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Spinraza access in Pakistan

A patient-first guide to accessing Spinraza (nusinersen) for spinal muscular atrophy in pediatric and adult patients in Pakistan, through the DRAP Special Permission pathway with intrathecal administration at tertiary neurology centers.

Quick orientation

Spinraza is the brand name for nusinersen, the first medicine approved anywhere in the world for the treatment of spinal muscular atrophy (SMA). It is an antisense oligonucleotide delivered by intrathecal injection (lumbar puncture), approved by the US Food and Drug Administration on 23 December 2016 for SMA in pediatric and adult patients across all SMA types and all ages. Spinraza is not currently fully registered with the Drug Regulatory Authority of Pakistan (DRAP), and Biogen's commercial presence in Pakistan is limited, so Pakistani families needing nusinersen rely on the DRAP Special Permission pathway for personal use import combined with intrathecal administration at a tertiary neurology center capable of pediatric or adult lumbar puncture procedures. Aga Khan University Hospital and Shaukat Khanum Memorial Cancer Hospital and Research Centre carry the pediatric capability. Reserve Meds orchestrates the US-side sourcing, cold-chain logistics, and the documentation kit. Reserved for you.

Why patients in Pakistan need Spinraza via NPP

Spinal muscular atrophy is a rare autosomal recessive neuromuscular disease, and consanguinity-driven autosomal recessive disease burden in Pakistan means SMA incidence is structurally higher than in many other populations. SMA Type 1, the most severe infantile-onset form, is fatal in the first two years of life without disease-modifying therapy. SMA Types 2, 3, and 4 progress more slowly but lead to significant motor disability over time. The clinical case for treatment is strong; the access architecture is the constraint.

In Pakistan, three patterns of access gap apply at once. First, Spinraza is not stocked routinely. Biogen's commercial presence in Pakistan is limited, and even where the drug can be sourced through a specialty importer, the supply chain is not consistently stocked at hospital pharmacies. Second, intrathecal administration gates dispensing: only a small number of neurology and pediatric neurology teams have the procedural capability and the trained staff to deliver a 12 mg lumbar puncture dose safely on the required schedule (Days 0, 14, 28, 63 for loading; every four months for life as maintenance). Third, the cash-pay reality. Public health system coverage for SMA disease-modifying therapy is minimal, Sehat Sahulat does not stretch to cover named-patient imports of unregistered specialty drugs at this price point, and private insurance typically excludes the indication.

The convergence of these three patterns is what makes Spinraza a recurring named-patient request for Pakistani families: the diagnosis is clinically established, the drug exists, the protocol is well-defined, and only the access architecture is missing. Reserve Meds steps into that gap.

The DRAP Special Permission pathway for Spinraza

DRAP regulates the import of medicines through the Quality Assurance and Laboratory Testing (QA<) Division's Import and Export Section. For unregistered or unavailable medicines

required for a specific patient, DRAP issues a Special Permission, also called the No Objection Certificate (NOC) for Personal Use Import. Applications are filed through DRAP's Online Import and Export System (OIES) portal by the patient or applicant, or for institutional dispensing, by the hospital pharmacy.

The application package for Spinraza centers on the SMA diagnosis confirmation. The clinical justification letter from the treating physician (neurologist or pediatric neurologist) addresses the patient's SMA diagnosis with confirmatory genetic testing (bi-allelic SMN1 mutation), SMA type (1, 2, 3, or 4) with disease severity and motor function baseline, prior therapies attempted where applicable, and the planned dosing schedule. The treating physician's Pakistan Medical and Dental Council (PMDC) license verification accompanies the letter, alongside the patient identifier (CNIC for adult patients, B-Form for minors), the destination dispensing facility license (the hospital pharmacy where Spinraza will be received and stored), and the chain-of-custody plan from the US source through international shipment with cold-chain (2 to 8 degrees Celsius) handling.

For Spinraza specifically, the genetic confirmation of bi-allelic SMN1 mutation is the gating clinical justification element. The treating institution must confirm this; the OIES filing references it. The dosing plan is the standard FDA label regimen of four loading doses (Days 0, 14, 28, 63), then maintenance every four months indefinitely, plus the FDA-approved high-dose regimen where clinically applicable.

Approval timelines for routine personal-use cases typically clear in four to eight weeks from a complete submission. Complex first-time cases involving newly diagnosed pediatric patients or off-label dosing extend to ten to sixteen weeks. Reserve Meds plans on the longer end of the routine range. The first-dose pressure is acute in infantile SMA Type 1; Reserve Meds intake flags Type 1 cases for accelerated coordinator review with cold-chain logistics pre-staged.

Where Spinraza gets dispensed in Pakistan

The institutions with the procedural capability for intrathecal Spinraza dosing concentrate in Karachi, Lahore, and Islamabad. Aga Khan University Hospital (AKUH) in Karachi operates strong pediatric neurology and neurology programs with established lumbar puncture capability. Shaukat Khanum Memorial Cancer Hospital and Research Centre (SKMCH&RC) in Lahore handles intrathecal procedures within its oncology program with potential extension to SMA cases. The Children's Hospital and Institute of Child Health in Lahore is the primary pediatric tertiary center in Punjab and handles pediatric intrathecal procedures including for chemotherapy.

The Indus Hospital and Health Network handles pediatric and neurology referrals across Karachi, Lahore, and Hyderabad. Liaquat National Hospital in Karachi, Shifa International Hospital in Islamabad, and the Combined Military Hospitals (CMH) network across Rawalpindi, Lahore, and other cantonment cities round out the institutional map. For patients with scoliosis, prior spinal fusion, or other anatomic challenges (common in older SMA Type 2 and Type 3 patients), interventional radiology guidance is sometimes required, which further narrows the candidate institutions to those with IR-supported neurology workflows.

For families outside Karachi, Lahore, and Islamabad, the practical flow is referral to a major center for treatment initiation, then continuing maintenance dosing at the same center on the every-four-months schedule. The 14-day room-temperature stability window (up to 30 degrees Celsius) on the unopened vial provides operational tolerance for cross-country in-country last-mile transport where needed.

Real cost picture for Spinraza in Pakistan

The Spinraza US wholesale acquisition cost (WAC) is approximately USD 125,000 per 12 mg vial (Biogen-stated WAC at launch in late 2016, maintained as the reference). First-year cost (six doses, comprising four loading plus two maintenance) is approximately USD 750,000. Subsequent years (three maintenance doses per year) run approximately USD 375,000 per year. At the current USD to PKR rate (approximately PKR 278 to 280 per USD on 8 to 9 May 2026), the per-vial cost converts to approximately PKR 34.8 to 35.0 million, with first-year total cost approximately PKR 208 to 210 million.

International cash-pay private-import pricing typically reflects ex-US wholesaler pricing plus Reserve Meds coordination, customs handling, and freight, and is materially below US WAC in most documented patterns; quotes are case-specific. Cold-chain refrigerated international air freight (validated 2 to 8 degrees Celsius shippers) adds a per-shipment surcharge in the range of USD 400 to USD 1,500 depending on the destination city and the specific lane.

Because the Pakistani Rupee has been volatile and inflation rose to 10.9 percent in April 2026, Reserve Meds quotes in USD. State Life, Adamjee, EFU, Jubilee, IGI, and Pak-Qatar Family Ta