

Every small
improvement with
DAYBUE® may open
up more possibilities



INTRODUCING

DAYBUE® STIX:
Now families have a choice



Holly (left) and Maddy (right), on 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 page 39. Please read the full Prescribing Information, including Patient Information.





See how DAYBUE is helping to open up more possibilities

DAYBUE is the first and only FDA-approved treatment shown to improve signs and symptoms of Rett syndrome in adults and children 2 years of age and older.

It's available in 2 formulations: DAYBUE and DAYBUE STIX. You can choose the option that best fits your family's needs.

Inside, you'll learn more about what may be possible with DAYBUE, including study results, stories of people who are already taking DAYBUE, and information about available resources and support.

Important Safety Information (continued)

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

- **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.

See additional Important Safety Information on page [39](#).



Madelyn, age 5, on DAYBUE since 2023



Henry, age 5, on DAYBUE since 2023



Nicole, age 29, on DAYBUE since 2023

Rett syndrome: A complex genetic disorder

In Rett syndrome, a majority of cases are caused by a change in the *MECP2* gene



MECP2 is thought to control how many genes work, including those important for brain development

MECP2=methyl-CpG-binding protein 2.



Changes in the *MECP2* gene are thought to disrupt the activity of the genes associated with the symptoms of Rett syndrome

Rett syndrome is a rare **neurodevelopmental** condition, not neurodegenerative, so brain cells do not become damaged or die—meaning symptom improvements may be possible at any age.

A range of symptoms that require lifelong care



Unique symptom experiences

Your loved one's experiences with Rett syndrome are unique to them—the symptoms can affect every individual in different ways, at different times, and at different stages of the disorder.



Communication and Rett syndrome

Along with a variation in symptoms, the ability to think and understand may also vary among children. Many children with Rett syndrome are cognitively aware but are unable to effectively act on their desire to communicate. This may leave them feeling frustrated and misunderstood.

