

MESSAGE FROM THE ACTION

HELIOS Community
Collaboration
LEARNING

OUR MEMORIES
2023-2025



As we conclude another successful year for HELIOS CA22119, we're proud of the vibrant scientific exchange and collaboration in our community.

This year, HELIOS hosted webinars on a diverse range of topics in research, clinical practice, and innovation in hemoglobinopathies. Meetings and collaborative activities strengthened our network. We increased funding for grants supporting training, mobility, and collaboration, especially for early-career researchers.

Looking ahead, the coming year brings renewal. With updated leadership, HELIOS will restructure its activities, launch new training initiatives, explore mentorship programs, and continue to fund engagement and innovation in its Working Groups.

We thank all members for their commitment and contributions and look forward to building the next year of HELIOS together.

Warm regards,
The HELIOS Team

HELIOS Renewal & Leadership Opportunities

HELIOS is entering an exciting phase of renewal as we restructure our activities for the next stage of the Action.

New leadership and coordination roles are now open, offering members, especially young researchers and innovators, the opportunity to actively shape future scientific, training, and collaborative initiatives!

Expression of interest deadline: January 11th

We warmly thank our outgoing leaders for their invaluable contributions and invite the community to be part of what comes next.



[Join the HELIOS Leadership Team](#)

HELIOS Webinar Series – Available on YouTube

Throughout the year, HELIOS hosted a rich and diverse webinar programme, bringing together experts, clinicians, researchers, and early-career investigators to share knowledge, experiences, and ideas.

All sessions are now available to watch on our YouTube channel:

- **Invited Speaker Series** – Expert talks covering cutting-edge research, clinical advances, and emerging topics in hemoglobinopathies.
- **FAIR Principles Series** – Focused discussions on data management, sharing, and reproducibility in line with FAIR principles.
- **Clinical Research & Patient Care Management Series** – Webinars addressing clinical practice, translational research, and patient-centred care.
- **Young Researchers & Innovators Monthly Discussion Club** – An interactive forum for early-career researchers to exchange ideas, challenges, and perspectives (not available on demand)

These webinar series will return in **2026** with fresh topics, new formats, and renewed energy, continuing to support learning, collaboration, and innovation across the HELIOS community.

HELIOS Webinars

Watch Our Webinars On-Demand!

CHECK OUT
OUR VIDEOS!



WATCH IT NOW ON
OUR CHANNEL



@HELIOSACTION



HELIOS UPCOMING 2026 EVENTS



Hackathon on Federated Analysis


 11-14 May 2026

 Cyprus

A hackathon focused on federated analysis methods, bringing together participants to explore collaborative, privacy-preserving data analysis



Training on Ethical Considerations in Hemoglobinopathies


 To be announced

 Italy

A focused training exploring ethical issues in research, patient care, and data governance.



Expert Consensus on Unstable Hemoglobin Disease

 To be announced

 Albania

A collaborative expert effort to develop shared recommendations for clinical practice and research.

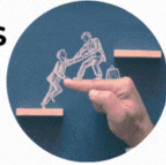
GRANT OPPORTUNITIES

We offer **five types of Grants** to help HELIOS members share their work, expand networks, and collaborate. These grants support travel, presentations, and gaining new knowledge. For eligibility criteria, visit our website: www.heliosaction.eu.

www.heliosaction.eu

INCLUSIVENESS TARGET COUNTRIES GRANT

Are you from ITC/NNC COST country?
Accepted for oral presentation?



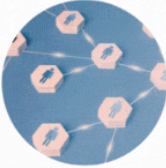
YOUNG RESEARCHER GRANT

Are you under 40 years old from a COST member country?
Accepted for oral or poster presentation?



DISSEMINATION GRANT

Are you from COST member country?
Accepted for oral presentation to disseminate HELIOS work?



SHORT-TERM SCIENTIFIC MISSIONS

Are you from COST member country?
Want to have a visit to a company, hospital, or institution and collaborate with people outside your country?



VIRTUAL MOBILITY

Are you from COST member country?
Want to contribute to HELIOS' work or collaborate with experts of the field online?



WORKING GROUPS UPDATES- NEW PUBLICATIONS!!!



WG1: Molecular research and diagnosis



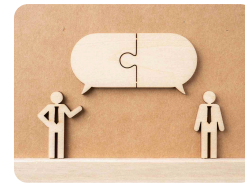
WG2: Clinical research and patient management



WG3: Data management, sharing and analysis



WG4: Education, training, and capacity building



WG5: Dissemination and outreach

HELIOS NEW PUBLICATION



Thrilled to share our newly published HELIOS Action article advancing research, education, and equity in hemoglobinopathies.

DOI: 10.1002/hem.3.70258

HELIOS Action: Advancing research, education, and equity in hemoglobinopathies across Europe and beyond — HemaSphere — Our first publication!

We are excited to share that the collective work of the HELIOS Working Groups is now being showcased through a growing portfolio of peer-reviewed publications. These outputs reflect the strong engagement of our community and the valuable contributions of members who responded to surveys and shared insights, helping us map the current landscape of hemoglobinopathies research, clinical practice, education, and data management across countries.

We warmly thank all HELIOS members who contributed their time and expertise, your input has been essential in generating evidence that informs practice, policy, and future research priorities.

[Read our first manuscript!](#)

Manuscripts currently in press:

- Mapping Expertise and Educational Needs for Hemoglobinopathies: Insights from HELIOS COST Action Healthcare Professionals — Blood Global Hematology

Submitted and under review:

- Mapping Diagnostic Practices in Hemoglobinopathies: A Cross-Country HELIOS COST Action Study — Blood Advances
- Mapping FAIR Gaps in Hemoglobinopathy Data: Insights from a Cross-Sectional Survey — Blood Advances
- Bridging the Gap from Haemoglobinopathy Research to Patient Care: A Multi-Country Assessment of Healthcare Professionals and Researchers — The Lancet
- Mapping Current and Emerging Laboratory Techniques for Haemoglobinopathy Carrier Detection and Prevention: A Narrative Review from the HELIOS Action
- Evaluating Artificial Intelligence Literacy and Perceptions Regarding Implementation among Healthcare Professionals Involved in Rare Hematological Disease Networks

Further publications are currently in development, underscoring the continued momentum of HELIOS and the strength of its collaborative, data-driven approach.

Join us in our mission to unveil insights into global haemoglobinopathies management! Complete our HELIOS Personal Data Declaration and Consent to receive our Working Group Surveys today!

[HELIOS Personal Data Declaration and Consent Form](#)

ETHICS, GENDER, AND EQUALITY NEWS

The HELIOS Working Group on Gender Equality and Inclusiveness invites institutions to join a brief survey on gender equality and inclusiveness in research and innovation.

This survey is for gender equality advisors or representatives. If unavailable, leadership, HR, or admin staff can complete it.

Taking 10–15 minutes, it will help develop HELIOS policy strategies through analyzed and published results, aiding evidence-based recommendations.

Your participation is crucial for fostering inclusive and equitable research environments.

[Building Gender-Inclusive Research Cultures – HELIOS Survey](#)

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