Participate in Research Bone Fragility in Boys with Duchenne Muscular Dystrophy



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Do you have Duchenne Muscular Dystrophy and are treated with Deflazacort? Consider participating in an observational research study about bone health

What is this study about:

This study is to understand more about how and when bones weaken in DMD resulting in a break of a bone. This will help develop better guidelines on how to monitor bones in DMD. We need this information to develop treatment for weak bones in DMD. Your participation will help us understand bone health in DMD.

Who can participate?

We are looking for boys with DMD

- Between 4 and 25 years of age
- Treated or about to start treatment with Deflazacort
- Are not treated with specific bone medications i.e. bisphosphonates
- Do not have another condition that affects bone health

What's involved?

The study has 2 visits one year apart that will occur at the same time as your neuromuscular clinic visit. It will add about 1 hour to your regular visit.

- You will have your regular bone density and x-ray to look at your bones
- You will be asked to answer questions about fractures, your diet, pain and quality of life
- Bloodwork will be drawn at both study visits

What are the risks?

Blood drawing may cause soreness or bruising at the site of the needle. Rarely, bleeding under the skin or an infection may develop. Some questions in the questionnaires may make you feel uncomfortable or upset. You do not have to answer anything you don't want to.

What are the benefits?

Participation in this study may not benefit you directly but will help determine when fractures occur in DMD and help guide decisions about when we should treat weak bones.

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