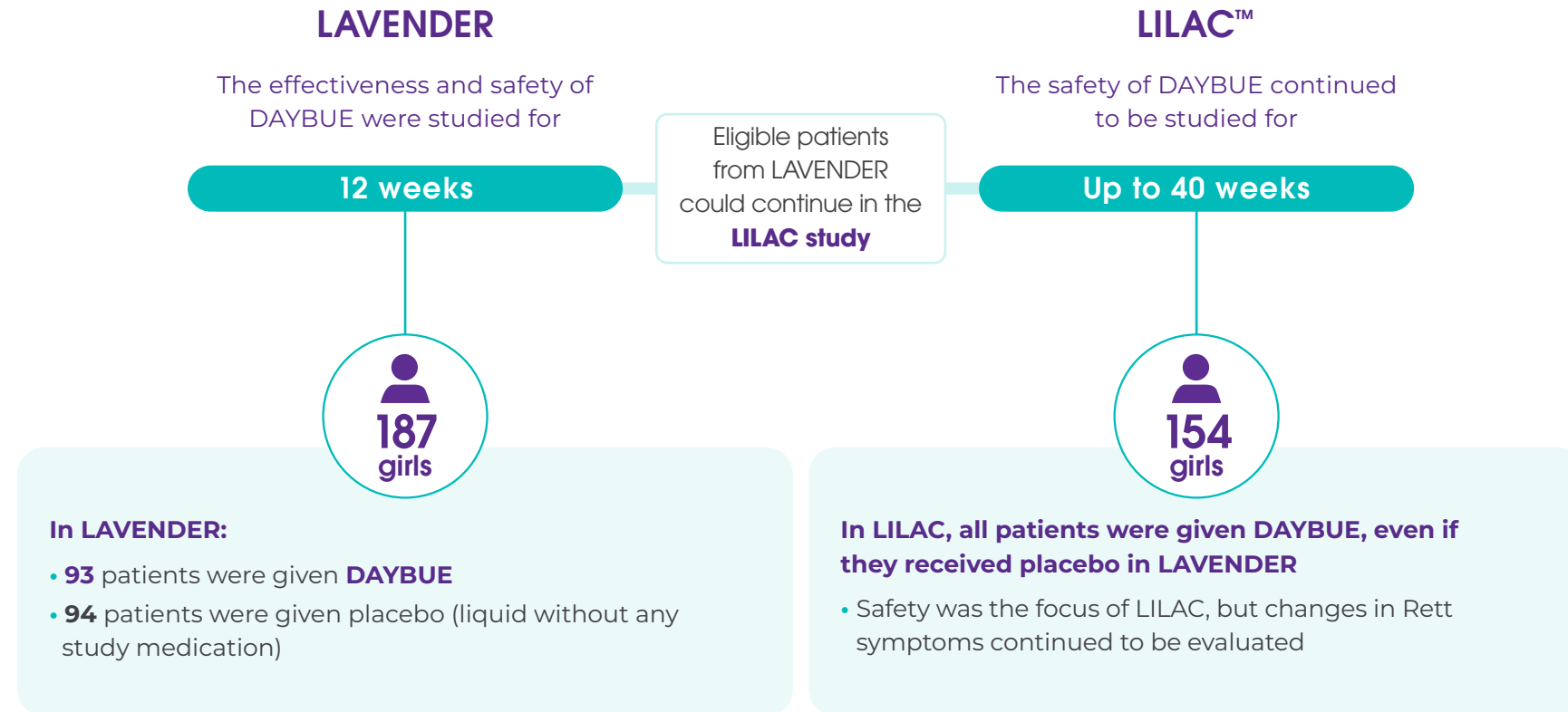


Setbacks and regressions

As varied as these symptoms can be, your loved one can also experience unexpected setbacks called regressions. **This may leave you and your family continually seeking new solutions to the ongoing changes in your loved one.**

DAYBUE was studied in the largest clinical study for Rett syndrome to date

The effectiveness and safety of DAYBUE were evaluated in the 12-week LAVENDER™ clinical study of 187 females aged 5 to 20 with Rett syndrome



Patients in LAVENDER all had a diagnosis of typical Rett syndrome according to the Rett Syndrome Diagnostic Criteria, and had a documented mutation in the *MECP2* gene. Patients in both groups of the study had a range of symptoms and disease severity, reflecting how unique Rett syndrome is for each person.

Doctors and caregivers

played a key role in evaluating DAYBUE.

Doctors evaluated if

patients improved or got worse, while caregivers

looked for changes in the

symptoms of Rett syndrome.



Holly, age 11, on DAYBUE since 2023 (center), with her family

Caregivers evaluated changes in a range of symptoms using the Rett Syndrome Behaviour Questionnaire (RSBQ)

RSBQ is a behavior questionnaire completed by caregivers in the clinical study to evaluate the range of symptoms of Rett syndrome.

What does the RSBQ measure?



- Caregivers evaluated 45 items on the RSBQ. Each item was scored as not true (0), somewhat or sometimes true (1), or very true or often true (2)
- These scores were added together to create the **RSBQ total score**
- Researchers looked at the change in average RSBQ total score from the start of the study to measure how DAYBUE impacted the symptoms of Rett at Week 12 when compared to patients receiving placebo

Important Safety Information (continued)

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

- **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.

See additional Important Safety Information on page [39](#).



Madelyn, age 5, on DAYBUE since 2023, with her dad

At 12 weeks, caregivers observed:

Significant improvements in the symptoms of Rett syndrome

as measured by average change in RSBQ total score with DAYBUE vs placebo

- At 12 weeks, the group of patients receiving DAYBUE (n=76) saw a decrease of 4.9 in average RSBQ total score from the start of the study when compared with a decrease of 1.7 in the placebo group (n=85)
- The difference between the two groups was -3.2. A lower score meant symptoms of Rett syndrome were less severe
- Before starting treatment, the average RSBQ total score for the DAYBUE group was 43.7. For the placebo group, the average RSBQ total score before treatment was 44.5
- Results varied between patients in the clinical study. The effect of DAYBUE on individual symptoms measured by RSBQ has not been shown. Individual results may vary with DAYBUE

Important Safety Information (continued)

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

- **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 page [39](#).





















What may be possible with DAYBUE?

