

RD helpline Coordinating Centre Veneto Region



M Mazzucato – P Facchin

The framework

D.M. 279/2001 on RD

Benefits for affected patients



The creation of a **care network** starting from Centres officially labelled by the Regional Health authorities on a regional/interregional basis

Area-based **Registries**



Milestones

2001 Italian RD law

2002-2007 State-Regions Agreement

2014

Italian National RD Plan

State-Regions Agreement on RD -2007

Coordinating Centres: functions

- guarantee the existence of an organization able to support the activities of collection and spreading of information on RD, also through dedicated **help-lines**



Ceci n'est pas une pipe.

Help-line

Institutional

Since 2002

**Is part of the care network,
supporting its functioning**

Database for contacts recording since 2002



RD Coordinating Centre HL- Veneto Region



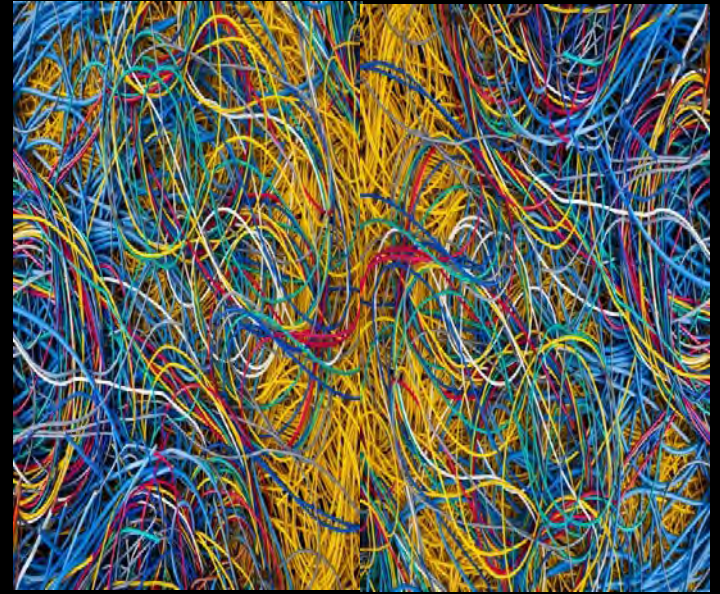
800 318811

+ 39 049 8215700

malattierare@regione.veneto.it

On-site visits

To create a network



1. nodes identification

2. Connections

(care pathways, information)

A unique and shared web-based protected system

Labelled C of expertise
(per groups of RD)

Other hospitals

Local health districts

Pharmaceuticals Services

Registry

Connects





INFORMATION

- COMMON TO ALL HEALTH PROFESSIONALS OF TEH NETWORK
- PATIENT-CENTERED
- COLLECTED TO PROVIDE CARE
- INNOVATIVE SOLUTIONS (pin)
- MORE THAN 3.500 HP INVOLVED
- MORE THAN 30.000 PATIENTS (VENETO REGION)

Population (millions inh)

