



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.

Draft Agenda

Workshop moderator: *Frédéric Destrebecq, Executive Director, European Brain Council - EBC*

14:00-14:15: Welcome and Introduction

Speakers:

- 14:00-14:05: Fred Destrebecq (Executive Director, EBC)
- 14:05-14:15: Gianmaria Silvello (Full Professor, 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:

Gianmaria Silvello (Full Professor, UNIPD, HEREDITARY Project Coordinator)

TBC Luca Alessandro Remotti, Managing Partner and Founder, DataPower, NextGen Project Partner)

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)

15:00-15:40: 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.

Session breakdown: 15:00-15:30 (Discussion) + 15:30-15:40: Audience Q&A

Speakers:

Loredana Babeau-Simulescu (Executive Director, Biomed Alliance)

TBC Jim Dratwa (Policy Lead, Science for Policy, European Commission)

TBC Solène Jouan (Policy Officer, European Patients' Forum - EPF)

15:40-16:00: Break, Networking, Buffer Time

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

Participants step into a simulated policy environment in this engaging exercise. Each person takes on the role of a real-world stakeholder - researcher, patient advocate, policymaker, legal expert, or industry representative - and works through a policy scenario linked to HEREDITARY themes, such as neurodegenerative disorders, the gut–brain axis, or AI diagnostics.

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

Speaker: Fred Destrebecq (Executive Director, EBC)