



Talking with your doctor
about 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

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.

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 page 5. Please read the full [Prescribing
Information](#), including [Patient Information](#).





Talking to your doctor about DAYBUE

Rett syndrome is a complex neurodevelopmental disorder that is typically caused by a mutation, or change, in the *MECP2* gene. DAYBUE is the first and only FDA-approved treatment for adults and children ages 2 and older with Rett syndrome.

With the FDA approval of a treatment for Rett syndrome, you may be wondering if DAYBUE is right for your loved one. **In this guide, you'll find helpful information about DAYBUE and some questions to help you prepare for a conversation with your loved one's doctor.**



Talk to your doctor to find out more about DAYBUE and whether it could be right for your loved one.
Visit [DAYBUE.com](https://www.daybue.com) to learn more.

Kate (right) with her brother

Important Safety Information (continued)

What are the possible side effects of DAYBUE? (continued)

- **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 page 5.



What to look for

- What symptoms could DAYBUE help address?
- When could I start to see improvements?
- Are improvements the same for everyone?
- Will improvements stop if my loved one stops taking DAYBUE?
- How long will my loved one need to be on DAYBUE?



Deciding if DAYBUE is right for your loved one

- Who is DAYBUE for?
- Does DAYBUE take the place of other medications my loved one is on?
- Will DAYBUE interact with other medications my loved one takes?



Getting started with DAYBUE

- Do I need to do anything in advance to prepare my loved one to take DAYBUE for the first time?
- Should I let others on my loved one's care team know they are beginning this treatment?
- Are there any support programs or resources available to help us get started?

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 page 5.





Taking DAYBUE

- How is DAYBUE given?
- Can I still give DAYBUE if my loved one has a G-tube or GJ-tube?
- How much DAYBUE will my loved one need to take?
- Are there any administration tips you can give?
- What does DAYBUE taste like?
- What if we have to travel—how do we take DAYBUE with us?
- What happens if my loved one misses a dose?
- How/where do I store DAYBUE?



Managing possible side effects

- Are there any possible side effects of DAYBUE?
- How many people experienced the side effects?
- If side effects occur, how do I manage them?
- Is there any information about using DAYBUE long-term?
- What are signs that I should call my doctor for more help?

Important Safety Information (continued)

What should I tell my healthcare provider before 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).

See additional Important Safety Information on page 5.



Indication and Important Safety 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.

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.
- **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.

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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 accompanying [Patient Information](#). Visit DAYBUE.com for the full [Prescribing 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 gastrojejun (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 or call 1-844-422-2342.

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

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