



# A JOURNEY THROUGH LIFE WITH A RARE DISEASE



RARE DISEASES INTERNATIONAL

Many rare diseases are present from birth. Their impact is felt throughout a lifetime and by the whole family.



The first symptoms can start at childhood...



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



Accessing, retaining, and returning to employment is a continuous challenge.



Reaching independence and transitioning to adult life is a complex journey.



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.



Starting a family can present a new set of challenges.



However, with the appropriate care and support persons living with a rare disease are increasingly living longer, fuller and better lives.