



Getting started with DAYBUE®



Indication

What is DAYBUE or DAYBUE STIX?

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

Important Safety Information

What are the possible side effects of DAYBUE or DAYBUE STIX?









- **Diarrhea:** Diarrhea is a common side effect of DAYBUE or DAYBUE STIX that can sometimes be severe. Diarrhea may cause you to lose too much water from your body (dehydration). Before starting treatment with DAYBUE or DAYBUE STIX, stop taking laxatives. Tell your healthcare provider if you have diarrhea while taking DAYBUE or DAYBUE STIX. 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 22-23](#).

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



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 Clare, age 9
On DAYBUE since 2021
See her story or visit
DAYBUE.com/stories



Getting started

DAYBUE and DAYBUE STIX are prescription medicines used to treat Rett syndrome in adults and children 2 years of age and older.

Now that your doctor has prescribed DAYBUE or DAYBUE STIX, 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.

DAYBUE and DAYBUE STIX are not cures for Rett syndrome and individual results will vary.

Important Safety Information

What are the possible side effects of DAYBUE or DAYBUE STIX?

- **Diarrhea:** Diarrhea is a common side effect of DAYBUE or DAYBUE STIX that can sometimes be severe. Diarrhea may cause you to lose too much water from your body (dehydration). Before starting treatment with DAYBUE or DAYBUE STIX, stop taking laxatives. Tell your healthcare provider if you have diarrhea while taking DAYBUE or DAYBUE STIX. 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 or DAYBUE STIX. 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 or DAYBUE STIX can cause weight loss. Tell your healthcare provider if you notice you are losing weight at any time during treatment with DAYBUE or DAYBUE STIX.
- **The most common side effects of DAYBUE or DAYBUE STIX include 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 or DAYBUE STIX. 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 22-23](#). Please read the full [Prescribing Information](#), including [Patient Information](#).



Kate, age 12
On DAYBUE since 2021
See her story or visit
[DAYBUE.com/stories](https://www.daybue.com/stories)





Available in 2 options

Both options have the same active ingredient, trofinetide, so you can expect the same benefits and safety.

The benefits and safety of DAYBUE STIX are supported by clinical studies of DAYBUE oral solution in people with Rett syndrome.

DAYBUE is a ready-to-take liquid



See pages [8-9](#)

DAYBUE STIX are individual packets that you prepare yourself



See pages [10-13](#)

Important Safety Information (continued)

What should I tell my healthcare provider before taking DAYBUE or DAYBUE STIX?

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

See additional Important Safety Information on [pages 22-23](#).

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

Here are some helpful things to remember

- ✓ Your doctor will determine the appropriate amount of medication based on your loved one's weight, medical history, and response to DAYBUE
- ✓ Always take DAYBUE or DAYBUE STIX exactly how your doctor and pharmacist tell you
- ✓ DAYBUE and DAYBUE STIX may be given orally or via a gastrostomy (G) tube. If your loved one has a gastrojejunal (GJ) tube, it must be given through the G-port
- ✓ DAYBUE and DAYBUE STIX are strawberry-flavored medications that are taken twice daily, once in the morning and once again in the evening. Both can be taken with or without food
- ✓ If your loved one misses a dose, skip that dose and administer the next dose at the usual time. Do not administer 2 doses to make up the missed dose
- ✓ If your loved one vomits after taking a dose, 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
- ✓ Use the measuring device provided by your pharmacy to measure each dose of DAYBUE or DAYBUE STIX. A household measuring cup is not an accurate measuring device





What to expect: DAYBUE (trofinetide) oral solution

Your DAYBUE prescription will be filled by a specialty pharmacy.

We partner with AnovoRx, a specialty pharmacy that focuses on medications that have special handling, storage, and delivery requirements, like DAYBUE. Once your loved one's prescription details are finalized, they will schedule delivery to the location you specify. Acadia Connect will reach out to you regularly to coordinate shipping refills.



Each month you will receive a refrigerated box containing:

- ✓ 6 or 8 bottles of DAYBUE depending on your loved one's weight-based dose
- ✓ 2 oral syringes and 2 Press-In Bottle Adapters (PIBA)

Questions about your delivery?

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

Once you receive your shipment:



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



Keep the child-resistant cap tightly closed



Do not freeze



Discard any unused DAYBUE after 14 days of opening the bottle



Always store DAYBUE in an upright position



Keep DAYBUE and all medicines out of the reach of children

Helpful tip

Measure your loved one's prescribed DAYBUE dose using an oral syringe or oral dosing cup provided by the pharmacy. Do not use a household measuring cup to ensure the liquid is measured accurately.

