Dojolvi

Kuwait · access guide

How to access Dojolvi for long-chain fatty acid oxidation disorders from Kuwait: 2026 pathway via Kuwait Pediatric Metabolic Centre at Mubarak Al-Kabeer, Kuwait Medical Genetics Centre, and MoH cross-border referral to KFSHRC Riyadh or Sidra Doha

By Reserve Meds clinical & regulatory team. Last reviewed 2026-05-20.

Kuwait has a paediatric metabolic centre at Mubarak Al-Kabeer Hospital that runs the in-country paediatric metabolic-genetics service, and the Kuwait Medical Genetics Centre operates the in-country diagnostic confirmation pathway for inborn errors of metabolism. Adult metabolic genetics infrastructure in Kuwait is more limited; complex paediatric and adult LC-FAOD cases are referred cross-border via the MoH Foreign Medical Treatment pathway to KFSHRC Riyadh (the MENA regional reference centre) or to Sidra Medicine Doha (the regional paediatric metabolic centre). Dojolvi (triheptanoin) is the only FDA-approved adjunctive therapy for long-chain fatty acid oxidation disorders (LC-FAOD), a group of rare autosomal-recessive metabolic disorders that includes CPT-II deficiency, CACT deficiency, VLCAD deficiency, LCHAD deficiency, and TFP deficiency. Dojolvi is not on the standard Kuwait MoH DFC formulary as of 2026. Access for a Kuwaiti patient typically follows the cross-border referral pathway via the MoH Foreign Medical Treatment programme, with the drug procured by the treating centre abroad; alternatively, hospital-mediated named-patient import via the Kuwait Pediatric Metabolic Centre is possible. For a Kuwaiti family with a child detected on newborn screening with abnormal long-chain acylcarnitines, or for an older paediatric or adult patient presenting with cardiomyopathy, rhabdomyolysis, or hypoketotic hypoglycaemia attributable to LC-FAOD, the operational question is which in-country or cross-border centre runs the workup, how the MoH Foreign Medical Treatment funding interacts with the supply, and what the lifelong dosing and follow-up rhythm looks like.

This page explains how the pathway works in 2026 for a Kuwait-resident paediatric or adult patient with confirmed LC-FAOD: when Dojolvi is indicated, who confirms the diagnosis, how the named-patient or MoH cross-border pathway works, what the day-to-day dosing and dietary structure looks like, and what the realistic cost band is.

Why Dojolvi, and when

Dojolvi is triheptanoin, a synthetic medium-odd-chain triglyceride composed of three molecules of heptanoic acid (the seven-carbon fatty acid, C7) esterified to glycerol. The FDA approved it in June 2020 as a source of calories and fatty acids in paediatric and adult patients aged 6 months and older with molecularly confirmed LC-FAOD. The clinical rationale is anaplerotic: triheptanoin is hydrolysed to heptanoic acid, which is metabolised through medium-chain beta-oxidation. The odd-chain length means the final cycle of beta-oxidation produces propionyl-CoA in addition to acetyl-CoA. Propionyl-CoA is metabolised to succinyl-CoA, a TCA cycle intermediate. This anaplerotic effect distinguishes triheptanoin from conventional even-chain MCT preparations. Standard MCT provides acetyl-CoA only; triheptanoin provides acetyl-CoA plus succinyl-CoA precursors.

For a Kuwaiti family with a child detected on NBS with abnormal long-chain acylcarnitine markers, the Dojolvi conversation begins at 6 months of age after confirmatory acylcarnitine profile and molecular testing have established the LC-FAOD diagnosis, typically through the Kuwait Medical Genetics Centre with cross-border confirmation at KFSHRC Riyadh or Sidra Doha for the complex-subtype subset. For an older patient presenting with cardiomyopathy, rhabdomyolysis, or hypoketotic hypoglycaemia, the conversation begins at the time of molecular confirmation. In both cases, the conversation runs through a metabolic-genetics service with a metabolic specialist and a metabolic dietitian.

What Dojolvi is, in plain language

Triheptanoin is a clear yellow oil taken orally, mixed into food or beverages at room temperature. The target dose is approximately 25 to 35 percent of total daily caloric intake from triheptanoin, divided across 4 or more daily doses taken with meals and snacks. Typical paediatric dosing is 1 to 3 mL/kg/day; typical adult dosing is determined by total daily caloric target and body weight, with most adults at 80 to 100 mL/day in divided doses. Titration starts at approximately 0.5 to 1 mL/kg/day and increases over 1 to 2 weeks to target, primarily to manage gastrointestinal tolerance.

