

Henrik Birgens Fellowship 2026

A Thalassaemia International Federation (TIF) educational programme
in collaboration with
the Danish Red Blood Cell Centre, Copenhagen University Hospital, Denmark,
a Thalassaemia International Federation (TIF) Collaborating Centre

REPORT FOR THE TRAINING PERIOD

21 – 25 September 2026

Venue:

Danish Red Blood Cell Centre, Copenhagen University Hospital, Denmark

Course Leaders/Coordinators:

Andreas Glenthøj, MD, PhD

Associate Professor

Head of the Danish Red Blood Cell Centre

Copenhagen University Hospital, Denmark

Marianne Hoffmann, MD, PhD

Senior Consultant

Department of Pediatric Haematology and Oncology,

Department of Paediatrics and Adolescent Medicine,

University Hospital Rigshospitalet, Copenhagen, Denmark.

Multidisciplinary team:

Specialists across different relevant medical and scientific disciplines

Foreword

We are delighted and honoured to present the **official completion report of TIF's Henrik Birgens Fellowship Programme 2026**.

This year's fellowship took place **from 21 to 25 September 2026** at the Danish Red Blood Cell Centre, Copenhagen University Hospital, Denmark, under the expert leadership and coordination of:

- **Andreas Glenthøj, MD, PhD**, Associate Professor and Head of the Danish Red Blood Cell Centre, Copenhagen University Hospital, Denmark.
- **Marianne Hoffmann, MD, PhD**, Senior Consultant, Department of Paediatric Haematology and Oncology, Department of Paediatrics and Adolescent Medicine, Rigshospitalet, Copenhagen University Hospital, Denmark.

The programme also benefited from the participation of distinguished medical specialists representing a range of relevant disciplines.

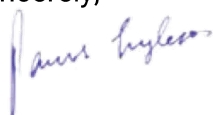
This year, the fellowship was awarded to **two medical doctors from Norway specialising in haemoglobin disorders**, with the aim of enhancing their clinical expertise and supporting their efforts to strengthen the quality of healthcare provided to patients with thalassaemia and sickle cell disease (SCD) in their country.

Through this intensive, hands-on training programme, the fellows gained valuable knowledge and practical insights, alongside a unique opportunity to observe, engage with and learn directly from the daily clinical practices of an internationally recognised reference centre. The programme placed particular emphasis on multidisciplinary care, knowledge exchange and exposure to clinical expertise within a centre renowned for its significant contributions to international research.

We extend our deepest appreciation to Dr Andreas Glenthøj and Dr Marianne Hoffmann for their outstanding leadership, dedication and coordination of the fellowship. We are equally grateful to all the medical specialists who generously contributed their time, knowledge and expertise to the training programme. Their invaluable commitment and collaboration were instrumental in making this initiative a success.

We look forward to continuing this important educational initiative in **2027**, offering another group of fellows the opportunity to benefit from this exceptional learning experience and further strengthening international collaboration and excellence in the care of patients with haemoglobin disorders.

Sincerely,



Dr Panos Englezos

President of the Board of Directors, Thalassaemia International Federation



Dr Androulla Eleftheriou BSc, MSc, PhD

Executive Director, Thalassaemia International Federation

General Information

The **Henrik Birgens Fellowship Programme** is a new educational initiative that further strengthens the Thalassaemia International Federation's (TIF) longstanding commitment to education and capacity building. Established in honour of **Professor Henrik Birgens**, founder of the Danish Red Blood Cell Centre at Copenhagen University Hospital, the programme recognises his outstanding contribution to the care of patients with haemoglobin disorders. Throughout his distinguished career, Professor Birgens has played a pivotal role in advancing clinical practice, laboratory diagnostics and specialised care for patients with haemoglobinopathies across the Nordic region.

Launched in **2026**, the fellowship is designed for physicians specialising in haematology, paediatrics or internal medicine from Nordic countries. It aims to enhance clinical expertise, promote multidisciplinary approaches to care and support the delivery of high-quality healthcare services for patients with thalassaemia and sickle cell disease (SCD).

