



WHY AND HOW CAN PATIENTS BE TRAINED IN SCIENTIFIC RESEARCH TO BECOME STRONGER PARTNERS?

ECRD 2018

Theme 1 “Structuring the research & diagnostic landscape”

Session 4 - Patient Involvement: Is it enough to be an expert by experience?

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Saturday 12th May 2018, Vienna

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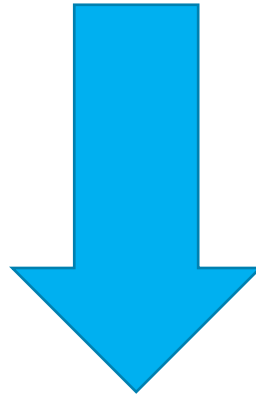
Why should RD patients be « trained » in research?

- Patients are **experts** on their diseases and have a **valuable contribution** to make for **shaping meaningful** rare disease **research**
- Training **empowers** patients and ensures they have the **confidence** and **knowledge** needed to bring their expertise to discussions on **research** (and also health care, medicines development) with policy makers, industry and scientists
- Going beyond primary purposes of providing training and information - foster **communication** and **facilitates common understanding** between RD patients, researchers and other stakeholders

Why should RD patients be « trained » in research?

- RD patients with a **good knowledge** of the RD research environment will be able to have a **stronger impact** in that environment (how to navigate, interact, influence, i.e. shape direction)
- Patient representatives should be considered **equal, credible** and strong **partners**

How can RD patients be « trained » in research?



By providing and facilitating access to relevant, targetted and adapted information

In cooperation with Solve-RD: Capacity building programme on scientific innovation and translational research



- 5-day annual on-site training on:
 - **Overview of the Research landscape/environment**
 - **Genetics/Diagnosis**
 - **Data collection/sharing**
 - **Gene therapies**
 - **ERNs: Diagnosis to Care**



First edition 19-23 March 2018 at the Imagine Institute for Genetic Diseases, Paris

30 patient representatives
15 speakers

A mixed approach:

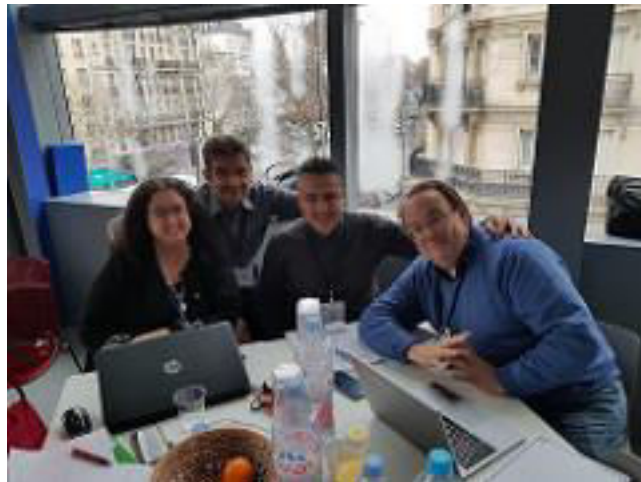
Interactive lectures



Site visits



Breakout group discussions



Networking





**Next edition 11-14
March 2019 at the
Imagine Institute for
Genetic Diseases,
Paris**

**Applications open
Summer 2018**



EURORDIS Summer School



- Capacity building programme started in 2008
- Therapeutic Development & beyond – Emphasis on Patient engagement all along the life cycle of product development
- Multi-stakeholder Programme Committee (EMA, LUMC, Catalan RD platform)
- 7 on-line pre-training modules
- 5-day annual on-site training in Barcelona on:
 - Clinical Research – Methodology, Ethics, etc
 - EU Regulatory Processes – EMA & patient engagement
 - HTA & Reimbursement
 - Networking



Plan for training for patient representatives and advocates on leadership and communication skills

- Strategy of **engagement** and **integration** of patients at all levels of **leadership, design, training, coaching and communication**
- Comprehensive **overview of working processes** involved in various **advisory, management and steering research committees**, governance processes and terminology
 - fostering **meaningful communication**, cooperation, and coordination strategies and **helping patient representatives carefully consider strategic health and research advocacy processes, roles, and responsibilities.**
- **Blended approach** of webinars, face to face workshops, one to one mentoring and e-learning modules



Thank you for your attention

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