



March 10, 2015

## CLOVES Syndrome Community NIH Survey Update



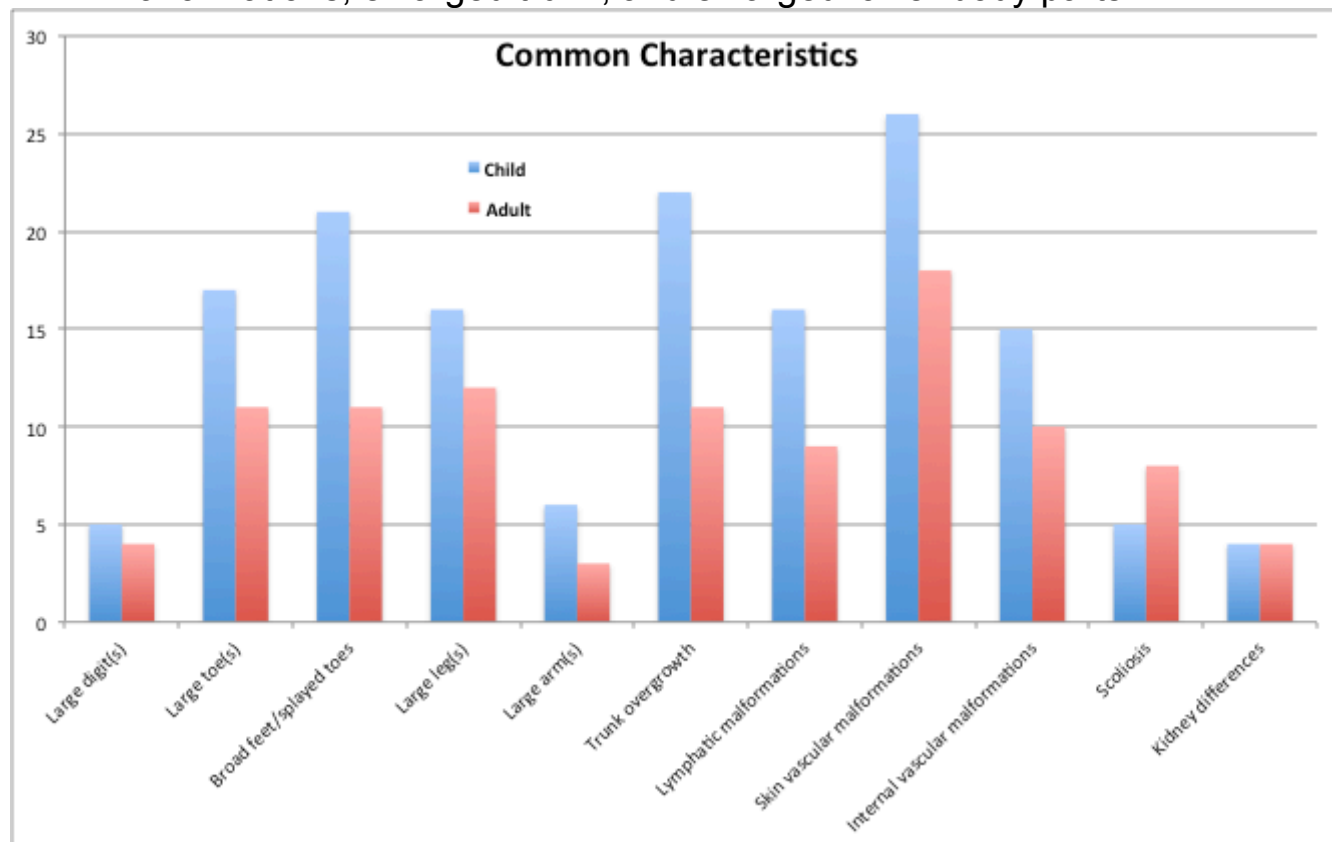
Hello!

On behalf of the National Institutes of Health research team, we would like to say **thank you** for your help in gathering valuable information about your community.

