

# DAYBUE® (trofinetide) Care Tracker

This Care Tracker is meant to provide you and your healthcare team with a more detailed understanding of how DAYBUE is affecting the signs and symptoms of Rett syndrome in your loved one. Use the first sheet to note the range of symptoms, behaviors, and moods you've seen in your loved one before treatment, then regularly fill out the rest to track any changes over time.

## How to use:

- ✔ Capture the day-to-day changes you notice in your loved one with DAYBUE
- ✔ Ask people in your loved one's care circle—like family, friends, teachers, and therapists—about any changes they've observed
- ✔ Note any changes in dosage or diet
- ✔ Note any side effects that you have noticed in your loved one. Tell your healthcare provider if your loved one has any side effects that are bothersome or do not go away
- ✔ Start a new sheet weekly, monthly, or at your own pace
- ✔ Share with your loved one's doctor

**Bring this to your next doctor appointment or share electronically and ask your doctor to consider saving a copy with your loved one's records.**

Visit [DAYBUE.com](https://www.daybue.com) for more information about DAYBUE and remember that your Acadia Connect® Family Support Educator is available to help you and your loved one in their Rett syndrome journey.

## 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 [next page](#). Please read the full [Prescribing Information](#), including [Patient Information](#).**

## What is DAYBUE?

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.

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### What are the possible side effects of DAYBUE?

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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.

### 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.

**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](http://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](http://DAYBUE.com).**

# DAYBUE® (trofinetide) Care Tracker

Name: \_\_\_\_\_

Date: \_\_\_\_\_

**Use this tracker** to record any changes you notice while your loved one is taking DAYBUE. Even small details may give your doctor valuable insight into how your loved one is responding to DAYBUE. **Bring this to your next doctor appointment or share electronically and ask your doctor to consider saving a copy with your loved one's records.**

Use the spaces below and on the back to track changes. The descriptions provide examples of what to look for.

 <b>Breathing</b> Hyperventilating, breath holding, or "blue spells"	<i>(eg, Fewer "blue spells")</i>
 <b>Hand movements or stereotypes</b> Restricted use of hands or involuntary, repetitive, or patterned movements	<i>(eg, Hands are more fluid and open)</i>
 <b>Repetitive behaviors</b> May include repetitive tongue or hand movements, rocking back and forth	<i>(eg, Teeth grinding much less)</i>
 <b>Nighttime behaviors</b> Crying, laughing, or screaming at night for no reason at all	<i>(eg, Fewer night terrors)</i>
 <b>Vocalizations</b> Uses nonverbal or verbal communication to express needs or wants	<i>(eg, Greater use of sounds as a response)</i>
 <b>Facial expressions</b> Grimacing expression with face or mouth or lack of facial expression	<i>(eg, Doesn't stick tongue out as much)</i>
 <b>Eye gaze</b> Uses eye gaze to convey feelings, needs, or wishes	<i>(eg, Can hold gaze to participate and engage)</i>
 <b>Mood</b> Crying, screaming, or irritability for no apparent reason	<i>(eg, Mood is better at home, in school, and in groups)</i>

See Important Safety Information on page 2. Please read the full Prescribing Information, including Patient Information.

Observations from other physicians, therapists, teachers, friends, or family members:

Describe side effects:

*Tell your healthcare provider if your loved one has any side effects that are bothersome or do not go away.*

Dietary changes:

Additional notes, observations, or questions you may have:

*(eg, Changes or variations of the target dose and doses given in the morning/evening, expanded care team notes, etc)*

**See Important Safety Information on page 2. Please read the full Prescribing Information, including Patient Information.**

**PATIENT INFORMATION**  
**DAYBUE™ (day-BYOO)**  
**(trofinetide)**  
**oral solution**

**What is DAYBUE?**

- 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.

**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.

**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 the way other medicines work and can cause serious side effects.

Know the medicines you take. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

**How should I take DAYBUE?**

- Take DAYBUE exactly as your healthcare provider tells you to take it.
- If you take laxatives, stop taking them before starting treatment with DAYBUE.
- Your healthcare provider may change your dose or stop treatment with DAYBUE if needed.
- Your pharmacist should provide an oral syringe or dosing cup that is needed to measure your prescribed dose. **Do not** use a household measuring cup.
- DAYBUE may be taken by mouth or given through a gastrostomy (G) tube. If DAYBUE is given through a gastrojejunal (GJ) tube, the G-port must be used.
- DAYBUE may be taken with or without food.
- Throw away any unused DAYBUE after 14 days of first opening the bottle.
- If you vomit after taking a dose of DAYBUE, **do not take** another dose to make up for that dose. Wait and take the next dose at your usual time. Call your healthcare provider if your vomiting does not stop.
- If you miss a dose of DAYBUE, skip that dose and take your next dose at your usual time. **Do not take 2 doses** to make up the missed dose.

**What are the possible side effects of DAYBUE?**

DAYBUE may cause side effects, including:

- **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). 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.
- **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.
- **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.

**The most common side effects of DAYBUE include diarrhea and vomiting.**

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. For more information, ask your healthcare provider or pharmacist. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

**How should I store DAYBUE?**

- Store DAYBUE in the refrigerator between 36°F to 46°F (2°C to 8°C). **Do not** freeze.
- Keep DAYBUE in an upright position.
- Keep the child-resistant cap tightly closed.

**Keep DAYBUE and all medicines out of the reach of children.**

**General information about the safe and effective use of DAYBUE.**

Medicines are sometimes prescribed for purposes other than those listed in a Patient Information leaflet. Do not use DAYBUE for a condition for which it was not prescribed. Do not give DAYBUE to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about DAYBUE that is written for health professionals.

**What are the ingredients in DAYBUE?**

**Active ingredient:** trofinetide

**Inactive ingredients:** FD&C Red No. 40, maltitol, methylparaben sodium, propylparaben sodium, purified water, strawberry flavor, and sucralose.

Marketed by Acadia Pharmaceuticals Inc., San Diego, CA 92130 USA

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For more information, go to [www.daybue.com](http://www.daybue.com) or call 1-844-422-2342.

This Patient Information has been approved by the U.S. Food and Drug Administration

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