



CLOVES SYNDROME COMMUNITY

SUPPORT - EDUCATION - HOPE - EMPOWERMENT

Dear Friends and Families with CLOVES Syndrome:

CLOVES Syndrome Community is pleased to announce that the National Institutes of Health/NIH (the organization that studied and discovered the genetic mutation for Proteus Syndrome), **has expanded their eligibility criteria to include CLOVES Syndrome and related conditions**. People with these conditions may be eligible to join this study.

The goal of the NIH is to better understand the range of medical concerns patients with overgrowth conditions have, so that we can improve our understanding of how these conditions may change over time, and develop more effective treatments for patients. The NIH is also very interested in understanding the genetic causes of overgrowth; and they will test blood and tissue samples for gene changes known to cause overgrowth and provide the results of this testing to families.

If you are interested in learning more, please check out the “Questions and Answers” document created by the NIH on the Research page of our website. Families may participate in research with the NIH by sending in samples through the mail or by visiting the NIH Clinical Center for an in-person evaluation. Participation is free and the NIH can cover most of the costs associated with participation, including shipment of specimens, and travel, lodging, and food expenses associated with an NIH visit.

The NIH will be hosting informational conference calls for families who are interested or have questions about the study, a few times during the month of May. If you'd like to participate, please email Kristen Davis at clovessyndrome@gmail.com so we may help organize/plan those conference calls with the NIH. A new research assistant with the NIH, will be available to answer questions, beginning in June, at the phone number listed on the FAQ

Best wishes!

Kristen Davis

Executive Director

CLOVES Syndrome Community

