INFORMATION & PUBLIC HEALTH
New approaches for training and awareness

The Italian model
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Italian Health System

- Universalistic
- Heavy decentralisation (20 Regions)
- Important role of GPs and paediatricians (different Societies and Federations)
- Regional Centres of Expertise
- Important national legislation for RD but different implementation at regional level
KEY ISSUES TO BE ADDRESSED

• Scarce information and training
• Delays in diagnosis
• Daily care
• Transition from childhood to adult age
• Useful tool to provide accurate information
• Common and shared pathway to care
• Centre of expertise
• Inequity
• Quality
RD Associations’ skills

ability to read the context, to manage relationships with institutions or bodies and with other social actors in the territory, to adopt appropriate strategies
Key words of our projects

• Inclusion (of relevant actors)
• Collaboration
• Co-Sharing
• “Good contamination”
• Community
Knowing to assist

A strategic action transformed into a project idea
A project idea born from a careful analysis aimed at:

- Raising the diagnostic suspicion
- Development of a global health and social care
- Development of procedures for the handover of the daily care from pediatric age to adult age
First step of the project

- First meeting: Farmindustria (Association of pharma companies) the presidents of the most important scientific federations of general practitioners (GPs) and paediatricians

- They liked project idea and a second meeting was held with several representatives of each federation:
  - Italian Federation of Family Doctors FIMMG
  - Italian Federation of Paediatricians FIMP
  - Italian Society of Pediatrics SIP
  - Italian Society of General Medicine SIMG
Condivision and support

- Together we established the path and the development of the project
- Together we defined the name of the project "Knowing to assist"
- Together it was decided the procedure to be used: sharing every step since the outset of the project development
- Funded by FARMINDUSTRIA, Association of Pharmaceutical Companies (Covenant of understanding signed in 2000)
- Three-year training project in 2009 with the aim of covering the whole Italian territory
- Extension of funding for another year to be reevaluated each year for the following ones
Goals

1- a new diagnostic sensitivity

2- to address, in a concrete and direct way, all the cross-cutting care issues (nutrition, gastroenterology, pulmonology, cardiology etc..) that the pediatrician and GPs have to face in the daily life of these patients and their families.

3- to lay the groundwork for the establishment of a handover protocol which allows the RD patients and their family to benefit from a real continuity of care

4- to create trainers able to transfer this knowledge and these messages in different contexts, at first regional and then provincial, through the organization of local educational courses as part of the required upgrading of the different health professionals.
Metodology of development

Each trainee becomes a trainer with the responsibility for developing and promoting the same format of the course at the local level

- The format is developed in two parallel sessions and two plenary sessions
- The outset is a plenary session based on the theoretical and practical concept of "network"
- Followed by two parallel sessions (pediatric / adult) on the suspected diagnosis and care - The cross cutting issues are dealt with either through lectures of competent specialists in the field of complex disability and through a session of interactive clinical cases where the participants can measure themselves with concrete examples with the guidance of specialist
- A plenary session on the transition from pediatric to adult age
Guidelines for the regional courses

1-Spreading awareness among doctors and patients and their associations that working together can achieve positive results in terms of research and assistance, but also in terms of common organized requests to be addressed to the central and local health and social system.

2-Promoting a transversal approach to the different pathologies according to the daily care needs.

3-Growing awareness on their role: not strictly limited to the health aspects but also including the patient's everyday life.
They must play a facilitative function to other subjects of the social health system (habilitation/rehabilitation, school, work, clubs, civil society, ....).
The successful path

The first pilot course in Rome 26-28 February coincided with the RDD 2009 whose slogan was: The patient care: a public affair!
The course was attended by 105 health professionals (44 GPs, 40 pediatricians, 7 medical specialists, 7 other professionals, 7 representatives of POs.

