



Getting Started with
DAYBUE® (trofinetide)

We're adding
more of her
sparkle to the
world around us

DAYBUE is the first and only FDA-approved
treatment for Rett syndrome

*Kate, age 9, living
with **Rett syndrome**,
with her parents*

Indication

DAYBUE is a prescription medicine used to treat Rett syndrome in adults and children 2 years of age and older. It is not known if DAYBUE is safe and effective in children under 2 years of age.

Important Safety Information

What are the possible side effects of DAYBUE?

- **Diarrhea:** Diarrhea is a common side effect of DAYBUE that can sometimes be severe. Diarrhea may cause you to lose too much water from your body (dehydration). Before starting treatment with DAYBUE, stop taking laxatives. Tell your healthcare provider if you have diarrhea while taking DAYBUE. Your healthcare provider may ask you to increase the amount you drink or take antidiarrheal medicine as needed.

See additional Important Safety Information
on pages 18–19. Please read the full [Prescribing
Information](#), including [Patient Information](#).



Getting started with DAYBUE

Now that your doctor has prescribed DAYBUE, you and your loved one are ready to explore your new path forward. As with any new medication, you may have questions when starting treatment; you'll have support available through Acadia Connect® to help you along the way.

This guide contains information on the following topics:

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Clare, age 8, living with
Rett syndrome, taking
DAYBUE since 2021



What is DAYBUE?

DAYBUE is a prescription medicine used to treat Rett syndrome in adults and children 2 years of age and older.

Over 1700 people living with Rett syndrome have started DAYBUE—including people with a variety of Rett symptoms, adults, girls, and boys.

Kate, age 9, living with Rett syndrome



About DAYBUE

DAYBUE is an oral medication that is:



Taken twice daily, in the morning and evening



Able to be taken with or without food



Strawberry flavored

See page 8 for more information about giving DAYBUE.

The amount of DAYBUE given will be dependent on your loved one's weight. **your loved one's doctor will decide the correct dose based on their medical history and response to DAYBUE.**

DAYBUE is not a cure for Rett syndrome and individual results will vary.

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- **Vomiting:** Vomiting is a common side effect of DAYBUE. Sometimes vomit can get into your lungs (aspiration), which could cause an infection (aspiration pneumonia). Tell your healthcare provider if you have severe vomiting or if vomiting happens often.
- **Weight loss:** DAYBUE can cause weight loss. Tell your healthcare provider if you notice you are losing weight at any time during treatment with DAYBUE.
- **The most common side effects of DAYBUE were diarrhea and vomiting.** Other side effects include fever, seizure, anxiety, decreased appetite, tiredness, and the common cold. These are not all the possible side effects of DAYBUE. Tell your healthcare provider if you have any side effects that bother you or do not go away.

See additional Important Safety Information on pages 18–19. Please read the full [Prescribing Information](#), including [Patient Information](#).



How will DAYBUE be delivered?

Your DAYBUE prescription can only be filled by a specialty pharmacy.

We partner with AnovoRx, our exclusive specialty pharmacy, to process and fill prescriptions. Once AnovoRx finalizes your loved one's prescription details, they will schedule delivery to the location most convenient for you. Acadia Connect will also reach out to you regularly to coordinate shipping refills.

What is a specialty pharmacy?

A specialty pharmacy is different from a retail pharmacy. It is a type of pharmacy that focuses on medications that have special handling, storage, and delivery requirements, like DAYBUE.

Each month you will receive a shipment in a refrigerated box containing:



Six or eight bottles of DAYBUE depending on your loved one's weight-based dose



Two oral syringes and two Press-In Bottle Adapters (PIBA)

Questions about your delivery?

Contact Acadia Connect for support at 1-844-737-2223, Monday–Friday, 8:00AM to 8:00PM ET.

How should I store DAYBUE?

Once you receive your shipment:



Store DAYBUE in a refrigerator at a temperature between 36°F to 46°F (2°C to 8°C)



Discard any unused DAYBUE after 14 days of opening the bottle



Always store DAYBUE in an upright position



Keep the child-resistant cap tightly closed



Do not freeze



Keep DAYBUE and all medicines out of the reach of children



Helpful tip

Make sure to write the date you open the bottle on the side label of your medication or another convenient location. DAYBUE must be used within 14 days of opening.

Important Safety Information (continued)

What should I tell my healthcare provider before taking DAYBUE?

Before taking DAYBUE, tell your healthcare provider about all of your medical conditions, including if you:

- have kidney problems.
- are pregnant or plan to become pregnant. It is not known if DAYBUE will harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if DAYBUE passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby while taking DAYBUE.

See additional Important Safety Information on pages [18–19](#).





How should I give DAYBUE to my loved one?

