

Invitation to Join the FH-EARLY Expert Patient Panel (EPP)

Are you living with familial hypercholesterolaemia (FH), or supporting someone who is? Would you like to help shape the future of FH research, diagnosis and care across Europe?

The <u>FH Europe Foundation</u> is inviting expressions of interest to join the Expert Patient Panel (EPP), as part of the Horizon Europe project <u>FH-EARLY</u>, an international initiative aimed at improving early detection and management of FH.

What is the EPP?

The EPP is a standing advisory body composed of individuals living with FH and their family members. As a member, you will:

- Act as a co-creator and advisor throughout the FH-EARLY project (01.01.2025-31.12.2028)
- Help shape ethical, social, and practical aspects of research
- Help ensure that research outputs (e.g. biomarker assays, AI tools, diagnosis pathways) truly address patients' needs and priorities
- Provide lived-experience insights to guide study design, data interpretation and dissemination
- Be acknowledged as a valued contributor to the project's success

What's Involved?

We ask for a commitment from August 2025 to December 2028, including:

- Quarterly virtual meetings (1-2 hours)
- Annual in-person workshops (travel supported)
- Participation in focus groups, technology foresight exercises, and pilot testing
- Ongoing input on ethics, informed consent, and communication strategies
- Optional co-authoring of publications and reviewing project outputs

Who can apply?

No previous research experience is required, your lived experience and insights are what matter most. To take part, you should:

- Have personal or family experience of living with FH
- Be comfortable speaking and reading in English
- Be available to attend regular online meetings and one in-person workshop per year (travel costs covered)
- Be willing to share your experiences and perspectives constructively
- Have an open mindset and willingness to learn
- Pose the ability to advocate on behalf of your community
- Ideally (but not necessarily), have completed training such as the FHEF Ambassador Programme, EURORDIS Summer/Winter Schools, EUPATI, or similar patient engagement initiatives
- Please note: The first (mandatory) EPP meeting is scheduled for 21 August 2025, at 3pm (CET)

Interested?

To express your interest, please email anthousi@fheurope.org by 15 August 2025, with a short message about yourself, your connection to FH, and why you'd like to join the EPP.

Let's work together to make FH research more inclusive, ethical, and impactful.



