

## RECOMMENDATIONS

1. As regards rare diseases, there should be a diffusion throughout the world of prevention in relation to expectant women and neonatal screening in order to recognise rare diseases that are already known about and achieve the rehabilitation of patients. Even countries that have the financial means to do so, do not take these steps adequately or do not engage in them at all. Together with this, centres of excellence should be created to achieve diagnoses rapidly. Overall support should be given to patients and their families.

2. A plan for the training of health-care personnel in all rich and poor countries should be created so that they at least have the ability to direct patients to centres of excellence.

3. Scientific research must be financed in a more regular way by States but one can also launch the idea of asking on a voluntary basis for a part of the profits of the pharmaceutical industry. The World Health Organisation should act in this direction.

4. The involvement of categories of patients in the planning of their treatment and rehabilitation, as well as support for families. This must be seen as ordinary practice.

5. The richest States in the world must engage in a transfer of medical technology and adequate means both for rare diseases and for neglected diseases. It is surprising that this is done swiftly in the case of the transfer of military technology and skills but that it is not done in the field of health care.

6. The environment and health constitute an indissoluble tandem. Governments and health-care workers must work with this deep awareness and work in a way that respects the environment. It is above all else medical doctors who must know that very many pathologies, in particular chronic illnesses (including rare and neglected diseases) and functional disturbances, have as their principal cause (or joint cause) factors with environmental origins.

7. We have to work for the involvement of the media at all level. Today the subjects of rare and tropical diseases are truly marginalised by the press, radio and television, whereas true ethics of this profession should lead the professionals of the various sectors to attend to the weakest parts of a population in order to sensitise governments and public opinion to the implementation of policies that provide support in this area.