August 30, 2021

Dear Rett Community,

Acadia will be conducting an additional clinical study of trofinetide. DAFFODIL™ will be a 12-week, multicenter, open-label safety, tolerability and pharmacokinetics study in girls with diagnosed Rett syndrome, 2 to 5 years of age, followed by a possible open-label extension for up to an additional 21 months.

Please recognize that the trial design criteria for DAFFODIL™ is limited to a small number (approximately 10 total) of female participants in specified weight ranges, to enable measurements of the blood levels of trofinetide, an investigational drug, and safety assessments across this age group.

Study information can be found on clinicaltrials.gov and at the study website: rettsyndromestudies.com. These will be updated with further information upon study and study site initiation.

Thank you to the International Rett Syndrome Foundation (IRSF) and the entire Rett community who help make this research possible. We appreciate your continued partnership on this journey to find a treatment to address the core symptoms of Rett syndrome.

COVID SAFETY PRECAUTIONS

The health of our volunteers and their families is our priority. We work 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.

FURTHER INFORMATION

If you have any questions about trofinetide or the clinical trials, please contact us at medicalinformation@acadiapharm.com

All our best,

The Acadia Rett Team