

**Renzo
Galanello
Fellowship
Programme**



THE RENZO GALANELLO FELLOWSHIP PROGRAMME

2019

OFFICIAL REPORT FOR THE TRAINING PERIOD

14 OCTOBER – 13 DECEMBER 2019



Co-funded by
the Health Programme
of the European Union

Compiled by Dr Androulla Eleftheriou,
TIF Executive Director



Venue:

**Joint Red Cell Unit of the Haematology
Department of the University College
London Hospital (UCLH)**

Leader:

**Professor John Porter, MD, MRCP, FRCPath,
Professor of Haematology**

Coordinator:

**Dr Perla Eleftheriou, MD, MRCP, FRCPath,
Consultant Haematologist**

Foreword

We feel extremely privileged and delighted to provide the official completion report of the latest Renzo Galanello Fellowship Programme 2019, which took place between 14 October to 13 December 2019 through the Joint Red Cell Unit of the Haematology Department of the UK University College London Hospitals (UCLH).

We are greatly indebted to each one of the specialists involved at the UCLH – most members of TIF's International Expert Advisory Panel - for their truly invaluable contribution without which the materialization of this effort would not have been possible as well as for their long term support to TIF's educational programme.

Allow me to underscore once again the importance of this course and the added value it entails to the further knowledge and experience of the participants who are given, through it, a unique opportunity to observe, discuss, interact and participate in the daily work of an internationally recognised Haematology Reference Centre with an eminent and well established multidisciplinary element and with an immeasurable contribution in international research.

We look forward to the next training period in October 2020 for yet another unique training experience.

Sincerely,

Mr Panos Englezos
President, Thalassaemia International Federation
Honorary President, Pancyprian Thalassaemia Association

Dr Androulla Eleftheriou
BSc, MSc, PhD
Executive Director, Thalassaemia International Federation
Head of the World Health Organisation (WHO) Collaborating Centre for Thalassaemia Control in Cyprus.

General Information

The Renzo Galanello Fellowship Programme is an educational initiative that comes to enrich the Thalassaemia International Federation's (TIF's) educational programme and honour the late Professor Renzo Galanello, pioneer in the field of thalassaemia research and management.

This training programme was initially developed in 2013 and is offered to physicians, specialists in the field of haematology, paediatrics or internal medicine. As of 2015, the programme is undertaken by the Joint Red Cell Unit, Haematology Department of the University College London, NHS Foundation Trust in London, UK.

TIF, through its work and activities globally, is aware of the fact that in many countries, there is a lack of trained medical staff and, as a result, the health care that haemoglobinopathy patients receive is suboptimal, inadequate and even rudimentary. This need is partially due to a generally poor interest by the haematology circles in non-malignant haematological disorders, another derivative of the absence of national control policies for Thalassaemia and/or Sickle Cell Disease (SCD). As haemoglobin disorders are regarded as rare, they are not given priority on national health agendas nor are they integrated into national strategies or programmes. Instead, and despite the documented public, health, social and economic burden and repercussions of the rare, chronic diseases on the national budget, health policy interest is diverted to other health 'priorities' and in particular to communicable and common non communicable diseases.

Establishing policies for the prevention and management of these rare disorders constitutes an immense and invaluable contribution towards the improvement of our patients' health and quality of life and towards reducing national, regional and international public health and social burden. Since such disorders are polyorganic in nature, have lifelong dependency on blood and are genetic in aetiology, they bear considerable medical, public health and social repercussions, in addition to the economic ones. At the same time, educational opportunities for healthcare professionals that include the latest developments in the field of haemoglobinopathies, is of utmost importance and a key step in promoting a better understanding by the policy and decision-makers with regard to the real value of effective national control programmes and, in extension, the improvement of our patients' health and quality of life.

Improving knowledge towards holistic care in Thalassaemia and SCD in every affected country has been a priority for TIF since its establishment. The occurrence of these diseases, consequent to heavy population movement and migration, are now occurring widely across the world and, therefore, the need for improving disease-related knowledge and healthcare services is manifest across geographical boundaries.

DURATION: Two (2) months (may vary based on the needs of the candidates from 2-4 months)

CANDIDATES: The fellowship is offered to 2-4 physicians per year.

SELECTION COMMITTEE: 2 members of TIF's Scientific Advisory Board on behalf of TIF and 2 chief medical specialists on behalf of the training centre. Applications review process is performed on clear and structured criteria.

The Renzo Galanello Fellowship Training Programme is offered by the Joint Red Cell Unit of the Haematology Department of the University College London Hospital (UCLH) under the leadership and co-ordination of Professor John Porter, Professor of Hematology and Dr Perla Eleftheriou, Consultant Haematologist, and with the participation of distinguished medical specialists of the department and of across different relevant medical and scientific disciplines.

