Dojolvi

United Arab Emirates · access guide

How to access Dojolvi for long-chain fatty acid oxidation disorders from the UAE: 2026 pathway via Cleveland Clinic Abu Dhabi, Al Jalila Children's, and the wider UAE metabolic and clinical-genetics network

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

The UAE has built a meaningful paediatric and adult metabolic-genetics infrastructure over the last decade. Cleveland Clinic Abu Dhabi runs a clinical-genetics service integrated with paediatric and adult care; Sheikh Khalifa Medical City carries an established paediatric metabolic clinic; Tawam Hospital in Al Ain runs the principal paediatric oncology and metabolic centre with paediatric metabolic clinic capacity; and Al Jalila Children's Specialty Hospital in Dubai is the dedicated paediatric metabolic and clinical-genetics hub for the northern emirates. 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 UAE EDE formulary as of 2026; UAE paediatric and adult metabolic centres access via single-patient Article 5 import under MOHAP coordinated with Ultragenyx International. For a UAE family with a child detected on newborn screening with abnormal long-chain acylcarnitines, or for an older paediatric or adult patient who has presented with cardiomyopathy, rhabdomyolysis, or hypoglycaemic crisis attributable to LC-FAOD, the operational question is which UAE metabolic centre runs the workup, how long the named-patient import takes, what the lifelong dosing schedule looks like, and what the realistic out-of-pocket cost band is for a therapy that is dispensed monthly and continued indefinitely.

This page explains how the pathway works in 2026 for a UAE-resident paediatric or adult patient with confirmed LC-FAOD: when Dojolvi is indicated, who confirms the diagnosis, how the named-patient import works, what the day-to-day dosing and dietary structure looks like, and what the realistic cost band is for the drug and for the broader metabolic-clinic infrastructure that wraps around it.

Why Dojolvi, and when

Dojolvi is triheptanoin, a synthetic triglyceride of heptanoic acid (C7, an odd-medium-chain fatty acid). It was approved by the FDA in June 2020 as adjunctive treatment of paediatric and adult patients aged 6 months and older with molecularly confirmed LC-FAOD. The clinical rationale is anaplerotic: on ingestion, triheptanoin is hydrolysed to heptanoic acid, which is absorbed and metabolised in the liver via medium-chain beta-oxidation. This pathway bypasses the defective long-chain beta-oxidation enzymes in LC-FAOD and yields both acetyl-CoA (energy substrate via the TCA cycle) and propionyl-CoA (which is carboxylated to succinyl-CoA, an anaplerotic substrate that replenishes TCA cycle intermediates depleted in LC-FAOD). This anaplerotic effect distinguishes triheptanoin from the conventional even-chain medium-chain triglyceride (MCT) preparations (C8 and C10) that have been the dietary mainstay of LC-FAOD management for decades.

For a UAE-resident family with a child detected on the UAE federal newborn screening programme with abnormal long-chain acylcarnitine markers, the Dojolvi conversation typically begins at 6 months of age (the minimum approved age) after confirmatory enzyme assay or molecular testing has established the LC-FAOD diagnosis. For an older paediatric or adult patient who presents with cardiomyopathy, rhabdomyolysis, or hypoglycaemic crisis, the Dojolvi conversation begins at the time of molecular confirmation of LC-FAOD, which may follow the acute decompensation by weeks. In both cases, the conversation is at a paediatric or adult metabolic clinic with a metabolic geneticist and a metabolic dietitian, not at a general paediatrician or general internist clinic.

What Dojolvi is, in plain language

Triheptanoin is a clear oily liquid taken orally as a food-component analogue, mixed into food or beverages. The target dose is approximately 25 to 35 percent of total daily caloric intake from triheptanoin, divided into 4 or more daily doses taken with meals and snacks. For a child receiving 1,500 kcal/day, target triheptanoin intake is approximately 50 to 60 mL/day in divided doses (triheptanoin caloric density is approximately 8 kcal/mL). For an adult receiving 2,500 kcal/day, target is approximately 80 to 100 mL/day in divided doses. Titration starts at approximately 10 percent of daily caloric intake and increases over 4 to 8 weeks to target, primarily to manage gastrointestinal tolerance (abdominal pain, diarrhoea, nausea, vomiting are common early in titration and improve with slower titration and smaller more frequent doses taken with food).

This is a lifelong therapy. Once started, Dojolvi is continued indefinitely. The conversation with the family is not about a course or a cycle; it is about a daily structured dosing pattern that integrates with meals and snacks, supported by careful dietary management of long-chain fat restriction plus structured carbohydrate intake plus fasting avoidance, and accompanied by a written sick-day plan for intercurrent illness. Dojolvi reduces but does not eliminate the risk of acute decompensation during illness, fasting, or surgery; the dietary discipline and sick-day plan remain non-negotiable regardless.