Caregiver's descriptions of improvements with DAYBUE:

Symptom areas (RSBQ)	 Quinn 6 years old Taking DAYBUE since 2021	 Clare 9 years old Taking DAYBUE since 2021	 Kate 12 years old Taking DAYBUE since 2021
 Hand movements or stereotypies	More control of hands. Can hold objects longer. Not grasping her body and face as much	Hands are more fluid and open, can hold a fork or cup, taps on fridge when hungry	More purposeful hand use. Able to use a spoon and point at and touch her tablet
 Repetitive behaviors	Teeth grinding much improved		
 Breathing	Less frequent breath holding and less hyperventilating		
 Nighttime behaviors		Less frequent night terrors allow her to sleep better	
 Vocalizations		Increased nonverbal vocalizations, able to let people know when she wants something	
 Facial expressions			
 Eye gaze	Can hold her gaze to participate and engage, especially in the classroom	Uses eye gaze more to convey feelings, needs, and wishes. Allows her to show family what she wants for a snack	Able to use her eye-gaze device better to convey wishes
 Mood	Her moods are more predictable and she cries a lot less	Less screaming and tantrums. Able to take an interest in the things around her	More peaceful at home, in school, and in groups

Important Notes:

- In the clinical study, individual response varied. Some patients had minimal to no improvements with DAYBUE
- These patients were also receiving other types of therapy, like physical, occupational, or speech therapy
- Some of these patients experienced side effects, including diarrhea, behavioral issues, or gas. See pages 20 to 35 to learn more about their DAYBUE experience

Symptom areas (RSBQ)	 Ellie 17 years old Taking DAYBUE since 2020	 Maddy 22 years old Taking DAYBUE since 2020	Symptom areas (RSBQ)
 Hand movements or stereotypies	Quiet, calmer hands. Can hold a cup and fork and grasp and reach for things	Less aggressive hand movements. More control of hands	 Hand movements or stereotypies
 Repetitive behaviors		Hardly grinds her teeth anymore	 Repetitive behaviors
 Breathing		Fewer "blue spells" (breath holding)	 Breathing
 Nighttime behaviors		Fewer night terrors and laughing spells—now family gets more sleep	 Nighttime behaviors
 Vocalizations	She makes a lot of chatty sounds. Says "fun, funny, and food"	No words, but makes more sounds to respond	 Vocalizations
 Facial expressions		Doesn't stick her tongue out as often	 Facial expressions
 Eye gaze	Uses her eyes to say yes or no and to make choices	Makes choices more quickly with her eyes. More of an interest in using her eye-gaze device	 Eye gaze
 Mood	She's able to regulate her emotions a little better. She's happier than she used to be	Mood is better, happier, much less crying for no apparent reason	 Mood

- Always speak with a healthcare provider to learn what to expect when starting DAYBUE, including side effects
- The families featured here were compensated for sharing their stories and participating in photo shoots. These stories were created in 2024

Important Safety Information (continued)

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

Diarrhea and vomiting are the most common side effects of DAYBUE that can sometimes be severe. DAYBUE can also cause weight loss. Other possible side effects include fever, seizure, anxiety, decreased appetite, tiredness, and the common cold.

See additional Important Safety Information on page 39.



Clare, age 9,
on DAYBUE since 2021

At 12 weeks, doctors observed:

Significant improvements in the signs and symptoms of Rett syndrome

as measured by the CGI-I (Clinical Global Impression-Improvement) scale vs placebo

The CGI-I scale was used by doctors to evaluate improvement or worsening of Rett symptoms

- 38% of patients (n=77) had improvement in symptoms with DAYBUE vs 15% of patients (n=86) taking placebo
 - Much improved (13% vs 5% for placebo), minimally improved (25% vs 10%)
- 61% of patients had no improvements in symptoms with DAYBUE vs 81% of patients taking placebo. Individual results may vary with DAYBUE



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.

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

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 page 39.



Understanding the possible side effects of DAYBUE or DAYBUE STIX

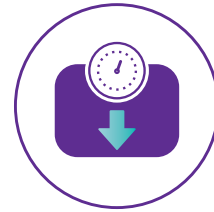
As with any medication, it's important to talk to your loved one's doctor about the possibility of side effects with DAYBUE or DAYBUE STIX. Not every person will experience the same side effects, and for some people, certain side effects, such as diarrhea and vomiting, may be more severe than others.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

Read on for tips and stories about how other families have managed potential side effects.