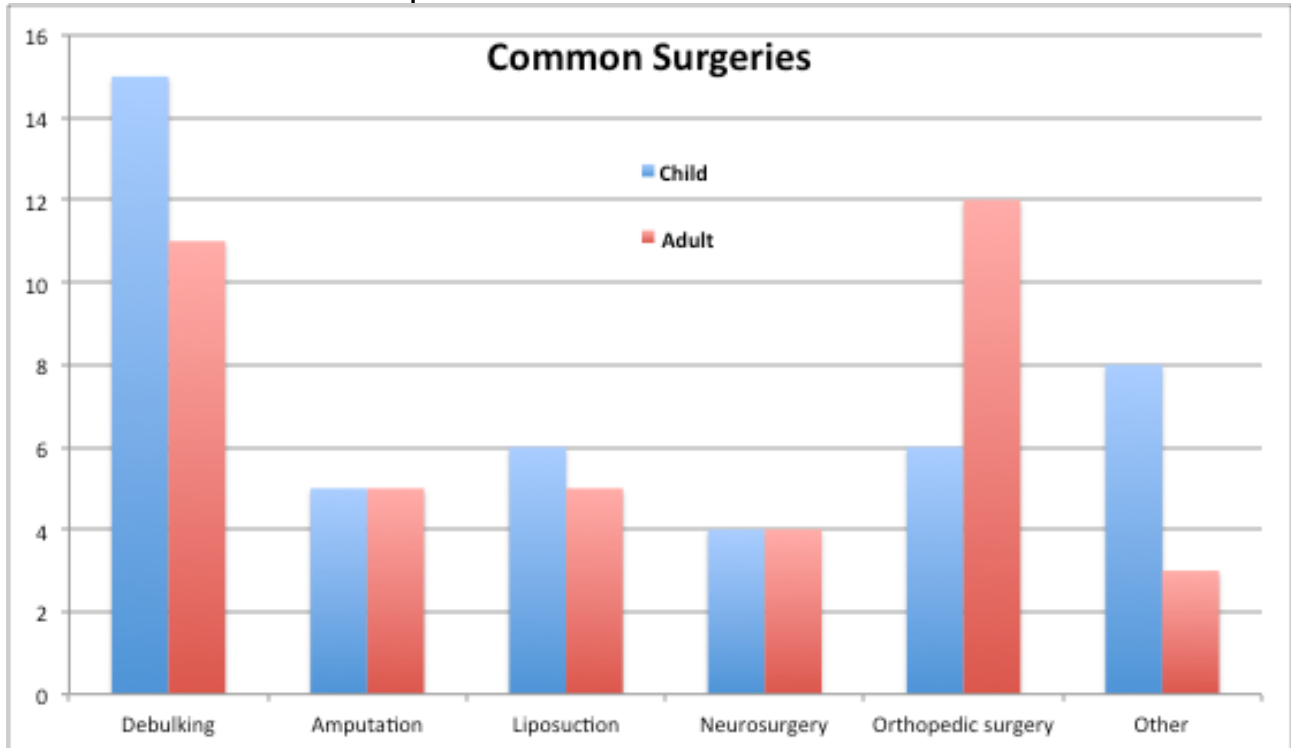
Since June, 2014, we have received **68 total responses** to the survey about your community. We will continue to have the **survey open until June, 2015**, so you still have a chance to participate if you would like.

Some of the most important findings so far are below:

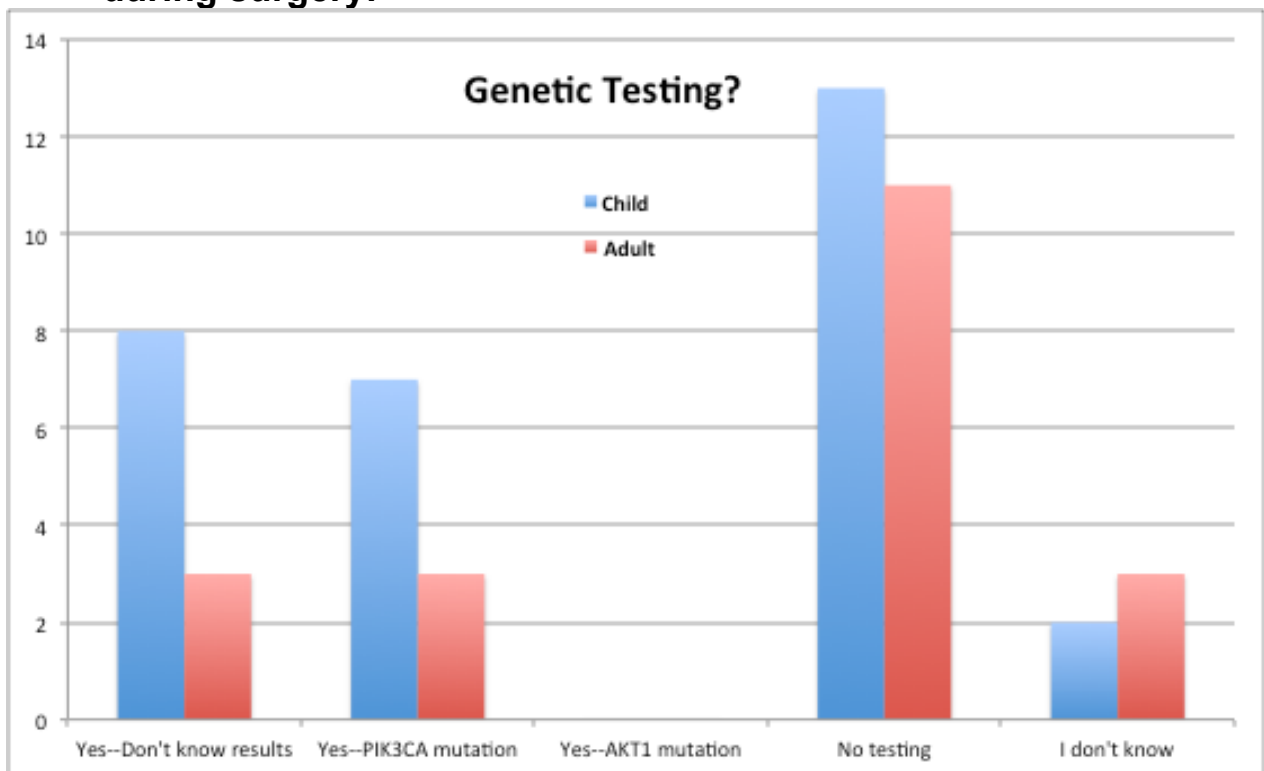
- 1) The most common features in your community include vascular malformations, enlarged trunk, and enlarged lower body parts.



2) **Surgery is very common** in your population, with debulking being the most common procedure.



3) There is **genetic testing available** for CLOVES Syndrome, and all that is needed is tissue from an affected area. **This can be taken during surgery!**



In sum, we are most thankful to all of you for your help in obtaining this valuable data. Please let us know if you have any questions or would like more information. The survey will be available until June, 2015 at the following link: <https://www.surveymonkey.com/s/G3L3FCS>.

Best,

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