This is also a diet-first medicine. Dojolvi is the adjunct, not the substitute. The metabolic dietitian is a central member of the care team. The metabolic geneticist coordinates the overall clinical management. Cardiology consultation is integrated for VLCAD and LCHAD subtypes for cardiomyopathy surveillance; hepatology consultation is integrated for the hepatic-presentation subtypes.

Eligibility for Dojolvi at a UAE metabolic centre

The UAE paediatric and adult metabolic centres apply the FDA-aligned eligibility criteria:

1. Molecular confirmation of LC-FAOD: pathogenic or likely-pathogenic variants in one of CPT2, CPT1A, SLC25A20, ACADVL, HADHA, or HADHB. Newborn screening detection of abnormal long-chain acylcarnitine markers (elevated C14, C16, C18, C18:1; reduced C2 acetylcarnitine) followed by confirmatory plasma acylcarnitine profile, urine organic acids (dicarboxylic aciduria), and molecular sequencing is the standard diagnostic pathway in NBS-capable systems. The UAE federal NBS programme is comprehensive and includes LC-FAOD acylcarnitine markers. 2. Age 6 months or older. Younger neonates are managed with conservative dietary management plus conventional MCT first; Dojolvi is added at 6 months when a longer feeding schedule is in place. 3. Established or escalating clinical disease: cardiomyopathy, hepatic dysfunction, rhabdomyolysis, hypoglycaemic events, or progressive myopathy. NBS-detected asymptomatic infants may also be initiated at 6 months to attempt to pre-empt clinical events. 4. Capacity for adherence to the structured dosing schedule of 4 or more daily doses with meals and snacks, and capacity for the gastrointestinal titration period. 5. Access to a metabolic dietitian for diet planning, dose calculation, sick-day management training, and family education. 6. Family or patient understanding that this is a lifelong adjunctive therapy added to dietary management, not a replacement for it.

The diagnostic workup that confirms eligibility is the standard LC-FAOD workup at a UAE paediatric or adult metabolic centre. Al Jalila Children's, Cleveland Clinic Abu Dhabi, SKMC, Tawam, and Latifa Hospital paediatric run the workup for paediatric cases; CCAD also runs adult cases through its clinical-genetics service. Molecular testing is sent to in-region reference laboratories or to international reference laboratories via the UAE hospital pathology network. The metabolic geneticist drives diagnosis; the metabolic dietitian leads the dietary intervention plan; the cardiologist (for VLCAD and LCHAD subtypes) leads the cardiomyopathy surveillance.

A UAE family or patient is not making the eligibility determination. The conversation runs through the metabolic clinic. The Reserve Meds concierge role in this pathway is to coordinate the named-patient import logistics with Ultragenyx International in parallel with the metabolic clinic conversation, to support family logistics including financial pre-authorisation, and to coordinate cross-emirate or cross-border referral when warranted (KFSHRC Riyadh is the regional reference centre for complex LC-FAOD cases).

The UAE prescribing and supply picture, plainly

The Emirates Drug Establishment (EDE) is the federal regulator. Dojolvi is not on the standard EDE registered formulary as of 2026. UAE metabolic centres access Dojolvi via single-patient Article 5 import under MOHAP, coordinated with Ultragenyx International (the manufacturer of Dojolvi in the US) and a regional distribution partner. The named-patient import process typically takes 4 to 8 weeks from prescription to delivery once the import authorisation paperwork is complete. Subsequent monthly resupply is run through the same channel with shorter lead times once the patient is established on therapy. [VERIFY: current EDE registration status and named-patient import lead times at the treating UAE centre at intake.]

The UAE paediatric and adult metabolic centre network:

- **Al Jalila Children's Specialty Hospital, Dubai**: dedicated paediatric metabolic and clinical-genetics centre with established LC-FAOD diagnostic and management pathway. Principal Dubai paediatric metabolic centre. - **Cleveland Clinic Abu Dhabi (CCAD)**: clinical-genetics service integrated with paediatric and adult care; LC-FAOD diagnostic capability and Dojolvi dispensing via named-patient import. - **Sheikh Khalifa Medical City (SKMC), Abu Dhabi**: paediatric metabolic clinic. - **Tawam Hospital, Al Ain**: paediatric oncology and metabolic centre with established paediatric metabolic clinic. - **Latifa Hospital paediatric (DXB Children's), Dubai**: paediatric metabolic referral capability. - **Sheikh Shakhbout Medical City (SSMC), Abu Dhabi**: clinical-genetics service expanding; adult metabolic referral pathway.