Although haemoglobin disorders have historically been rare in the Nordic countries, their prevalence has been increasing in recent decades, largely due to migration from regions where these conditions are more common, including the Middle East, Southeast Asia, Africa and parts of Southern Europe. This changing epidemiological landscape presents new challenges for healthcare systems, highlighting the need to strengthen disease-specific knowledge, specialised services and coordinated approaches to patient management.

Haemoglobin disorders are inherited, lifelong conditions that can affect multiple organs and systems, requiring complex and often highly specialised care. Beyond their medical implications, they present considerable public health, social and economic challenges. Ensuring timely diagnosis, appropriate treatment, long-term monitoring and access to multidisciplinary care is therefore essential to improving patient outcomes and quality of life.

At the same time, **the therapeutic landscape of haemoglobin disorders is undergoing unprecedented transformation**. Advances in disease-modifying treatments, innovative pharmacological therapies, haematopoietic stem cell transplantation and, more recently, gene addition and gene-editing technologies are creating new opportunities to improve disease management and, for selected patients, offer potentially curative treatment options. These developments are reshaping clinical practice and introducing new considerations regarding patient eligibility, long-term safety, specialised infrastructure, affordability and equitable access to innovation.

Against this rapidly evolving scientific and therapeutic landscape, **continuous medical education and specialised professional training are more important than ever**. Healthcare professionals must be equipped not only with up-to-date knowledge of established standards of care but also with the expertise required to evaluate and integrate emerging therapies into clinical practice, support informed patient decision-making and ensure appropriate long-term follow-up.

Since its establishment, **TIF has placed education, capacity building, patient empowerment and advocacy for equitable access to quality healthcare at the centre of its mission**. While initially focused on thalassaemia, the

Federation has progressively expanded its activities to encompass sickle cell disease, recognising the shared challenges faced by patients and healthcare professionals, as well as the importance of coordinated approaches to prevention, diagnosis, treatment and long-term care.

Through initiatives such as **the Nordic Forum for Haemoglobin Disorders**, TIF promotes regional collaboration, knowledge exchange and the development of sustainable healthcare strategies tailored to the evolving needs of affected populations. The Henrik Birgens Fellowship Programme builds upon these efforts by offering physicians direct exposure to the clinical practices, multidisciplinary expertise and research activities of an internationally recognised reference centre.

The fellowship represents an important investment in strengthening clinical capacity across the Nordic region, bridging the gap between scientific advances and everyday clinical practice. By equipping healthcare professionals with the knowledge and skills needed to address both established and emerging challenges in haemoglobin disorder management, the programme ultimately seeks to contribute to better health outcomes, improved access to innovative care and enhanced quality of life for patients with thalassaemia and sickle cell disease.

The Henrik Birgens Fellowship Programme 2026

21 – 25 September 2026

Copenhagen University Hospital – Rigshospitalet Denmark

Application and Selection process

The applications' review process is performed on clear and structured criteria.

The applications are reviewed by a Selection Committee that is comprised of: two (2) members of TIF's Scientific Advisory Board on behalf of the Thalassaemia International Federation (TIF) and two (2) chief medical specialists on behalf of the Training Centre. The selection of the successful fellows is obtained through common consultation and consensus.

The Training Centre/The Course team

Course team

■ Course Leader/Course Co-ordinator:

- **Andreas Glenthøj, MD, PhD**, Associate Professor and Head of the Danish Red Blood Cell Centre, Copenhagen University Hospital, Denmark.
- **Marianne Hoffmann, MD, PhD**, Senior Consultant, Department of Paediatric Haematology and Oncology, Department of Paediatrics and Adolescent Medicine, Rigshospitalet, Copenhagen University Hospital, Denmark.

