

EUPATI FELLOWS

COHORTS 1-8



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:



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



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

The following are the characteristics of the EUPATI Fellows **Cohorts 1 to 8 (2015-2025)**

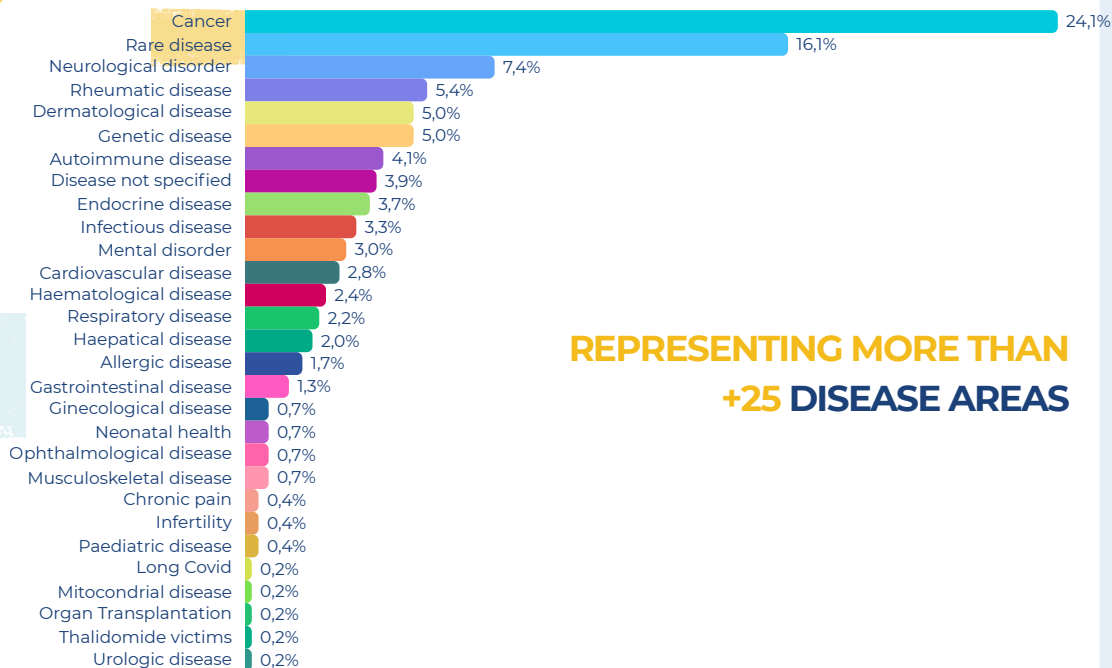
GEOGRAPHIC REPRESENTATION



**COMING FROM
60 COUNTRIES**

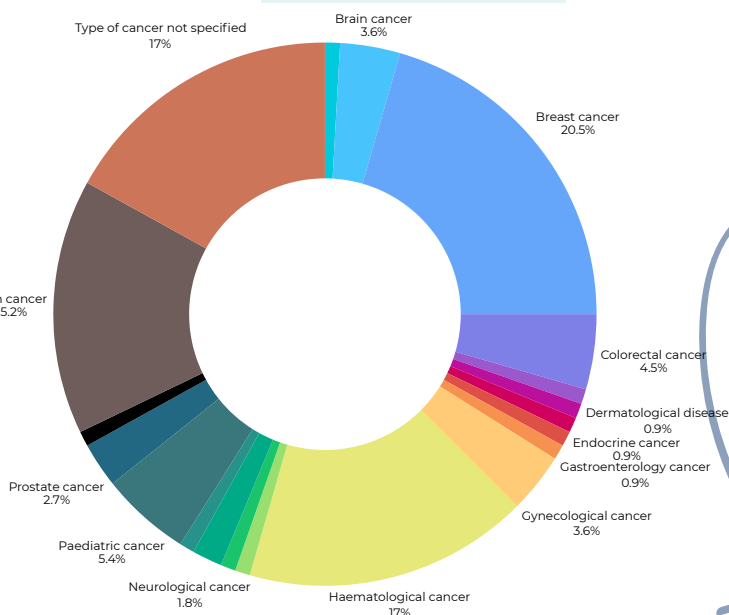
DISEASE AREA REPRESENTATION

Cancer and rare diseases are most common conditions among the Fellows



REPRESENTING MORE THAN +25 DISEASE AREAS

TYPES OF CANCER



RARE DISEASES

- Addison's disease
- ARID1B-RD
- 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
- Generalized Pustular Psoriasis
- GNE Myopathy
- Hereditary hemorrhagic telangiectasia (HHT)
- LHON, Retinosis pigmentosa
- Muscular dystrophy
- Osteonecrosis of the jaw
- Pemphigus/Pemphigoid
- Pitt Hopkins Syndrome
- Primary Sclerosing Cholangitis
- Propriospinal myoclonus
- Rare genetic disease
- Rare liver disease
- Rare neurological disease
- Rare neuromuscular disease
- Rare optic diseases
- Rare paediatric disease
- Rett syndrome
- Sanfilippo Syndrome
- Spinal Muscular Atrophy
- Systemic Lupus Erythematosus
- Trisomy 8
- Usher Syndrome

Duchenne and Cystic Fibrosis are the most common rare diseases with 9 and 8 Fellows respectively.

STAKEHOLDER REPRESENTATION



90%
Patients

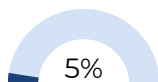
Patient, caregiver or patient representative

5% have also a role in Industry or Academia

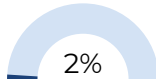
Other stakeholders



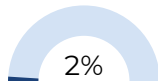
Industry representative



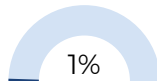
Academic/ Researcher



Healthcare professional



Other
Consultants, HTA bodies,
regulatory agency representative



REPRESENTING A DIVERSE GROUP

Note: Other Stakeholders were only introduced from Cohort 5