JOHNS HOPKINS MEDICINE

Approved November 26, 2019

If your daughter or a loved one has been diagnosed with Rett Syndrome, consider participating in the **LAVENDER** study.

[Recipient Name]
[Address]
[City, ST ZIP Code]

lavender™

Investigational Treatment Option for Patients with Rett Syndrome

lilac™

Talk to your doctor

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RETT SYNDROME STUDY

Rett syndrome is a genetic neurological condition that is mostly seen in girls and causes problems with brain function affecting speech, movement, moods and emotions, breathing, swallowing, heart function, and digestion. The purpose of this research study is to determine how well an investigational drug works in improving various symptoms associated with Rett syndrome.

By participating in a clinical trial, you can help researchers learn something that may help other people with Rett syndrome someday.

IS YOUR DAUGHTER OR A LOVED ONE ELIGIBLE FOR THIS STUDY?

Girls and women may be eligible for the study if they:

- Are 5 to 20 (inclusive) years old at the screening visit
- Have classical/typical Rett syndrome
- Weighs at least 12 kg (26.5 lbs)
- Can swallow study medication (provided as a liquid solution) or can take it by gastrostomy tube

TALK TO YOUR DOCTOR OR NURSE TO LEARN MORE

Your doctor or nurse is the best person to talk to about the LAVENDER study. He or she can give you further information and help determine if this is the right option for you or your daughter. If you know someone else who would benefit from this information, please feel free to pass this information along. To learn more, contact the participating doctor listed below.

FIND OUT MORE ABOUT THE LAVENDER STUDY

For more information please contact:

Kennedy Krieger Institute
The Clinical Trials Unit
1741 Ashland Ave
Baltimore, Maryland, 21205
443-923-3850

Researchtrials@kennedykrieger.org

Dr. Smith Hicks
IRB:00218168
Visit us on the Web:
RettSyndromeStudies.com

Contact Us

Kennedy Krieger Institute

WHAT SHOULD I EXPECT?

Participation is voluntary. Before participating in a study, a detailed description of the study, as well as possible risks and benefits, will be provided in writing in an “Informed Consent Document” and discussed with you.

Qualified individuals will participate in the study for approximately 19 weeks. During the treatment period half of the study participants will receive an investigational medication called trofinetide and half will receive placebo. The LAVENDER study will be followed by the LILAC study, a 9-month (40-week) open-label extension study in which all study participants will receive trofinetide.

Those who qualify may receive study-related care at no cost. Travel assistance and reimbursement may also be available for volunteers that do not live near a research site.

Feel free to discuss participation, procedures, and how you feel with the study doctor or research staff members at any time during the study.