- Trainees have been recruited by the medical societies amongst their members.
- Nov 2010 - January 2012 10 courses took place in 10 different regions with a total of 514 participants
- 2012-13 6 courses are planned to be held in other regions
A useful tool (in progress)

- At the same time the Federation has worked to create and update/enrich a database [www.malatirari.it](http://www.malatirari.it) gathering information on different topics.
- The initiative was funded for 80% by the Ministry of Labour and Social Policy (Mercury Project).
- A simple and comprehensible database meeting the daily needs of patients and their families, at first and as second step, the operative needs of the health professionals.
- Surveys distributed to the Patients’ Organisation (legislative regional procedure- POs’ activities- leisure- social services).
- Six focus groups have been carried out with the objective of bringing out the needs of knowledge of the family doctors.
- Health professionals are at the same time authors and guarantors of the information on the disease from a scientific point of view but also users.
Two paths same goal: information

Up to date [www.Malatirari.it](http://www.Malatirari.it) offers two paths designed and developed for different audiences and users with a validated glossary for the comprehension of scientific terms

- The first path is aimed at health professionals who face the complexity of rare diseases, and guides them through an operative itinerary (dedicated area with password)
- The second path is aimed at a wide audience of users, patients and family, institutions and citizens interested in the topics covered
Il malato raro è al centro del sistema
Tutte le informazioni per rendere il quotidiano del paziente raro più facile: dalla diagnosi alla presa in carico, dalle normative alle notizie sui farmaci orfani, ma anche gli aspetti della vita di tutti i giorni - scuola, lavoro, sport, alimentazione, vacanze e tempo libero. Condividere in rete il "sapere" maturato

- Potrei avere una malattia rara, cosa devo fare?
- Ho una malattia rara, cosa devo fare?

Cerca malattia per nome

- Ricerca avanzata malattia
- Centri di riferimento
- Ho una malattia rara, cosa posso fare?
- Approfondimenti
Why building a Community for RD?

heavy decentralization of the Italian health and social system where Regions have the responsibility and accountability for the planning and organization of services

✓ to develop a community of practice with the representatives of the main actors of the RD field patients, family members, health professionals, institutions, as a modern instrument of democratic participation where to exchange perspectives and sharing experiences on relevant issues

✓ to promote their participation in the processes of consultation in public health matters as rare diseases
Autors' methodology support and focus

- The project is based on the development of a training/information path addressed to people with rare disorders and their families, physicians, general practitioners, pediatricians and health professionals, public institutions (27 different entities/institutions)
- Through the exchange of emails and plenary meetings
- Relevant European and Italian legislation and documents have been considered and disseminated
- Funded by FINECO BANK

Focus

- Priority issue of creating a shared model for assessing the quality of the Centres of Expertise for Rare Disease:
- The identification of quality criteria of CoE based on a multidimensional approach of the concept of quality as indicators to be added to the required criteria for the accreditation of the Centers by the Regions
Agreement on the definition of Centre of Expertise

- The Centres of Expertise are functional units, consisting of one or more organizational/operative units, managing the diagnostic path to achieve the earliest possible identification of the disease and defining the path for the health and social individual care of the person with the disease rare.

- These Centers should provide multidisciplinary expertise: diagnostic, therapeutic and care competences, aimed at maintaining patient’s functions and autonomy, the quality of life, the dignity of the person and his/her inclusion in the family and in the social contexts. They must therefore necessarily gather a large user base (critical mass) and develop clinical research.