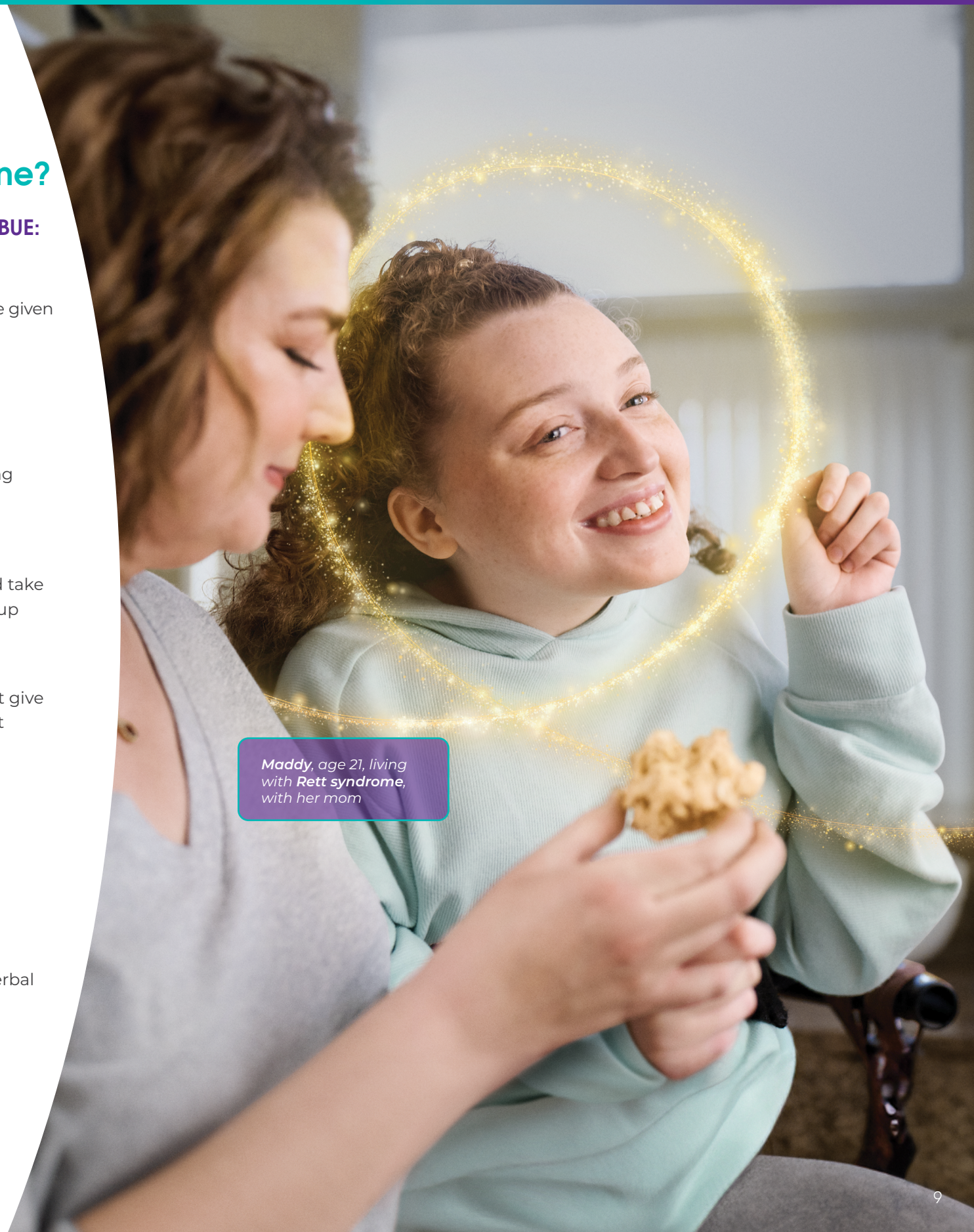
Here are some helpful things to know about how to give DAYBUE:

- ✓ DAYBUE may be taken orally or via a gastrostomy (G) tube. If your loved one has a gastrojejunal (GJ) tube, DAYBUE must be given through the G-port
- ✓ Give DAYBUE exactly as your doctor tells you to
- ✓ Measure each dose of DAYBUE accurately using the measuring device provided by the pharmacy. Do not use a household measuring cup
- ✓ If your loved one misses a dose of DAYBUE, skip that dose and take the next dose at the usual time. Do not take 2 doses to make up the missed dose
- ✓ If your loved one vomits after taking a dose of DAYBUE, do not give another dose to make up for that dose. Wait and give the next dose at the next scheduled time. Call your doctor if vomiting does not stop
- ✓ DAYBUE can be taken with or without food

Important Safety Information (continued)

Tell your healthcare provider about all of the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Taking DAYBUE with certain medicines may affect how the other medicines work and can cause serious side effects.

