Dojolvi

Saudi Arabia · access guide

How to access Dojolvi for long-chain fatty acid oxidation disorders from Saudi Arabia: 2026 pathway via KFSHRC Riyadh, KFMC, KKUH, and the wider Saudi paediatric and adult metabolic-genetics network

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

Saudi Arabia operates the deepest paediatric and adult metabolic-genetics infrastructure in the wider Gulf region. King Faisal Specialist Hospital and Research Centre (KFSHRC) Riyadh runs the regional reference centre for MENA paediatric and adult metabolic disorders; King Fahad Medical City (KFMC) runs an established paediatric and adult metabolic clinic; King Khalid University Hospital (KKUH) Riyadh runs a King Saud University paediatric metabolic clinic with clinical-genetics integration; and King Abdulaziz Medical City (KAMC) Riyadh and Jeddah run National Guard Health Affairs paediatric and adult metabolic clinics. 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 SFDA registered formulary as of 2026. KFSHRC Riyadh and KFMC access Dojolvi via named-patient import coordinated with Ultragenyx International and a local commercial agent. For a Saudi family with a child detected on the national newborn screening programme 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 Saudi metabolic centre runs the workup, how the named-patient import is coordinated, what the lifelong dosing schedule looks like, and how the public funding pathway (Ministry of Health / NUPCO) and private insurance interact for a high-cost lifelong therapy.

This page explains how the pathway works in 2026 for a Saudi-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 the broader metabolic-clinic infrastructure.

Why Dojolvi, and when

Dojolvi is triheptanoin, a synthetic triglyceride of heptanoic acid (C7). The FDA approved it 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: triheptanoin is hydrolysed to heptanoic acid, which is metabolised 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 TCA cycle) and propionyl-CoA (which is carboxylated to succinyl-CoA, replenishing 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 Saudi family with a child detected on the national NBS programme with abnormal long-chain acylcarnitine markers, the Dojolvi conversation begins at 6 months of age after confirmatory enzyme assay or molecular testing has established the LC-FAOD diagnosis. For an older paediatric or adult patient presenting with cardiomyopathy, rhabdomyolysis, or hypoglycaemic crisis, the conversation begins at the time of molecular confirmation. The conversation happens at a paediatric or adult metabolic clinic with a metabolic geneticist and a metabolic dietitian.

What Dojolvi is, in plain language

Triheptanoin is a clear oily liquid taken orally, 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 with meals and snacks. For a child receiving 1,500 kcal/day, target 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. Titration starts at approximately 10 percent of daily caloric intake and increases over 4 to 8 weeks to target, primarily to manage gastrointestinal tolerance.

This is a lifelong therapy. Once started, Dojolvi is continued indefinitely. Dojolvi is an adjunct to dietary management (long-chain fat restriction plus structured carbohydrate intake plus fasting avoidance), accompanied by a written sick-day plan for intercurrent illness. The drug reduces but does not eliminate the risk of acute decompensation during illness, fasting, or surgery; dietary discipline and sick-day planning remain non-negotiable.

Eligibility for Dojolvi at a Saudi metabolic centre

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

1. Molecular confirmation of LC-FAOD: pathogenic or likely-pathogenic variants in CPT2, CPT1A, SLC25A20, ACADVL, HADHA, or HADHB. NBS detection of abnormal acylcarnitine markers followed by confirmatory plasma acylcarnitine profile, urine organic acids, and molecular sequencing is the standard pathway in NBS-detected cases. The Saudi MoH NBS programme covers selected metabolic disorders including VLCAD and LCHAD nationally. 2. Age 6 months or older. 3. Established or escalating clinical disease (cardiomyopathy, hepatic dysfunction, rhabdomyolysis, hypoglycaemic events, or progressive myopathy), 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.

