Ctexli

Saudi Arabia · access guide

How to access Ctexli for cerebrotendinous xanthomatosis from Saudi Arabia: 2026 pathway via KFSHRC metabolic and genetics programmes | Reserve Meds

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

Saudi Arabia carries one of the highest documented prevalences of cerebrotendinous xanthomatosis (CTX) in the Gulf because of the underlying consanguinity rate and the long-standing capture of metabolic neurology cases at King Faisal Specialist Hospital and Research Centre (KFSHRC) Riyadh, King Abdulaziz Medical City (KAMC) Riyadh and Jeddah, and King Fahad Medical City (KFMC). A patient with CTX in Saudi Arabia is almost always already in the metabolic genetics or neurology system, not a newcomer. The 2026 question is whether to source Ctexli, the first FDA-approved oral chenodeoxycholic acid replacement therapy, through SFDA registration, MoH personal-import, or named-patient supply.

Why Ctexli, why now

Ctexli received FDA approval in February 2024 as the first treatment specifically labelled for CTX in adults and paediatric patients. CTX is an inborn error of bile-acid synthesis caused by CYP27A1 mutations, with cholestanol accumulation driving progressive neurologic deterioration, tendon xanthomas, juvenile cataracts, and early atherosclerosis. Ctexli is FDA-approved less than 24 months ago, so the Saudi pathway is named-patient or personal-import under SFDA. Domestic registration is not yet in place.

What Ctexli is, in plain language

Ctexli is oral chenodiol (chenodeoxycholic acid) capsules. It replaces the missing bile acid your body cannot make, restoring the feedback signal that suppresses cholestanol production. It does not reverse damage already done. It slows or halts progression and reduces cholestanol. Dosing is weight-based, three times daily with food, for life.

Eligibility at a Saudi metabolic or neurology clinic

The patient must have a confirmed CTX diagnosis: biallelic CYP27A1 pathogenic variants on genetic testing, plus elevated plasma cholestanol. KFSHRC and KAMC both run metabolic genetics services that can confirm. Paediatric cases are managed through paediatric neurology at KFSHRC, KFMC, or Sidra Medicine in Qatar by referral; adults are managed through adult neurology or metabolic clinic.

The Saudi prescribing and supply picture

Ctexli is not SFDA-registered as of 2026. Access is via named-patient import under SFDA's personal medication importation framework or via institutional special-access request from KFSHRC pharmacy. Reserve Meds coordinates the import file, the prescription chain from the treating neurologist or metabolic specialist, and the cold-chain or temperature-controlled shipping from US or EU source.

Cost band

USD 150K-220K annual per patient (SAR 565K-825K), weight-dependent. The drug is dosed three times daily and continued for life. MoH coverage for rare-disease imports is case-by-case under the Council of Health Insurance rare disease policy; private insurance coverage is unusual.

What to expect, week-by-week

Weeks 0 to 4: confirm diagnosis if not already on file, get the prescription, file the import authorisation, place the order. Weeks 4 to 8: shipment arrives, initiation under metabolic-clinic supervision, baseline cholestanol and liver enzymes documented. Weeks 8 to 24: monitor cholestanol trend, liver function, and tolerability; dose adjustments are uncommon. Month 6 and 12: full metabolic and neurologic re-assessment, MRI for white-matter status.

When Ctexli is the wrong drug

If the diagnosis is not biallelic CYP27A1, this is not the drug. If cholestanol is normal, the diagnosis is in question. If the patient already has end-stage neurologic disease, the realistic goal becomes stabilisation rather than reversal; family must be counselled accordingly. Pregnancy data are limited; women of childbearing age need a documented contraception plan.

Closing

Reserve Meds runs the Ctexli import file from the KFSHRC or KAMC metabolic-genetics referral through SFDA named-patient authorisation, US or EU sourcing, and delivered supply. The clinical decision sits with your treating metabolic specialist or neurologist. We handle the rest.

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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