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Background

The creation of ePAG Italy was promoted by 3 Italian ePAG (European Patient Advocacy Group) Advocates who started the process by contacting EURORDIS and the Italian Rare Disease Alliance (UNIAMO). The Italian group “ePAG Italia” was founded in 2019 and it includes 45 Italian ePAGs from 17 ERNs.



Methods



Three democratic, transparent, bottom-up surveys defined the needs and the objectives of the group and collected the profile of each ePAG Representative. The group agreed on an intense collaboration with the National Rare Disease Alliance and on the establishment of a Coordination Team.

Main objectives

- Create an active group of patients’ representatives that could foster the Integration of ERNs into the Italian Health System.
- Contribute to the national decision-making processes on ERNs and rare diseases, bringing European expertise and experiences at institutional national working tables.



Our activities

- Website**
- Facebook page
- WhatsApp groups

Information

Education

• Education

Realization of webinars on transversal topics (Registries, Assessment of ERN HCPs, EMA, etc)

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

Regular web-conferences

Dissemination

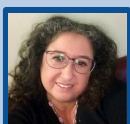
• Dissemination

Participation to national and regional meetings with different stakeholders (as in Pisa for the RDD 2020).

The Coordination Team



Isabella Brambilla



Ilaria Galetti



Diana Marinello



Loris Brunetta



Diana Vitali



Claudio Ales



Annalisa Scopinaro



Conclusions

Building a national ePAG group can provide a crucial added value in achieving tangible results for the patient community of rare and complex diseases. ePAG Italy also demonstrates the potential impact of patients’ involvement in ERNs in providing a framework for the integration of the European activities in the national scenario and therefore contributing to the actual integration of ERNs into the national health systems.

** www.epag-italia.it