Know the Basics: How can I level up my patient advocacy?

ONGOING AND UPCOMING TRAINING OPPORTUNITIES FOR PATIENT ADVOCATES

APRIL 22, 2024

www.ccieurope.eu

Childhood Cancer International EUROPE

HOUSEKEEPINKG ITEMS

#CCIEGOLD WEBINARS

1. Smile! The webinar is being recorded.

2. Use the chat for your burning questions.

3. We'd love to hear from you! Burning questions right after each presentation, and later in Q & A session ☺

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CONTENT

Childhood Cancer International EUROPE

1. The CCI Coursera Programme

2. The KickCancer Expert Patient Training

3. WECAN Academy

4. EURORDIS: Rare Disease Europe Open Academy

5. EUPATI – Patient Engagement Through Education

#CCIEGOLD WEBINARS

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THE CCI COURSERA PROGRAMME

CCI AND COURSERA ARE OPENING THE DOORS TO GLOBAL LEARNING!

Raluca Popa

Global Programme Manager

Childhood Cancer International

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1 ABOUT coursera

- an online global learning platform
- over ??? universities and companies worldwide
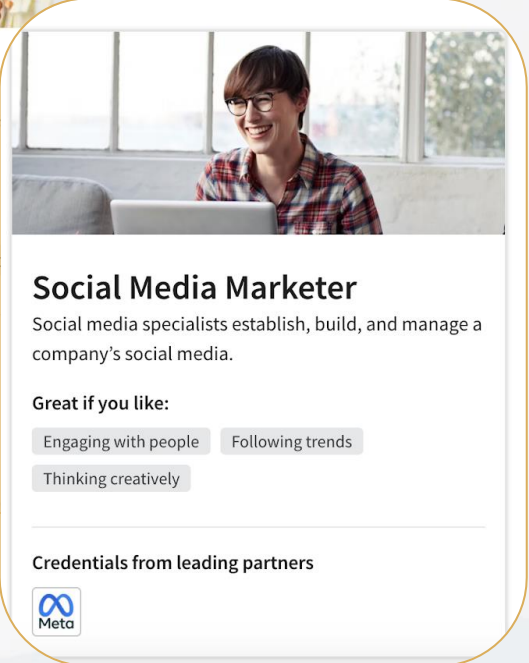- interactive learning
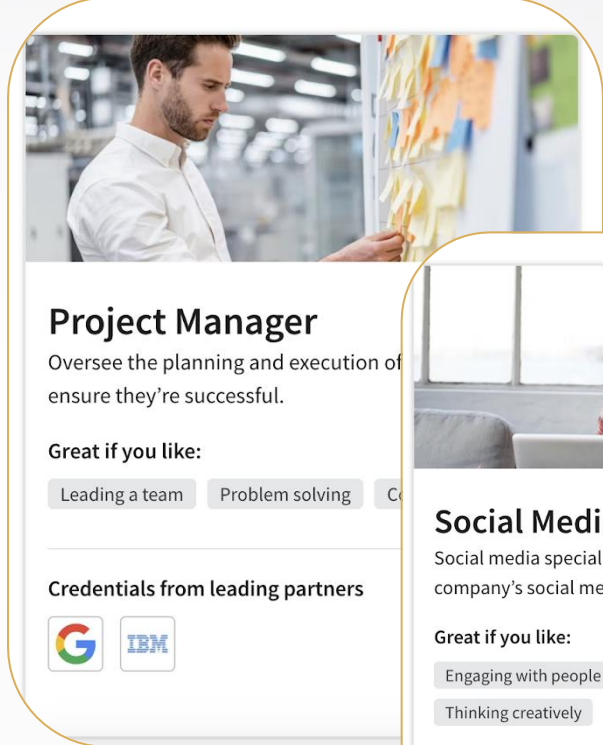- mostly in English
- certifications

2 CONTEXT

Programme supported by **Sanofi Global – 'A million conversations**' – and dedicated to:

- CCI members who wish to develop staff, volunteers and improve their skills and abilities in managing their organisations and childhood cancer programmes
- Survivors who wish to access short courses for skills development, or even to acquire certifications to validate their learning

A catalog of free courses on: project management, marketing, fundraising, financial management, leadership, advocacy, communication, psychosocial support and more!