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 or DAYBUE STIX with certain medicines may affect how the other medicines work and can cause serious side effects.

See additional Important Safety Information on pages 22-23.
Please read the full [Prescribing Information](#), including [Patient Information](#).





What to expect: DAYBUE STIX (trofinetide) for oral solution

Your DAYBUE STIX prescription will be filled by a specialty pharmacy.

We partner with AnovoRx, a specialty pharmacy that focuses on medications that have special handling, storage, and delivery requirements, like DAYBUE STIX. Once your loved one's prescription details are finalized, they will schedule delivery to the location you specify. Acadia Connect will reach out to you regularly to coordinate shipping refills.

Each month you will receive a shipment containing:

- ✓ 1 or 2 boxes of DAYBUE STIX packets
- ✓ Measuring device (syringe)
- ✓ Oral and G-tube syringes
- ✓ Optional: syringe tips and adapters



Questions about your delivery?

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

Once you receive your shipment:



Store DAYBUE STIX at room temperature between 68 °F to 77 °F



Keep DAYBUE STIX and all medicines out of the reach of children

Helpful tip

Keep a to-go bag with all the supplies you need, including a bottle of water or water-based beverage, the supplied measuring device (syringe), mixing cup, and a spoon or stirrer.

Important things to know about DAYBUE STIX:

- Your doctor will prescribe the appropriate packet strength and the number of packets required for your loved one's dose
- AnovoRx Pharmacy will provide you with a measuring device and instructions with the recommended amount of liquid, along with how much of the prepared solution to give your loved one

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How should I prepare DAYBUE STIX?

Read this before your loved one takes DAYBUE STIX and each time you get a refill. This does not replace advice or instructions from your doctor or pharmacist.

What you will need

- ✓ DAYBUE STIX packet(s) and instructions from AnovoRx Pharmacy
- ✓ Measuring device (syringe) from AnovoRx Pharmacy
- ✓ Mixing cup, mixing spoon, and scissors to cut open packet(s)
- ✓ Water or water-based beverage (cold to room temperature)

Before you get started








DAYBUE STIX were designed to be prepared immediately before use. The prepared solution cannot be kept for later use.

- Only open a packet when you're ready to prepare. Use the full packet each time, as instructed by your pharmacist. Do not attempt to use partial packets to prepare a dose
- Give the prepared solution right away
- If your loved one's dose is less than what you prepared, discard the extra in a secure trash can
- As with all medications, do not pour leftover DAYBUE STIX into the sink or toilet to avoid putting it directly into the water system

Step-by-step instructions

DAYBUE STIX must be dissolved in cold-to-room-temperature water or a water-based beverage (juice, tea, lemonade, limeade, or liquid hydration). DAYBUE STIX cannot be dissolved in dairy-based products.

 Measure	 Combine	 Stir	 Give	 Dispose
<p>Measure liquid using one of the supplied syringes (measuring device)</p> <p><i>Do not use a household measuring cup</i></p>	<p>Add the liquid and the entire contents of packet(s) into mixing cup</p> <p><i>Do not attempt to use partial packets to prepare a dose</i></p>	<p>Stir to create a completely dissolved solution</p>	<p>Measure and give the prescribed dose immediately</p> <p><i>Do not store solution for later use</i></p>	<p>Dispose of any leftover solution in a secure trash can</p> <p><i>Do not pour into sink or flush</i></p>

My loved one's prescription

Prescribed dose _____ (mg).

Combine _____ (mL) of liquid with _____ packet(s) of _____ (mg) strength DAYBUE STIX.

Give _____ (mL) of dissolved solution.

Take this amount twice daily with or without food.

See additional Important Safety Information on pages 22-23. Please read the full [Prescribing Information](#), including [Patient Information](#).





Tips for giving DAYBUE or DAYBUE STIX



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



Dip your medication syringe in sweet syrup* and gently squirt DAYBUE or DAYBUE STIX 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 or DAYBUE STIX, 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

*DAYBUE oral solution or DAYBUE STIX for oral solution should not be mixed directly with any sweetener.

See additional Important Safety Information on pages 22-23. Please read the full [Prescribing Information](#), including [Patient Information](#).



