

June 23, 2022

Dear HTC Healthcare Providers

Dr. Courtney Thornburg and her research team at Rady Children's Hospital-San Diego (RCHSD) Hemophilia Treatment Center are conducting a research study about shared decision-making for hemophilia gene therapy. The study is funded by the National Hemophilia Foundation Innovative Investigator Award and BioMarin Pharmaceuticals.

The study is designed to develop shared decision-making tools that can be used in clinical discussions with patients with hemophilia who may be eligible for gene therapy. Dr. Thornburg and her research team developed a prototype of the Clinician Decision Box tool, and they are looking for feedback from HTC healthcare providers prior to pilot testing with patients. The research involves reviewing the tool and providing feedback during a 45-60 minute interview by telephone or video conference with a member of the research team. Participants who complete the interview will receive a \$100 electronic gift card to compensate for their time.

You are being asked to participate in this research study because you have been identified as a provider to patients with hemophilia. Participating in this research study is voluntary. If you do not want to participate in this research study, you can ignore this request. If you would like to participate, please contact our team via e-mail at: htcstudy@rchsd.org or via phone at: 858-966-1700 x 227376 or complete this four-question form to provide your contact information to the study team.

Please click here to complete the form:

https://ucsd.co1.qualtrics.com/jfe/form/SV_cTKr5wJN7SfuaXQ

Thank you for your participation and contribution to the bleeding disorder community!

Sincerely,

Courtney Thornburg

Rady Children's Hospital San Diego Hemophilia Treatment Center