Project Manager
Oversee the planning and execution of ensure they're successful.

Great if you like:

Leading a team   Problem solving   C

Credentials from leading partners

G   IBM

Social Media Marketer
Social media specialists establish, build, and manage a company's social media.

Great if you like:

Engaging with people   Following trends

Thinking creatively

Credentials from leading partners

Meta

3 PROGRAMME GUIDELINES

Eligibility criteria:

- staff or volunteers within a CCI member organisation, who have a formal role (such as board member or volunteer parent supporter); or

- cancer survivors, with the age of 15 years old or above; and

- individuals who commit to completing the courses requirements; and

- individuals who will participate in surveys focused on sharing feedback and the personal benefits of using Coursera, upon request of the CCI.

- Each CCI member organisation has the right to claim their one Coursera licence by 23 April. After the date, if licences are still left, will be applied the rule first come, first served.

- Claiming the licence by filling in the application form (only legal representatives)

- One licence, multiple users, but not at the same time

- Catalog of courses, professional certifications, and specialisations

- Certifications upon successful completion
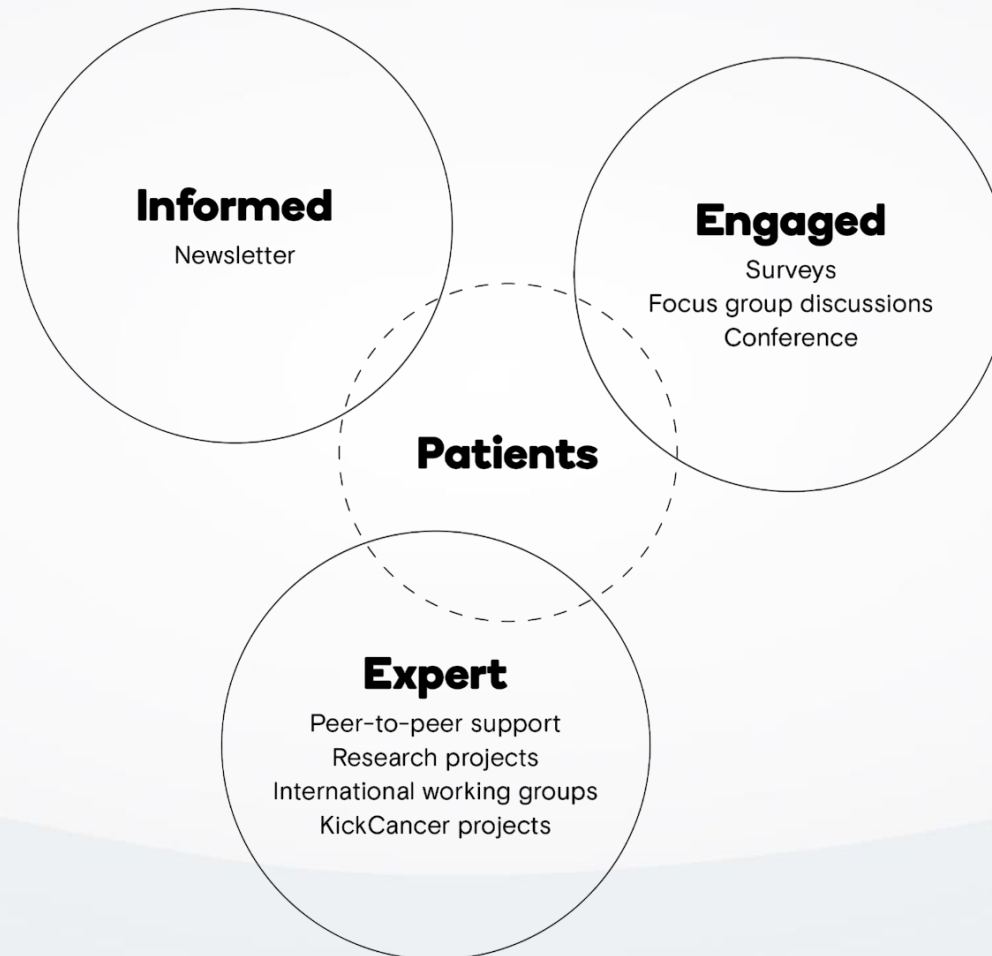
5 JOIN THE CCI COURSERA PROGRAMME!

