CATNAP: The Childhood Ataxia Telangiectasia Neuroimaging Assessment Project

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Study Information Sheet

We are asking you if you would like to take part in our research project to help us to better understand your medical condition called A-T (A-T stands for Ataxia-Telangiectasia).

Before you decide if you want to take part, it is important that you understand why we are doing this research and what we will ask you to do. This is why we want you to carefully read this leaflet. You can ask us all the questions you want to find out more. Also talk to your family, friends, doctor or nurse about this study if you wish.

Why are we doing this research?

To find new treatments for A-T we need to understand A-T better. In this study we will try to understand how A-T affects the brain by using a powerful but harmless type of scanner called an **MRI scanner**. The MRI scanner will allow us to look at your brain and make measurements of its healthiness. We think that these measurements may be very helpful in making and testing new treatments for A-T.

Why have I been invited to take part?

You are being invited to help us with this research because your doctors have diagnosed you with A-T. We will also ask 30 other children with A-T to take part.

Do I have to take part?

No. It is up to you. If you chose to help us, we will ask you for your agreement, and your parents or carer will be asked to sign a form to say that they also agree to you taking part. You are free to opt out at any time during the research without giving a particular reason. If you decide to stop, this will not affect the care you receive.

What will happen to me if I take part?

If you agree to take part, we will invite you to come to the Queens Medical Centre.

Before your visit we will send you an internet link to a short cartoon that explains what happens when you have an MRI scan. As this is a new film made especially for us, we would like to ask you for your thoughts on the film, and whether it helped in preparing for the scan.

When you arrive we will begin by showing you our MRI scanner. The MRI scanner can be used to take pictures of the inside of your body. But don’t worry, an MRI is harmless and you won’t feel a thing. Once you are happy and asked us all the questions you like about the MRI we will ask you to take part in a MRI scan. In the MRI scanner you will be lying comfortably on a bed for 30 to 40 minutes while we take images of your head. Because MRI scanners are a bit noisy you will be given headphones and earplugs to wear. You can also listen to music during the examination. If you wish, your parents can stay with you at the MRI machine for the scan.

The MRI scanner at QMC that will be used for the study

After the MRI exam, one of the doctors will do an examination to see how the A-T affects you, much like in a normal clinic appointment. Afterwards you are all done and free to go home.

What are the possible risks of taking part?

The MRI machine is like a very big and very strong magnet. Any metal will stick to it. Before we do the MRI scan we will make sure you don't have any metal on you and it is safe for you to go in the MRI.

What are the possible benefits of taking part?

We cannot promise the research will be of help to you, but the information we get might allow us and other researchers to develop a treatments for children with A-T.

What happens when the research study stops?

Your care will continue as usual.

What if there is a problem?

We take any complaint you may have very seriously. Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be investigated fully.

Will anyone else know about my participation?

Your information will be treated in the strictest confidence. This means we will only tell those who need to know or have the right to know. Wherever possible, we will only send out information that has your name and address removed

Who is organising and funding the research?

The study is being organised by members of the University of Nottingham and the Nottingham Children's Hospital. The study is jointly funded by the Ataxia Telangiectasia Children's Project and Action for A-T. This study is supported by the Ataxia Telangiectasia Society.

Who has reviewed the study?

Before any research goes ahead it has to be checked by a Research Ethics Committee which will ensure that the research is fair. This project has been checked by the Derby NHS Research Ethics Committee.

Thank you for reading this – please feel free to ask any questions you may have!