**List of patients associations with expert patients in research (through contact point)**

Date of creation: 11/03/2025

**1. European Cancer Patient Coalition (ECPC)**

* Overview: ECPC represents the voice of cancer patients in Europe, working with over 400 member organizations in more than 40 countries.
* Expert Patients Involvement: ECPC involves expert patients in research groups, policy advocacy, and public health initiatives across Europe.
* Contact Point:
	+ Email: info@ecpc.org
	+ Website: <https://www.ecpc.org>
	+ Phone: +32 2 439 78 55

**2. European Organisation for Research and Treatment of Cancer (EORTC)**

* Overview: EORTC is an international non-profit organization dedicated to conducting clinical trials to improve cancer treatment. They have a patient involvement program.
* Expert Patients Involvement: EORTC includes expert patients in their Patient and Public Involvement (PPI) group to guide clinical trial designs and research strategies.
* Contact Point:
	+ Email: patientinvolvement@eortc.org
	+ Website: <https://www.eortc.org>
	+ Phone: +32 2 774 16 22

**3. Europa Donna (The European Breast Cancer Coalition)**

* Overview: Europa Donna is an organization that works on improving breast cancer care, advocating for patients' rights, and fostering research across Europe.
* Expert Patients Involvement: They actively involve breast cancer survivors as advocates, especially in clinical trials and policy discussions.
* Contact Point:
	+ Email: info@europadonna.org
	+ Website: <https://www.europadonna.org>
	+ Phone: +39 02 897 32 050

**4. European Association for Cancer Education (EACE)**

* Overview: EACE is dedicated to cancer education, offering programs and support to cancer professionals and patients in Europe.
* Expert Patients Involvement: They collaborate with patient advocates to improve cancer education and patient empowerment.
* Contact Point:
	+ Email: info@eace.eu
	+ Website: <https://www.eace.eu>

**5. Cancer Research UK**

* Overview: Although primarily based in the UK, Cancer Research UK has a significant impact across Europe with its extensive research and cancer awareness programs.
* Expert Patients Involvement: Their Patient Advisory Groups help shape the direction of research, clinical trials, and patient care initiatives.
* Contact Point:
	+ Email: supportercare@cancer.org.uk
	+ Website: <https://www.cancerresearchuk.org>
	+ Phone: +44 300 100 200

**6. Myeloma Patients Europe (MPE)**

* Overview: MPE is a European patient organization that focuses on improving the quality of life and care for myeloma patients.
* Expert Patients Involvement: MPE supports the involvement of myeloma patients in clinical trials, advocacy, and research to advance treatment options.
* Contact Point:
	+ Email: mpe@myeloma-europe.org
	+ Website: <https://www.myeloma-europe.org>
	+ Phone: +34 932 175 729

**7. International Brain Tumour Alliance (IBTA)**

* Overview: The IBTA is a global organization supporting people affected by brain tumors. They work with patient groups across Europe and globally.
* Expert Patients Involvement: IBTA collaborates with brain tumor patients to inform and drive research and clinical trials.
* Contact Point:
	+ Email: info@theIBTA.org
	+ Website: <https://www.theibta.org>
	+ Phone: +44 20 3405 4060

**8. The European Lung Cancer Group (ELCG)**

* Overview: ELCG is a network of lung cancer specialists and researchers dedicated to improving lung cancer care.
* Expert Patients Involvement: They involve patient representatives in lung cancer research, offering opportunities for patients to participate in clinical trials and discussions.
* Contact Point:
	+ Email: info@elcgroup.org
	+ Website: <https://www.elcgroup.org>

**9. Ovarian Cancer Europe (OCE)**

* Overview: Ovarian Cancer Europe is a European network advocating for ovarian cancer awareness, better care, and improved research outcomes.
* Expert Patients Involvement: OCE involves ovarian cancer patients in advocacy, research discussions, and providing support in clinical trial design.
* Contact Point:
	+ Email: info@ovariancanceurope.org
	+ Website: <https://www.ovariancanceurope.org>

**10. European Society for Medical Oncology (ESMO)**

* Overview: ESMO is a leading European professional association for oncology specialists, offering numerous resources for both professionals and patients.
* Expert Patients Involvement: ESMO runs a Patient Advocacy program where expert patients can engage in oncology education and provide input into clinical guidelines and research directions.
* Contact Point:
	+ Email: info@esmo.org
	+ Website: <https://www.esmo.org>
	+ Phone: +41 91 973 19 91

**11. The European Cancer Leagues (ECL)**

* Overview: ECL is a network of cancer societies across Europe working together to fight cancer through prevention, treatment, and research.
* Expert Patients Involvement: They work with cancer patients and advocates to influence cancer policy and improve healthcare systems across Europe.
* Contact Point:
	+ Email: info@europeancancerleagues.org
	+ Website: <https://www.europeancancerleagues.org>
	+ Phone: +32 2 732 27 00

**12.** Leukemia & Lymphoma Society of Europe (LLS Europe)

* Overview: LLS Europe is dedicated to helping people affected by leukemia and lymphoma in Europe.
* Expert Patients Involvement: They involve expert patients in advocacy, research, and educational programs to improve outcomes for blood cancer patients.
* Contact Point:
	+ Email: info@llseurope.org
	+ Website: <https://www.llseurope.org>

**13. The European Multiple Myeloma Coalition (EMMC)**

* Overview: EMMC represents multiple myeloma patient organizations across Europe and works to improve the treatment, care, and outcomes for patients.
* Expert Patients Involvement: They advocate for patient involvement in clinical trials, research projects, and policymaking to improve care for multiple myeloma patients.
* Contact Point:
	+ Email: emmc@myeloma-europe.org
	+ Website: <https://www.emmcoalition.org>