1. Read the Programme Guidelines or watch the webinar

2. Submit the form to CCI global to apply for a licence

3. Receive the licence

4. Meet the timelines of the courses, and requirements from Coursera and CCI

5. and Enjoy the global learning!

Alice Gerbaux

Kicker in empowerment

KickCancer

Patients Committee

Informed
Newsletter

Engaged
Surveys
Focus group discussions
Conference

Patients

Expert
Peer-to-peer support
Research projects
International working groups
KickCancer projects

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Expert patient training

Generic

* Why do we need patient advocates

- Relevant areas
- Limits of contribution (vs. healthcare professionals)

* Level playing field information:

- Healthcare landscape
- Privacy, rights, ethics
- Drug development

* Dealing with emotions

Generic oncology

* Cancer development & terminology

* Cancer treatments

* Role of nutrition

* Patient's rights

Paediatric oncology

* Major types of paediatric cancers and treatments

* Late phase clinical study

* Psychological burden of paediatric cancers

* LT follow-up

* Paediatric oncology landscape

Knowledge Hub!

WECAN ACADEMY

CCI Europe Gold Webinar

Sara Dederichs,
PM WECAN Academy

Who are WE?

WECAN is a platform for Cancer Patient Advocacy Umbrella Organisations to collaborate and share experiences.

The network consists of 24 Umbrella Organisations mainly active in Europe and some active also on Global level.

WECAN Workstream

EDUCATION

- Strengthen Cancer Patient Advocacy

- Provide Resources for Patient Organisations

- Create educational programs to enhance skills and understanding of key issues of patient advocates

  ➤ WECAN Academy F2F training event
  ➤ WECAN Online Academy available open source on:

RESEARCH

- Study patient needs and experiences.

- Analyse data to guide advocacy efforts.

- Collaborate on a pan-cancer level in research projects

  ➤ WECAN Evidence-based Advocacy Programme
  ➤ EBA Workshop (January 2024)
  ➤ European Atlas on Clinical Trials in Cancer and Haematology: EuroACT

POLICY

- Advocate for patient rights and healthcare access.

- Engage policymakers to address legislative gaps.

- Contribute to healthcare reform in policy forums.

- Identify where policy actions are helpful on a pan-cancer level.

WECAN Educational Strategy

3 Tracks

Advocacy Tools & Skills

- Accessing information.

- NGO governance.

- Financial Management.

- Managing volunteers.

Healthcare Systems, Policy & Access

- Access to treatment & care.

- Regulatory processes.

- Healthcare system: EU vs country level.

- Patients' Rights/ Inequalities in Cancer Patients Healthcare.

Research & Data

- How research & development works.

- Patient Reported Outcomes (PROs).

- Reading scientific papers & interpreting data.

- Evidence-based advocacy

Throwback WECAN Academy 2023

OVERVIEW

FRANKFURT HIGHLIGHTS FROM 1st – 4TH July 2023

GOAL: Increase the capacity and number of well-trained patient advocates and patient experts to further grow our community of activists that can induce change.

- 4 Days of Training
- 90 Patient Advocates
- 24 Sessions
- 12 Speakers
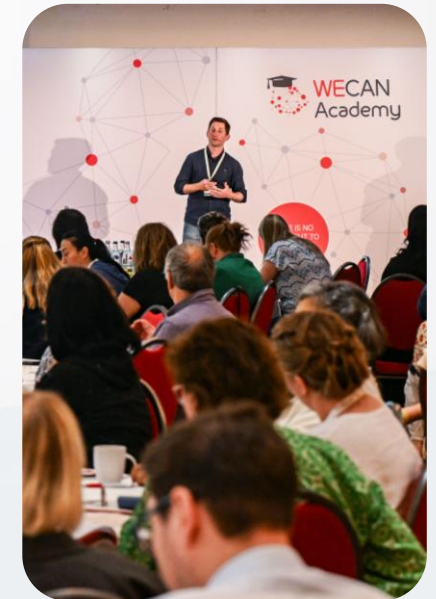- 12 Programme Committee Members
- 3 Tracks:
  Advocacy Tools & Skills
  Healthcare Systems, Policy & Access
  Research & Data

WECAN Academy 2024 Overview

THINGS TO REMEMBER

Who would you meet?

