KEY STATISTICS ON RARE DISEASES

**OFFICIALS BETWEEN 3.5% TO 5.5% OF THE POPULATION ARE GENETIC.**

Almost 300 million people living with a rare disease in the world, representing a significant group of citizens that need support to be integrated in society and enjoy the full respect of their human rights.

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**6000 RARE DISEASES**

are attributed to genetic causes, while many more are of unknown origin. Often they are disabling and frequently life threatening. The cost of treatment for rare diseases is often significant both for patients and their families.

**72% OF RARE DISEASES ARE GENETIC.**

**70% OF GENETIC RARE DISEASES START IN CHILDHOOD.**

The cumulative point prevalence of rare diseases is estimated to be 300 million people, or 3.5% to 5.5% of the population.

**NO CURE**

is found for the majority of rare diseases, which are of unknown origin. Due to the rarity of each individual disease, therapies, etc.

**01 POPULATION**

People living with a rare disease have more complex needs than those of the general population. National authorities need to pay special attention to this when developing their UHC essential health service package in order to ensure that needs of patients living with rare diseases are addressed.

**02 SERVICES**

Policy makers should:

- Provide access to high quality healthcare and ensure that there is no financial hardship.
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- Reduce out-of-pocket expenses.
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- Promote research on rare diseases.
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- Include other services and adapt existing ones.
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- Protect the rare disease population from further impoverishment.
- Protect the rare disease population from further impoverishment.
- Ensure a good work-life balance and protection from loss of employment.
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- Facilitate access to accurate and timely diagnosis.
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- Support the inclusion of patient and expert centres.
- Support the inclusion of patient and expert centres.
- Create policies for the identification, accreditation and certification of centres.
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- Ensure that patients and caregivers receive the level of care and support of the majority.
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**03 DIRECT COSTS**

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