

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

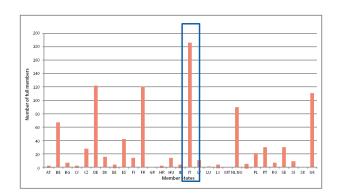


1. The initial situation

Before ePAG Italy

Italy and ERNs





Italy is the most represented Member State in ERNs

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



ENDO ERN ERN LUNG ERN EPICARE ERN ReCONNET ERN EURACA ERN RITA ERN EUROBLOODNET ERN-RND ERN EUROGEN ERN SKIN

ERN EURO-NMD ERN TRANSPLANT-CHILD

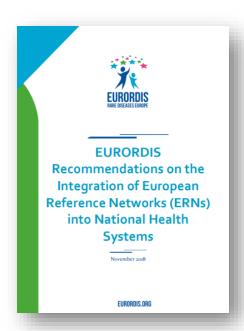
ERN GENTURIUS METABERN ERN GUARD-HEART VASCERN

ERN ITHACA

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

Statement of the ERN Board of Member States

of the European Reference Networks to the healthcare systems of Member States

(adopted Statement on 25 June 2019)

European Reference Networks (IERSs) were created under the 2011 Directive on Patient Right's in Cross-Barder Healthman. They are based on the volutariary cooperation of Member States that contribute to the ERN's activities in accordance with their national legislation. ERNs are operational since March 2017. To ensure a proper and solutanished functioning of the ERNs and no reap all hereful for patients suffering from rure and low prevalence complex diseases across the U. (the ERNs and no reap all indeed in innertune and domain transition across the complex diseases across the U. (the ERNs across the new touses of the innertune and domain transition across the contribute of the contribute

This Statement aims to give incentives to Member States to further enhance the integration process based on the input provided by the Working Group on Integration¹.

Member States are encouraged to facilitate the integration of ERNs to their healthcare systems by:

- (a) assessing and if needed adapting or updating the national policy and/or legal framework to ensure a smooth integration of the ERNs into the national healthcare systems of the Member States, including e.g. the national rare diseases plans or strategies and national cancer control plans;
- (b) crasting appropriate (clear and well-defined) patients' pathways in order to improve the care and management of patients with complex or use disease. The objective is to build on existing pathways, where possible, and link them to the ERNs where they have not hitherto been foreseen. Member States that have no defined pathways for complex or ruse disease patients are encouraged to build these along current best practices and in accordance with the diseasespecific pathways being developed by the ERNs;
- (c) developing clear systems for referral to ERNs to be used by the healthcare providers. Referral procedures shall be transparent, scamless and effective. The referral is relatively easier when a Member State has one or more healthcare provider that are Members or Affiniated Partners' of an ERN. It is also important that Member States identify the link between any healthcare providers that provider care for patients with rare or complet cleases and healthcare providers that are the Members or Affiniated Partners of an ERN. Rules on cooperation at national level are needed in case of multiple Members or Affiniated Partners.
- (d) developing a clear strategy for communicating and disseminating information about ERNs towards all levels of healthcare providers in their territory and by facilitating access for healthcare professionals to the knowledge generated by the ERNs (clinical guidelines, training materials on b).
- (e) reflecting on the means to best support (administrative, financial, organisational, informational, etc.) Coordinators, ERN Members and Affiliated Partners to ensure patients will have access to the best available expertise. Strengthening the coordination role of national authorities shall be automated.

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

Statement of the ERN

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



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



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.



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.



Cooperate

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



Contribute

Contribute to the **national decisionmaking processes** on ERNs and RDs, bringing EU expertise and experiences at national 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.



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.

Methodology





A bottom-up survey aiming to:

- Understand the need of an Italian ePAGGroup
- Outline in specific the mission and the scopes of the group
- Have the profile of Italian ePAGs for future activities

ePAG Italy: our members





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

ENDO ERN

ERN EPICARE

ERN EURACA

ERN EUROBLOODNET

ERN EUROGEN

ERN EURO-NMD

ERN GENTURIUS

ERN GUARD-HEART

ERN ITHACA

ERN LUNG

ERN ReCONNET

ERN RITA

ERN-RND

ERN SKIN

ERN TRANSPLANT-CHILD

METABERN

VASCERN

The Executive Committee of ePAG Italia Bucharest 2019





Isabella Brambilla ERN EpiCare



llaria Galetti ERN ReCONNET



Diana Marinello ERN RITA



Loris
Brunetta
ERN Euro BloodNet



Diana Vitali ENDO ERN



Claudio Ales Genturis



Annalisa Scopinaro UNIAMO/ITHACA



Our main activities



- Website
- Facebook page
- WhatsApp groups

 Monthly meetings
 Every third Monday a webconference takes place Information

Education

Education

Realization of webinars on transversal topics

Regular webconferences

Dissemination

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

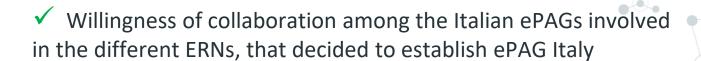


4. Lesson learned

Challenges and opportunities

Lesson learned and success factors







- ✓ 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

Europear Patient Advocacy Group

- 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

