



MESSAGE FROM THE ACTION

As we enter the final quarter of 2025, we take the opportunity to reflect on the scientific and collaborative progress achieved this year and to look ahead to the important work still to come.

From in-depth webinars and scientific meetings to collaborative initiatives across our network, HELIOS has continued to serve as a platform for advancing research, clinical practice, and innovation in hemoglobinopathies.

In this edition, you will find summaries of recent events, insights from ongoing projects, and details of upcoming opportunities to contribute and connect. Together, we are strengthening the global exchange of knowledge and fostering the collaborations that drive meaningful change for patients worldwide.

In This Issue:

**Event Highlights:** Key takeaways from this year’s past meetings and webinars.

**Upcoming Scientific Events:** Information on future HELIOS sessions and participation opportunities.

**Looking Forward:** Initiatives and collaborations shaping the months ahead.

Thank you for your contribution, commitment, and active engagement in our shared mission. We look forward to building on our achievements and advancing the field together.

Warm regards,  
The HELIOS Team

HELIOS WEBINARS

Webinar Series – 2025 Highlights & Our Commitment to Continued Learning

This year, HELIOS has been privileged to host an outstanding lineup of webinars, thanks to the expertise and generosity of our invited speakers.

We extend our sincere appreciation to all who contributed to the **Invited Speaker Series**, the **FAIR Principles Series**, and the **Clinical Research & Patient Care Management Series**.

From advances in diagnostics and treatment strategies to discussions on healthcare system challenges, genetics, and the integration of AI in hemoglobinopathies, each session has enriched our collective understanding and strengthened our community’s capacity to drive innovation in the field.

We also thank every participant who joined these sessions to expand their knowledge and engage with peers. Your active involvement is at the heart of what makes HELIOS a vibrant, collaborative network.

**Our commitment remains clear: to continue fostering scientific exchange, highlighting cutting-edge research, and providing opportunities for shared learning across our network.** We look forward to welcoming you to our upcoming webinars as we close 2025 with even more opportunities to connect, learn, and advance the field together.

↔ *If you missed our previous webinars you can watch them on-demand on HELIOS YouTube channel: @heliosaction.*

HELIOS Webinars

Watch Our Webinars On-Demand!

HELIOS EVENT HIGHLIGHTS – MAY 2025

In May, HELIOS hosted two significant events that brought our community together for training, collaboration, and scientific progress:

**HELIOS Training School on FAIR Principles (3 days)** – An intensive theoretical and hands-on workshop introducing participants from diverse backgrounds in hemoglobinopathies to the FAIR (Findable, Accessible, Interoperable, Reusable) data principles. The program equipped attendees with practical skills and knowledge to apply FAIR principles in research and clinical practice, fostering better data sharing and collaboration across the field.

**WG1 Task Force Meeting** – The WG1 team convened to work intensively on a narrative review manuscript examining the current state of preventive measures for hemoglobinopathies, as well as the barriers to global harmonization and equitable access to care. The meeting marked a key step toward producing a comprehensive, evidence-based resource to guide future strategies and policies.

Both events reflect HELIOS's ongoing commitment to advancing knowledge, building capacity, and driving collaborative efforts that support innovation and improve patient outcomes worldwide.



## HELIOS UPCOMING EVENTS



### Transcranial Doppler (TCD) Training School

18 September 2025

Department of Pediatrics and Adolescent Medicine  
Ulm University Medical Center

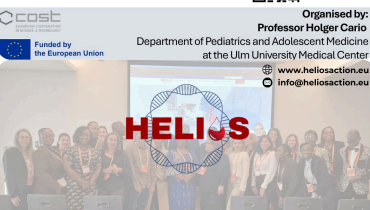
One full day dedicated to a blend of theoretical and practical sessions.