Holly, age 11
On DAYBUE since 2023
See her story or visit
[DAYBUE.com/stories](https://www.daybue.com/stories)



Henry, age 5
 On DAYBUE since 2023
 See his story or visit
DAYBUE.com/stories



Hear Rett Experts answer FAQs
 at DAYBUE.com/experts



Possible side effects of DAYBUE or DAYBUE STIX

As with any medication, it's important to talk to your loved one's doctor about the possibility of side effects with DAYBUE or DAYBUE STIX. 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 or DAYBUE STIX 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 or DAYBUE STIX, stop taking laxatives. Tell your doctor if your loved one has diarrhea while taking DAYBUE or DAYBUE STIX. 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 or DAYBUE STIX. 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 or DAYBUE STIX can cause weight loss. Tell your doctor if you notice your loved one is losing weight at any time during treatment with DAYBUE or DAYBUE STIX.

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 or DAYBUE STIX. 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 22-23](#).

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





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 before starting DAYBUE or DAYBUE STIX.

Tips before your loved one starts DAYBUE or DAYBUE STIX:

- ✔ 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

Visit [DAYBUE.com/resources](https://www.daybue.com/resources) for tracking tools



Starting DAYBUE or DAYBUE STIX 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.



Tips 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 at home so you can manage diarrhea as needed
- Your doctor may reduce the dose of DAYBUE or DAYBUE STIX, or may ask you to stop treatment until diarrhea improves. Do not stop treatment before talking to your doctor



Tips for managing 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 diarrhea and vomiting. Talk to your doctor about making a plan that is tailored to your loved one's unique needs.

See additional Important Safety Information on pages 22-23. Please read the full [Prescribing Information](#), including [Patient Information](#).



How soon are improvements seen with DAYBUE?

In the LAVENDER study, 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:

- ✓ Write down signs and symptoms before starting DAYBUE or DAYBUE STIX
- ✓ Ask everyone in your loved one's care team to notice changes—even if they're small—and report them
- ✓ Track hand movements, eye gaze, nighttime behaviors—any aspect of your loved one's life that is impacted by Rett syndrome
- ✓ Share these updates with your doctor so they can adjust your loved one's treatment journey as needed

Visit [DAYBUE.com/resources](https://www.daybue.com/resources) for tracking tools



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 22-23](#). Please read the full [Prescribing Information](#), including [Patient Information](#).



Maddy, age 22
On DAYBUE since 2020
See her story or visit
[DAYBUE.com/stories](https://www.daybue.com/stories)

**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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- **Vomiting:** Vomiting is a common side effect of DAYBUE or DAYBUE STIX. 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 or DAYBUE STIX can cause weight loss. Tell your healthcare provider if you notice you are losing weight at any time during treatment with DAYBUE or DAYBUE STIX.
- **The most common side effects of DAYBUE or DAYBUE STIX include 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 or DAYBUE STIX. 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 or DAYBUE STIX?

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

Tell your healthcare provider about all of the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Taking DAYBUE or DAYBUE STIX 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](tel:1-800-FDA-1088). You can also call Acadia Pharmaceuticals Inc. at [1-844-4ACADIA \(1-844-422-2342\)](tel:1-844-4ACADIA).

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

DAYBUE STIX for oral solution powder is available in 5,000 mg, 6,000 mg, and 8,000 mg packets.

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.



[Click here](#) to learn what's been possible from caregivers and their loved one's experiences on DAYBUE





acadia connect

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 or DAYBUE STIX is prescribed. The team will help you with:

- Understanding Rett syndrome
- Providing information about DAYBUE or DAYBUE STIX
- Answering questions on insurance coverage
- Information on potential financial assistance options
- Support and education throughout the DAYBUE or DAYBUE STIX 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
- Provides in-person or virtual one-on-one education
- Answers questions about insurance coverage
- Helps you prepare for potential 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

AnovoRx Specialty Pharmacy

Acadia Connect partners with AnovoRx to process and fill your loved one's DAYBUE or DAYBUE STIX prescriptions.

- Available 24/7
- Answer questions and offer treatment support
- 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](tel:1-844-737-2223), Monday–Friday, 8:00AM to 8:00PM ET.



Jill,
Family Support
Educator



Getting started

How you and your loved one can prepare for treatment:



Keep track of your loved one's symptoms and changes over time



Work with your doctor to make a side effect management plan



Always follow your doctor's and pharmacist's instructions exactly for giving DAYBUE or DAYBUE STIX



Remember, you can reach out to Acadia Connect if you have any questions or need treatment support

Has DAYBUE opened up more possibilities for your loved one?
[Share what's been possible](#)



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Daybue[®]
(trofinetide) oral solution



Daybue[®] Stix
(trofinetide) for oral solution