



March 23, 2020

Dear Rett Community,

As a result of the many uncertainties surrounding the coronavirus (COVID-19) pandemic, we wanted to provide you with an update on the trofinetide Phase 3 LAVENDER study.

The health and safety of clinical study patients, caregivers, investigator staff and all study partners are paramount. ACADIA is taking proactive steps to advance our research programs considering guidance from the U.S. Food and Drug Administration (FDA) and local policies during this public health crisis to protect the safety of patients and the integrity of the clinical trial data. At this time, we are not planning to enroll new patients in the LAVENDER study until we believe we have the ability to collect data from new patients while ensuring their safety. This modification does not impact patients already enrolled in the LAVENDER study.

As we have shared before, both LAVENDER and LILAC are progressing, and most study sites are open. LAVENDER is a 12-week study that will evaluate the efficacy and safety of trofinetide and placebo in approximately 180 girls and young women aged 5 to 20 years with Rett syndrome. All girls and young women completing the LAVENDER trial are eligible to enroll in the LILAC study, a 40-week extension study in which all participants receive trofinetide and are followed to evaluate long term tolerability, safety, and effectiveness of the drug.

If you have visited the LAVENDER study web site (www.rettsyndromestudies.com) and registered interest in participating, your information has been appropriately recorded and passed on to the closest clinical study site available.

If you have any questions about trofinetide, please contact us at medicalinformation@acadia-pharm.com.

Thank you for your continued support, and we wish you and your families well during this unprecedented time. For additional information on how ACADIA is responding to the COVID-19 pandemic, please visit www.acadia-pharm.com.

All our best,
The ACADIA Rett Team