See additional Important Safety Information on pages 18–19.



Maddy, age 21, living with Rett syndrome, with her mom



Helpful tips for giving DAYBUE

The following tips may help you when giving DAYBUE by mouth:



Use something cold to numb the taste buds like ice cream, an ice cube, or cold water before giving DAYBUE



Dip your medication syringe in sweet syrup* and gently squirt DAYBUE into the side of your loved one's cheek. Do not squirt into the back of the throat, as this could cause choking



Use play to help increase your loved one's involvement in taking DAYBUE, like pretending to give medicine to a favorite toy



Give a strong-tasting food or drink after to help remove the taste



When you are done, consider giving your loved one a reward, like playing a favorite game

Kate, age 9, living with Rett syndrome

*DAYBUE should not be mixed directly with any sweetener.

 **Daybue**
(trofinetide)



Henry, age 4, living
with *Rett syndrome*



Helpful tip

Take steps to plan ahead. This might include stocking up on supplies like wipes, chucks, and extra diapers, or creating a backup bag with a change of clothes for when you're away from home.

Understanding the possible side effects of DAYBUE

As with any medication, it's important to talk to your loved one's doctor about the possibility of side effects with DAYBUE. Not every person will experience the same side effects, and for some people, certain side effects, such as diarrhea and vomiting, may be more severe than others.

Side effects may include:



Diarrhea

Diarrhea is a common side effect of DAYBUE that can sometimes be severe. Diarrhea may cause your loved one to lose too much water from their body (dehydration). Before starting treatment with DAYBUE, stop taking laxatives. Tell your doctor if your loved one has diarrhea while taking DAYBUE. Your doctor may ask you to increase the amount your loved one drinks or give antidiarrheal medicine as needed.



Vomiting

Vomiting is a common side effect of DAYBUE. Sometimes vomit can get into your loved one's lungs (aspiration), which could cause an infection (aspiration pneumonia). Tell your doctor if your loved one has severe vomiting or if vomiting happens often.



Weight loss

DAYBUE can cause weight loss. Tell your doctor if you notice your loved one is losing weight at any time during treatment with DAYBUE.

The most common side effects include:

- Diarrhea
- Vomiting

Other possible side effects include fever, seizure, anxiety, decreased appetite, tiredness, and the common cold. You and your loved one's doctor should monitor side effects and work together to help manage them.

These are not all the possible side effects of DAYBUE. Tell your healthcare provider if you have any side effects that bother you or do not go away.

See additional Important Safety Information on pages [18-19](#).





Helpful tips for managing GI side effects

Many people with Rett syndrome have gastrointestinal (GI) issues like constipation or reflux. If your loved one has GI issues, talk to your doctor about a plan for starting DAYBUE.

Here are some tips before your loved one starts DAYBUE:

- ✓ Consider keeping a log to track stool consistency/frequency for one week before starting treatment
- ✓ Tell your doctor if you are giving your loved one stool softeners and other medicines or dietary supplements for the treatment of constipation
- ✓ Stop use of laxatives
- ✓ Talk to your doctor about any recommended dietary changes including potential use of supplemental fiber

Starting DAYBUE if diarrhea is a concern:

- Based on your doctor's clinical judgment and experience, they may decide to start with a lower dose and increase to the FDA-recommended weight-based dose over time
- Improvements may not occur until your loved one reaches the recommended dose and continues treatment
- The impact of this approach on diarrhea was not studied in LAVENDER™. Individual patient response may vary

The LAVENDER study findings were based on starting patients at the FDA-recommended weight-based dose of DAYBUE and continuing treatment for 12 weeks.

See additional Important Safety Information on pages 18–19.



If diarrhea occurs:

- ✓ Tell your doctor if your loved one has diarrhea
- ✓ Keep an eye on your loved one's fluid intake and watch for signs of dehydration, increase oral fluids, if needed. Your doctor may also suggest a fiber supplement, if appropriate
- ✓ It is recommended that you have antidiarrheal medications such as loperamide (IMODIUM®) at home so you can manage diarrhea as needed
- ✓ Your doctor may reduce the dose of DAYBUE or may ask you to stop giving your loved one DAYBUE until the diarrhea improves. Do not stop giving DAYBUE before talking to your doctor



General tips to manage vomiting:

- ✓ Tell your doctor if your loved one has vomiting. Your doctor may suggest they take medication to help manage vomiting
- ✓ Have meals somewhere calm. Your loved one's stomach can be sensitive to stress. Finding somewhere relaxed to eat can reduce the likelihood of vomiting
- ✓ Avoid meals before bedtime or naptime
- ✓ Keep a meal journal. A journal can help you track connections between certain foods and vomiting. By removing foods one-by-one you can figure out if a particular food is causing vomiting
- ✓ Talk to your doctor if vomiting does not stop

This is not a complete list of the ways to manage vomiting. Talk to your doctor about making a plan that is tailored to your loved one's unique needs.



