

All Aboard to a Better Health Future

EUPATI National Platform ITALY

***14 December 2016 – The Square
Brussels, Belgium.***

EUPATI National Platform ITALY

- **Patient representatives:** Filippo Buccella, *Parent Project Onlus*; Antonella Celano, *APMAR Onlus*; Silvia Starita, *Parent Project Onlus*; Linda Henderson, *ATTA Lazio Onlus*
- **Academic representative:** Dominique Van Doorne, *AME*
- **Industry representative:** Moreno Busolin
- **EUPATI Mentor:** Silvano Berio
- **EUPATI Patient Experts:** Claudia Crocione, Walter Dal Pos, Nora Hantsch, Paola Kruger, Stefano Mazzariol
- **Communications Officer:** Francesca Ceradini
- **AIFA representatives:** Silvia Miriam Cammarata, Luisa Muscolo
- **AIFA General Director:** Mario Melazzini
- **Ex General Director:** Luca Pani

2012 – 2015 at a glance...

- **National supporters of EUPATI in Italy** first gathered in 2012 and over the course of 2013, they worked together to raise awareness of EUPATI among local health partners.
- In 2014 a strong partnership with **AIFA** and **ISPOR** Rome Chapter was established
- In 2014 - **Accademia dei Pazienti Onlus** - a legal entity was created to enable EUPATI Italy to operate independently, increase its national profile, and receive donations and grants from Italian funding partners.
- In 2014, a **16-member strong Scientific Board** (comprising of distinguished representatives of patient organizations, industry, institutions, CROs, media, academia) was formally established and preparations began to support **the launch of a EUPATI National Platform in April 2015**

EUPATI National Platform BOARD



2016... a year of consolidation

- **A two-day national workshop in April 2016 marked the launch of the Italian language version of the EUPATI Toolbox.**
- **EUPATI Patient Experts started to be included in the pharmaceutical industries' activities as full members (e.g. *Medical Evaluation Board to approve a new medicine for Cholangitis and prepare pricing dossier to be submitted to AIFA*)**
- **EUPATI Patient Experts increasingly participate as speakers in many institutional events (e.g. Celgene 10 year anniversary meeting, Janssen 20 year anniversary meeting, Meeting in AIFA on sustainable innovation, Journalist Course on Rare Diseases organized by the Superior Institute of Health, European Biotech Week)**

Our vision is to multiply the number of patient experts and to empower a new generation of patients by:

- Launching a **Patient Expert course in Italian language**
- **Becoming a proper enterprise** in order to access additional funding opportunities
- **Promoting the EUPATI toolbox** among patient associations and the patient community in general
- Evaluating **twelve national Formative Courses regarding R&D**, proposed by the members of the platform, Accademia and Industry, among others. Those selected by the Scientific Board will become Courses for the public in 2017/2018
- **Continuing to identify opportunities for EUPATI Patient Experts to engage in stakeholders' activities**
- **Expanding our communication activities** to establish our expertise in Italy



ACCADEMIA DEI PAZIENTI



CONOSCERE PER DECIDERE



The Pillars of effective Collaboration

Paola Kruger



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The three Pillars

Our EUPATI experience has led us to identify three Pillars needed to have a positive collaboration with Research and Industry:

- **Education**
- **Trust**
- **Rules**

Patient Education

- **Certified courses that lead to a professional title**
 - **Many courses available, but check who is running them and where the content comes from**
 - **EU and National Authorities should recognise the Patient Expert as a Professional in his/her own right**

Building Trust

- **Patient Experts, Research and Industry need each other for better health outcomes.**
- **Trust is built through dialogue**
- **Patient Experts should be part of the decision-making process (target: mandatory)**

Clear Rules of Engagement

- **Authorities should adopt frameworks that spell out when and how Patient Experts should be involved to avoid misunderstandings and to guarantee their involvement in all relevant situations**



AIFA

Agenzia Italiana del Farmaco