

RARE DISEASES: AN INTERNATIONAL PUBLIC HEALTH PRIORITY

The patient movement worldwide has adopted the following twelve main recommendations to be addressed at international level as a matter of priority:

Visibility of Rare Diseases

1. Enhance visibility of rare diseases at an international level in terms of public awareness and within the healthcare system as a human rights issue and a public health priority.
2. Better classification and codification of rare diseases can support the process towards better recognition of rare diseases worldwide.

Patient Empowerment

3. Support and empower patients and families to play an active role in shaping national health care provision that is appropriate to their needs.
4. Develop, gather, share and disseminate information on rare diseases in linguistically and culturally appropriate formats.
5. Promote international cooperation in the field of services to patients and families.

Universal Access to Healthcare

6. Improve access to services that will facilitate informed decisions about prevention and screening that are legally permissible, and improve access to accurate and timely diagnoses.
7. Facilitate universal access to high quality healthcare and treatments for rare diseases patients, including surgeries, special diets, transplants, and medical devices, common and orphan medicinal products.
8. Create policies on rare diseases that promote specific measures in regional / national / international strategies, including identification and support of specialised expert providers as well as their national and international networking.
9. Promote recognition that rarity requires increased international cooperation and mobility of experts as well as of patients when expertise is not available locally.

Research

10. Coordinate worldwide research efforts on rare diseases through international and national research initiatives.
11. Build opportunities for effective networking of patient registries.

Cooperation in policy shaping at international level

12. Elaborate policies based on common values (equity, solidarity and Social Justice) that have a positive impact on the lives of rare disease patients.