- Participants form Cancer Patient Organisations that are members of WECAN.

How was the programme designed?

- WECAN members voluntarily join the Academy Programme Committee
- Input from the PC alongside the feedback of the former participants and voices of the members were used to identify the need of education for PA in a specific area, on a specific topic.
- The Academy PC designes the programme in detail, thoughtfully deciding on formats and timing of each session.

What is the participation criteria?

- Nominees have not attended the same level of training before.
- Nominees have been suggested by a WECAN Member Organisation
- Participants are Patient Advocates or willing to be active in Patient Advocacy.
- Good proficiency in English.

Key Outline

✓ **Project Date: 11th – 14th July 2024**

Advocacy tools & skills	Healthcare systems policy & access	Research & Data

- Education in the three pillars of patient advocacy.

- 4-day face-to-face training.

- Free for patient advocates, travel grant of up to 400€ provided for each participant.

- Open to 4 nominees per WECAN member organisation.

- Audience – novice patient advocates & leaders in advocacy.

WECAN Academy 2024 Timeline

DATES TO REMEMBER

- The WECAN face-to-face educational training event for patient advocates is from 11th July 2024 to 14th July 2024.

- SmartStart participants are invited to attend the Academy from 11th July, 8:30am to 13th July, 3:00pm. (Arrival is recommended for the 10th July)

- MasterClass participants should plan to join from 12th July, 12:30pm to 14th July, 4:00pm. Arrival is recommended for the 11th July)

- The nomination period is **now** open and will close on 26th April 2024.

- Confirmation of accepted nominees will be sent by 30th April 2024.

- Registration process for all attendees is closed by 10th May 2024

11th – 14th July 2024, Gran Hotel Rey Don Jaime in Castelldefels, (Barcelona)

WECAN Academy — THERE IS NO SHORTCUT TO KNOWLEDGE
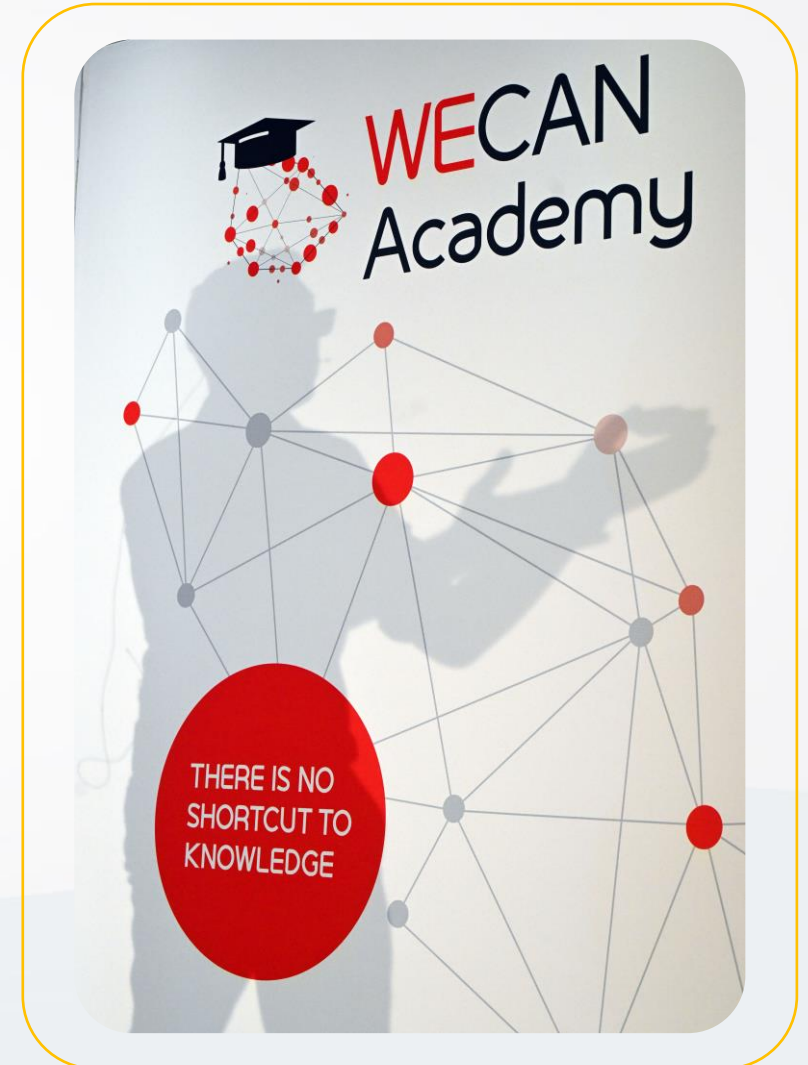
More opportunities to learn
Visit: https://academy.wecanadvocate.eu/