The Renzo Galanello Fellowship Training Programme 2019 took place in the 2-month period from 14 October to 13 December 2019.

The Training Centre

The Joint Red Cell Unit of the University College London Hospital (UCLH) Haematology Department is considered a Reference Centre for Haemoglobin Disorders at the national and international level due to its work, research and published data.

Course team

- Course Leader: Professor John Porter, MD, MRCP, FRCPath, Professor of Haematology
- Course Coordinator: Dr Perla Eleftheriou, MD, MRCP, FRCPath, Consultant Haematologist,
- Multidisciplinary team: Constituted by high calibre health professionals with international expertise in their field and in relation to haemoglobinopathies:
 1. Dr Farrukh Shah, Consultant Haematologist
 2. Dr Emma Drasar, Consultant Haematologist
 3. Dr Bernard Davis, Consultant Haematologist
 4. Dr Sarah Trompeter, Consultant Haematologist and Paediatric Haematologist
 5. Dr John Malcolm Walker, Consultant Cardiologist
 6. Mrs Bernadette Hylton, Haemoglobinopathy Clinical Nurse Specialist
 7. Dr Mary Petrou, Consultant Clinical Molecular Geneticist and Honorary Senior Lecturer
 8. Dr Deepak Suri, General Gastroenterologist & Hepatologist
 9. Dr Sarita Naik, Diabetologist
 10. Mrs Amy Mullins, Clinical trials coordinator
 11. Mrs Nancy Huntley, Apheresis sister
 12. Mrs Dawn Collier, Supportive care lead nurse
 13. Mrs Sandy Garner, Ferriscan/ CMR T2* coordinator

The Training Programme

The programme sought to provide clinical training to the selected, based on criteria, fellows, as well as the opportunity to undertake clinical research and 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
- Haemoglobinopathy Genetic Counselling
- Adult Red Cell Clinic
- MDT
- Ward round for review of the inpatients
- Cardiology clinic
- Evening clinic
- Apheresis unit

The candidates submitted a written assessment pre- and post-programme.

TIME ALLOCATION

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

THE RENZO GALANELLO FELLOWSHIP TRAINING PROGRAMME

Day	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY
am	9am –1pm : Clinical trial clinic (Dr Eleftheriou) 9 am –12: CNS led Haemochromatosis/polycythaemia clinic (Ms Bernadette Hylton) 9 am consultant- led ward round	8:30-1pm: Adult Red Cell Clinic (Dr Eleftheriou, Prof Porter) Or 9-1pm Genetic risk assessment/couns elling clinic (Dr Mary Petrou)	Am: audit/projects Visit of apheresis/suppor tive care/labs 2pm onwards: Cardiology clinic (Dr Walker)	Audit/projects 9-1pm Genetic risk assessment/counselling clinic (Dr Mary Petrou) 9-1pm Paediatric TCD clinic (TBC)	9-11 am Consultant-led Ward round

pm	2-5 pm: Paediatric clinic (Dr Trompeter)	1-3 pm: MDT	4-8pm: Multidisciplinary thalassaemia Evening clinic (Prof Porter, Dr Eleftheriou, Dr Davis)	Audit/projects	Apheresis unit (after 11 am) every other Friday 1-5 pm General Haematology clinic (Dr Eleftheriou)
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INFORMATION FOR THE FELLOWS

AIMS:

- ☐ Aim of programme: to provide the selected international fellows clinical training and the opportunity to undertake clinical research and audit, leading to a presentation at national or international meetings.
- ☐ Fellows will have honorary contracts at the UCLH.
- ☐ Their clinical timetable will focus on sessions to facilitate the acquisition of knowledge and practical experience in the management of sickle cell disease and thalassaemia.

NOTE:

1. Ward rounds for review of the inpatients take place every day by the SHO and SpR (junior doctors). 2 times a week, consultant led ward rounds take place. Usually Mondays and Fridays but check with the consultant. Attending Consultants: Dr Eleftheriou October, Dr Trompeter November, Dr Eleftheriou December.
2. Haemoglobinopathy Genetic Counselling clinics with Dr M. Petrou take place Tuesday mornings (9-1pm). You are encouraged to visit at least 2 of these during your stay (1 fellow at a time of each clinic)
3. The thalassaemia evening clinics on Wednesdays are multidisciplinary: services provided simultaneously: haematology. Clinical psychology, diabetology, cardiology, hepatology, andrology. You are encouraged to observe the practice across all the disciplines.
4. Next TCD paediatric clinic 2nd of November
5. Audits/projects and their deadline will be decided and allocated at the start of the fellowship
6. All clinics (except paediatric), take place at the McMillan Centre, 4th floor, haematology outpatients
7. The paediatric clinics take place at Elisabeth Garrett Anderson Hospital, in the lower ground.
8. You will be informed about any other relevant meetings as needed.
9. Professor Porter's research lab is situated on Huntley Street and you can make arrangements to visit the lab under his supervision.
10. Fellows are encouraged to arrange between them a plan of when to visit which clinic (multidisciplinary wed pm clinic, Dr Petrou's clinic). Contact Dr Petrou to come up with a mutually convenient plan.

