



National Human Genome Research Institute
National Institutes of Health
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Ms. Kristen Davis
Executive Director
CLOVES Syndrome Community
PO Box 406
West Kennebunk, ME 04094

Re: NIH Overgrowth Study

Dear Ms. Davis,

We are pleased to announce that we have expanded the eligibility criteria of our study of overgrowth conditions at the National Institutes of Health (NIH). Since our study began over 10 years ago, we have made significant progress in improving our understanding of the cause and treatment of Proteus syndrome and we hope to make similar progress by learning about other overgrowth conditions such as CLOVES syndrome, hemihypertrophy multiple lipomatosis (HHML), macrodactyly, and fibroadipose overgrowth. Patients with any of these other overgrowth conditions may be eligible to join this study and we hope that you will consider passing along information about our study to your members.

We hope that the attached "Questions and Answers" document will provide helpful information for your members as families consider participating in our study. Families may participate by sending in samples through the mail or by visiting the NIH Clinical Center for an in-person evaluation. Participation is free and we can cover most of the costs associated with participation, including shipment of specimens, and travel, lodging, and food expenses associated with an NIH visit.

Our goal 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. We are also very interested in understanding the genetic causes of overgrowth; we will test blood and tissue samples for gene changes known to cause overgrowth and provide the results of this testing to families.

We may only enroll limited numbers of families in this study and not all who wish to participate will be able to. If you think that your members may be interested in our study, please pass along our contact information and we would be happy to discuss the details of the study. We can be reached by calling (301) 435-6689.

Sincerely,

Julie Chevalier Sapp, ScM, CGC
Genetic Counselor

Leslie G. Biesecker, MD, FACMG
Clinical Geneticist