Insurance pathways: Thiqa for Emirati nationals covers Dojolvi through MoH-coordinated case-by-case pre-authorisation; Daman and commercial cover for residents varies substantially by carrier and by plan tier; many private plans require case-by-case pre-authorisation given the high annual cost of Dojolvi. The financial pre-authorisation conversation needs to start at the time of metabolic-clinic diagnosis, not retrospectively after several months of therapy.

For UAE-resident families where the molecular diagnosis is complex (rare subtype variants, suspected dual diagnoses, or where international consultation is warranted), referral to KFSHRC Riyadh as the regional reference centre for MENA LC-FAOD diagnosis and management is the operational pathway. KFSHRC Riyadh runs the deepest paediatric and adult metabolic-genetics service in the Gulf.

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. A paediatric patient at 60 mL/day target is in the lower portion of the range; an adult at 100 mL/day target is in the upper portion. At indicative 2026 cross rates the annual drug-only band is approximately AED 220,000 to AED 367,000 per year. Full cost of care including metabolic clinic visits, 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. Over a paediatric lifetime, the cumulative drug cost runs into the millions of dirhams. Insurance pre-authorisation, employer-plan tier confirmation, and Thiqa pathway verification are core financial-pre-authorisation work that needs to happen at the time of metabolic-clinic diagnosis, alongside the named-patient import logistics. Reserve Meds coordinates the financial pre-authorisation work alongside the named-patient import work; we do not dispense, prescribe, or self-service price the drug.

What to expect on the Dojolvi pathway

Week 0 (diagnostic confirmation): metabolic geneticist confirms LC-FAOD diagnosis through plasma acylcarnitine profile, molecular testing, and clinical correlation. Metabolic dietitian initiates dietary planning and family education. Cardiology consultation engaged for VLCAD and LCHAD subtypes. Named-patient import process initiated with Ultragenyx International. Financial pre-authorisation initiated with the insurance carrier.

Weeks 1 to 8 (drug procurement and titration): Article 5 import paperwork through MOHAP, drug arrives in 4 to 8 weeks. Once drug arrives, titration begins at approximately 10 percent of daily caloric intake and increases over 4 to 8 weeks to target 25 to 35 percent. Daily 4-or-more divided doses with meals and snacks. Gastrointestinal tolerance assessed at each metabolic clinic visit; titration rate adjusted as needed.

Weeks 8 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 (echocardiogram and ECG) and repeated annually or more frequently per clinical indication. Liver function tests and creatine kinase monitored. Sick-day plan written, family trained, emergency-letter documentation issued.

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; insurance pre-authorisation renewal as the carrier requires (typically annually).

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

For a UAE patient under 6 months of age, the 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 of Dojolvi despite slower titration and adjusted dose-distribution, the operational alternative is to remain on conventional even-chain MCT plus dietary management; conventional MCT provides energy substrate but does not provide TCA cycle anaplerosis, and the clinical conversation about this trade-off happens at the metabolic clinic. For a patient with suspected LC-FAOD on NBS or clinical grounds but without molecular confirmation, the diagnostic workup is completed first; Dojolvi initiation waits for molecular confirmation.

Carnitine supplementation (L-carnitine) is commonly used adjunctively in LC-FAOD with documented total or free carnitine deficiency; clinical practice on routine carnitine supplementation in LC-FAOD varies by subtype and clinician and is independent of the Dojolvi decision.

Family screening and pregnancy planning

LC-FAOD is autosomal recessive. Consanguinity is common in the UAE and the wider Gulf, and autosomal recessive disorders including the LC-FAOD subtypes have higher carrier prevalence in consanguineous extended-family pedigrees. Carrier testing for siblings and at-risk extended-family members is offered as part of the metabolic-genetics conversation in any newly diagnosed LC-FAOD family.

Pregnancy planning for women of childbearing age with LC-FAOD or with carrier status for LCHAD or TFP requires coordination across the metabolic clinic, the maternal-fetal medicine service, and the obstetric team. 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. Continuation of Dojolvi during pregnancy is generally favoured to maintain maternal metabolic stability; the pregnancy-specific data are limited and the conversation is individualised.

What Reserve Meds does on this case

We are a US-based concierge coordinator. We are not the prescriber and not the dispensing pharmacy, and on a Dojolvi case we are not driving the clinical decision-making at the UAE metabolic centre. On a UAE Dojolvi case we coordinate named-patient import logistics with Ultragenyx International in parallel with the metabolic clinic conversation, run financial pre-authorisation alongside clinical pre-authorisation, support the family through the titration period and ongoing maintenance, coordinate cross-emirate or cross-border referral when warranted (KFSHRC Riyadh is the regional reference centre), and stay with the family for the long arc of lifelong therapy management. Clinical decisions remain with your treating metabolic geneticist and the metabolic clinic care team.

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.

Composite case examples. This document is for general information only and does not constitute medical advice. Please consult your treating physician.

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