

UNITING ✦ HARMONIZING ✦ EDUCATING

“ADVANCING HAEMOGLOBINOPATHY SCIENCE TO IMPROVE PATIENT OUTCOMES”



HELIOS Newsletter September 2024

www.heliosaction.eu



Message from the Action

Dear HELIOS members,

As we reach the end of the first year of HELIOS, we want to extend our heartfelt thanks to each of you for your unwavering dedication and time you have dedicated to HELIOS. Together, we have laid a strong foundation for the years ahead, and we are excited to continue our journey to empower the field of hemoglobinopathies by fostering collaborations, creating new opportunities, and spreading valuable knowledge.

In This Issue:

- Events: Stay tuned for new and exciting events that will keep you engaged and informed.
- Working Group Updates: Catch up on the latest progress and initiatives from our 5 dedicated working groups.
- Member Contributions: Discover insightful contributions and perspectives from our diverse network of members.

And there's more! We are thrilled to announce the launch of our **Invited Speaker Series**—a new platform for sharing expertise and insights from leaders in the field.

Once again, thank you for your continued support and enthusiasm. Let's keep the momentum going as we move forward together!

The HELIOS team

P.S. Don't forget to share this newsletter with your colleagues!

HELIOS EVENTS

HELIOS Invited Speaker Series:



INVITED SPEAKER SERIES

Online webinars on the latest publications and innovations on hemoglobinopathies



23
OCT

"The genetic dissection of fetal haemoglobin persistence in sickle cell disease in Nigeria"

Dr Oyesola Ojewunmi Microsoft Teams app
4PM - 5 PM EEST



13
NOV

"Costs and impact of disease in adults with sickle cell disease: a pilot study"

Dr Sophie Lanzkron Microsoft Teams app
5PM - 6PM EEST

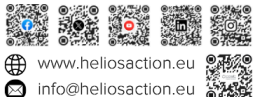


18
DEC

"Gaps during paediatric to adult care transfer escalate acute resource utilisation in sickle cell disease"

Dr Kristen Howell Microsoft Teams app
6PM - 7PM EEST

FREE REGISTRATION!



Organized by:
Ms Stephanie Muth



Join our **invited speaker webinar** where you'll have the chance to hear directly from the authors of the latest high-impact publications in the field of hemoglobinopathies. This series is designed to provide our members and the broader community with cutting-edge knowledge on a variety of critical haemoglobinopathies related topics, including:

- Innovative Diagnostic Approaches
- Managing Associated Health Conditions
- New Treatment Strategies
- Transitioning Care Across Age Groups
- Healthcare System Challenges
- Genetic Advancements and Patient Care
- The Use of AI in Hemoglobinopathies

This is a unique opportunity to stay informed about the latest developments and engage with experts who are driving the field forward.

Don't miss the first speakers, mark your calendars and spread the word!

Register for each webinar by visiting our website:

FREE REGISTRATION!

HELIOS Young Researchers and Innovators Discussion Club

HELIOS **08th of October**
3 pm EEST
Microsoft Teams

MONTHLY DISCUSSION CLUB



"Long-read-amplicon haplotyping for β -thalassaemia preimplantation genetic testing for couples with no additional family members"

by Ms Florentia Romanou

www.heliosaction.eu
info@heliosaction.eu

cost logo and European Union funding logo

social media icons

Join our fourth online Monthly Discussion Club. During our monthly club, young researchers and innovators within the network have the opportunity to showcase their work, share publications, introduce new ideas, and engage in discussions on topics relevant to haemoglobinopathies. Join us for a stimulating discussion and connect with your peers while exploring exciting developments in the field.

Ms Antri Florentia Romanou from the Cyprus Institute of Neurology & Genetics will be our next presenter on the 8th of October. Florentia will be presenting her STSM project with topic "Long-read-amplicon haplotyping for β -thalassaemia preimplantation genetic testing for couples with no additional family members".

Contact us!

HELIOS first scientific meeting at ASCAT!

HELIOS **ASCAT**
Annual Academy For
Sickle Cell And
Thalassaemia
Conference

HELIOS 1ST
SCIENTIFIC MEETING

HELIOS at
ASCAT!

October 2-5, 2024
ETC VENUES, COUNTY HALL
LONDON, SE1 7PB

cost logo and European Union funding logo

www.heliosaction.eu
info@heliosaction.eu

social media icons

HELIOS will host its inaugural scientific meeting "HELIOS: Fostering Collaboration and Harmonisation in Haemoglobinopathy Research and Training through Synergistic Networking" at the esteemed 19th Sickle Cell Disease and Thalassaemia conference in London this year.

ASCAT's mission for equitable progress and collaborative action resonates with HELIOS's overarching goals. Two initiatives will bolster these efforts, inviting members to convene in London.

Stay tuned for content from the event by following HELIOS social media!

