

March 31, 2021

Dear Rett Community,

We are pleased to announce the opening of four new clinical trial sites for the Phase 3 LAVENDER study in:

- Seattle, WA (Seattle Children's Hospital)
- Chapel Hill, NC (University of North Carolina)
- Baltimore, MD (Kennedy Krieger Institute/ Johns Hopkins School of Medicine)
- Bronx, NYC (Montefiore Medical Center)

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

ABOUT THE LAVENDER AND LILAC CLINICAL TRIALS

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.

COVID SAFETY PRECAUTIONS

Your family's health is our priority. 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.

SUPPORT FOR TRAVEL

Travel assistance and reimbursement may also be available for volunteers that do not live near a research site.

FURTHER INFORMATION

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

All our best,

The Acadia Rett Team