Why Invest in Rare Diseases?

WORLDWIDE, THERE ARE

300 MILLION
PEOPLE LIVING WITH A RARE DISEASE

OVER 7,000
RARE DISEASES HAVE BEEN IDENTIFIED

These conditions can be chronic, progressive, degenerative, disabling and frequently life threatening. The 149 most frequent of these diseases account for 80% of rare disease diagnoses.

72% of RARE DISEASES
are genetic
70% of these diseases start in childhood

73% of PLWRD
have been MISDIAGNOSED at least once

On average, people living with a rare disease in HICs wait 6 years for a diagnosis

Diagnosis takes even longer in the case of ultra-rare diseases and in LMICs.

The financial burden of RARE DISEASES is

15 times higher than that of common diseases

In addition to direct costs, PLWRD face indirect costs such as loss of income and barriers to education and employment due to stigma. The task of caring for family members with rare diseases falls most often upon women, amplifying gender inequity.
Make Rare Diseases a HEALTH PRIORITY

We are few. We are many.
There are over 300 million Persons Living with a Rare Disease (PLWRD) around the world. To ensure that they receive the services they need, we need to prioritise and integrate rare diseases within regional and national UHC and primary health care plans.

Improve SERVICES for Persons Living with a Rare Disease

Persons Living with a Rare Disease have complex needs, beginning with the diagnostic journey, which can last 5-8 years - or in some cases, continue indefinitely. By strengthening primary healthcare and referral pathway capacities, we can ensure the timely diagnosis of rare diseases. After diagnosis, PLWRD need services that encompass a multidisciplinary approach. By developing sustainable programs dedicated specifically to rare diseases, we can enable rapid and equitable access to diagnosis, treatment and social support.

Reduce the FINANCIAL BURDEN of Rare Diseases

Persons living with a Rare Disease face financial burdens due to the high cost of treatments and medications. They must often travel long distances to access specialized care. PLWRD and their families also face high indirect costs, such as loss of income. Women are disproportionately affected, often taking responsibility for caring for a family member with a rare disease. By investing in rare diseases, we can lower costs in the long term and improve equity for PLWRD and their families.

Enhance KNOWLEDGE SHARING on Rare Diseases

International collaboration is key to improving treatment and knowledge of rare diseases. Ethical and responsible international data sharing can support diagnosis, increase clinical collaboration, facilitate research and accelerate treatment of undiagnosed and rare conditions. By increasing education and awareness of rare diseases, we can reduce the stigma and discrimination faced by PLWRD.

The vast challenges of treating PLWRD cannot be resolved by a single country or entity. They can only be addressed by a global, multidisciplinary, and collaborative approach.

A WHA Resolution: a catalyst for systemic and sustainable change to improve the lives of Persons Living with a Rare Disease.