



Daybue in Saudi Arabia

The SFDA named-patient coordination pathway — indicative 2026

NEUROLOGY · RETT SYNDROME THERAPY

The clinical situation

Daybue (trofinetide) is the first FDA-approved therapy specifically indicated for Rett syndrome, a synthetic analogue of an IGF-1-derived tripeptide, taken as a twice-daily weight-based oral liquid. Developed by Acadia Pharmaceuticals. Rett syndrome is a rare, progressive, X-linked neurodevelopmental disorder typically affecting girls from early childhood. Eligibility is based on clinical diagnosis with MECP2 genetic confirmation. GI tolerability (diarrhoea, vomiting) requires a structured hydration and dose-adjustment plan.

The pathway, 5 steps

- 1 Consultation & clinical rationale.** Paediatric neurologist confirms Rett diagnosis with MECP2 report and writes the rationale.
- 2 Baseline assessment.** Weight, Rett-specific functional scales, GI baseline, and hydration plan documented.
- 3 SFDA named-patient application.** Physician or hospital pharmacy files rationale, genetic report, patient reference, and chain-of-custody plan.
- 4 US-side sourcing & logistics.** Reserve Meds coordinates product through our US-licensed DSCSA-compliant specialty wholesale partner.
- 5 Arrival & dispensing.** Hospital pharmacy releases the bottle to the family with weight-based dosing and GI-management guidance; monthly refills on rolling cadence.

Indicative economics

Reference US cash-pay range: USD 375,000–575,000 per year weight-dependent (drug-only reference; Reserve Meds provides a transparent delivered quote at intake).

Indicative first-dose timing

7–14 days from a complete SFDA application to first dispensation, once cohort intake opens. Indicative — not guaranteed.

Reserve Meds's role

Sourcing. US-licensed specialty wholesale partner, DSCSA chain-of-custody. **Documentation.** Regulatory package for your physician and SFDA review, keyed to MECP2 diagnosis and GI-tolerability plan. **Logistics.** Chain-of-custody shipment on monthly-refill cadence with refills planned around school terms, Hajj, and Ramadan. **Concierge case lead.** Inclusive of whichever family members the primary caregiver designates. **We are a coordinator** — not the prescriber, not the dispensing pharmacy. All clinical decisions remain with your treating paediatric neurologist.

COMPOSITE EXAMPLE · PRE-LAUNCH WAITLIST

Join the Daybue × Saudi Arabia first-cohort waitlist. *Our concierge reaches out as we open intake.*

reservemed.com/access-guides/daybue-saudi-arabia.html



SCAN TO JOIN

Reserve Meds · US-based concierge for cross-border specialty medicine. We are a coordinator; we are not the prescriber and not the dispensing pharmacy. All clinical decisions remain with the treating physician. Not medical advice.

Reserve Meds is in pre-launch. Service availability is limited to our first cohort; all timelines published are indicative, not guarantees. Composite case examples only.

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