See additional Important Safety Information on page 39.

Common side effects in the 12-week LAVENDER study

Side Effects	DAYBUE (% of 93 patients)	Placebo (% of 94 patients)
Diarrhea	82%	20%
Vomiting	29%	12%
Fever	9%	4%
Seizure	9%	6%
Anxiety	8%	1%
Decreased appetite	8%	2%
Tiredness	8%	2%
Common cold	5%	1%

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



Preparing for potential GI side effects

Before your loved one starts treatment, talk to your doctor about a management plan to address the possible side effects while on treatment with DAYBUE or DAYBUE STIX.

Many people with Rett syndrome have gastrointestinal (GI) issues like constipation or reflux. If you are used to managing constipation, diarrhea may be new to you.

Here are some tips before your loved one starts DAYBUE or DAYBUE STIX:

- ✔ Tell your doctor about any existing GI issues like vomiting, swallowing difficulty, or acid reflux to make a management plan
- ✔ Keep a log to track stool consistency/frequency for 1 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
- ✔ Work with your doctor to form a management plan that addresses diarrhea and learn about any recommended dietary changes, including potential use of supplemental fiber

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.



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

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

Important Safety Information (continued)

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 page 39.



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 nap time
- 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



We're mixing it up—DAYBUE is available in 2 options

You have a choice: DAYBUE or DAYBUE STIX

DAYBUE is a ready-to-take liquid

DAYBUE STIX are individual packets you prepare yourself

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.



Talk to your doctor about choosing the DAYBUE formulation that is right for you.



Given orally or via G-tube	✓	✓
Taken twice daily with or without food	✓	✓
Strawberry flavored	✓	✓
No Red Dye 40, maltitol, or preservatives		✓
Stored at room temperature (68 °F to 77 °F)		✓
Delivered to your door from a specialty pharmacy	✓	✓

DAYBUE STIX: You asked, we listened

Formulated with families in mind, DAYBUE STIX is **free of red dye, preservatives, and maltitol**—and contains fewer carbohydrates than the original DAYBUE liquid. Carbohydrate level can vary based on chosen water-based beverage.

Flexibility that fits your loved one's needs

Your doctor will prescribe the appropriate dose based on your loved one's weight and determine a liquid volume that is right for them.

Choices when preparing DAYBUE STIX

DAYBUE STIX is dissolved into cold-to-room-temperature water or water-based beverages (juice, tea, lemonade, limeade, or liquid hydration), so you have the flexibility to customize to your loved one's taste.

Easy-to-store packets that you can take with you

DAYBUE STIX come in compact boxes and are stored at room temperature (68 °F to 77 °F). The individual packets fit easily into a purse or bag so you can take them wherever you go.

Important Safety Information (continued)

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

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 page 39.

Maddy, age 22,
on DAYBUE since 2020





Clare's improved eye gaze has helped her share her feelings



Hand movements or stereotypes

Clare's hands are more fluid and open. She can even feed herself and hold her own ice cream cone



Nighttime behaviors

Clare has night terrors less often and is able to sleep better



Vocalizations

Clare is vocalizing more, and she is babbling more to let people know she wants something



Eye gaze

Clare's eye gaze has improved, which allows her to connect better with her family and classmates



Mood

Clare is able to take an interest in what's around her. She also is screaming less and has fewer tantrums

Important Safety Information (continued)

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

- **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.

See additional Important Safety Information on page 39.



Diagnosis and symptoms

Clare was diagnosed with Rett syndrome at age 4. **Some of her signs and symptoms have included:**

- Difficulty controlling her hands—her mom says “her hands would get in the way of themselves”
- Loss of communication abilities
- Frequent screaming spells and night terrors

Other treatments

Clare attends occupational therapy, physical therapy, speech therapy, horse therapy, swim lessons, gymnastics classes; sees a physiatrist for muscle tone checks; wears shoe inserts; sees a gastroenterologist and nutritionist.

