

BENDY

The best way to treat
benign joint hypermobility syndrome (BJHS) in children research study



Before you decide if you want to join in it's important to understand why the research is being done and what it will involve for you. So please read this leaflet carefully. Talk about it with your family, friends, doctor or nurse if you want to.

What you need to know about the research

Your doctor thinks that you may have a problem with your joints called 'Benign joint hypermobility syndrome' (BJHS). You may be very flexible and have uncomfortable joints.

We are asking if you would take part in a research project to find the answer to the question... 'what is the best way to treat benign joint hypermobility (BJHS) in children?'

Why is this project being done?

Research is a way we try to find out the answers to questions about health and illness. We want to see if one way of treating the condition you have is better or worse than another way of treating it.

Who is doing it?

This research is being done by some of the people that look after you at the hospital and some other people from the University.

Why have I been asked to take part?

You have been asked to take part because we are asking all children aged between 5 and 16 years old who have (or may have) BJHS.

Did anyone else check the project is OK to do?

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 that the research is fair.



Do I have to take part?

No. Taking part in research is voluntary. This means it is up to you and your parents/guardians to decide whether or not you would like to take part. This leaflet has been given to you to help you decide.

What will happen to me if I take part in the research?

If you take part in this study you will need to come to the hospital for STUDY VISITS and you may also have to come for TREATMENT VISITS.

First you will come to the hospital to see a physiotherapist. We call this STUDY VISIT 1. The physiotherapist will look at how your joints move and will ask you and your parents or carer to fill in some questionnaires. You can have some help to do this if you want.

After this, if you want to carry on the research you will be put in one of two groups; either the 'standard treatment' group or the 'structured treatment' group. You will not be able to choose which group you are in. This will be decided by chance, a bit like flipping a coin. You will not meet any of the other young people in your group or the other group.

What happens if I am in the STANDARD TREATMENT group?

If you are put in this group, you will already have come to hospital to see the doctor and get some advice about your BJHS, so you will not have any more treatment visits unless you have any problems which mean that you need to see a doctor again. This is what would normally happen to children with BJHS.

What happens if I am in the STRUCTURED TREATMENT group?

If you are put in this group, you will have 4 TREATMENT VISITS - 3 at the hospital and 1 at your home, with a physiotherapist and an occupational therapist. In these visits you will be given some help and advice about dealing with BJHS and shown how to do some strengthening exercises that you can do at home. The therapists will also contact your school to give your teachers some advice about how to help you and see how you are getting on.

If you are in either group - you will come back to the hospital after 3 months to see the physiotherapist, and again after 12 months (STUDY VISITS 2 and 3). This is to talk about you, your exercises and what you think of them. We also want to see if your BJHS has got better, worse or stayed the same. This will be done by asking some more questions and looking again at your joints. We may contact you when you have finished STUDY VISIT 2, to ask if you would like to take part in another study that will ask you about your experiences of this research.



Is there any other treatment I can have instead?

Yes. If you decide not to take part in the research, you will be treated in the way that the doctor usually treats children with BJHS. That would be one visit to the hospital to get some advice from the doctor.

Will taking part in the research help me?

We cannot promise the research will help you but we hope that the information we get will help us to give young people with BJH the best treatment in the future.



What happens when the research stops?

After the research stops, your doctor will carry on looking after you whenever you need help and advice.

What if something goes wrong during the research?

We don't think anything will go wrong but if it does, the doctors, physiotherapists and occupational therapists who are carrying out the research will do everything they can to sort the problem out and will explain everything to you and your parents/guardian.

Will anyone else know I'm doing this?

We will keep your information in confidence. This means that only those people who need to know about you taking part in the research will be told. This would include the team who are doing the research and your family doctor (GP).

What if I don't want to do the research anymore?

If at any time you don't want to do the research anymore, just tell your parents, doctor or nurse. They will not mind. Your doctor will continue to look after you .



If you would like more information about this research project please contact:

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