



## **HEREDITARY Advocacy Workshop 2026**

Bridging the gap between scientific research and policymaking, understanding the implications of research outcomes on policy decisions, and how researchers can make a difference.

**Online, Zoom | 30 June 2026, 14:00 - 17:00 CEST**

The HEREDITARY Advocacy Workshop is an extension of the broader [HEREDITARY project](#): an expansive, EU-funded initiative designed to enhance disease detection, improve treatment preparedness, and advance medical knowledge. This is achieved through an integrated framework that leverages diverse health data while ensuring strict adherence to data protection and privacy regulations.

Positioned within this context, the workshop serves as a targeted advocacy and capacity-building initiative aimed at strengthening the interface between scientific research, policy development, and society. Led by the [European Brain Council \(EBC\)](#), the workshop will convene HEREDITARY consortium partners, researchers, and civil society stakeholders to develop the strategic skills necessary to engage meaningfully in evidence-based advocacy. The overarching goal is to empower participants to contribute to and influence policy decisions within the European brain research landscape. Beyond immediate policy engagement, the workshop is designed to foster long-term impact by equipping participants with the tools and confidence to act as ambassadors for scientific research throughout their careers. Participants will be introduced to the EU policymaking environment and gain insight into key legislative frameworks shaping research and innovation, including emerging considerations such as neuroethics. Core policy areas will include health data governance, artificial intelligence in healthcare, and cross-border research collaboration.

The workshop adopts an interactive and applied learning approach. Participants will engage with these themes through a multi-stakeholder panel discussion and moderated Q&A, a hands-on mock policy exercise simulating real-world decision-making scenarios, and a guided reflection to consolidate learning and identify actionable next steps. To support continued engagement beyond the session, participants will receive a post-workshop resource package, including practical tools, key references, and advocacy guidance to facilitate implementation in their respective fields.

## Agenda

**Workshop Moderator:** *Frédéric Destrebecq (Executive Director, European Brain Council - EBC)*

### 14:00-14:15: Welcome and Introduction

**Speakers:**

Frédéric Destrebecq (Executive Director, European Brain Council - EBC)

Gianmaria Silvello (Full Professor of Computer Engineering, University of Padua - UNIPD;  
HEREDITARY Project Coordinator)

### 14:15-14:25: Peer to Peer Dialogue – Why Science-policy Dialogue Matters

*This short segment grounds the workshop in lived experience. Two researchers reflect on what it means, in practice, to implement research beyond the lab and engaging with policy contexts. The discussion highlights examples where limited interaction between science and policy has created challenges and explores ways to strengthen collaboration.*

**Speakers:**

Joëlle Rüegg (Professor of Environmental Toxicology, Uppsala University; Re-MEND Project Coordinator)

Narsis Aftab Kiani (Senior Researcher; Lab Leader, Karolinska Institutet; WISDOM Project Representative)

Vebjørn Andersson (Medical Doctor, Oslo University Hospital; AI-Mind Assistant Project Coordinator)

### 14:25-15:00: Session 1 – Science and Policy in the EU

*Participants will be introduced to the EU policymaking environment and explore how scientific evidence shapes pivotal legislative and regulatory processes. Key EU legislation relevant to brain disease research will be presented alongside concrete clinical and scientific case studies.*

**Speaker:** Hugo Hermantin (Policy Coordinator, European Brain Council - EBC)

**Session 1 Breakdown: 14:25-14:50 (Presentation) + 14:50-15:00: Audience Q&A**

### **15:00-15:50: Session 2 – From Research Findings to Policy**

*An interactive panel discussion exploring the translation of scientific findings into policy-relevant communication within the EU context. The session will address communicating complex research to wider audiences, navigating the timing and structure of EU processes, and the career pathways available to researchers seeking deeper policy engagement throughout their careers.*

#### **Speakers:**

Christina Kyriakopoulou (Policy Officer at DG Research & Innovation, European Commission)

Danai Spentzou (Accredited Parliamentary Assistant, European Parliament)

Loredana Babeau-Simulescu (Executive Director, Biomed Alliance)

Yann Heyer (Policy Officer, European Patients' Forum - EPF)

***Session 2 Breakdown: 15:00-15:40 (Discussion) + 15:40-15:50: Audience Q&A***

### **15:50-16:00: Break, Networking, Buffer Time**

### **16:00-16:45: Session 3 – Policy Mockup Exercise**

*Participants enter a simulated policy environment in this two-part interactive exercise. After a short icebreaker that invites reflection on gaps in current EU policy landscape, the session shifts to a hands-on stakeholder simulation grounded in HEREDITARY's themes. Each participant takes on the role of a real-world stakeholder - researcher, patient advocate, policymaker, legal expert, or industry representative - and works through an open-ended policy scenario designed to surface ethical and regulatory tensions that stakeholders in this field will face throughout their careers.*

***Session 3 Breakdown: 16:00-16:45 (Exercise) + 16:45-16:50: Report back in Plenary Room***

### **16:50-17:00: Concluding Remarks, Key Takeaways and Reflection**

#### **Speakers:**

Frédéric Destrebecq (Executive Director, EBC)

Gianmaria Silvello (Full Professor of Computer Engineering, UNIPD; HEREDITARY Project Coordinator)