

## Financial Burden of ALS in the Republic of Kazakhstan

**Kuanova L. B.**

University Medical Center, Nazarbayev University, Astana, Kazakhstan

### **Abstract:**

**Introduction:** Given the unmet needs of ALS patients in the Republic of Kazakhstan (RK) and the importance of financial and economic data for dialogue with state healthcare authorities, a survey on indirect medical costs was conducted among patients and/or their caregivers.

**Methods:** The survey included 33 patients or their caregivers in 2024.

**Results:** The primary predictors of high disease costs were progressive loss of individual autonomy. ALS patients require vital, costly equipment necessary for maintaining respiratory, mobility, and communication functions. The cost of non-invasive ventilation devices, power wheelchairs, electric patient lifts, electric hospital beds, Tobii eye-tracking devices (for computer control), and laptops with specific parameters ranged within 3 875 000 tenge (8 218 USD).

Government social security assistance is currently limited to providing two mechanical wheelchairs annually, diapers, sanitary pads, and sanitary products worth 1 056 093 tenge (2 240 USD).

The average annual total treatment cost for one patient was – 4 306 322 tenge (9 133 USD) per patient, which is 16.5 times higher than the average per capita cost in the RK (per capita income is 261,186 tenge or 554 USD in 2023).

**Conclusion:** The disease is one of the most expensive in terms of direct medical and non-medical costs, far exceeding the average per capita income in the RK.

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