

The creation of ePAG Italy

EURORDIS Good Practice
16th April 2020

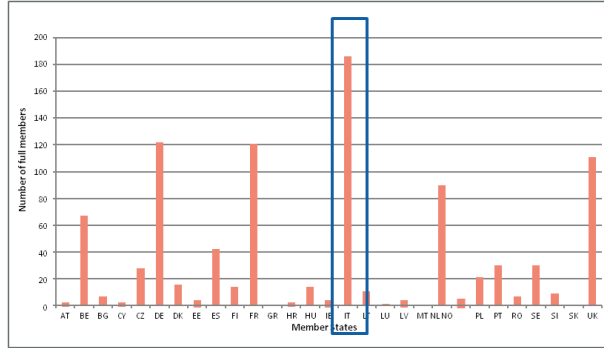
Today's presentation

1. The initial situation
2. Mission and vision of the group
3. The creation of ePAG Italy
4. Lesson learned

1. The initial situation

Before ePAG Italy

Italy and ERNs



Italy is the most represented
Member State in ERNs

Italian Patients Representatives are active
in **17 ERNs**

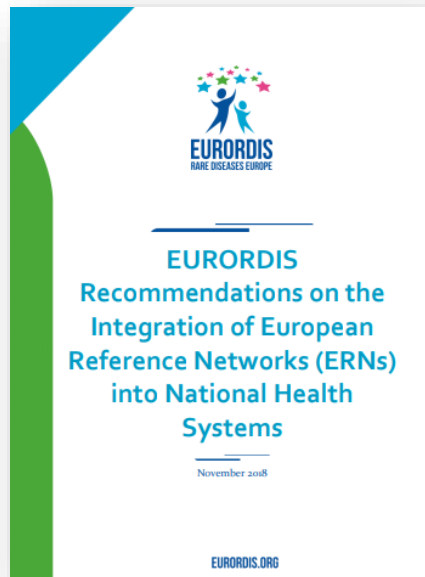
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METABERN
VASCERN

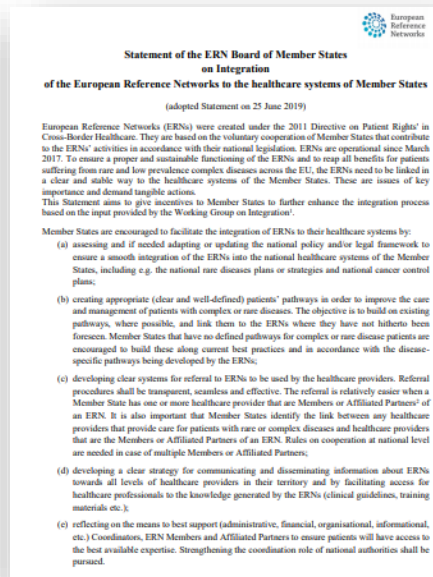


Integration of ERNs into National Health Systems: key to the success of ERNs

EURORDIS Recommendations on the Integration of ERNs into National Health Systems



http://download2.eurordis.org.s3.amazonaws.com/ern/Draft%20Recommendations%20for%20Integration_final.pdf



https://ec.europa.eu/health/sites/health/files/ern/docs/integration_healthcaresystems_en.pdf

Statement of the ERN BoMs on the Integration of ERNs into the healthcare systems of Member States

Integration of ERNs into National Health Systems: key to the success of ERNs



A small group of Italian ePAGs and representatives of the Italian Rare Diseases Alliance (UNIAMO), decided to join forces and to establish a national group of ePAG Advocates



ePAG Italy

2. Mission and vision

Aims and objectives of ePAG Italy



The main aim of ePAG Italy

Establish a national group of ePAG Advocates with the main aim of creating an active group of patients' representatives that could contribute to the Integration of ERNs into the Italian Health System

Our mission



Collaborate

Cooperate with all Italian RD patients' organisation to integrate the **needs** and **priorities** at EU level.



Cooperate

Create a transversal group of ePAGs to **share** experiences and **join** efforts to reach crucial goals at EU, national, regional and local level.



Inform

Create a point of contact for the Italian RDs communities, where they can find reliable and updated **information** on ERNs and on other initiatives related to RDs.



Educate

Organize **educational activities** to enable Italian ePAGs to engage in the different WGs, Task Forces and other initiatives also at national, regional and local level.



Contribute

Contribute to the **national decision-making processes** on ERNs and RDs, bringing EU expertise and experiences at national level.



Advocate

Build a **national network of patient organizations** to advocate for the improvement of the lives of rare and complex diseases patients with a group of experienced and knowledgeable patient advocates.

3. The creation of ePAG Italy

How the group was established

The involvement of Italian ePAGs



The creation of ePAG Italy was promoted by 3 Italian ePAG Advocates* that started the process by contacting both EURORDIS and the Italian Rare Disease Alliance. An agreement was found.

