



# A JOURNEY THROUGH LIFE WITH A RARE DISEASE

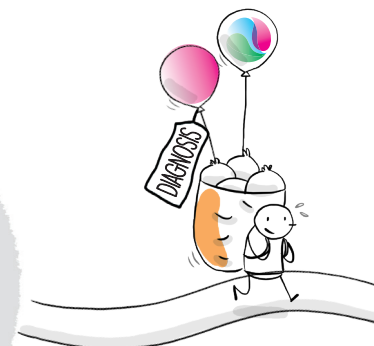


RARE  
DISEASES  
INTERNATIONAL

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



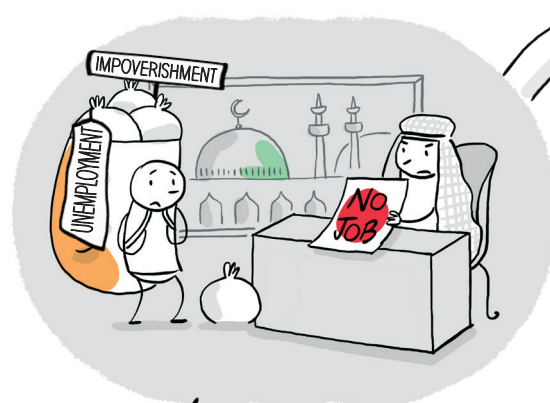
The first symptoms can start  
at childhood...



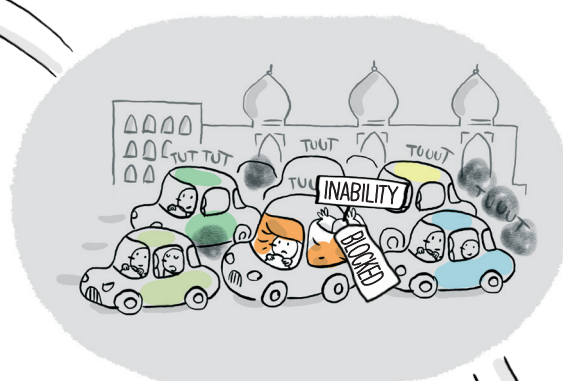
...and school systems are often ill-adapted  
for children living with a rare disease.



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.



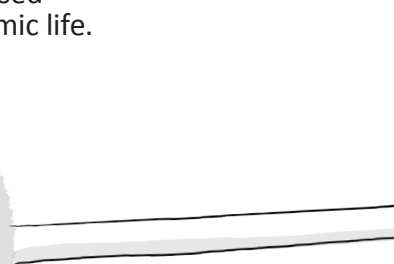
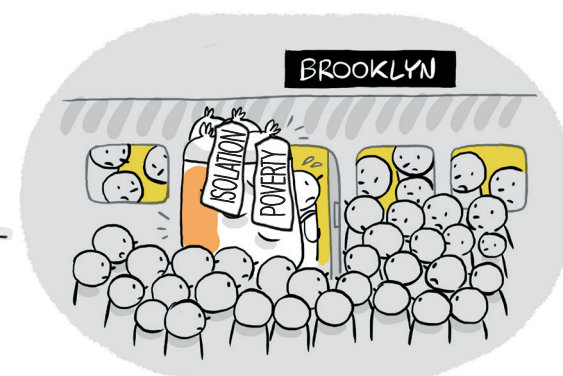
Spaces and opportunities to fully  
participate in social life and integrate  
into society can be limited.



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.



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