Managing side effects

After starting DAYBUE, Clare began experiencing behavioral outbursts and anger. She did not want to eat, didn't sleep, and cried frequently. Clare's parents worked with her doctor on how to manage these side effects. Clare's dose was lowered, and her mood improved. Every time her dose was increased, Clare experienced the same side effects again. In consultation with her doctor, Clare is currently taking an adjusted, tolerated dose.



*Clare's eye gaze has improved. **She looks at me, which is amazing. She is using eye gaze more to convey her feelings, needs, and wishes.***

– Allison, Clare's mom

Important Note: The effectiveness and safety of DAYBUE were evaluated in the 12-week LAVENDER clinical study of 187 female patients aged 5 to 20 with Rett syndrome. Because each individual with Rett syndrome is unique—with a unique set of symptoms—the response to DAYBUE may be different for everyone. See the results from the clinical study. Clare's family was compensated for sharing their story and participating in a photo shoot. This story was created in March 2024. Clare was a DAYBUE clinical study participant and has continued to take DAYBUE. Clare's experience on treatment is unique to her.



Clare, age 9, on DAYBUE since 2021, with her mom



Ellie's improved vocalization has helped her showcase more of her personality



Hand movements or stereotypes

Ellie's hands are calmer and more controlled. She can hold her fork, put food in her mouth, and can now point to what she wants



Vocalizations

Ellie is making more vowel sounds and trying to get more words out to express her feelings, needs, and wants



Eye gaze

She makes more choices with her eyes now. Because her eye gaze has improved, her family can understand her wants, needs, and wishes



Mood

Ellie's mood has improved. She seems happier, she smiles more, and gives her family big belly laughs when she thinks something is funny. And she laughs at TV shows at the right time



Facial expressions

At physical therapy, her mom asked for a kiss and she leaned in and kissed her on the face

Important Safety Information (continued)

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

- **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.

See additional Important Safety Information on page 39.



Diagnosis and symptoms

Ellie received her Rett syndrome diagnosis at age 7. **Some of her signs and symptoms have included:**

- Failure to reach developmental milestones
- Loss of communication abilities
- Repetitive hand movements

Other treatments

Ellie has been on different therapies since she was 2 years old, including speech therapy and yoga. Since her Rett syndrome diagnosis, she's participated in occupational, horse, swim, massage, music, and regular physical therapy.

Managing side effects

Initially after starting DAYBUE, Ellie had some changes in her bowel movements, including diarrhea a couple times. She has experienced gas pains, and her doctor prescribed additional medications to help. Ellie's family works closely with her doctor about any changes or side effects they notice.



*With DAYBUE, words didn't happen right away. **But now, she says words like "funny," "fun," and "food" and is making new noises. She is vocalizing more with intent.***

– Heidi, Ellie's mom



[Click here to watch Ellie's story](#)



Ellie, age 17, on DAYBUE since 2020 (center), with her family

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Henry's improved mood has helped him participate in more activities



Hand movements or stereotypies

Henry has more intentional hand movement and can hold a weighted spoon with assistance



Repetitive behaviors

Henry grinds his teeth and taps his fingers less



Vocalizations

Henry has a greater variety of vocalizations, especially when he wants something. When he sees a soccer ball, he says, “ba ba ba”



Eye gaze

Henry has been able to use his eyes to make progress with his eye-gaze device to communicate



Mood

Henry is less anxious, calmer, and yells less. He can sit calmly at story time and restaurants

Important Safety Information (continued)

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

- **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 page 39.



Henry, age 5, on DAYBUE since 2023

Diagnosis and symptoms

Henry was diagnosed with Rett syndrome when he was almost 2 years old.

Some of his signs and symptoms have included:

- Failure to reach developmental milestones
- Repetitive hand movements and behaviors
- Loss of communication skills
- Bursts of anxiety and irritability
- Tremor

Other treatments

Henry has a comprehensive treatment plan developed by his neurologist. It includes physical and occupational therapy 5 times a week at the school he attends for children with complex needs. He also uses an eye-gaze communication device.

Managing side effects

For the first few weeks after starting DAYBUE, Henry experienced diarrhea. Then, with guidance from their doctor, Henry’s family decided to take a wait-and-see approach while adjusting his diet to include more bananas. Henry’s diarrhea is managed with the help of their doctor.