■ Multidisciplinary team:

1. **Hilde Hylland MD, PhD**; Physician, Paediatric Blood Cell Transplantation and Immune Disorders, Rigshospitalet
2. **Nina Toft MD, PhD**; Specialist Physician and Head of Clinical Services, Danish Red Blood Cell Centre, Rigshospitalet
3. **Sarah Carlsen MD**; Specialist Physician in Red Blood Cell Disorders, Danish Red Blood Cell Centre, Rigshospitalet
4. **Amina Nielsen Nardo-Marino, MD, PhD**; Postdoctoral Researcher, Danish Red Blood Cell Center, Department of Haematology, Copenhagen University Hospital - Rigshospitalet
5. **Tanja Wejergang**, Healthcare Social Worker and Team Leader, Department of Psychology, Pedagogy and Social Work, Rigshospitalet
6. **Mathilde Langevad**

The Training Programme

The programme sought to provide clinical training to the fellows, as well as the opportunity to become familiar with how audit, peer review and multidisciplinary meetings, amongst others, are conducted and integrated into the services of a Haemoglobinopathy Centre with the aim to offer holistic care to the patients.

Training Schedule

The clinical timetable was focused on sessions to facilitate the acquisition of knowledge and practical experience in the management of sickle cell disease and thalassaemia including (and not confined to):

- Clinical trial clinic
- Adult RBC Clinic
- Paediatric RBC Clinic
- Adult Haematology Ward
- Paediatric Haematology Ward
- RBC Laboratory
- MDT
- Ward round for review of the inpatients

TIME ALLOCATION

Below is an approximation of the time allocation per week, albeit based on clinical or participants needs, this may have been altered accordingly.

Henrik Birgens Fellowship 2026 – Training Programme

Copenhagen University Hospital – Rigshospitalet | 21–25 September 2026

Day	Morning programme	Afternoon programme
Monday, 21 September	Adult RBC Clinic	Tour of Adult Haematology Ward; Treating adults living with haemoglobinopathies; Danish haemoglobinopathy care: structure, meetings and collaborations
Tuesday, 22 September	Adult RBC Clinic	Tour of RBC Laboratory; Haemoglobinopathy screening and laboratory diagnostics; RBC Multidisciplinary Team Meeting (14:00–15:00)
Wednesday, 23 September	Paediatric RBC Clinic	Tour of Paediatric Haematology Ward; Tour of Paediatric BMT Ward (13:00); Gene therapy
Thursday, 24 September	Paediatric RBC Clinic	Treating children living with haemoglobinopathies; Transition; Safeguarding and social challenges
Friday, 25 September	Tour of Blood Bank and Apheresis Centre	Whole-genome sequencing for rare anaemias; Current clinical trials; Gene therapy: patient experience and perspectives; Nordic RBC Meeting 2027

The Candidates

The Henrik Birgens Fellowship Programme 2026 was offered to two (2) candidates, medical doctors from two different hospitals in Norway.

1. Dr Aba Sarr, MD; Resident Doctor, Akershus University Hospital, Department of Hematology, Norway.
2. Dr. Marte Holmboe Berg, MD; Consultant, Hematology, Department of Internal Medicine, Lovisenberg Hospital Trust, Norway

Follow up activities and benefits for the candidates who completed the fellowship programme.

Following the completion of the Henrik Birgens Fellowship Programme, the candidates automatically become members of TIF's International Health Professionals Network and Honourable Associate members. In this context, these medical specialists are entitled to other benefits including reduced registration fees (or free of charge where applicable) in TIF's conferences and other events as well as in TIF's educational activities in their country.

As a follow up of the Henrik Birgens Fellowship Training Programme and in the context of the collaboration established with TIF, the candidates are invited to:

1. Provide support to the planning of the 2027 Nordic Red Blood Cell Meeting.
2. Provide regular reports on any achievements made in their country.
3. Support TIF's efforts to establish and/or strengthen relations with the national Thalassaemia Patients Associations and health professionals' network.
4. Contribute to various projects by undertaking specific tasks in collaboration with TIF.
5. Propose to TIF ways or promoting haemoglobin disorders programmes in their country.

Feedback from the course leader/course co-ordinator Dr Andreas Glenthøj, MD, PhD

"The two fellows were very friendly and engaged colleagues"

Feedback from the candidates (extracts from the candidates' post course evaluation reports)

"It was very educational, and the department have done an excellent job in improving care for these patients. My experience there will contribute to making changes in my own department. It was very nice to join consultations in the outpatient clinic, both for adults and children."

"Talking to patients who had received gene therapy was also a highlight."

"Overall, the experience was amazing. I definitely recommend to colleagues"

"We will implement certain new routines, better transitioning from child to adult care."