How soon are improvements seen with DAYBUE?

In LAVENDER, caregivers and doctors saw improvements in the signs and symptoms of Rett syndrome as soon as 12 weeks after starting DAYBUE when compared to placebo. Not all patients in the study responded to treatment with DAYBUE. Individual results may vary.



Tips for tracking signs and symptoms of Rett syndrome:

- ✓ Write down signs and symptoms before starting DAYBUE
- ✓ Ask everyone in your loved one's care team to notice and report any changes
- ✓ Track hand movements, eye gaze, nighttime behaviors—any aspect of your loved one's life that is impacted by Rett syndrome
- ✓ Notice impact of even small changes

The time to treatment response may vary from person to person. It may take time to see improvements in symptoms. Work closely with your doctor to understand your loved one's baseline symptoms and how to track them over time.



See additional Important Safety Information on pages [18–19](#).



Maddy, age 21, living with Rett syndrome, (right), with her mom

We continue to use DAYBUE because we continue to see improvements.

– Amy, Maddy's mom

Amy is a paid consultant to Acadia Pharmaceuticals Inc.



Indication and Important Safety Information

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- are pregnant or plan to become pregnant. It is not known if DAYBUE will harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if DAYBUE passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby while taking DAYBUE.

Tell your healthcare provider about all of the medicines you take,

including prescription and over-the-counter medicines, vitamins, and herbal supplements. Taking DAYBUE with certain medicines may affect how the other medicines work and can cause serious side effects.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088. You can also call Acadia Pharmaceuticals Inc. at 1-844-4ACADIA (1-844-422-2342).

DAYBUE is available as an oral solution (200 mg/mL).

The risk information provided here is not comprehensive. To learn more, talk with your healthcare provider and read the full [Prescribing Information](#), including [Patient Information](#), also available at DAYBUE.com.



Support by your side

Acadia Connect team members are ready to help

Acadia Connect is a patient and family support program that connects you and your family with educational support and resources before and after DAYBUE is prescribed. The team will help you with:

- Understanding Rett syndrome and information regarding DAYBUE
- Answering questions on insurance coverage
- Information on potential financial assistance options
- Support and education throughout the DAYBUE treatment journey



Family Support Educator

Your Family Support Educator is dedicated to providing ongoing support and product education for DAYBUE treatment.

- Helps you learn more about Rett syndrome and potential treatment with DAYBUE
- Provides in-person or virtual one-on-one education
- Answers questions about insurance coverage
- Helps you prepare for treatment with DAYBUE, including education on side effects
- Keeps you informed on new learning resources, events, and more
- Connects you with others in the community



Nurse Care Coordinator

The Nurse Care Coordinator is dedicated to helping your loved one get their DAYBUE treatment and providing support whenever you need it.

- Verifies your insurance benefits
- Provides information on potential financial assistance options
- Coordinates with you and AnovoRx Specialty Pharmacy for timely delivery of DAYBUE



Patient Access Manager

The Patient Access Manager is dedicated to helping your doctor with the prescription and insurance process for DAYBUE® (trofinetide), so that your loved one can get started with treatment.

- Provides your doctor with information on how to get DAYBUE covered for your loved one
- Continues to provide insurance support to your doctor to help reduce gaps in your loved one's treatment journey with DAYBUE



acadia connect®

Acadia Connect partners with AnovoRx specialty pharmacy

AnovoRx will process and fill DAYBUE prescriptions and has clinical pharmacists, available 24/7, to:



Answer questions and offer treatment support for DAYBUE



Provide information about potential side effects



Offer clinical recommendation(s) when appropriate

Questions?

Your Acadia Connect team is here to support you at 1-844-737-2223, Monday–Friday, 8:00AM to 8:00PM ET.



Jill,
Family Support
Educator

For your patients 2 years and older with Rett syndrome

Get the most out of your journey with DAYBUE

Key ways you and your loved one can prepare for treatment:



Track the symptoms of Rett syndrome

Work with your care team to write down the symptoms your loved one is experiencing before starting treatment and track changes over time



Be prepared with a side effect management plan

Before starting treatment, work with your loved one's doctor to make a plan for managing potential side effects. Always tell the doctor right away if a side effect occurs and is bothersome or does not go away



Follow instructions for giving DAYBUE

Always follow the instructions of your loved one's doctor for giving DAYBUE



Reach out for treatment support

Acadia Connect is here to provide you with education support and resources throughout the treatment journey



Visit [DAYBUE.com](https://daybue.com) to hear a caregiver share her experience starting DAYBUE

Maddy, age 21, living with Rett syndrome, with her mom, Amy

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