The first symptoms can start at childhood…

…and school systems are often ill-adapted for children living with a rare disease.

Within the family, women are often the primary caregivers and are disproportionately affected by the challenges of life with a rare disease.

Spaces and opportunities to fully participate in social life and integrate into society can be limited.

Families often have more expenses, less income, greater risk of impoverishment and increased isolation and exclusion from social and economic life.

Increasingly persons living with a rare disease are living longer, fuller and better lives.