, SCN2A and others) at least 6 months prior
- Have access to a computer/smartphone/tablet and Internet connection

3. Do I have to be in this study?

You do not have to participate in this study if you don’t want to. You and your parents/carers will decide if being in this study is the right thing for you. Both you and one of your parents must take part. Even if you take part at the beginning and change your mind later and don’t want to be a part of the study anymore; that is okay as well. All you need to do is tell the researcher or your parents/carers that you don’t want to take part anymore.

4. What will happen to me in this study?

SIBS-ONLINE

You will complete the SIBS-ONLINE program with one of your parents. The sessions will take place once per week over 6 weeks on your phone, laptop or other device. You and your parent will complete the sessions on separate devices from a location that suits you best e.g., at home in your bedroom. In each session, you will be joined by 4-5 other siblings and 2 group leaders. In two of the sessions, you will speak separately with your parent, one-on-one, away from the larger group. The group leader will drop-in on these one-on-one sessions to help guide the conversations.

SIBS-ONLINE involves:

Session 1	An introduction to the intervention and other siblings (20 minutes).
Session 2	You will learn how to ask questions about your brother or sister's illness, share challenges with other siblings and write questions for your parent (60 minutes).
Session 3	A joint one-on-one session with your parent to ask them questions (20-60 minutes).
Session 4	You will focus on writing down your emotions and feelings at the moment and how your parent can help you (60 minutes).
Session 5	A second joint one-on-one session where you present your wishes to your parent (20-60 minutes).
Session 6	Conclude the program with and ask questions and provide feedback about the program.

Surveys

You will complete some online surveys that take about 20-30 minutes. It is important to collect this data so we can test whether the program helps you. The surveys include:

- Questions about yourself e.g., age, gender, etc
- Two questionnaires:
  - One about how you are feeling and behaving, like if you're having trouble with friends, feeling worried or doing well in school.
  - One about how you and your parent talk to each other, whether you feel listened to or if you argue a lot.
- Five questions about knowledge of your sibling's condition
- Some questions about your experience with SIBS-ONLINE after you have finished the program

Interview

After finishing SIBS-ONLINE, we will ask everyone who is interested to attend an online interview to discuss their thoughts about the program and give the research team feedback. The discussion should take around 30-40 minutes. This is optional.

5. Can anything bad happen?

There is a chance that you may experience some sadness, stress or other emotions when completing the surveys or the SIBS-ONLINE program. This is because you will be thinking about your brother or sister and how their illness has impacted you. If any of the questions make you feel uncomfortable, skip to the next question or section, and you can let a member of the research team know. You can also talk with your parents.

During the SIBS-ONLINE sessions, you can stop at any time by telling one of the group leaders. If this happens, a group leader will have a chat with you and we can decide how to best help you. If you want to stop the research, your parents will be told and the researchers can help you do that.

If you tell a member of the research team about your sadness, stress or other emotions, we will keep this private. We will not tell your parents unless you want us to. However, if we think you are at risk of harming yourself or others, we have to report this to your parents to keep you safe. If this happens, we can give you some ideas of who to go to for mental health support.

This study is monitored by a trial management group, to make sure that everyone involved is safe.

6. What will I get from the study?

We hope that by participating in SIBS-ONLINE, you will feel more comfortable having conversations with your parents about your feelings. You will also help us improve a future program that may help other families in Australia. Access to SIBS-ONLINE is currently only available in Australia by participating in this study.

We want you to feel like your voice is valued and heard. To show our appreciation for the time you are taking to complete the extra surveys and interview (optional), we will provide you with $20 for each survey and $30 for the optional interview. The amount depends on how much of the study you complete e.g., if you complete all surveys and the interview, we will provide you with $90.

7. What will happen to my information

We will collect written information about you using online surveys and video/audio-recorded information from SIBS-ONLINE sessions and optional interview. Your information will be protected at all times in this study. We will not release any information to anybody outside of the research team that could be used to identify you, unless we are required to do so by law. For example, researchers are required to report if a participant is believed to be at risk of harm.

The study team will remove any information that may be used to identify you from any study documents. Instead of your name on study documents, you will be identified by a specific study code number that applies only to you. Your identity as part of the study will be kept completely private. Only the study team listed will have the ability to link this code number with your personal information, and the linking information will be kept on a password-protected database. Your data will be stored for a minimum of 15 years after the study finishes or until the youngest participant turns 25.

If you decide to leave the study, we will not collect any more information about you. We can delete any questionnaire and interview data already collected. Please tell a member of the research team if you want your data removed. However, we will be unable to remove your data from the SIBS-ONLINE groups once you have participated, as these are group discussions.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the UNSW Privacy Management Plan.

8. What will happen to the study results?

We would like to share the study results by publishing them in journal articles and presenting them at different conferences.

You can also tell us on the consent form if you want to receive a simple summary of the study findings at the end of the project.

9. Who should I contact if I have any questions?

If you have any questions or want more information about this study before or during participation, you can talk to:

Maddy on maddison.c.smith@unsw.edu.au (PhD student)

Lauren Kelada on +61 2 9065 2902 or l.kelada@unsw.edu.au (Principal Investigator)

You can also ask your parents/carers to talk to us. Both you and your parent will sign a consent form.

10. Who do I contact if I have concerns about the study?

All research in Australia involving humans is reviewed by an independent group of people called an ethics committee. This study has been approved by the University of New South Wales HREC (iRECS8910).

Please talk to your parents/carers if you are worried about being in this study, or you have a complaint. You or you parent can talk to:

Position	UNSW Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
HC Reference Number	iRECS8910

Here is a list of support services you can access at any time if you are feeling worried or distressed.

- Lifeline, If you are experiencing a personal crisis or have suicidal thoughts, 13 11 14
- Kids Helpline, For a free, private and confidential phone and online counselling service for young people aged from 5 to 25, 1800 551 800
- 13Yarn, for an Aboriginal or Torres Strait Islander Crisis Support Line, 13 92 76
- Headspace, to chat with a clinician, for young people aged between 12 and 25 experiencing mental health issues (https://headspace.org.au/)