*Before DAYBUE, Henry used to have bursts of irritability. **Since starting DAYBUE, Henry’s mood has improved.** He’s less anxious and his first line of defense isn’t to yell. We feel more confident taking him out to restaurants.*

– Carrie, Henry’s mom

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Holly's improved hand movements have helped her explore more of her interests



Hand movements or stereotypies

Holly can now pick out the chocolate and macadamia nuts from her trail mix



Breathing

Holly doesn't hold her breath as often and has been hyperventilating less



Mood

Holly's mood has improved significantly. She is less anxious and more engaged in structured activities. She also participates more in school



Vocalizations

As noted by her teachers and principal, her improvements in communication have led to less frustration in class



Eye gaze

Holly's eye gaze has always been good, but now she's able to focus more on other things, like watching sports or TV

Important Safety Information (continued)

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 page 39.



Diagnosis and symptoms

Holly was diagnosed with Rett syndrome when she was around 4 years old.

Some of her signs and symptoms have included:

- Loss of purposeful hand use
- Breath holding
- Loss of communication abilities

Other treatments

Holly attends physical therapy as well as occupational and speech therapy.

Managing side effects

Holly occasionally has diarrhea. Her parents have adjusted her diet to include bananas and sometimes add psyllium to her beverages.



We love seeing her surprise herself as she tries new things.

Her mood has improved, and because of that, her frustration levels have gone down, and she seems happier.

– Kammy, Holly's mom

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Holly, age 11,
on DAYBUE since 2023



Kate, age 12, on DAYBUE since 2021

Kate's improved eye gaze has helped her make her own choices



Hand movements or stereotypes
Kate is able to use a spoon and point at and touch her tablet



Eye gaze
Kate is better able to use her eye-gaze device to convey her wishes and needs



Mood
Her parents describe her as more peaceful—at home, at school, and in groups



She'll use her eye-gaze (device) and maybe navigate to a page, and then once she's there, she'll make her choices with her hand.

– Jen, Kate's mom

Important Safety Information (continued)

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

- **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.

See additional Important Safety Information on page 39.



Diagnosis and symptoms

Kate was diagnosed with Rett syndrome at age 3. **Some of her signs and symptoms have included:**

- Repetitive hand behaviors
- Loss of purposeful hand use
- Loss of communication abilities

Other treatments

No daily medications to manage symptoms; attends occupational therapy to strengthen hand function, as well as speech and physical therapy.

Managing side effects

Shortly after starting DAYBUE, Kate started having diarrhea. While it doesn't happen every day, when it does occur, it can require multiple diaper changes and can happen multiple times a day. This was a different experience for her family, as Kate struggled with constipation before the study and sometimes had to take laxatives. **When the diarrhea first started, Kate's parents worked with their healthcare team to come up with strategies for managing the diarrhea.** In consultation with her doctor, Kate's parents stopped giving her laxatives and instead started an antidiarrheal every day, which has helped make her bowel movements more solid.

Important Note: The effectiveness and safety of DAYBUE were evaluated in the 12-week LAVENDER clinical study of 187 female patients aged 5 to 20 with Rett syndrome. Because each individual with Rett syndrome is unique—with a unique set of symptoms—the response to DAYBUE may be different for everyone. See the results from the clinical study. Kate's family was compensated for sharing their story and participating in a photo shoot. This story was created in March 2024. Kate was a DAYBUE clinical study participant and has continued to take DAYBUE. Kate's experience on treatment is unique to her.





Maddy's improved eye gaze has helped her engage with the people she loves most



Hand movements or stereotypies

Maddy's hands are less aggressive, and she has more control of them



Vocalizations

Maddy still has no words, but vocalizes more when someone talks to her or asks her questions



Repetitive behaviors

Maddy hardly sticks her tongue out and grinds her teeth less



Facial expressions

Maddy's face is calmer and more relaxed. She doesn't grimace as much



Breathing

Maddy's breath holding has improved significantly



Eye gaze

Maddy is able to make quicker choices with her eyes (such as choosing what she wants to wear)



Nighttime behaviors

Maddy has fewer night terrors and laughing spells, allowing her to sleep better



Mood

Maddy has experienced less anxiety in crowds and is happier

Important Safety Information (continued)

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

- **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.

