



July 31, 2019

Dear Rett Community,

We are pleased to update you on the progress of the trofinetide LAVENDER and LILAC clinical studies. The LAVENDER study, which remains on track to begin in the fourth quarter of this year, is a 12-week, Phase 3 study that will evaluate the efficacy and safety of trofinetide and placebo in approximately 180 females aged 5 to 20 years with Rett syndrome. The LAVENDER study will be followed by the LILAC study, a 40-week, open-label extension study, in which all participants will receive trofinetide and be followed to evaluate long term tolerability and safety of the drug.

At this time, we can confirm that the following 16 cities will have clinical study sites for the LAVENDER and LILAC studies with additional cities possibly added later this year.

- Aurora, CO
- Baltimore, MD
- Birmingham, AL
- Boston, MA
- Chicago, IL
- Cincinnati, OH
- Cleveland, OH
- Greenwood, SC
- Houston, TX
- La Jolla, CA
- Nashville, TN
- New York City, NY
- Philadelphia, PA
- Phoenix, AZ
- St. Louis, MO
- St. Paul, MN

Our teams continue to engage with many physicians and families about the importance of enrolling in clinical trials and what we can do to make the decision to enroll easier for families. Importantly, ACADIA will conduct a second, open-label study that will follow the 40-week, open-label LILAC study. This second study, called LILAC-2, will enroll eligible patients who completed the LAVENDER and LILAC studies and will continue to receive trofinetide. This is an exciting development and we hope this helps families who are considering whether or not to enroll in the LAVENDER and LILAC trials.

For patients and their caregivers who wish to learn more about the studies, please visit the web site www.rett syndromestudies.com. To reach a member of our Medical Affairs team with questions about trofinetide, please contact us at medicalinformation@acadia-pharm.com.

All our best,

The ACADIA Rett Team