What is EURORDIS Syndrome?

Background

Genetic disorder – diagnosed by a genetic test
Affects both male and female children
Usual onset at 6-10 years old
Heterogeneous manifestation

Prevalence:
1 in 300,000
Approximate population estimated at 2500 patients across Europe

Symptoms

Pain
Progressive impairment of muscles weakness, co-ordination and motor skills
Life expectancy: 7-10 years post diagnosis
Wheelchair use within 3-5 years of diagnosis
Death by age of 20 years

Current treatment

Strict diet (no sugar or wheat) for symptom control
Physiotherapy to improve muscle strength and manage pain
24/7 care required at later stage of disease