- The Centres of Expertise must maintain links between the actions implemented by the various actors involved in care including hospital networks and the local networks of primary care and rehabilitation, maintaining the clinical history and the health evolution of the patient also in the transition from childhood to adult age.
<table>
<thead>
<tr>
<th>Criteria and Sub-Criteria Shared with All Stakeholders</th>
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<tbody>
<tr>
<td><strong>Continuity of Care</strong></td>
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<tr>
<td>• Continuity over time of the service</td>
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<tr>
<td>• Management of the transition from childhood to adult</td>
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<tr>
<td>age</td>
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<tr>
<td>• Multidisciplinary: availability of a team of health</td>
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<tr>
<td>professionals</td>
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<td><strong>Expertise</strong></td>
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<tr>
<td>• Expertise: Specific expertise on Rare Diseases (on a</td>
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<tr>
<td>single disease or group of diseases)</td>
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<tr>
<td>• Diagnostic</td>
</tr>
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<td>• Total patient care/follow up</td>
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<td>• Health professionals’ experience</td>
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<td><strong>Links (Collaborations—Networking)</strong></td>
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<tr>
<td>• Networking and coordination with other CoE at inter-</td>
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<tr>
<td>regional and national level</td>
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<tr>
<td>• Networking and coordination with other international</td>
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<tr>
<td>CoE</td>
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<tr>
<td>• Use of regional, national and international registries,</td>
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<td>monitoring/assessment</td>
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<td>• Use of national and international information databanks</td>
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<td>on RD</td>
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<tr>
<td>• Link with biobanks</td>
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<tr>
<td><strong>Infrastructures and Technologies</strong></td>
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<td>• Use of procedures of HTA</td>
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<tr>
<td>• Availability of technologies for diagnosis, care and</td>
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<td>rehabilitation on site or functionally linked to the</td>
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<td>Centre</td>
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<tr>
<td><strong>Health and Social Care Integration</strong></td>
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<tr>
<td>• Collaboration with GPs and Pediatricians for the</td>
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<tr>
<td>management of the patient</td>
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<tr>
<td>• Collaboration with local health care providers where</td>
</tr>
<tr>
<td>the patient resides (Hospitals, health districts etc)</td>
</tr>
<tr>
<td>• Collaboration with local social welfare services where</td>
</tr>
<tr>
<td>the patient resides (School, Municipality etc)</td>
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<tr>
<td><strong>Relationship with the Patient and His/Her Family</strong></td>
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<tr>
<td>• Provide complete and updated information for patients</td>
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<td>and their families on the process of access to the</td>
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<td>Centre and care</td>
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<tr>
<td>• Ability to welcome, listen and filter</td>
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<tr>
<td>• Provide psychological support to patients and families</td>
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<tr>
<td>• Completion of the assessment of psychological-</td>
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<tr>
<td>behavioral profile</td>
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<td>• Adaptation to the needs of multi ethnic patients</td>
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# Criteria and sub criteria

<table>
<thead>
<tr>
<th>RELATIONSHIP WITH PATIENTS’ ORGANISATIONS</th>
<th>SATISFACTION OF THE PATIENT AND HIS FAMILY</th>
<th>TRAINING</th>
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</table>
| • Collaboration with Patients’ organisations | • Existence of a structured and systematic detection with procedures established to measure the perception of the patient and family on various areas  
• Level of satisfaction of the patient and family on the different aspects | • Internal staff ongoing training  
• Implementation of upgrade paths to other healthcare professionals  
• Development of training pathways |

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<th>RESEARCH AND INNOVATION</th>
<th>INFORMATION SYSTEM</th>
<th>ACCESSIBILITY</th>
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| • Management of research  
• Translation of new advancements into clinical practice  
• Development of innovative guidelines and protocols on diagnostic–therapeutic pathways and care (HTA) | • Presence of a dedicated and integrated information system  
• Management of the information shared with other subjects of the social health system | • Sustainability of waiting time to access the Centre  
• Physical accessibility to the Centre  
• Ensure ease of remote contact with the patients |

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<tr>
<th>OUTCOMES</th>
<th>FACILITIES</th>
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| • Improvement of patient’s quality of life  
• Improvement of family’s quality of life | • Interior spaces of the center  
• Venues and facilities to support the family |
2012-2013 Goal

testing the model for the evaluation of the Centres of Expertise to verify its sustainability, for assessing the clarity of the instruments used, the validity, the reliability and sensitivity of the indicators, refining the model before its implementation on a larger scale

This phase will be funded by AGENAS National Agency for regional health services
Italians (are trying to) do it better, together!

Thank you