The Candidates

The Renzo Galanello Fellowship Training Programme 2019 was offered to three candidates:

1. **Dr Wolfgang Novak**, Dr Med. Univ, BSc in Molecular Biology, Resident physician in Pediatrics, Outpatient Department of Hematology, Oncology & Immunology, St. Anna Children's Hospital Vienna, Austria
2. **Dr Georgios Kaltsounis**, Specialist in Clinical Pathology (Laboratory Medicine), MSc Degree in Translational Research and Biomedicine, Clinical Pathologist at the Blood Bank Department of AHEPA University General Hospital of Thessaloniki, Greece

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

Following the completion of the Renzo Galanello Fellowship Training 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 Renzo Galanello Fellowship and in the context of the collaboration established with TIF, the candidates are invited to:

1. Provide regular reports on any achievements made in their country.
2. Advise the focal points and decision makers in their country of how they could improve policies related to better health and quality of life for patients with haemoglobin disorders and how TIF could support this effort.
3. Support TIF's efforts to establish and/or strengthen relations with the national Thalassaemia Patients Associations and health professionals' network.
4. Contribute in various projects by undertaking specific tasks assigned by TIF.
5. Propose to TIF ways or promoting haemoglobin disorders programmes in their country.

TIF will provide a comprehensive information to the Ministry of Health of the participants' countries as well as to the Director of their clinic/department/hospital.

PENDING

Feedback from the candidates (Extracts from the candidates' post course reports)

«The knowledge gathered through the project has been very much appreciated here at my hospital and I want to thank the TIF again for the wonderful programme provided»

«First of all I have to say that it was a great honor to receive training in such a renowned environment. I very much appreciated the warm hospitality of all members of the Joint Red Cell Unit and it has been amazing to see such a high standard of clinical care for patients with hemoglobinopathies. Seeing treatment at the forefront of clinical development in this field was probably the most exciting aspect for me»

«Through this training my understanding of hemoglobinopathies enormously increased and I got a much broader view on the many aspects included in managing a patient with hemoglobinopathies. I am convinced that through this training the standard of care in our hospital will reach another level for patients with these diseases»

«Dr. Perla Eleftheriou has been a fantastic organizer of the programme and a great example to learn from. Moreover, the possibility to get into contact with a world leading physician like Prof. Porter has been a significant experience for me»

“We had the opportunity to observe all aspects of care and interact with all implicated health professionals in two different hospitals. Moreover, running a small project motivated us to get hands-on training, get more involved with patients’ history and background and even contribute to patients’ care. Observing clinical trials clinic, attending local conferences and meetings and establishing networking ties with UK experts were also among the highlights of this training for me”

“The Renzo Galanello fellowship is an excellent educational resource for doctors involved in the care of patients with hemoglobinopathies. The training programme covered all aspects of care and everyone involved was very welcoming and friendly. We received valuable input which can be helpful in our practice back in our countries. I would like to express my gratitude to Professor Porter and Dr Perla Eleftheriou for being brilliant hosts, devoting time and effort to our training and putting everything together, Dr Shah for all her help at the Whittington hospital, Dr Mary Petrou for being an excellent coordinator in our project and everyone else for making us feel part of their team. Regarding practical issues, our cooperation with the UKTS for our stipend, etc, has been excellent and they were most helpful.”

Special thanks to the contributors

The Board of Directors of the Thalassaemia International Federation (TIF), its President Mr Panos Englezos, TIF's Executive Director Dr Androulla Eleftheriou, TIF's Medical Director Dr Michael Angastiniotis and the TIF office staff, convey their sincere appreciation and gratitude to the:

- **Course leader, Professor John Porter** and the **course co-ordination Dr Perla Eleftheriou** for their invaluable and significant contribution in materialising this programme and in building up and strengthening one of the new pillars of the educational programme of TIF.
- **Members of the multidisciplinary group** who through their vast experience and expertise have provided, along with the course leader and the course co-ordinator a unique training experience to the candidates
- **Administration department of the ULCH** for facilitating the admission of the candidates and their journey to the fellowship programme
- **UKTS**, for facilitating and supporting this programme.







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.

