

Will anyone else know I am taking part in the study?

Only the doctors doing the study, your teachers, and doctors who normally look after you will know that you are taking part.

What if I have any questions about the study?

If you have any questions, you can ask your parents or the doctor that told you about the study. If you have questions that they can't answer, then you can contact:

Amy Burns or Ami Brooks

Telephone: 07919 528164/ 0161 306 7953

Dr Emma Burkitt Wright

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Understanding the disorders of the RAS-MAPK pathway

Information sheet



Investigators:
Dr Emma Burkitt Wright
and Dr Bronwyn Kerr

Why is this study being done?

We want to find out more about your condition, to better understand how it affects you and people like you, and what might be helpful for it.

Why have I been chosen?

Your doctor has said that you have Noonan Syndrome, Cardio-facio-cutaneous Syndrome or Costello Syndrome, or a condition very similar to these.

Do I have to take part?

You do not have to take part in this study. You and your family can take time to discuss and decide if you want to take part. If you do decide to take part, both you and your parent or carer will be asked to sign a consent form, but you can change your mind about taking part at any time.

Has anyone said it is OK to do this study?

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure the research is fair. The Northwest Research Ethics Committee has said it is ok to do this study. Your Mum and Dad, or another person who looks after you, will also be told about the study and asked if it is OK for you to take part.



What will happen to me if I do take part?

We will ask you, your mum or dad and your doctor some questions about your health. We would then look at you, as happens when you go to your own doctors, and might ask to take some photographs of you. We would then ask you to play some special laptop computer games, which we would explain at the time. If you find it tiring, then you can stop for a rest in the middle. We will also ask you and your parents whether we can ask your teachers about your concentration at school.

What else might happen to me?

There may be a sample from a previous blood test that you had that we can use for the study. If not, we might ask you to have a blood test, but we can use some special cream so that it doesn't hurt. We might also be able to use a special sample of your spit instead.

If you are having an operation, then we might also ask the person doing the operation for a tiny piece of tissue to look at in the study as well. This would not make any difference to the operation or your recovery afterwards.

Any samples that are taken will be stored safely.

Will the study help me or my family?

Information from the study might help us to understand why your condition and conditions like it happen. This may mean we can give better help and advice to people with conditions like yours in the future.