"The programme was well organized, and the doctors and nurses were very welcoming. I felt included in their work, and there was great dialogue with sharing of experience both ways."

"It was great to meet patients after successful gene therapy, as we do not have access to this therapy in Norway – but hopefully we will soon. Their talks were moving to hear, and an important story to hear before talking to our own patients about their treatment options."

"This week gave me many new contacts for my future work. Nordic collaboration is valuable as we all are small countries and few people, and our health systems have many similarities."

"It inspired me to focus on transition, and the collaboration between pediatrics and adult hematologist in Norway. I, and other adult hematologists will attend a pediatric network meeting for benign hematology in the spring, and hopefully we will get a broader network in the future."

We are also exploring the possibility to establish a national MDT meeting, for diagnostics of rare anemias.

If/when gene therapy is accepted by Norwegian government, we will have a lot of information to start the process of treating patients in Norway from our stay in Copenhagen."

Special thanks to the contributors

The Board of Directors of the Thalassaemia International Federation (TIF), its President, Mr Panos Englezos, Executive Director, Dr Androulla Eleftheriou, Medical Director, Dr Michael Angastiniotis, and the entire TIF team extend their heartfelt appreciation and sincere gratitude to the two Course Leaders and all healthcare professionals involved in the programme.

Their dedication, expertise and invaluable contributions have been instrumental in the successful implementation of this initiative and in establishing and strengthening a new pillar of TIF's educational programme, further advancing the Federation's commitment to capacity building, knowledge sharing and excellence in the care of patients with haemoglobin disorders.



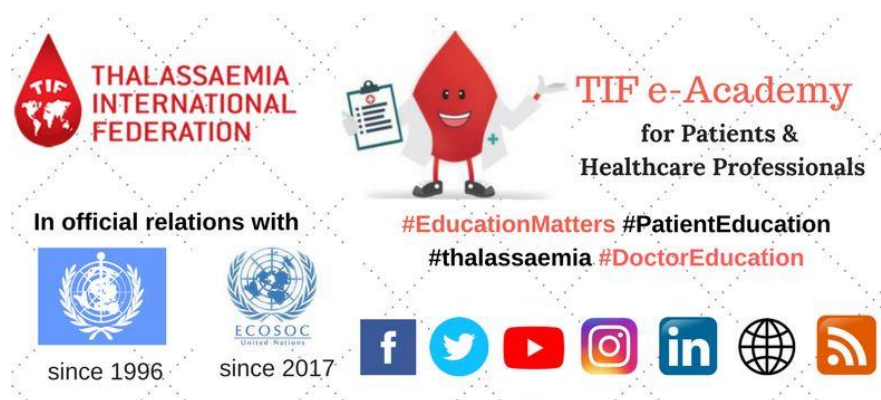
A few words about Thalassaemia International Federation (TIF):

TIF

The Thalassaemia International Federation (TIF) was founded by patients with thalassaemia and their parents in 1986 and registered in Cyprus as a Non-Profit, Non- Governmental Organisation, under the Cyprus Company Law in 1987. Governed by its constitution, the Federation is presided over by an 18-member Board of Directors (maximum two representatives per country), elected for a four-year term and comprised of 50% of patients with thalassaemia.

MISSION and VISION **MISSION:** The development and implementation of national disease-specific programmes for thalassaemia in every country, which encompass both the component of prevention and that of management.

VISION: Establishment of equal access to quality health, social and other care for all patients with thalassaemia globally, in a truly patient-centred health care setting. Noteworthy and although TIF has been established to address, and by constitution to serve the needs of patients with thalassaemia globally through its activities, sickle cell disease and many other issues pertaining to public health are also addressed in the context of TIF's activities to a significant extent.



Your Personal Thalassaemia Guide

We're excited to introduce an AI-powered chatbot designed to assist individuals living with thalassaemia, their families, carers, and medical professionals.

- Get instant answers to your questions based on trusted TIF resources, including publications, clinical updates, and more.
- Available 24/7 to provide reliable, concise, and relevant information in a number of languages.
- Designed with you in mind, reflecting the look and feel of our website.