See additional Important Safety Information on page 39.



Diagnosis and symptoms

Maddy was diagnosed with Rett syndrome at age 3—just a few years after the discovery of the *MECP2* gene. **Some of her signs and symptoms have included:**

- Loss of purposeful hand use
- Breath holding
- Loss of communication abilities
- Waking up in the middle of the night with laughing spells or night terrors

Other treatments

Maddy attends physical, occupational, speech, massage, and music therapy.

Managing side effects

Maddy has had some reflux and vomiting with DAYBUE. Maddy's parents told her doctor the first time it happened and together, **they developed a plan to help manage vomiting.** With this plan in place, her parents have felt this side effect has been manageable for Maddy.



We are happy with the breathing improvements we have noticed since starting DAYBUE.

– Amy, Maddy's mom



[Click here to watch Maddy's story](#)

Important Note: The effectiveness and safety of DAYBUE were evaluated in the 12-week LAVENDER clinical study of 187 female patients aged 5 to 20 with Rett syndrome. Because each individual with Rett syndrome is unique—with a unique set of symptoms—the response to DAYBUE may be different for everyone. See the results from the clinical study. Maddy's family was compensated for sharing their story and participating in a photo shoot. This story was created in March 2024. Maddy was a DAYBUE clinical study participant and has continued to take DAYBUE. Maddy's experience on treatment is unique to her.



Maddy, age 22, on DAYBUE since 2020 (right), with her dad and brother



Madelyn's improved hand movements have given her more ways to play



Hand movements or stereotypies

Madelyn has shown improvements in feeding herself and playing with toys, which she is very proud of



Repetitive behaviors

Madelyn has been grinding her teeth less. She's now able to control her tongue more and can "put her tongue away" on request



Breathing

Madelyn is holding her breath less frequently and hyperventilating less



Vocalizations

Madelyn now vocalizes intentionally and has distinct sounds for excitement and needing help



Eye gaze

Madelyn used to avoid eye contact but now looks when her name is called



Mood

Madelyn now engages more and tolerates environments better. She enjoys watching other kids; she smiles at them

Important Safety Information (continued)

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

- **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 page 39.



Diagnosis and symptoms

Madelyn was diagnosed with Rett syndrome when she was around 3 years old.

Some of her signs and symptoms have included:

- Repetitive hand behaviors
- Loss of purposeful hand use
- Loss of communication abilities

Other treatments

Madelyn does weekly physical, occupational, and speech therapy. She also takes DAYBUE "like a rock star."

Managing side effects

Madelyn has had some diarrhea since starting DAYBUE but takes a fiber supplement and eats bananas to help.



Since starting DAYBUE, Madelyn seems happier, and she smiles more. It's helped her mood and our lives.

– Angie, Madelyn's mom

Important Note: The effectiveness and safety of DAYBUE were evaluated in the 12-week LAVENDER clinical study of 187 female patients aged 5 to 20 with Rett syndrome. Because each individual with Rett syndrome is unique—with a unique set of symptoms—the response to DAYBUE may be different for everyone. See the results from the clinical study. Madelyn's family was compensated for sharing their story and participating in a photo shoot. This story was created in April 2025. Madelyn initiated treatment on DAYBUE in June 2023 and was not a clinical study participant. Madelyn's experience on treatment is unique to her.



Madelyn, age 5, on DAYBUE since 2023, with her mom



Quinn, age 6, on DAYBUE since 2021

Quinn's improved mood has helped her participate in more family activities



Hand movements or stereotypies

Quinn has more control of her hands and she grabs at her face and body less



Repetitive behaviors

Quinn's teeth grinding has improved



Breathing

Quinn still holds her breath occasionally, has fewer "Rett episodes," and hyperventilates less



Eye gaze

Quinn can hold her gaze to participate and engage, especially in the classroom and in her therapies



Mood

Quinn's moods are more predictable and she cries a lot less

Important Safety Information (continued)

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 page 39.



Diagnosis and symptoms

Quinn was diagnosed with Rett syndrome when she was 15 months old.