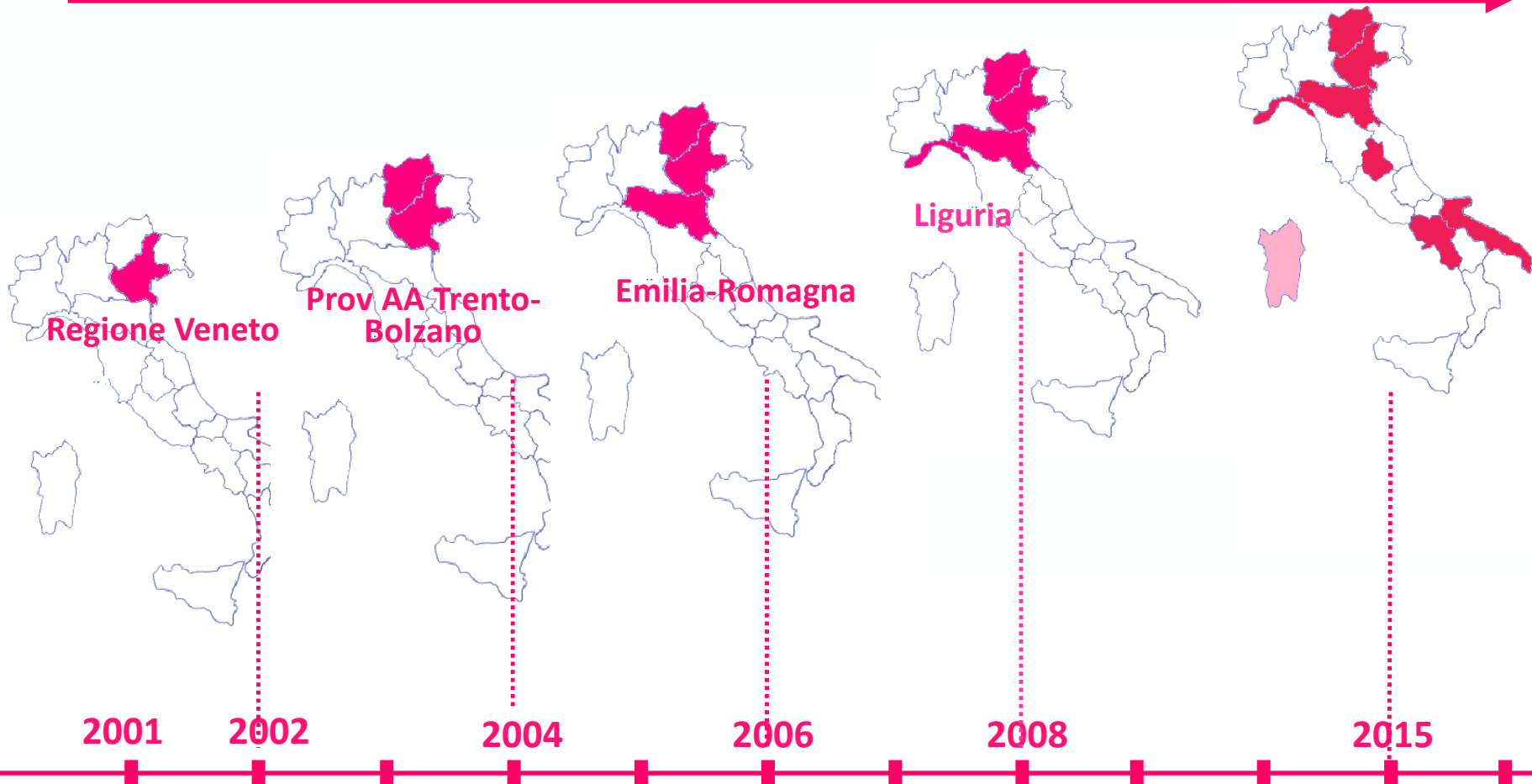
4.9

5.9

10.3

11.9

22.8



2001

2002

2004

2006

2008

2015

DM 279/2001

31.704 followed in Veneto Region

98.000 RD PATIENTS

- 1. Institutional (sustainability)**
- 2. Within the Coordinating Centre
(link with the care network)**



Malattie rare

Per informazioni e prenotazioni è attiva una linea telefonica riservata alle malattie rare:

Numero: 049 8212015 dal lunedì al venerdì dalle ore 9.00 alle ore 12.00

- 3. University environment**
- 4. Multidisciplinarity i.e. staff
(MD, PHARM, PSYC)**



Access to treatments

Systematic off-label use of drugs in RD

Availability on the market in Italy

Products on the market abroad
(challenging access for RD patients)

Essential treatments not
automatically reimbursed by the NHS

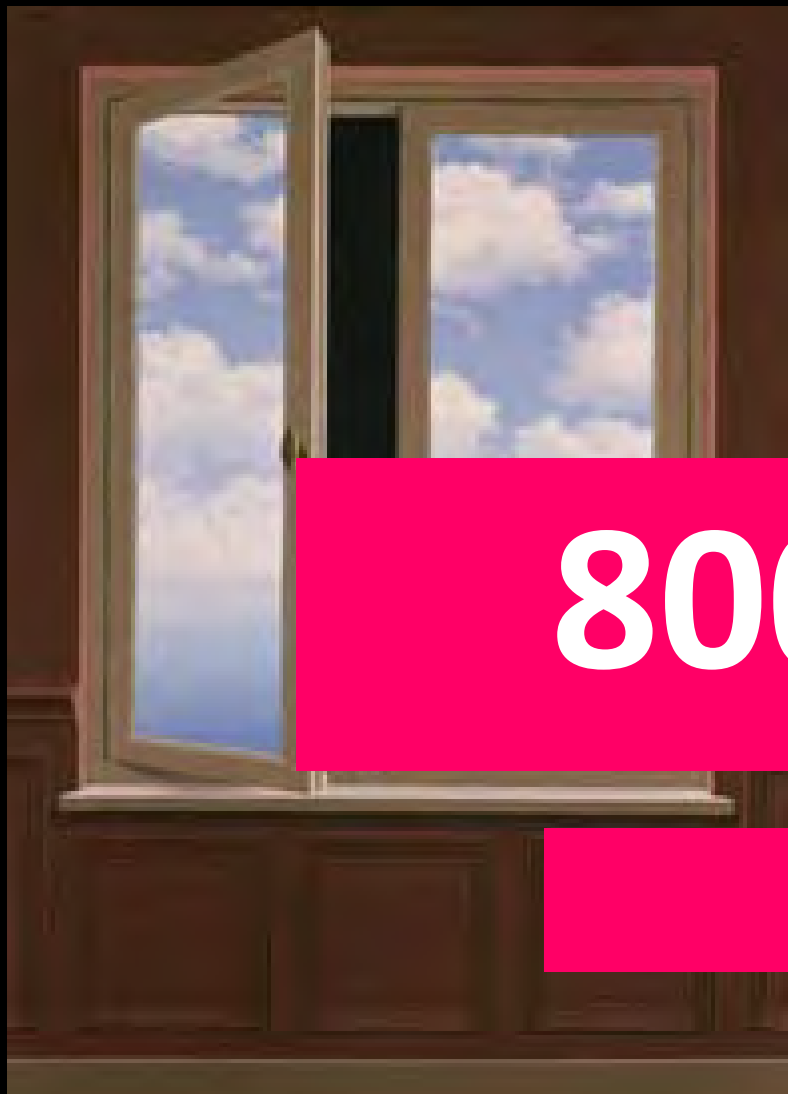
Medical foods

Parapharmaceuticals

Galenicals

Medical devices

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