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