Some of her signs and symptoms have included:

- Breath holding
- Repetitive behaviors (teeth grinding)
- Loss of purposeful hand use

Other treatments

At school, Quinn participates in physical, speech, and occupational therapy. Outside of school, Quinn does additional physical, oral motor, and swim therapy.

Managing side effects

After starting DAYBUE, Quinn began experiencing diarrhea. Some days, it occurs once or twice, other days as much as seven times. Quinn's parents worked with their doctor on different tactics to help manage the diarrhea.



The improvements in Quinn's symptoms, especially in her mood, have given us more confidence to have more flexibility as a family. Before DAYBUE, we didn't go to many places. Now we can all go to parties, family cookouts, and our other kids' sports events.

– Lindsay, Quinn's mom

Important Note: The effectiveness and safety of DAYBUE were evaluated in the 12-week LAVENDER clinical study of 187 female patients aged 5 to 20 with Rett syndrome. Because each individual with Rett syndrome is unique—with a unique set of symptoms—the response to DAYBUE may be different for everyone. See the results from the clinical study. Quinn's family was compensated for sharing their story and participating in a photo shoot. This story was created in March 2024. Quinn was a DAYBUE clinical study participant and has continued to take DAYBUE. Quinn's experience on treatment is unique to her.





Cheryl,
Family Support
Educator

Educational support for families living with Rett syndrome

Whether you're considering treatment with DAYBUE or still trying to understand Rett syndrome, you're bound to have questions. **Family Support Educators** can help you better understand Rett syndrome and the impact DAYBUE may have.



Education that fits your schedule

Family Support Educators can help you to learn more about Rett syndrome and potential treatment with DAYBUE, and can discuss the facts and answer your questions.

Family Support Educators can meet with you one-on-one virtually or in-person. Connect with a Family Support Educator for a partner in navigating your family's Rett syndrome journey and be better prepared for conversations with your doctor.

Family Support Educators can't provide medical advice or treatment recommendations—those are decisions for you and your doctor.

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 page 39.



Your Family Support Educator can:

- ✓ Help you learn more about Rett syndrome and potential treatment with DAYBUE
- ✓ Provide in-person or virtual one-on-one education
- ✓ Answer questions about insurance coverage
- ✓ Help you prepare for treatment with DAYBUE, including education on side effects
- ✓ Keep you informed on new learning resources, events, and more
- ✓ Connect you with other caregivers in the community

The decision to pursue DAYBUE treatment is always between you and your doctor. If you do move forward, your Family Support Educator will help you transition to a member of our Acadia Connect team for ongoing treatment support



Ready to connect? Schedule an online meeting to start the conversation with your Family Support Educator. Once you're connected, future talks can happen online, by phone, or in person—whatever you prefer. [Click here to book now](#)



Nancy,
Family Support
Educator

Support by your side

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.

Jill,
Family Support
Educator



acadia
connect®

Acadia Connect team members are ready to help

The team will help you with:

- ✓ Understanding Rett syndrome
- ✓ Providing information about DAYBUE
- ✓ Answering questions on insurance coverage
- ✓ Information on appropriate financial assistance options
- ✓ Support and education throughout the DAYBUE treatment journey

Acadia Connect consists of a dedicated, experienced support team:

Nurse Care Coordinator: Provides information about insurance coverage and financial assistance options for DAYBUE, and coordinates medication delivery

Patient Access Manager: Offers education and support to help your loved one's doctor with obtaining coverage for DAYBUE

Visit AcadiaConnect.com or call 1-844-737-2223, Monday–Friday, 8:00AM to 8:00PM ET to learn more about our individualized support program designed to help meet the needs of your loved one taking DAYBUE.

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.

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**. 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).

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.

Ready to see what may be possible?

Ask your doctor if DAYBUE or DAYBUE STIX is right for your family

➔ **Connect** with a Family Support Educator for one-on-one guidance or visit [DAYBUE.com](https://www.daybue.com) to learn more



Important Safety Information

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.

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See additional Important Safety Information on page 39. Please read the full [Prescribing Information](#), including [Patient Information](#).



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Kate, age 12,
on DAYBUE since 2021