
From a lady in Ohio

Posted by awalk - 2007/04/24 23:22

This was originally posted on the old site.

Hi, Thank you so much for your site!! I've been trying to find more information about LDS and your site was extremely helpful. They suspect my children and I have Ehlers Danlos, but I'm really wondering if it is actually LDS. We have many features of the vascular ED but we don't totally fit the description. I had a genetic test for the ED IV but it came out negative.

I've found one picture of LDS (the one on your site), but I was wondering if you'd be willing to share some of your son. My children look a lot like that little girl, but I'd like to see more for comparison. My son was born with severe bilateral clubfeet, his head was abnormally bony and his bones closed early (although we did not have any problems related to it). He doesn't have the split uvula but he has a very high palate and pointy chin. He's got the wide space between his eyes. He's also got diastasis recti and GI reflux. We are being referred to a cardiologist because he often looks dusky on his face and his facial and neck veins are becoming really pronounced (especially the one side of his neck).

Do you know if this is found in adults too or only children?

Thanks so much for your help and your site!

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Re:From a lady in Ohio

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If you go to the "links" portion of the website and look at the article from the New England Journal article, there are multiple pictures there of both children and adults.

It'd be a good idea to talk to your geneticist about testing (blood test). I'd be happy to try and answer any other questions you might have privately at goswald1@jhmi.edu

Gretchen--genetic counselor, Johns Hopkins University

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