

**Sharing best practices on integrative approach
to rare diseases in different countries**



Country name: Italy

In collaboration with

EUROPLAN
European Project for Rare Diseases National Plans Development



Strategies for rare diseases

- *Official definition of RDs used in your Country*
 - *Prevalence $\leq 5 / 10.000$*
- *Please, provide information on national and/or regional measures, established by law, addressing specific aspects regarding RDs*
 - *RDs are a priority within the general health plan*
 - The Legislative Decree 279/2001 (Regulation of the institution of a national network for rare disease surveillance and the exemption from patient participation in the costs of the relevant healthcare)
 - Decree of the Ministry of Health on implementation of regional initiatives on RD-focused programs and action plans -



Funding of actions, regarding rare diseases



How different issues, concerning RDs are funded:

- *RDs costs are included in the national health care budget*
- *RDs initiatives are also financed by the Ministry of Health with funds dedicated to the implementation or strengthening regional networks (30 MEuro for 2007, 5 MEuro for following years)*

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Provision of information for rare diseases



- **Availability of website-based information**

The official website of the Ministry of health provides information about legislative and administrative issues.

Regional websites are also available.

A specific and complete service is run by the National Institute of Health.

Other services are run by patients associations

- **Help Lines**

– Yes both at national and regional level

- **Availability of an official list of RDs**

- *The Ministerial Decree 279/2001 establishes a list of RDs*

- *The purpose of the list is to identify the RDs exempted from patient participation in the costs of the relevant healthcare and those under epidemiological surveillance*

(4 Regional legislative acts extend the number of RDs that are exempted from patient participation in the costs)

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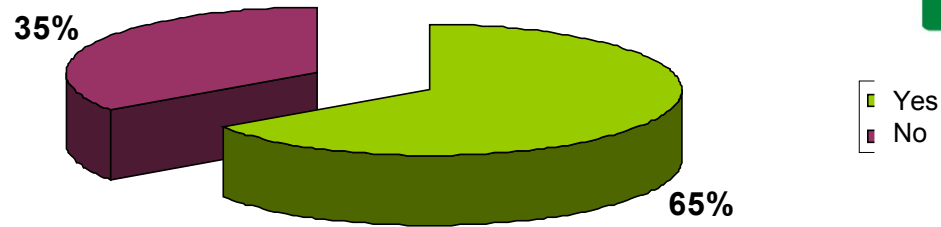
Research on rare diseases

- *Availability of research programme for RDs*
 - *Research programme dedicated to RDs and orphan drugs funded by Ministry of Welfare and the Italian Drug Agency*
 - *In addition Italy participates to the ERA-Net scheme for RDs E-Rare project (funded by Ministry of Health and ISS)*
 - *Other research programmes are run and funded by non governmental bodies such as patient's organisations and private foundations*

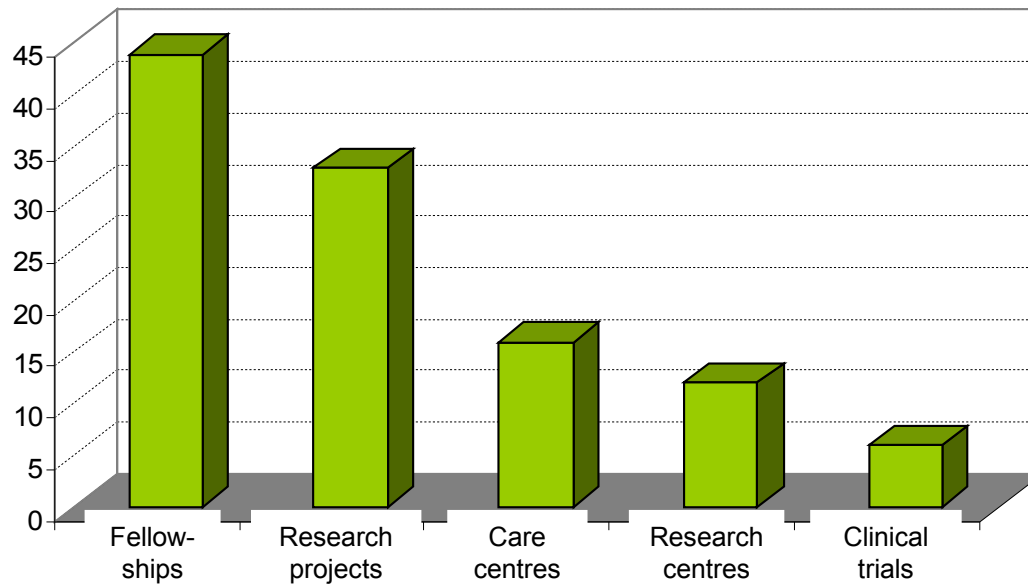


Activities supported by patients' associations

Support of activities/projects



activities funded



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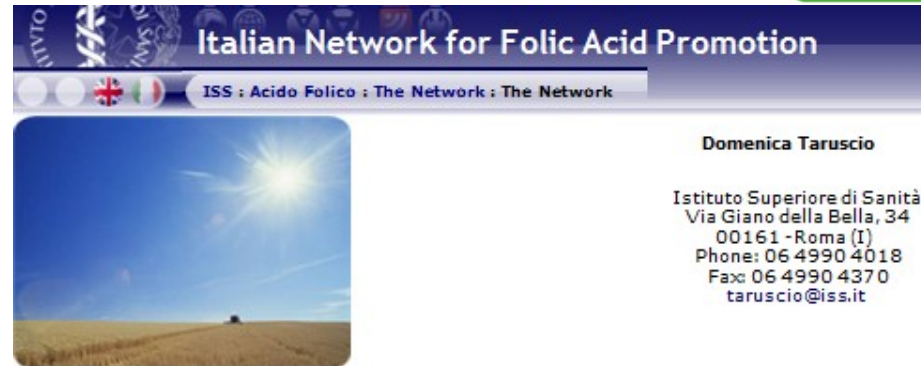
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Prevention

- *Folic acid*
- *Neonatal screening*
Congenital Hypothyroidism,
PKU,
Cistic Fibrosis (some Regions)



Italian Network for Folic Acid Promotion

ISS : Acido Folico : The Network : The Network

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The Network

By Network we mean a synergy among institutions of whatever nature (for example: research institute, scientific societies, registries, regional offices and councils, patient associations and newspapers) in

- basic biomedical, clinical and social-healthcare research;
- registration of congenital malformations;
- transfer of results from research to clinical practice and social-healthcare legislation;
- training, informing and updating of practitioners and receivers of healthcare services;
- promotion of public health;
- care-givers of people affected with congenital malformations (spina bifida, congenital cardiopathy, or renal malformations, etc...);
- evaluation of healthcare services.

The evidence in favour of a greater intake of folic acid by women of childbearing age to reduce the risk of congenital malformations is sufficient to justify great interest in the Scientific Community and in the Italian Public Health Authorities.

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Empowerment of patients organisations

The Consulta, a body representing all patients' organizations, was officially established by the Ministry of Health.

Meetings of the Consulta are organised to discuss:

- legal documents*
- issues related to care and treatment*
- research for RDs*

Patients do not receive financial support to attend the meetings

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Specialised social services



- **Respite Care Services**
 - *Such services are rare in Italy and unevenly distributed within the national territory.*
 - *Where the service exists is mainly provided by governmental or accredited institutions but also by the private sector.*
- **Services aimed at the integration of patients in daily life**
 - *There are institutions and laws promoting the social integration including integration in schools and in the work place of patients with disabilities.*
 - *Additional initiatives are run by private organizations*

