EUPATI FELLOWS

COHORTS 1-6

The EUPATI **Patient Expert Training Programme** is a training programme about the medicines' development process that covers the entire lifecycle of medicines(R&D).
The Programme was originally designed for patients and patient representatives. Today, while is still **mainly addressed to patients** and **patient representatives**, it is open to all individuals interested in medicines R&D and patient engagement.
The Programme consists of **6 online modules and 2 training events of 4 days each**. Completing the entire program usually takes between 12 and 14 months. Each **cohort** is a group of trainees who have completed the program over the same period of time and have participated in the events together.

The selection process per cohort:

Cohort 1-4

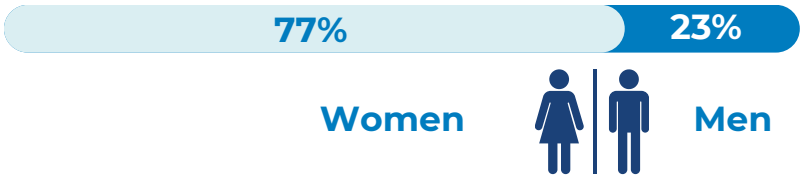
Rigorous application and selection process (to ensure wide geographical and disease-area representation but also exclude representatives from any other stakeholder group).

From Cohort 5

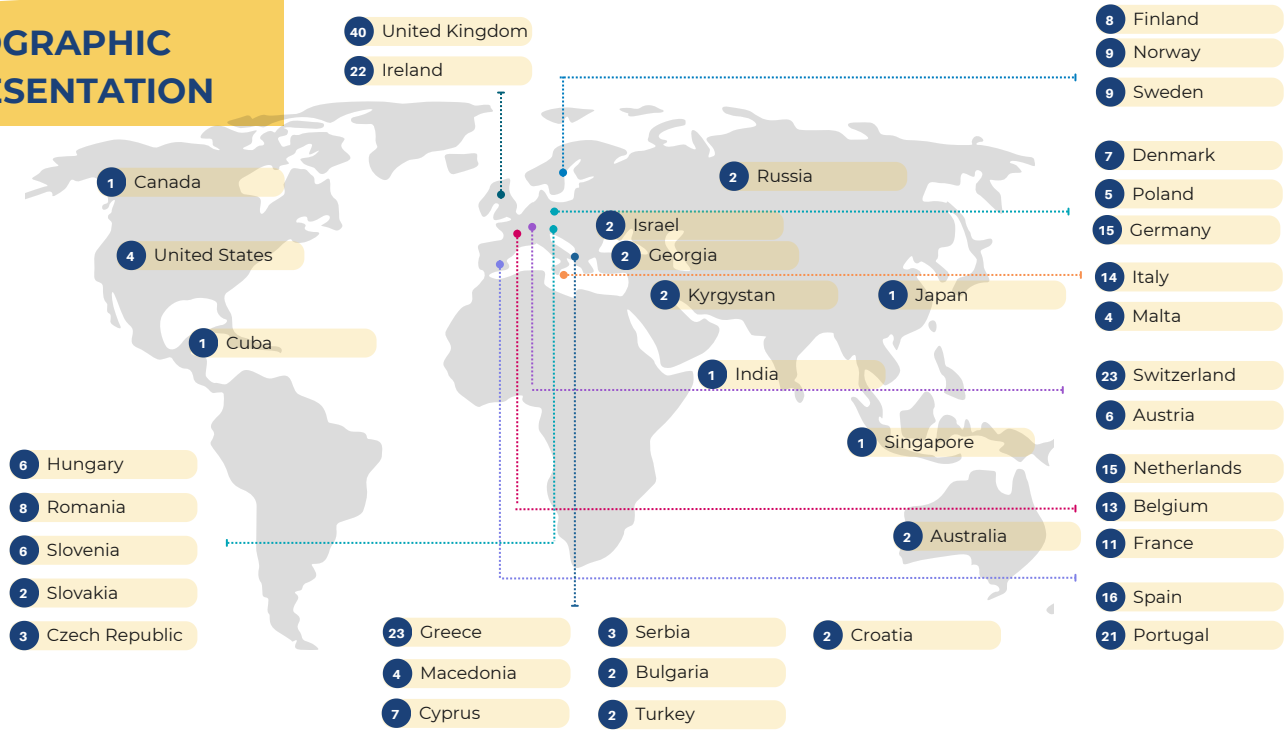
Non-selective approach that opens up the programme to a limited number of other stakeholders representatives

The following are the characteristics of the trainees who have completed the Patient Expert Training Programme from **Cohort 1 to 6 (2015-2023)**