This is a lifelong therapy. Dojolvi is an adjunct to dietary management (long-chain fat restriction, structured carbohydrate intake, frequent feeding, fasting avoidance), accompanied by a written sick-day plan. The drug reduces but does not eliminate the risk of acute metabolic decompensation during illness, fasting, or surgery.

Eligibility and the Kuwait pathway

The eligibility criteria are FDA-aligned:

1. Molecular confirmation of LC-FAOD: pathogenic or likely-pathogenic variants in CPT2, CPT1A, SLC25A20, ACADVL, HADHA, or HADHB. NBS-detected abnormal long-chain acylcarnitine profile followed by confirmatory plasma acylcarnitine profile, urine organic acids, and molecular sequencing. 2. Age 6 months or older. 3. Established or escalating clinical disease, or NBS-detected asymptomatic infant initiated at 6 months to pre-empt clinical events. 4. Capacity for adherence to the structured 4-or-more daily dosing schedule and for the gastrointestinal titration period. 5. Access to a metabolic dietitian for diet planning, dose calculation, sick-day management training, and family education.

For a Kuwaiti patient, the diagnostic workup and ongoing management run through the in-country centres with cross-border support for complex subsets:

- **Kuwait Pediatric Metabolic Centre, Mubarak Al-Kabeer Hospital**: paediatric metabolic-genetics service. The in-country reference for paediatric inborn errors of metabolism, including LC-FAOD diagnostic confirmation and ongoing management. Coordinates with Kuwait Medical Genetics Centre for molecular confirmation and with KFSHRC Riyadh for complex tertiary input. - **Kuwait Medical Genetics Centre**: diagnostic confirmation pathway for inborn errors of metabolism in Kuwaiti families. Plasma acylcarnitine profile, molecular sequencing, and clinical-genetics counselling. - **NBK Children's Hospital, Kuwait**: paediatric subspecialty support; coordinates with the Pediatric Metabolic Centre for paediatric LC-FAOD cases. - **Adult metabolic referral via KFSHRC Riyadh through the MoH Foreign Medical Treatment pathway**: Kuwait does not have a dedicated adult metabolic-genetics clinic at the Sidra or Hamad level; complex adult LC-FAOD cases are routinely referred cross-border to KFSHRC Riyadh via the MoH Foreign Medical Treatment programme for diagnostic confirmation and for ongoing surveillance.

The metabolic specialist drives diagnosis. The metabolic dietitian leads the dietary intervention plan. The cardiologist (for VLCAD and LCHAD subtypes) leads cardiomyopathy surveillance with annual echocardiograms.

The Kuwait prescribing and supply picture, plainly

The Kuwait MoH Drug and Food Control (DFC) is the national regulator. Dojolvi is not on the standard Kuwait MoH DFC registered formulary as of 2026. Two operational pathways apply for a Kuwaiti patient confirmed to have LC-FAOD:

1. **MoH Foreign Medical Treatment cross-border supply**: the drug is procured by the treating centre at KFSHRC Riyadh or Sidra Doha through that centre's named-patient pathway; the patient travels to the centre for initial titration and for periodic surveillance visits, with the drug supply carried by the patient or shipped as part of the cross-border care arrangement. MoH Foreign Medical Treatment funding for Kuwaiti nationals covers the relevant care components subject to pre-authorisation. 2. **In-country named-patient import via Mubarak Al-Kabeer**: the Pediatric Metabolic Centre pharmacy files a named-patient import authorisation with MoH DFC and coordinates with Ultragenyx International. Lead time is typically 6 to 12 weeks for the first dispense, longer than the KSA pathway. Monthly resupply runs through the same channel.

[VERIFY: current MoH DFC registration status and named-patient import lead times at Mubarak Al-Kabeer Pediatric Metabolic Centre at intake.]

For Kuwaiti nationals using the MoH Foreign Medical Treatment pathway to KFSHRC or to Sidra, MoH funding typically covers the drug-acquisition cost as part of the cross-border care episode. For Kuwaiti nationals using the in-country named-patient import via Mubarak Al-Kabeer, MoH rare-disease formulary funding is the typical mechanism, subject to case-by-case pre-authorisation. For expatriate residents, private insurance pre-authorisation runs in parallel.

Cost band and insurance positioning

US list price for Dojolvi is approximately USD 60,000 to USD 100,000 per year, varying by patient weight and target dose. At indicative 2026 cross rates the annual drug-only band is approximately KWD 18,400 to KWD 30,700. Full cost of care including the cross-border centre visits or in-country metabolic care, metabolic dietitian time, cardiac and hepatic surveillance, and intercurrent emergency care runs approximately 20 to 40 percent above drug-only cost.

