Daybue

Oman · access guide

How to access Daybue from Oman, the named-patient import pathway, 2026

By Reserve Meds · Clinical & regulatory team · Last reviewed 2026-04-23

A Oman family of a child, adolescent, or adult with Rett syndrome may receive a prescription for Daybue (trofinetide) from their treating paediatric neurologist. Daybue is FDA-approved as the first therapy specifically indicated for Rett syndrome, developed by Acadia Pharmaceuticals. Rett syndrome is a rare, progressive, X-linked neurodevelopmental disorder affecting primarily girls, with onset typically in early childhood. In Oman, Daybue is not locally registered, which is why your paediatric neurologist will navigate the Directorate General of Pharmaceutical Affairs and Drug Control (DGPADC) named-patient import pathway on your behalf.

This guide explains the legal pathway, what documentation your physician needs, typical timing and cost bands, and where Reserve Meds fits in.

The clinical situation

Daybue is a synthetic analogue of a naturally occurring tripeptide derived from insulin-like growth factor 1 (IGF-1), taken as an oral liquid twice daily dosed by weight. Eligibility is based on clinical diagnosis of Rett syndrome, typically supported by genetic confirmation of a pathogenic variant in MECP2, and ongoing management by a paediatric neurologist familiar with Rett syndrome. Your neurologist will confirm diagnosis, baseline function (using standardised Rett-specific scales), and set up monitoring. Daybue can cause diarrhoea and vomiting, so families are counselled on hydration and dose-adjustment strategies. Because Daybue is oral, in-country administration is straightforward once the prescribing plan is in place.

Is Daybue legally importable into Oman?

Yes, through the DGPADC named-patient import framework, administered in coordination with the Ministry of Health for patients treated in public tertiary centres.

The named-patient mechanism allows a Oman-licensed physician to import a medicine not locally registered when: (a) the medicine is approved by a recognised reference authority such as the US FDA, (b) no clinically equivalent locally registered alternative is available, (c) the physician takes clinical responsibility, and (d) chain of custody is documented end to end. For Rett syndrome in Oman, there is no locally registered disease-specific alternative, making the clinical rationale direct.

How the pathway works, step by step

1. **Consultation with your treating paediatric neurologist.** Clinical diagnosis of Rett syndrome with supporting MECP2 genetic confirmation, and a written clinical rationale.
2. **Baseline assessment.** Weight, Rett-specific functional scales, GI tolerance baseline, and hydration plan are documented.
3. **DGPADC named-patient application.** Your physician or hospital pharmacy files the application with clinical rationale, genetic report, patient reference, and chain-of-custody plan.
4. **US-side sourcing.** Reserve Meds coordinates with our US-licensed specialty wholesale partner to secure Daybue from authorised distribution.
5. **Shipment.** Daybue ships with chain-of-custody documentation; manufacturer handling conditions apply during transport.
6. **Arrival and dispensing.** The hospital pharmacy releases the bottle to the family with weight-based dosing instructions and GI-symptom management guidance.

What documentation your physician needs

Your physician will typically need to provide:

- A clinical rationale letter confirming Rett syndrome diagnosis, MECP2 report, baseline function, and Daybue as the indicated treatment
- Verification of their Oman medical licence (SCFHS / MOH)
- A copy of the MECP2 genetic diagnostic report
- Patient identifier (anonymised reference where possible)
- Planned dosing schedule based on weight, with a plan for dose adjustments as the child grows and for management of GI tolerability

Reserve Meds provides a physician documentation kit that bundles the templates DGPADC reviewers expect to see for rare-paediatric-neurology named-patient imports, including the GI-tolerability and hydration-management plan central to Daybue adherence.

Costs and timing

Daybue's US cash-pay drug-only reference cost is weight-dependent because dosing scales with body weight. Indicative 2026 annual cost sits in a broad range of roughly USD 375,000-575,000, with adult patients and larger adolescents at the higher end of that range. International logistics, DGPADC documentation handling, and concierge coordination add incremental cost. Reserve Meds issues a full transparent quote at the start of intake.

Indicative timing for first dispense after cohort intake opens is 7-14 days from the moment a complete DGPADC application is submitted. Refills ship on a rolling basis against the monthly dispensing schedule.

Fulfilment availability is limited to our first cohort, and all timelines published on this site are indicative. If your clinical situation is time-sensitive, tell us at intake. We triage accordingly.

A culturally-aware note: Rett syndrome primarily affects girls and places long-term caregiving demands on mothers, aunts, and extended female family. In Oman families this often extends to a multigenerational caregiving pattern with grandmothers and older sisters taking structured roles. Our concierge coordination is deliberately inclusive of whichever family members the primary caregiver designates, and refill logistics are planned around school terms, Hajj, and Ramadan.

Reserve Meds's role

Reserve Meds is a US-based concierge coordinator for cross-border specialty medicine. For Daybue specifically, we provide:

- **Sourcing.** Through our US-licensed specialty wholesale partner, operating under DSCSA chain-of-custody.
- **Documentation.** Regulatory package for your physician and for DGPADC review.
- **Logistics.** Chain-of-custody shipment coordination to your prescribing hospital pharmacy.
- **Concierge case lead.** A named point of contact for the family, coordinating long-term refills and weight-based dose adjustments as the child grows.

What we do not do: we are not the prescriber, we do not practise medicine, and we are not the dispensing pharmacy. All clinical decisions remain with your treating paediatric neurologist.

Frequently asked

Is this legal in Oman? Yes, when executed through the DGPADC named-patient framework with appropriate documentation. Cross-border named-patient import for rare-paediatric-disease therapies is a recognised mechanism. See our trust and compliance page.

Is Daybue a cure? No. Daybue is a disease-modifying therapy intended to improve certain Rett-syndrome symptoms. Pivotal study endpoints focused on functional improvement. Your paediatric neurologist will discuss realistic outcome expectations.

How is GI tolerability managed? Diarrhoea and vomiting are recognised on-label effects. Your neurology team will advise on dose adjustment strategies, hydration planning, and anti-diarrhoeal supportive measures.

Can an adult with Rett syndrome receive Daybue? Yes, FDA labelling covers paediatric and adult patients. Your physician will advise on age- and weight-appropriate dosing.

Will insurance or MoH coverage apply? Cash-pay is the default. Some Oman patients may receive partial MoH or private-insurance consideration; we supply documentation for submission but do not process claims directly.

Reserve Meds's role

US-based concierge coordinator for cross-border specialty medicine. We are not the prescriber, not the dispensing pharmacy, and not the manufacturer. All clinical decisions remain with your treating physician.

Reserve Meds

reserved for you.

Composite case examples. This document is for general information only and does not constitute medical advice. Please consult your treating physician.
Reserve Meds is in pre-launch. Published timelines and cost ranges are indicative, not guarantees.
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