

Jimmy Holder, MD, PhD
1250 Moursund St., Suite 1150
Houston, TX 77030

November 1, 2017

Dear RettSyndrome.org registrant,

This letter is being sent to registrants of the Rett Syndrome Registry. We are conducting a study to determine individual and family quality of life in three neurodevelopmental disorders: Rett Syndrome, Phelan-McDermid Syndrome and *SYNGAP1* related disorder. This is a comparative study for these disorders and not part of the Rett Syndrome natural history study. For the study, we will ask you to complete a web-based survey which will take approximately 15 minutes. Your child may be eligible for this study if he/she has been diagnosed with Rett syndrome.

This study is voluntary and your child can drop out at any time without penalty to your child's healthcare.

If you would like to participate in this study, please proceed to the link for the survey at
https://baylor.qualtrics.com/jfe/form/SV_7ZC1GYeDBVHSZsV.

If you have any questions about this study, please contact the study investigator, Jimmy Holder, MD, PhD holder@bcm.edu. If you are not interested in participating, please feel free to disregard this letter.

Thank you for your consideration.

Sincerely,

Jimmy Holder, MD, PhD
Assistant Professor of Pediatrics
Baylor College of Medicine