

An information service on rare diseases: the experience of the Coordinating Centre for Rare Diseases of the Veneto Region

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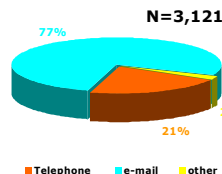
BACKGROUND

Need for appropriate information represents a crucial issue especially in the field of RD, characterized by paucity of available information on the diseases, on the existence of Centres of expertise for the diagnosis and treatment of these conditions, on available therapies and social support resources.

In 1999 the Veneto Region, NE of Italy, 4,7 mill inh, established the Registry for RD, which is now part of the Coordinating Centre for Rare Diseases.

According to the State-Regions Agreement on RD (2007) the activities of the Coordinating Centre are:

- Maintenance of the RD Register (interregional);
- the spreading of information on RD to citizens, RD patients, their relatives and patients' associations;
- Coordination of the care network based on labelled Reference Centres officially recognized by the Regional Authority;
- Support to health care professionals regarding RD issues and availability of appropriate treatments for RD patients;
- Organization of training activities on RD;
- Support patients' associations activities

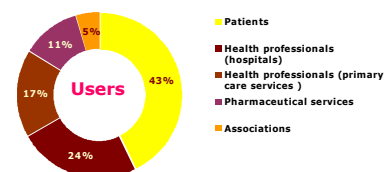


ACTIVITY 2009

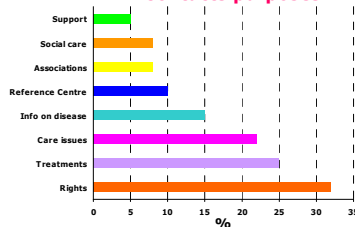
Contact modality

(cfr 2008)

Telephone	+33%
e-mail	+19%
other	+5%



Contacts purposes*



* total exceeds 100% as users may have more than one request



+ 39 049 8215700

malattierare@pediatria.unipd.it

INFORMATION SERVICE

Information Service Identity Card

- Creation date: 2002
- Mandate: Institutional
- Supporting the RD care network
- Deals with general RD topics & specific diseases issues

- Modality of contacts: phone/e-mail/fax/on-site visits/web-site

- 3,121 Contacts /year
- Database for contacts recording

- Staff: (planned work-shifts) 6 physicians, 1 psychologist, 1 pharmacist, 1 secretary

- Respects national privacy Law

- Languages: Italian-English

Specific requests

- Diagnostic facilities
- Reference Centres: existence, contacts, professionals, etc.
- Prise en charge: rehabilitation services, home care assistance, palliative care network
- Specific care problems

Treatments: orphan drugs, therapeutic options, other interventions, etc.

Tailored bibliographic researches: Literature- access to medical DB, articles, on-line university library, expert opinions

Information provided on

Rights

- benefits: exemption, reimbursement for drugs, dietetic products, other medicinal products, devices, etc.
- access to services: disability centres/respite centres
- administrative procedures
- other available economic provisions
- Laws (not necessarily RD specific)
- school-work access
- social support

Miscellanea

- Persons without diagnosis
- Ethical issues
- Contact with other patients
- Feed-back from users

Patients' associations

- Existence, contacts and activities (regional/extraregional/abroad)

CONCLUSIONS

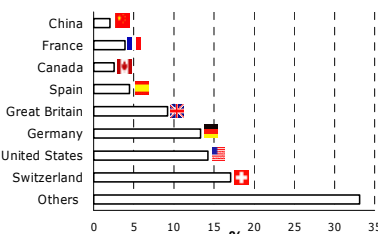
<http://malattierare.regione.veneto.it>

- Website- information on: diseases, Reference Centres, care pathways, benefits, etc.
- Search tool on all contents
- Languages: Italian-English

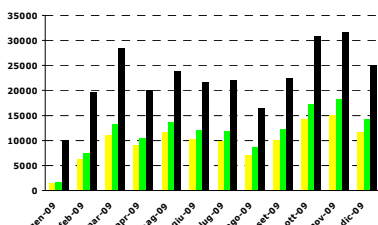
Total 2009

N visitors	118056
N visits	141480
Pages	272367

Visitors from other countries (n=1,704)



Statistics - 2009



The information service fulfils 3 main functions:

- informative
- supportive
- and monitoring one.

Its added value is that it is an institutional service, an aspect that guarantees the possibility of monitoring the functioning of the RD care network established by the Regional Health Authority.

Requests from users often generate other contacts and/or interventions, especially when contacts deal with the resolution of potential problems affecting patients' care pathways.

Moreover, the Information Service represents an excellent observation tool through which the Regional Health Authority can receive feedback both from patients' and from professionals concerning the functioning and possible improvements of the established care network.