Patients in Publications

Open-access online course for patient advocates on how publish their own research and survey data, and how to act as co-authors or peer-reviewers
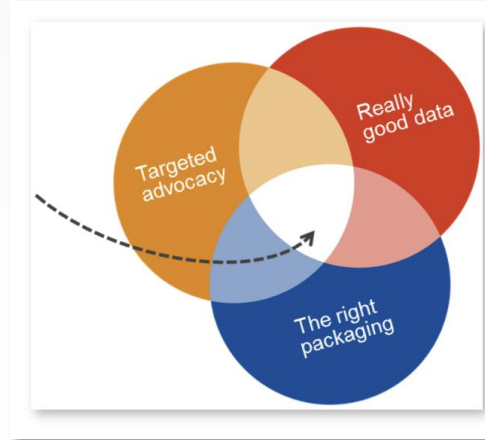
Evidence Based Advocacy

Special training programs on evidence generation, analysing and publishing data, and the practical use of data to drive change

COMING OUT SOON!!!

Patient Experience Data Course

Throughout this course you will discover the importance of Patient Experience Data in improving health outcomes and quality of care.

EJP RD Massive Open Online Courses (MOOCs)

- **Diagnosing Rare Diseases: from the Clinic to Research**

  - Explore the role of research, clinical investigation and data sharing in diagnosing rare diseases.

- **From Lab to Clinic: Translational Research for Rare Diseases**

  - Gain an overview of the issues, challenges, and opportunities in translating research into treatments for rare disease patients.

Open Academy e-learning

- Over **25 introductory courses** freely available online.

- Topics such as:
  - *Ethics in clinical trials;*
  - *Establishing an international cooperation;*
  - *Sharing patient data;*
  - *Conflict of interest in patient engagement;*
  - And many more....

- Developed with **subject-area specialists**, courses are regularly updated for the latest information on all topic areas.

- Designed to be **interactive, engaging & accessible**.

Open Academy Schools

- **Medicines Research & Development**

  - Gain the knowledge needed to become experts in medicines research and development.

- **Scientific Innovation & Translational Research**

  - Learn skills to effectively participate in discussions with stakeholders responsible for research/research infrastructures.

- Includes **off-site visits**, sessions from **top experts** in the field, **networking opportunities** and access to our **Alumni network** and resources.

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Rare Disease Week

- Taking place in November 2024 – **applications open now!**

- Three days in Brussels where you will:
  - Learn about the EU and how to effectively participate in advocacy activities at the EU level;
  - Meet MEPs and influence the decisions that have a direct impact on patient's lives;
  - Raise awareness of rare diseases and present a strong and united message with fellow advocates.

- Includes **leadership training** in relevant subjects, **networking opportunities** and access to our **Alumni network** and resources.

Next steps....

- **Sign up to the Open Academy Newsletter** to stay up to date on training opportunities from us and our contacts

- Go to the **Open Academy website** to explore our courses

- Go to the **EJP RD website** to check out their patient resources

EUPATI

Patient Engagement Through Education

A patient-led partnership working across stakeholders to enhance patient engagment

Laia Bisbal Arnal

Open Classroom Coordinator

EUPATI

Where do we come from?