This is a lifelong cost. Kuwaiti nationals using the MoH Foreign Medical Treatment pathway or the in-country rare-disease pathway have substantially reduced out-of-pocket exposure; expatriate residents have variable cover through private insurance.

What to expect on the Dojolvi pathway

Week 0 (referral and diagnostic confirmation): Kuwait Medical Genetics Centre and the Pediatric Metabolic Centre at Mubarak Al-Kabeer coordinate the in-country diagnostic confirmation, with cross-border referral to KFSHRC Riyadh or Sidra Doha through the MoH Foreign Medical Treatment programme for the complex-subtype subset or for adult cases. Metabolic specialist confirms LC-FAOD diagnosis through plasma acylcarnitine profile, molecular testing, and clinical correlation. Metabolic dietitian initiates dietary planning. Cardiology consultation engaged for VLCAD and LCHAD subtypes. Named-patient import process or cross-border supply pathway initiated.

Weeks 1 to 12 (drug procurement and titration): named-patient import paperwork complete; drug arrives in 4 to 12 weeks depending on pathway. Titration begins at approximately 0.5 to 1 mL/kg/day and increases over 1 to 2 weeks to target 1 to 3 mL/kg/day in paediatric patients, with proportional adult dosing. Daily 4-or-more divided doses with meals and snacks.

Weeks 12 to 24 (early maintenance): target dose maintained; metabolic-clinic visits every 4 to 8 weeks initially, transitioning to every 12 weeks once stable. Cardiac surveillance baseline established and repeated annually.

Ongoing (lifelong): metabolic-clinic visit every 12 weeks in stable patients; metabolic dietitian review at each visit; annual cardiac surveillance for VLCAD and LCHAD subtypes; intercurrent illness management per the sick-day plan; named-patient resupply monthly; MoH or insurance pre-authorisation renewal as required.

When Dojolvi is the wrong drug or not yet the right drug

For a Kuwaiti patient under 6 months of age, conservative paediatric metabolic management with conventional even-chain MCT, structured carbohydrate intake, and frequent feeding is the operational pathway; Dojolvi is added at 6 months. For a patient with confirmed LC-FAOD who cannot tolerate the gastrointestinal titration despite slower titration, the operational alternative is to remain on conventional MCT plus dietary management. For a patient with suspected LC-FAOD on NBS or clinical grounds but without molecular confirmation, the diagnostic workup is completed first.

Family screening, consanguinity, and pregnancy planning

LC-FAOD is autosomal recessive. Consanguinity is common in Kuwait and the wider Gulf. Carrier testing for siblings and at-risk extended-family members is a routine part of the metabolic-genetics conversation. Kuwait Medical Genetics Centre and the cross-border centre at KFSHRC coordinate the carrier-testing pathway. Pregnancy planning for women of childbearing age with LC-FAOD or with carrier status for LCHAD or TFP requires multidisciplinary coordination. HELLP syndrome and acute fatty liver of pregnancy (AFLP) are documented elevated-risk conditions in pregnancies where the fetus is LCHAD-affected or where the mother is heterozygous for LCHAD or TFP variants.

Religious-ethical considerations

Triheptanoin is a synthetic triglyceride manufactured from heptanoic acid of vegetable or fermentation origin. The product is not derived from animal tissue or human plasma. There is no porcine, bovine, or other religiously-significant animal component. The Islamic bioethics consensus on prescribed therapies for lifelong metabolic disorders is broadly permissive, and the synthetic vegetable-origin sourcing removes the dietary-law concerns that arise with some animal-derived products.

What Reserve Meds does on this case

We are a US-based concierge coordinator. We are not the prescriber and not the dispensing pharmacy. On a Kuwait Dojolvi case we coordinate the in-country and cross-border referral logistics with Kuwait Medical Genetics Centre, Mubarak Al-Kabeer Pediatric Metabolic Centre, and the cross-border centre (KFSHRC Riyadh or Sidra Doha), coordinate named-patient import logistics with Ultragenyx International, run financial pre-authorisation alongside clinical pre-authorisation (MoH Foreign Medical Treatment or in-country rare-disease pathway; private insurance for expatriates), support the family through the titration period and ongoing maintenance, and stay with the family for the long arc of lifelong therapy management. Clinical decisions remain with your treating metabolic specialist at Mubarak Al-Kabeer or at the cross-border centre.

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.

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