

TVMR

Telefono Verde Malattie Rare

Toll Free Number for Rare Diseases

Un numero raro,
prezioso e gratuito.

Telefono Verde Malattie Rare
800.89.69.49

Background

The Minister of Health, the Honourable Senator Livia Turco:

- Has established the national committee of patients associations (“Consulta) for rare diseases on the 05 of June 2007
- Has designated The Istituto Superiore di Sanità as the institution with technical and scientific know-how to promote activities and meetings of the committee
- Has highlighted the importance of establishing in the Center of Rare Diseases-ISS a Toll Free number devoted to rare diseases

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The 6 workgroups of the Committee

3 workgroups have been activated on the 03 of July 2007:

- 1) To assess and certify disability and exemption
- 2) Continuity of care
- 3) Integration of social and medical care

Additional 3 groups have been activated on the 08 of September 2007:

- 4) Training of staff and uniformity of medical care nationally
- 5) Scientific Research
- 6) Information and Communication

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Critical aspects: lack of information

Possible solutions

- To standardise all the information supplied locally and nationally
- To elaborate specific technical and scientific forms about specific rare diseases
- To promote public campaigns on TV and radio and print leaflets about rare diseases
- To promote a national day devoted to rare diseases
- To collect and make valuable the informative material of local and regional associations and charities
- To make available throughout the web the material collected
- To ensure that help lines are available to patients, staff and citizens

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29 February 2008 rare diseases day

The conference at the ISS and the other national activities

<http://www.iss.it/site/cnmr/dina/29febbr2008/giornata.html>

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The service was launched in February 29, 2008 : an active service to inform and help patients, citizens, operators and Associations

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The Toll Free Number for Rare Diseases (TVMR) is a public Service, managed by the National Centre for Rare Disease (CNMR).

TVMR is a **national service** giving the opportunity to spread information about rare diseases nationally.

The **service** is **anonymous** and **totally free** *for all users*.

Currently, TVMR is open from Monday to Friday from 9 a.m. to 1 p.m.

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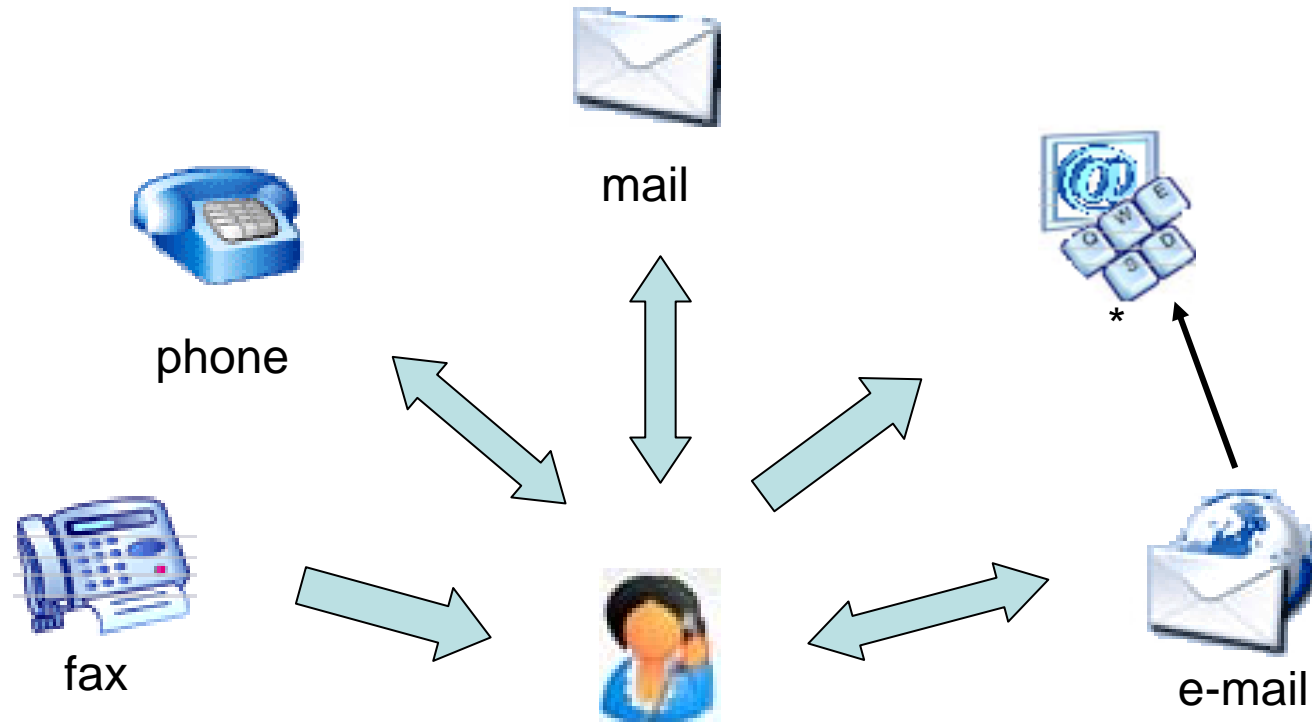
Objectives of TVMR

- to **inform** about **public health services** caring and treating rare diseases nationally
- to **give contacts and information about Patients Associations** nationally
- to **give support** about legal and administrative questions related to rare diseases
- to give **scientific information** about rare diseases
- to support psychologically patients with rare diseases

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Means of communication utilised



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The methodology: Counselling

Telephone counselling is the methodology used by operators of TVMR.

The counselling allows to:

Provide scientific information updated and personalised (useful for the specific need/request of the person calling): ***informative counselling***

Contribute to identify the real problem of the person calling in order to identify possible solutions: ***problem solving counselling***

Support the person during critical situation: ***crisis counselling***

Reduce anxiety and discomfort in order to improve the communication and the understanding of the message/information provided facilitating behavior changes: ***decision making counselling***

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Information and communication

Centro Nazionale Malattie Rare



CNMR

MALATTIE RARE FARMACI ORFANI



1 LE MALATTIE RARE...

Sono un ampio gruppo di patologie definite dalla bassa prevalenza nella popolazione. A livello europeo, si definisce rara una malattia che colpisce non più di 5 persone su 10.000 abitanti. Nel loro insieme queste patologie sono molto numerose; si stima che ne esistano più di 6.000.



3 IL CENTRO NAZIONALE MALATTIE RARE

Ricerca scientifica finalizzata alla prevenzione, sorveglianza, diagnosi e trattamento delle malattie rare è la principale attività del CNMR dell'Istituto Superiore di Sanità.

2 ...I FARMACI ORFANI

Sono prodotti potenzialmente utili per trattare una malattia rara ma che non hanno un mercato sufficiente a ripagare le spese del loro sviluppo. Vengono definiti orfani proprio perché è scarso l'interesse delle industrie farmaceutiche ad investire su farmaci destinati a pochi pazienti.



Workshops and meetings

- **Workshops**: on RD national register functioning, primary prevention, genetic testing
- **International meeting**: annual international meeting on orphan drugs and rare diseases