* ERN EpiCare, ERN ReCONNET, ERN RITA

Methodology

A bottom-up survey aiming to:

- ① Understand the need of an Italian ePAG Group
- ② Outline in specific the mission and the scopes of the group
- ③ Have the profile of Italian ePAGs for future activities



ePAG Italy: our members



ePAG Italy involves 45 Italian ePAG
Advocates from **17 ERNs**

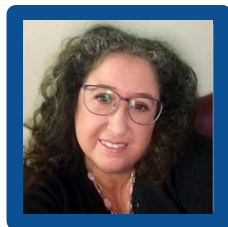
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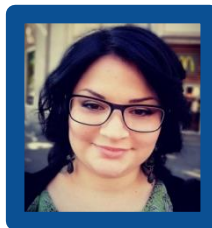
The Executive Committee of ePAG Italia Bucharest 2019



Isabella
Brambilla
ERN EpiCare



Ilaria
Galetti
ERN ReCONNET



Diana
Marinello
ERN RITA



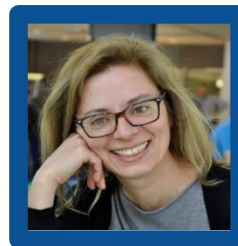
Loris
Brunetta
ERN Euro BloodNet



Diana
Vitali
ENDO ERN



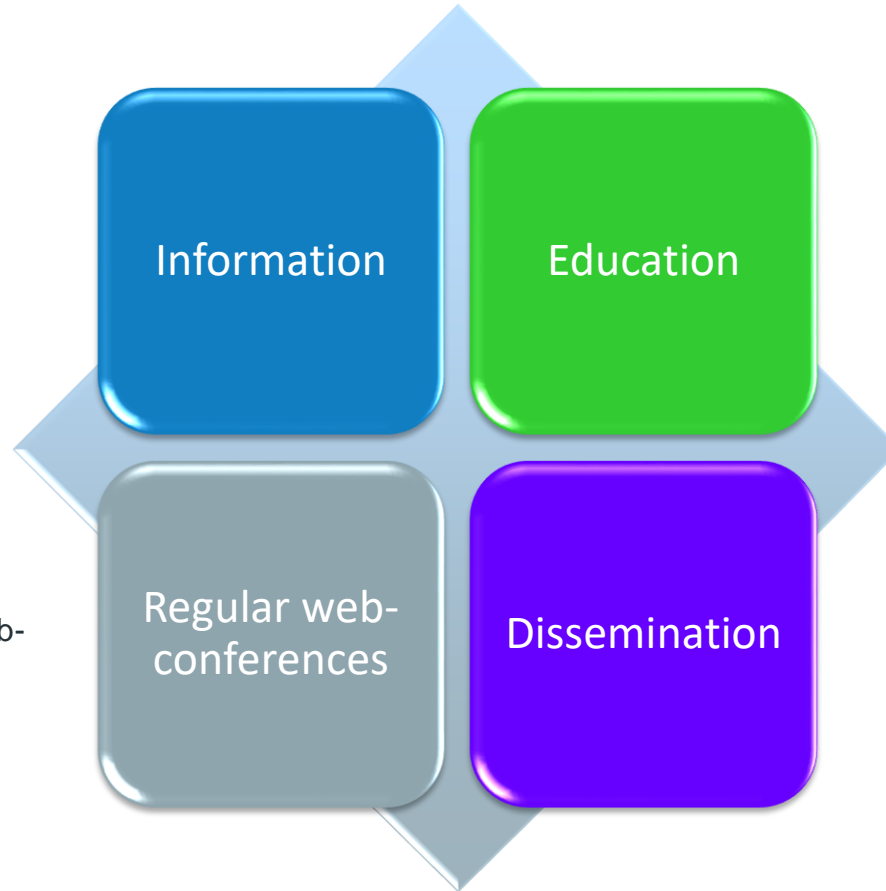
Claudio
Ales
Genturis



Annalisa
Scopinaro
UNIAMO/ITHACA

UNIAMO
FEDERAZIONE ITALIANA
MALATTIE RARE
ONLUS

Our main activities



- Website
- Facebook page
- WhatsApp groups

- Monthly meetings
Every third Monday a web-conference takes place

- Education
Realization of webinars on transversal topics

- Dissemination
Participation to national and regional meetings with different stakeholders (as in Pisa for the RDD)

Our website

www.epag-italia.it



Our webinars

- ✓ Registry
- ✓ ERN HCPs assessment
- ✓ National Alliance and the Integration of ERNs
- ✓ The development of new medicinal products
- ✓ EMA
- ✓ ERNs and the role of ePAGs

4. Lesson learned

Challenges and opportunities

Lesson learned and success factors



- ✓ Willingness of collaboration among the Italian ePAGs involved in the different ERNs, that decided to establish ePAG Italy
- ✓ Establishment of the group via democratic process
- ✓ Identification of a framework of collaboration with National Alliance
- ✓ Collaboration and the active engagement of the National Alliance
- ✓ Ensure the inclusion of members and non-members

Future perspectives and challenges

- ePAG Italy to be included in national and regional specific WGs on RDs to address the requests of the ERNs' transversal working in the National/Regional Healthcare Policies and initiatives
- Establish a closer collaboration with ERN Coordinators and representative of BoMS
- Inclusion of newly appointed Italian ePAG Advocates in ePAG Italy
- More educational activities and regular information/updates on ERNs needed



Thank
you!

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