HELIOS 1ST SCIENTIFIC MEETING

DATE: 3RD OF OCTOBER

TIME: 2-5:30 PM GMT+1

Working Groups updates



WG1: Molecular research and diagnosis



WG2: Clinical research and patient management



WG3: Data management, sharing and analysis

WG1 , WG2, & WG3 HELIOS Surveys

Mapping Existing Practices in Haemoglobinopathies Management Across Europe and Beyond

During this year, HELIOS Working Groups 1,2, and 3 have developed specialised surveys to map current practices in haemoglobinopathies worldwide. These surveys aim to provide a comprehensive global overview and facilitate knowledge sharing to improve patient outcomes and advance the field:

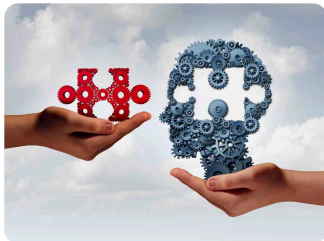
WG1: Surveys the latest techniques and tools for diagnosing haemoglobinopathies like Sickle Cell Disease and Thalassemia.

WG2: Collects information on clinical approaches, treatment protocols, and patient management strategies across various healthcare settings.

WG3: Assesses systems for data collection, storage, sharing, and analysis in haemoglobinopathy research and care (WG3 survey will follow shortly after the first two WGs surveys).

We've been thrilled by the remarkable participation from our members in completing these surveys, and we extend our deepest thanks! **If you haven't yet completed the surveys, please take the time to do so (by clicking the link to the personal survey below) and contribute to our efforts in mapping current hemoglobinopathies practices across Europe and beyond!**

HELIOS Personal Data Declaration and Consent Survey

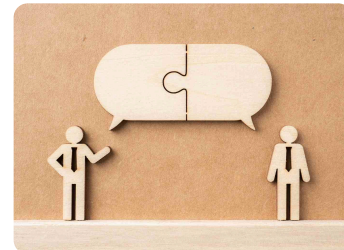


WG4: Education, training, and capacity building

WG4 is gearing up for **upcoming training events**. These include collaborative in-person sessions with WG2, focusing on clinical techniques, and WG3, which will cover the FAIR principles (Findability, Accessibility, Interoperability, and Reusability).

To ensure these trainings meet your needs and interests, WG4 has developed a survey aimed at gauging member interests and mentorship availability for future HELIOS activities.

Your feedback is crucial in helping us tailor these events and initiatives to best support your professional development. Stay tuned for more details, and please take a moment to fill out the survey when it arrives—your input makes a difference!



WG5: Dissemination and outreach

WG5 has been dedicated to disseminating HELIOS's work and actively engaging both the public and our members through various channels. Over the past year, we developed a diverse range of outreach tools, allowing us to consistently share news and updates from the HELIOS network and wider field of hemoglobinopathies.

We look forward to continuing these efforts and expanding our reach even further in the coming months.

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

GRANT OPPORTUNITIES

One of HELIOS Action and COST Association's primary focuses is to disseminate knowledge globally. To empower HELIOS members in sharing their work, expanding their networks, and fostering collaborations, **we offer four types of Grants**. These grants provide financial 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.



ITC Conference Grant

A dedicated grant for Young Researchers and Innovators from ITC countries to attend high-level conferences and present their work through oral or poster presentations.

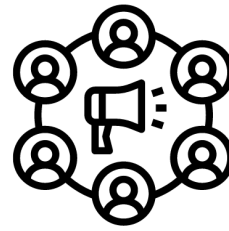
The maximum budget offered is **2000 EUR** for in-person events and **500 EUR** for virtual events.



Dissemination Conference Grant

If you wish to disseminate HELIOS work, you can apply for the Dissemination Grant to make an oral presentation and share the Action's aims, efforts, and outcomes.

The maximum budget offered is **2000 EUR** for in-person events and **500 EUR** for virtual events.



Virtual Mobility (VM) Grant

The VM Grant supports Working Group efforts by providing members with funding to collaborate virtually and perform activities related to the Action's objectives, such as conducting surveys, creating questionnaires, analyzing results, and more.

The maximum budget offered is **1500 EUR**.



Short-Term Scientific Mission (STSM) Grant

The STSM Grant provides members with the opportunity to travel to another institute, university, or company of their choice worldwide. This allows them to collaborate, gain new knowledge, and learn new techniques.

The maximum budget offered is **4000 EUR**.

[HELIOS Grant opportunities!](#)

BLOG NEWS

Our **HELIOS's Blog**, was officially launched in June 2024!

Our initial posts highlight the journeys of our first STSM grantees, who, with HELIOS's support, visited labs in Portugal, Belgium, Greece, and the United Kingdom. Explore their experiences and discover how these visits have helped them enhance their skills, expand their knowledge, and build or strengthen connections. Visit our blog through the link below to learn more.

[Learn more about our first STSM!](#)



Let's talk figures:

HELIOS COST Action began in 2023 and will run until 2027

Number of Members



188

Participant Countries



31

Event Participants



122

Number of Grants awarded



10

Join us:

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

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!



This email was sent to {{ contact.EMAIL | default : "HELIOS members" }}

You've received it because you're a member of the HELIOS COST Action CA22119 or you have subscribed to our newsletter through our website.

[Unsubscribe](#)

[Privacy Policy](#) | [Unsubscribe](#)