GENDER REPRESENTATION

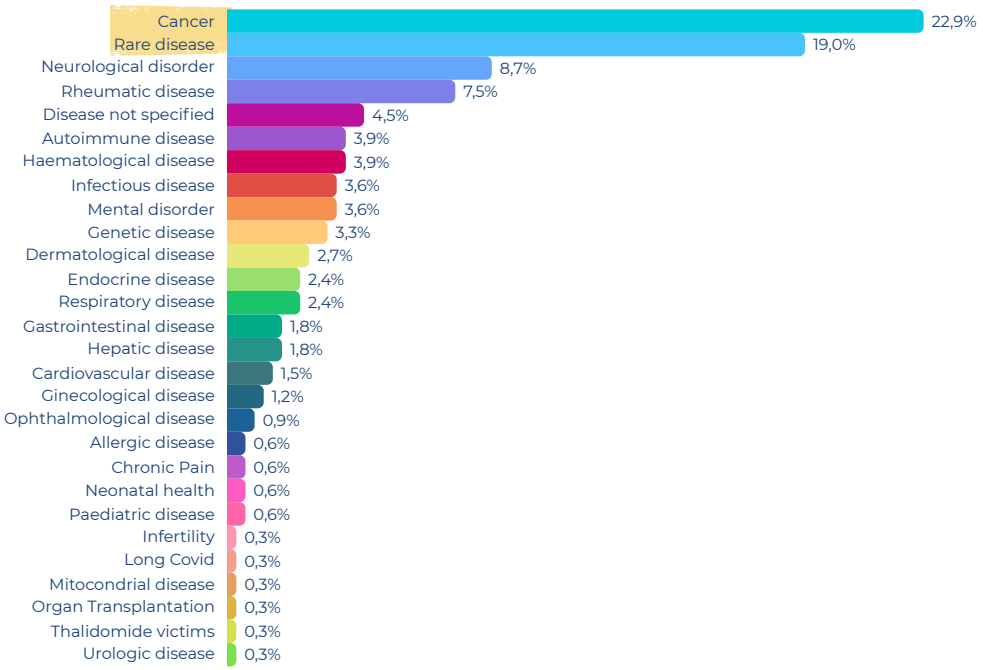


GEOGRAPHIC REPRESENTATION



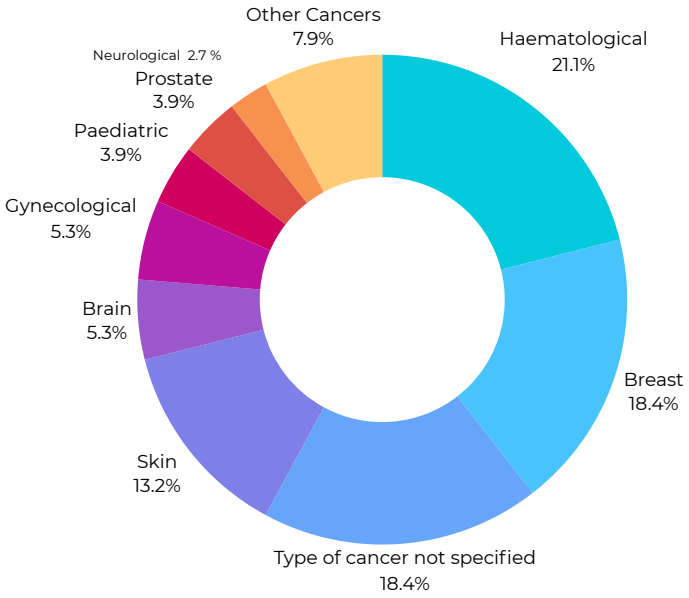
1 Bosnia Herzegovina, Latvia, Lithuania, Luxemburg, Republic of Moldova, Ukraine

DISEASE AREA REPRESENTATION



Cancer and rare diseases are most common conditions among the Fellows

TYPES OF CANCER



RARE DISEASES

Addison's disease
Autoinflammatory disease
COAT's
Congenital Disorder of Glycosylation
Cystic Fibrosis
Duchenne Muscular Dystrophy
Ehlers-Danlos syndrome
Epidermolysis bullosa
Fibrodysplasia ossificans progressiva
Friedreich's ataxia
Gaucher disease
GNE Myopathy
Hereditary hemorrhagic telangiectasia (HHT)
Muscular dystrophy
Osteonecrosis of the jaw
Pitt Hopkins Syndrome
Propriospinal myoclonus
Rare genetic disease
Rare liver disease
Rare neuromuscular disease
Rare optic diseases
Rare Paediatric disease
Sanfilippo Syndrome
Spinal Muscular Atrophy
Trisomy 8
Usher Syndrome

Duchenne and Cystic Fibrosis are the most common rare diseases with 8 and 7 trainees respectively.

STAKEHOLDER REPRESENTATION

Patients

92%

Patient, caregiver or patient representative

6% have also a role in Industry or Academia

Other stakeholders

Industry representative

4%

Academic/ Researcher

2%

Healthcare professional

2%

Other

1%

Note: Other Stakeholders were only introduced from Cohort 5