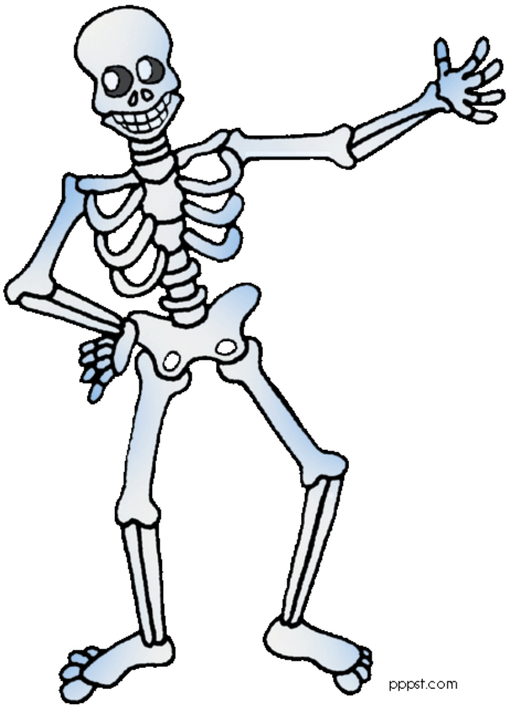
BENDY

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

What you need to know about the research



Your doctor has diagnosed you with a condition with your joints called 'Benign joint hypermobility syndrome' (BJHS). This means that you may have extra flexibility and some pain in your joints.

We are asking if you would like to take part in a research project to find the answer to the question… 'What is the best way to treat BJHS in children?

> 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.

Why is this research 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 project is being done by a team of healthcare professionals and researchers from the Norfolk and Norwich hospital and the University of East Anglia.

Why have I been asked to take part?

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

Did anyone else check the research is OK to do?

Before any research is allowed to happen, it has to be checked by a Research Ethics Committee. They make sure that the research is fair.

Do I have to take part?

No. Taking part in the research is entirely voluntary. It is up to you and your parents/guardians to decide whether or not you would like to take part. Please read this leaflet carefully to help you decide.

What will happen to me if I decide to 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 collect some information by asking 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 with 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.

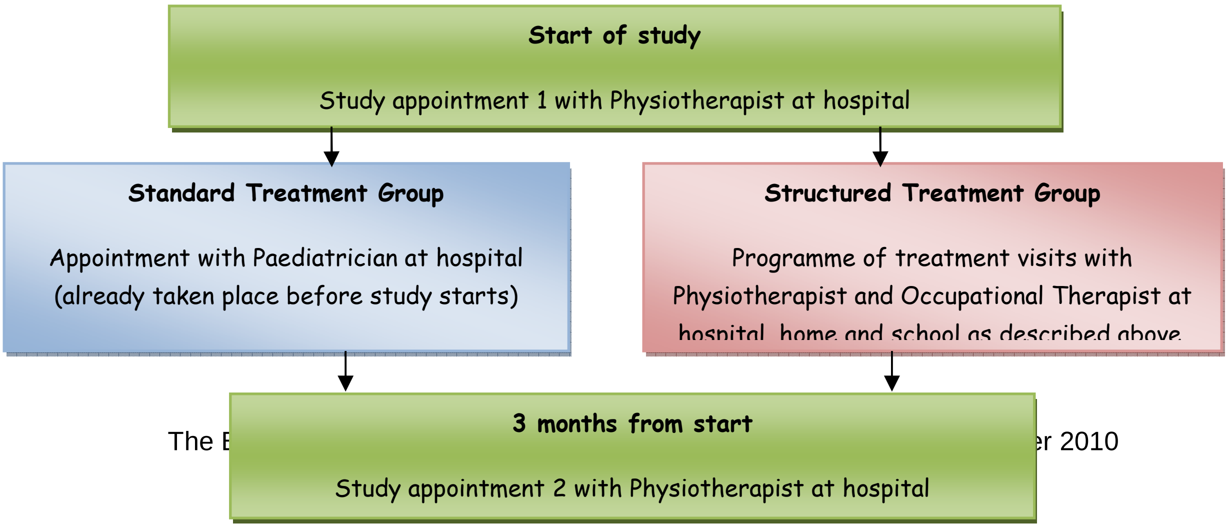
What will happen if I am in the 'STANDARD TREATMENT' group?

If you are put in this group, you will already have come to hospital to see the doctor when you were first diagnosed with BJHS to get some advice, so no more treatment visits will take place unless you have any problems which mean that you need to see a doctor again. This is what would normally happen to young people with BJHS.

What will happen 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 to 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 or 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 another sort of treatment I can have instead?

Yes. If you decide not to take part in the study, you will be treated in the way that the doctor usually treats young people with BJHS. That would be a visit to the hospital to get some advice from the doctor and more visits if you need them.

Will taking part in the research help me?

We cannot promise the study will help you but we hope that the information we get will help us to give young people with BJHS 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 won't mind. Your doctor will continue to look after you.

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

Professor Alex MacGregor

Consultant Rheumatologist

Norfolk & Norwich University Hospital

Tel: 01603 593570