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Information Statement for children & adolescents participating in the Research Project:

Genetic disorders in children: An assessment of familial coping strategies and positive growth.

Document version 2, dated 20/05/2015

The research project is conducted by Dr Linda Campbell at the University of Newcastle.

Why is the research being done?

When a child has 22q11.2 deletion syndrome / VCFS, it affects everyone in the family. Some people manage well and others find it really tough. We would like to find out what it is like to have a sibling with 22q11.2 deletion syndrome / VCFS. We would like to meet with kids, teenagers, and adults who have a sibling with 22q11.2 deletion syndrome / VCFS. We will be asking you some questions about how you are dealing with things. We will also ask about the nice things (and hard things) about having a sibling with 22q11.2 deletion syndrome / VCFS.

Who can participate in the research?

In this study we are asking people who have a sibling with 22q11.2 deletion syndrome / VCFS who are aged 12 years or older to participate in the study. You must live in the Sydney or Hunter regions of NSW.

What choice do you have?

It's your choice if you want to take part or not, and you and your parent/guardian will sign a form if you are happy to take part after you have read this information sheet. If you have any more questions you can always ask us over the phone, by email or when you meet us. If you decide not to take part in the study that is fine, you can also stop taking part in the study at any time without us asking why. You do not have to take part in all aspects of the study if you don't want to. Sometimes, the researchers might stop the study too. If this happens, the researcher will explain why and let you know if you need to do anything else. You can do the interview with or without your parent in the room. It is your choice. If your parent is not in the interview with you, we will not tell your parent what we have discussed. This is because the interview is confidential. If you decide to withdraw from the study, you have the option to withdraw all data including the interview

relating to you. That means we will get rid of anything you have done for us. The only time we can't get rid of your information is when there is an "adverse event", or "serious adverse event", where the information needs to be kept for regular reporting. These kinds of events don't usually happen, but if one does, we'll let you know.

What would you be asked to do?

1. Firstly, we talk to you or your parents you to see if you can take part in our study. We will also ask you and your parents or guardian about you and your sibling with 22q11.2 deletion syndrome / VCFS, for example how old you are.
2. We will then come and talk to you about you what it is like to have a sibling with 22q11.2 deletion syndrome / VCFS. We will record this conversation and it will take about 1 hour. Some of the questions might be, "*What are the hardest parts about having a sibling with 22q11.2 deletion syndrome / VCFS?*" and "*What are the easier or nicer parts about being having a sibling with 22q11.2 deletion syndrome / VCFS?*"

You are of course welcome to take a break from the interview at any time if you want to. You do not have to answer any questions if you don't want to.

What are the risks and benefits of participating?

Your participation will help us to understand what it is like for siblings whose brother or sister has 22q11.2 deletion syndrome / VCFS. **However, there are no immediate benefits to participating in the study.**

Talking about your sibling might make you feel sad. If you do feel upset, you can stop the interview at any time. If you want to speak to someone about these feelings, you can contact Headspace. They support young people who are having a hard time:
<https://www.eheadspace.org.au/> or 03 9027 0100

Or you can call the Kids Helpline on 1800 55 1800.

How will your privacy be protected?

We will keep your information secret. We won't tell or show anyone any information we have about you, unless you let us.

How will the information collected be used?

We plan to publish the results in a scientific journal, which will be available sometime after study completion. This is like an article in a magazine, except that it is for doctors and other people who work in health. You won't be able to find anything that is just about you because the article will be about lots of children like you who have taken part. If you would like a copy of the article, you can ask us for one. If you would like, we can give you an easy-read summary of the study results once our study has been completed.

We will store your information in paper copy and computer file. We will remove any information that can identify you (such as your name and date of birth) and give all of your data a special code. Only individuals with ethics approval will have access to your information. It is possible that we may wish to use your data in future studies and/or share it with other researchers, but we will only do this if you let us. We will keep your information on file for a period of 7 years, or until we have no further use for it. At this time, your information will be permanently deleted or shredded.

What do you need to do to take part?

Please read this Information Statement and be sure you understand what you will have to do before you consent to participate. If there is anything you do not understand, or you have questions, please ask us.

If you would like to take part, please ask your parent/guardian to complete the attached Consent Form together with you and return it in the reply paid envelope provided. We will then contact your family to arrange a time when we can come and interview you.

How will we reimburse you?

We will give you/your parent a gift voucher for \$20 as compensation for your time spent participating in the study.

Yours sincerely,



Linda Campbell

Complaints

This project has been approved by the University of Newcastle Human Research Ethics Committee, Approval No. H-2012-0129.

Should you have concerns about your rights as a participant in this research, or if you have a complaint about the manner in which the research is conducted, you can either contact Dr Linda Campbell directly on email: Linda.E.Campbell@newcastle.edu.au, or contact an independent person at the Human Research Ethics Office, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia by phone: (02) 49216333 or email: Human-Ethics@newcastle.edu.au.