

Five-years experience as a Regional network on rare diseases

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In the last years, the need to promote a network of reference centres for rare diseases has been considered a priority in European Community. Italy has officially adopted the concept of centres of reference for rare diseases with a National Plan in 2001. The Plan includes: accreditation of centres of reference in each region for one or more diseases, establishment of regional coordinating centres, and implementation of a registry of patients to be based at the Istituto Superiore di Sanità in Rome.

The Lombardy Region, an area of 9 million people in Northern Italy, was among the first to identify regional reference centres in December 2001. Criteria of eligibility were: high level of expertise documented through scientific publications/training activities, expertise in the diagnosis, clinical care and treatment of rare disorders, volume of activity, demonstration of a multi-disciplinary approach, links with other centres at national and international level, collaboration with patients associations. Twenty-nine reference centres were identified. The Clinical Research Centre for Rare Diseases, Aldo e Cele Daccò, of the Mario Negri Institute was nominated as Regional Coordinating Centre.

Patients referred to a reference centre and suspected or already recognized as affected by one of the rare diseases included in the list, are exempted from the costs of all diagnostic procedures in the investigation and in the follow up phase. They also receive all drugs free of charge. Goals of the Lombardy network are also to enhance networking capacity among clinicians and researchers.

Here we are presenting data about the following ongoing initiatives: Information Centre for Rare Diseases, databases as a tool for clinical studies on rare diseases, bank of biological materials, collaboration with patients' support groups, regional registry for rare diseases.

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