2012
IMI Project

2017
Hosted by EPF

2020
EUPATI Foundation

Who are we and what do we do?

WHO WE ARE

Vision

EUPATI's vision is to improve health outcomes through the contribution of patients and patient representatives as valued stakeholders.

Mission

EUPATI's mission is to provide accessible, innovative and inclusive education that empowers patients and patient representatives with the right knowledge, skills and competencies to effectively engage and partner with all other stakeholders in medicines R&D.

EUPATI

EUPATI TOOLBOX

EUPATI Open Classroom
PATIENT EDUCATION

NATIONAL PLATFORMS

EUPATI Connect
EUPATI CONNECT
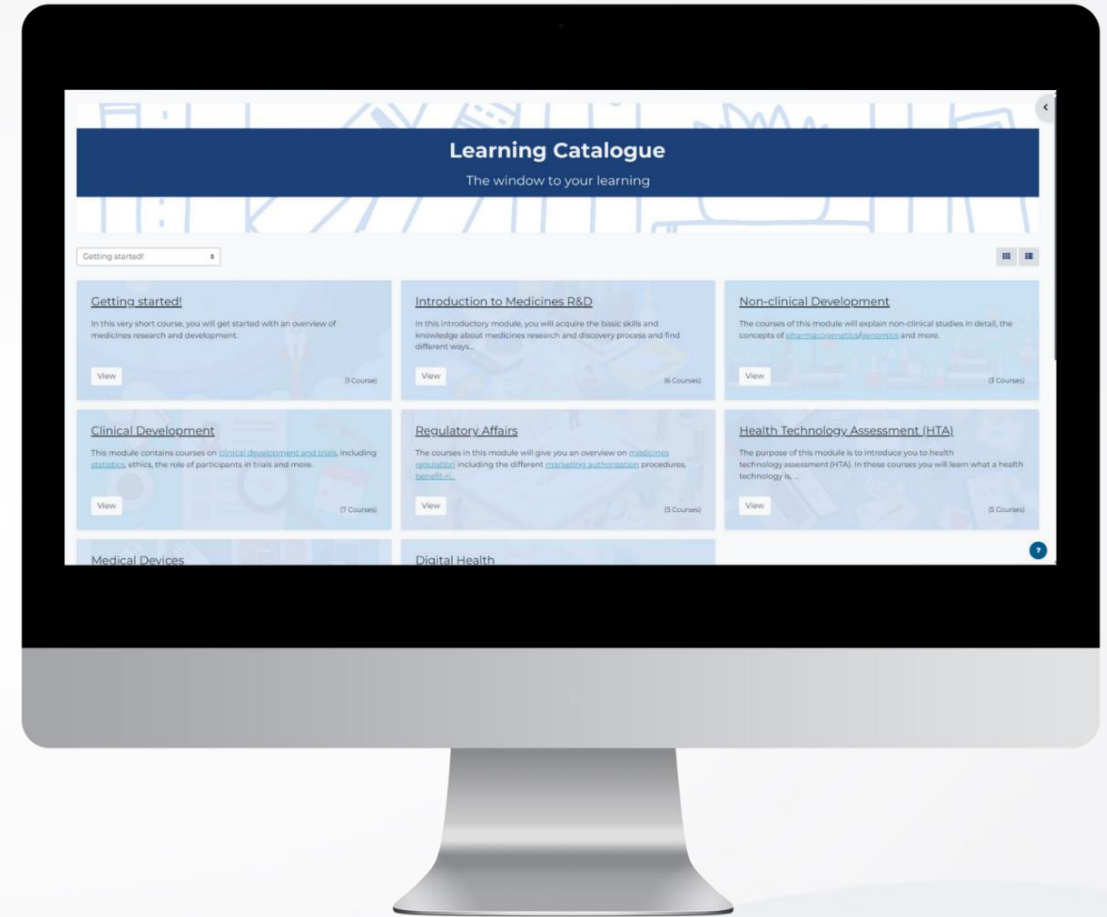
STAKEHOLDER EDUCATION

OTHER INITATIVES

WHAT WE DO

Patient Education

EUPATI Open Classroom

- **EUPATI Open Classroom** is a **user-friendly platform** providing training **in Medicines R&D, Digital Health and Medical Devices.**

- It is **not necessary to register to access the full content.**

- To obtain a **certificate** for a course, there is an administrative fee of 8 euros to unlock and successfully complete the assessment.

