



EATRIS Plus patient engagement Latvia node event

June 6, 2023 | 10.00 EEST (GMT+3) | Riga Stradins University Anatomy Museum - 9 Kronvalda Boulevard (2nd floor), Riga, Latvia

AGENDA

10:00 – Opening – **Liene Ņikitina-Zaķe** – National Director of EATRIS Latvia; Director of RSU Research Department – <u>Objectives of the meeting</u>

Uldis Berķis – Governor of EATRIS Latvia; Head of Research and Innovation strategy for smart specialization unit; Lead Researcher, RSU Development and Project Department – <u>Latvia</u> – <u>full member of EATRIS</u>

10:15 – Justīne Krūmiņa – Project Manager at Research Department, Acting Researcher – Eatris Plus Latvia node

10:20 — **Barbara Rivera** — Principal investigator hereditary cancer program — <u>Patient engagement from research</u> perspective - 10-years of patient research

10:40 - **Oriana de Sousa** — Patient advocate and **Barbara Riviera** — Principal investigator hereditary cancer program - A practice case -Network for advance of rare cancers

10:50 - Q&A

11:00 - Coffee break

11:20 – **Laila Matveja** – Deputy Head of State Agency of Medicines of Latvia, Clinical Trials Unit, – <u>Public portal of the EU Clinical Trial database and points to consider before enrolment in a clinical trial</u>

11: 35 — **Bojana Mirosavljevic** — President of Patient Organisation for rare diseases "Life" — <u>Value of patient engagement in rare disease clinical trials</u>

11:55 - Gunilla Göran - President of European Network of Fibromyalgia Associations - The role of patient associations

12.15 - Q&A

12:35 - Anatomy Museum visit

13.00 - Lunch break

14:00 – **Baiba Ziemele** – Coordinator of Latvian Network of Patient Organizations (LPOT) – <u>Patient engagement in</u> Latvia

14: 20 - Alain Volny-Anne - European AIDS Treatment Group (EATG) - Why must we patients engage in research?

14:40 – **Karina Huberman** – Senior Consultant Partnership, Development & Community Engagement; European AIDS Treatment Group; Coordinator of the EATRIS Plus Patient Advisory Committee – <u>Presentation of the Patient Engagement Resource Centre for Translational Researchers</u>

15:00 - Q&A

15:10 - Coffee break

15:30 – Working group discussion – <u>How to connect patients with researchers in Latvia?</u> (Patients, patient representatives, researchers, government representatives), Leader **Karina Huberman**

16:00 – Closing remarks – **Zaiga Nora-Krūkle** – EATRIS Latvia National hub coordinator; Director and Lead Researcher at Institute of Microbiology and Virology