APPLY NOW



Organised by:  
Professor Holger Cario  
Department of Pediatrics and Adolescent Medicine  
at the Ulm University Medical Center  
www.heliosaction.eu  
info@heliosaction.eu



HELIOS at ASCAT

Meet us again this year!  
1-4 October 2025



### Transcranial Doppler Training School - September 2025

17 18 September 2025

Department of Pediatrics and Adolescent Medicine, Ulm University Medical Center

Transcranial Doppler (TCD) training, organized by **Prof. Dr. Holger Cario**.

This specialized session will be led by renowned experts in the field, providing participants with both theoretical insights and practical skills in the use of TCD for the assessment and management of patients with hemoglobinopathies. The training promises to be an invaluable opportunity for clinicians and researchers to deepen their expertise and exchange knowledge with leaders in the discipline.

### HELIOS Session at ASCAT - October 2025

17 3 October 2025

Excel, London

We are excited to share that **HELIOS will once again be present at one of the largest global conferences on sickle cell disease and thalassemia – the ASCAT Conference in London.**

We will host our **own dedicated session** to present the outcomes from our first two years of activity. The session will highlight the invaluable contributions of our members in advancing the understanding of the current state of hemoglobinopathies worldwide. In addition, our presence will extend beyond the stage—**visit us at our booth** to learn more about our initiatives, explore our resources, and connect with the HELIOS team in person.

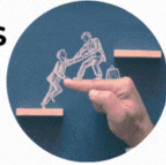
## GRANT OPPORTUNITIES

To empower HELIOS members in sharing their work, expanding their networks, and fostering collaborations, **we offer five types of Grants**. These grants provide support for members to travel worldwide, present their work, and gain new knowledge and practical experience.

For more information on eligibility criteria head to our website: [www.heliosaction.eu](http://www.heliosaction.eu).

**INCLUSIVENESS TARGET COUNTRIES GRANT**

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



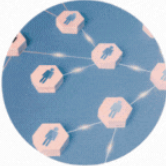
**YOUNG RESEARCHER GRANT**

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**



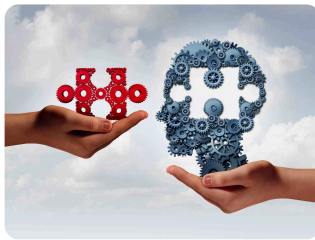
**WG1: Molecular research and diagnosis**



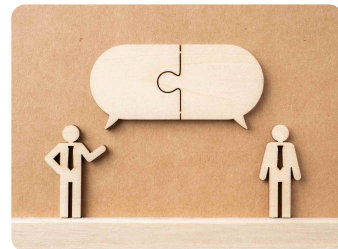
**WG2: Clinical research and patient management**



**WG3: Data management, sharing and analysis**



**WG4: Education, training, and capacity building**



**WG5: Dissemination and outreach**

**Mapping Existing Practices in Haemoglobinopathies Management Across Europe and Beyond**

HELIOS Working Groups continue to build on the insights gathered through our specialized surveys on diagnosis, treatment, and data management in hemoglobinopathies. The valuable input from members has been instrumental in identifying current needs and challenges, and the data is now being analysed for [upcoming publications and training opportunities including a new mentorship program and an expert consensus on unstable hemoglobin disease](#).

**The surveys remain open**—we encourage all members to participate and help us create the most comprehensive global overview possible. Your contributions are vital to advancing knowledge and improving patient care worldwide.

**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**

In December 2024, the European Commission published the results of a survey on Gender Stereotypes.

This survey provides an overview of the perceptions of gender stereotypes in various contexts: household and work, politics and leadership positions, and perceptions of different treatment by gender in everyday situations. The results show that EU citizens consider that gender equality is beneficial for

both women and men. However, gender stereotypes persist in different domains, with variations among Member States and age groups.

[Discover More!](#)

## JOIN US!

Are you passionate about haemoglobinopathies?  
Join HELIOS to make a difference in global disease management and improve patient lives!

[Become a HELIOS Member!](#)

If you would like to continue to receive our quarterly newsletters subscribe to them through our website. If you know anyone that might be interested in HELIOS please forward our newsletter to them!

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