The diagnostic workup that confirms eligibility is the standard LC-FAOD workup at a Saudi paediatric or adult metabolic centre. KFSHRC Riyadh, KFMC, KKUH, KAMC Riyadh and Jeddah, and KFSHRC Jeddah run paediatric and adult metabolic clinics with molecular and biochemical diagnostic capability. Molecular testing is performed in-house at KFSHRC and KFMC; smaller centres send testing to KFSHRC or to international reference laboratories. The metabolic geneticist drives diagnosis; the metabolic dietitian leads dietary intervention; the cardiologist (for VLCAD and LCHAD subtypes) leads cardiomyopathy surveillance.

The Saudi prescribing and supply picture, plainly

The Saudi Food and Drug Authority (SFDA) is the national regulator. Dojolvi is not on the standard SFDA registered formulary as of 2026. KFSHRC Riyadh, KFMC, and other Saudi metabolic centres access Dojolvi via named-patient import coordinated with Ultragenyx International (the manufacturer of Dojolvi in the US) and a local commercial agent. The named-patient import process typically takes 4 to 8 weeks from prescription to first delivery; monthly resupply runs through the same channel with shorter lead times once the patient is established. [VERIFY: current SFDA registration status and named-patient import lead times at intake.]

The Saudi paediatric and adult metabolic centre network:

- **KFSHRC Riyadh**: regional reference centre for MENA paediatric and adult metabolic genetics. Genetic disorders centre runs molecular and biochemical diagnostic workup for LC-FAOD; metabolic clinic dispenses Dojolvi via named-patient import; cardiology and hepatology consult integration for the VLCAD and LCHAD subtypes. KFSHRC is the regional reference for MENA LC-FAOD diagnosis and management. - **KFSHRC Jeddah**: secondary paediatric and adult metabolic site coordinated with KFSHRC Riyadh. - **KFMC Riyadh**: established paediatric and adult metabolic clinic with NBS-confirmation pathway. - **KKUH Riyadh**: King Saud University paediatric metabolic clinic with clinical-genetics integration. - **KAMC Riyadh and Jeddah**: National Guard Health Affairs paediatric and adult metabolic clinics. - **Princess Noorah Oncology Center and Princess Sultan Military Medical City (PSMMC), Riyadh**: paediatric and adult metabolic referral pathway coordination.

Insurance pathways: the Ministry of Health public funding pathway through NUPCO is the primary funding channel for Dojolvi in Saudi nationals at MoH facilities and at KFSHRC; high-cost rare-disease formulary inclusion is on a case-by-case basis. Tameen the general medical insurance scheme covers expatriates and private-sector employees with case-by-case pre-authorisation; GOSI covers the social insurance subset. Financial pre-authorisation runs in parallel with the clinical pathway and is initiated at the time of metabolic-clinic diagnosis.

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 SAR 225,000 to SAR 375,000 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. Saudi national patients at MoH facilities and at KFSHRC who qualify for rare-disease formulary coverage have substantially reduced out-of-pocket exposure through NUPCO and the MoH catastrophic-illness pathway; private-sector employees and expatriates have variable cover through Tameen and through commercial insurance carriers.

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 NUPCO or with the insurance carrier.

Weeks 1 to 8 (drug procurement and titration): named-patient import paperwork complete, drug arrives in 4 to 8 weeks. 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 and repeated annually or more frequently per clinical indication.

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 or NUPCO pre-authorisation renewal as required.

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

For a Saudi 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 gastrointestinal titration 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.

Family screening, consanguinity, and pregnancy planning

LC-FAOD is autosomal recessive. Consanguinity is common in Saudi Arabia (estimated 25 to 50 percent of marriages depending on region), and autosomal recessive disorders including the LC-FAOD subtypes have higher carrier and affected prevalence in consanguineous extended-family pedigrees. Carrier testing for siblings and at-risk extended-family members is a routine part of the metabolic-genetics conversation in any newly diagnosed Saudi LC-FAOD family. KFSHRC Riyadh runs the regional reference clinical-genetics service for carrier testing and pregnancy-planning conversations.

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 Saudi metabolic centre. On a Saudi 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 (NUPCO or Tameen pathway), support the family through the titration period and ongoing maintenance, coordinate any out-of-kingdom referral logistics when warranted, 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.

reservemeds.com · hello@reservemeds.com