Learning Catalogue
The window to your learning

Getting started!

Getting started!
In this very short course, you will get started with an overview of medicines research and development.

View   (1 Course)

Introduction to Medicines R&D
In this introductory module, you will acquire the basic skills and knowledge about medicines research and discovery process and find different ways..

View   (6 Courses)

Non-clinical Development
The courses of this module will explain non-clinical studies in detail, the concepts of pharmacogenetics/genomics and more.

View   (3 Courses)

Clinical Development
This module contains courses on clinical development and trials, including statistics, ethics, the role of participants in trials and more.

View   (7 Courses)

Regulatory Affairs
The courses in this module will give you an overview on medicines regulation including the different marketing authorisation procedures, benefit-ri...

View   (5 Courses)

Health Technology Assessment (HTA)
The purpose of this module is to introduce you to health technology assessment (HTA). In these courses you will learn what a health technology is...

View   (5 Courses)

Medical Devices   Digital Health

EUPATI
Open Classroom

What are our learning pathways?

Individual courses

Individual modules

Patient Expert Training Programme PETP
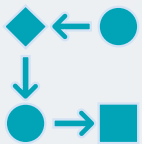
Patient Expert Training Programme

The **EUPATI Patient Expert Training Programme** is a training programme about the medicines' development process. (Non-disease specific)

The **overall objective** of the programme is to obtain a thorough understanding of the medicines R&D process, the patients' role within and build capacity among the patient community to take on an active role in collaboration with the other involved stakeholders.

While the programme is mainly addressed to **patients and patient representatives** it is **open to all individuals** interested in medicines R&D and patient engagement.

OPEN Registrations open	Registrations close	Introductory webinar	Kick-off webinar	Event 1 Virtual (Modules 1-4 finalised)	Meet the ENPs webinar	Event 2 In-Person + Graduation (Modules 5-6 finalised)
June 2023	1 November 2023	December 2023	February 2024	April 2024	May 2024	October 2024

What other resources are available?

PATIENT ENGAGEMENT ROADMAP

The roadmap highlights specific opportunities for patient involvement along the key stages of the medicines R&D lifecycle and is illustrated with concrete examples.

TOOLBOX

The Toolbox is an online library on the A-Z of medicines research and development (R&D) and patient engagement. There are videos, presentations, glossary terms..

EUPATI National Platforms

EUPATI has established National Platforms (ENPs) in 24 countries across Europe and worldwide. All aim to promote patient education and engagement at the national and local level.

What do the Fellows say?

General satisfaction with the **training** and the **Face-to-Face** meetings

- Better **grasp of R&D-specific language**
- Busted **communication skills**
- **More connections** with R&D stakeholders

- More **partnerships** with R&D stakeholders in different forms
- **Mediator role** between patients and R&D stakeholders
- **Increased efficiency** in their tasks as patient experts

- **More opportunities** for new Fellows
- **Boosted EUPATI Fellows' active role** in patient involvement
- **Development of a network** within the R&D sector

Childhood Cancer International EUROPE

Links

CCI Coursera Programme
https://bit.ly/42EqWdv

KickCancer Expert Patient Training
https://kickcancer.org/p/patients-advocacy-committee

WECAN Academy
https://academy.wecanadvocate.eu/

EURORDIS Open Academy
https://openacademy.eurordis.org/

EUPATI Open Classroom
https://learning.eupati.eu/

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Let us know what you think!
Give us your *feedback.*

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Childhood Cancer International
EUROPE

CCI EUROPE
CONFERENCE
2024

14TH CHILDHOOD CANCER INTERNATIONAL - EUROPE

C⊕NFERENCE

15-18 MAY 2024
MILAN, ITALY

Regular rate
registration **ends** on
April 24