



Statement on Angelman Syndrome Natural History Study during the COVID-19 Pandemic

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Dear Angelman Syndrome Community,

We hope you and your loved ones are well during these uncertain and anxiety-provoking times. As you are probably aware, all of the institutions that are involved in the ongoing Angelman Syndrome Natural History study have suspended non-urgent clinical operations, including all elective surgeries, clinic visits, and research visits, until the pandemic is under control and the physical distancing recommendations are lifted. While we hope that research visits can be conducted again from May-June 2020 onwards, no one knows when normal operations will resume at each institution.

We greatly appreciate your ongoing support of our study. The health and safety of our families is paramount, so we will not be having in-person visits until it is safe to do so again. We plan to **continue with the Angelman Syndrome Natural History study by completing the questionnaires and standardized assessments that can be performed remotely** via telephone calls, Skype, Zoom, or other means. We appreciate that your schedules may be unpredictable right now, but our study teams will work with you and your family to arrange remote visits at your convenience. Once we are able to, in-person visits will resume to enable us to complete the components of the study that could not be performed remotely such as a physical examination and development assessments.

We understand that this is a highly stressful time for all of you, but we hope that you will continue to support this study, which is generating critical data that will contribute to the development of new treatments for Angelman syndrome.

Thank you very much for your continuing support. Please feel free to contact me or Catherine Merton (catherine.merton@childrens.harvard.edu) if you would like us to provide additional information or have further questions.

Stay safe and well

Wen-Hann Tan, on behalf of the Angelman Syndrome Natural History Study Team

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