



June 15, 2020

Dear Rett Community,

We hope you and your families are doing well during this challenging time. We appreciate your patience as we navigate the coronavirus (COVID-19) pandemic.

As the nation begins to reopen its doors, we remain committed to the health and safety of all patients, families, caregivers and clinical staff participating in the ongoing LAVENDER and LILAC studies. We are working closely with clinical sites and study investigators to take all necessary precautions identified through local and national guidance. In addition to protecting the health of study participants and clinical staff, we are also taking appropriate measures to safely and effectively collect patient data to ensure the integrity of study results.

In light of these collaborative and protective measures, as well as the easing of restrictions throughout the country, we are pleased to announce that we are re-initiating enrollment in the Phase 3 LAVENDER study. Each site will begin enrolling again on its own timetable based on the availability of staff, their site-specific policies, and an agreement on the site's plan for the safe conduct of clinical study visits.

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.

To learn more about the LAVENDER study and determine interest in participating, you can visit the study website at www.rettsyndromestudies.com or the [LAVENDER study page](#) on clinicaltrials.gov. If you have already registered, your information has been appropriately recorded and passed on to the closest clinical study site available.

If you have any questions about trofinetide or enrolling into the LAVENDER study, please contact us at medicalinformation@acadiapharm.com.

Thank you for your continued support and we hope you and your families are healthy and safe. We will continue to provide updates as appropriate.

All our best,
The ACADIA Rett Team