Spinraza access in the United Arab Emirates: the EDE named-patient pathway

How UAE families pursue nusinersen, an intrathecal antisense oligonucleotide for spinal muscular atrophy, across pediatric and adult patients on a lifelong dosing cadence.

Last reviewed 2026-05-12 by the Reserve Meds clinical and regulatory team. This page combines the UAE country research module with the Spinraza drug module to describe the path families actually walk.

Quick orientation

Spinraza (nusinersen) is the first medicine approved anywhere in the world for the treatment of spinal muscular atrophy (SMA). The US FDA approved it on 23 December 2016 for pediatric and adult patients with SMA across all types and all ages. Spinraza is an antisense oligonucleotide that modulates SMN2 splicing to restore production of functional survival motor neuron protein. It is administered as an intrathecal injection by lumbar puncture: four loading doses, then maintenance every four months, indefinitely. Spinraza is registered with the UAE Ministry of Health and Prevention. The access gap UAE families encounter is rarely registration. It is some combination of local stocking, intrathecal procedural capability, the lifelong cadence, and payer access criteria. Reserved for you.

Why UAE patients need Spinraza via a named-patient pathway

SMA is rare, and the patients identified in any one country are unevenly distributed. The Emirati Genome Programme is identifying SMN1 carriers and affected patients with higher fidelity each year, and SMA newborn screening has been adopted in several UAE settings. Even so, three patterns drive UAE families toward private cross-border supply. First, registered but not stocked. A drug that sits on the UAE federal register may still not be on hand at the specific hospital pharmacy on the day a lumbar puncture is scheduled, and the every-four-months cadence punishes any gap. Second, registered but rationed. National payer or insurer access criteria gate the drug to specific SMA types, ages, or severity bands, and families who fall outside those gates often choose private cash-pay rather than wait for a reassessment. Third, the intrathecal procedure itself constrains where the dose can be given. Patients with scoliosis, prior spinal fusion, or other anatomic challenges, common in older SMA Type 2 and Type 3 patients, sometimes need interventional radiology guidance, which can constrain site selection in any country.

Reserve Meds expects UAE Spinraza inquiries from three broad family types: pediatric SMA Type 1 cases under time pressure, SMA Type 2 and Type 3 children and adolescents on a steadier cadence, and adults with SMA Type 3 or Type 4 where local public access criteria do not align with the family's clinical preference.

The EDE named-patient pathway applied to Spinraza

The federal pathway for a UAE-licensed physician to obtain a medicine that is not registered or not stocked locally is the unregistered-medicine import permit, administered through the Emirates Drug Establishment (EDE) portal at ede.gov.ae since 29 December 2025, when the EDE took over 44 core services from MOHAP under Federal Decree-Law No. 38 of 2024. The framework allows hospitals and licensed pharmaceutical establishments to import a specific medicine for a specific patient when the medicine is approved by a recognised reference authority such as the US FDA and a locally registered alternative is not suitable. Because Spinraza is registered in the UAE, the EDE path is most commonly used when the local supply chain cannot deliver in the patient's required window or when the local register reflects a different indication context than the patient's case.

The clinical justification letter for a Spinraza case typically addresses the patient's confirmed SMN1 biallelic mutation, the SMA type and copy number where established, the age and current motor function status, the prior treatment history (including Evrysdi or Zolgensma where applicable), the rationale for nusinersen specifically rather than the available alternatives, the planned loading and maintenance schedule (Day 0, Day 14, Day 28, Day 63, then every four months), and the proposed treatment center for the intrathecal procedure. Pediatric cases include weight context and pediatric-specific monitoring plans; adult cases with anatomic challenges document the planned imaging-guided approach.

A complete EDE application typically includes the clinical justification letter, the treating physician's UAE licence (MOHAP, DHA, DOH, or Sharjah Health Authority depending on practice location), an anonymised patient identifier, full product details (12 mg per 5 mL single-dose vial, vial count for the loading and first maintenance window), the destination dispensing facility name and licence, the cold-chain handling plan (2 to 8 degrees Celsius, validated shippers), and pre-dose laboratory test schedule (platelet count, coagulation testing, quantitative spot urine protein, periodic renal function). Approval timelines for routine cases are 5 to 15 business days; urgent oncology and life-threatening cases sometimes receive expedited review, and pediatric SMA Type 1 cases are routinely framed for accelerated review although timelines remain at the EDE's discretion.

Where Spinraza gets dispensed in the UAE

Spinraza is administered by intrathecal lumbar puncture and must be dispensed by a treatment center with the procedural capability. Within the UAE, several institutions hold the pediatric and adult neurology services and the procedural infrastructure for routine intrathecal administration. Cleveland Clinic Abu Dhabi (M42 group) operates adult neurology services with strong procedural depth. Sheikh Khalifa Medical City (SEHA, managed by the Cleveland Clinic) operates pediatric subspecialty services with intrathecal capability. Tawam Hospital in Al Ain operates neurology and pediatric oncology services with procedural infrastructure. American Hospital Dubai (Mayo Clinic Care Network member) and King's College Hospital London Dubai run neurology services with procedural depth. NMC Healthcare flagship sites and Mediclinic City Hospital in Dubai Healthcare City also handle imported specialty therapies at scale.

For old