



**T H E R E N Z O
G A L A N E L L O
F E L L O W S H I P
P R O G R A M M E**

**OFFICIAL REPORT FOR THE
TRAINING PERIOD
16 OCT – 15 DEC 2017**

Compiled by Dr Androulla Eleftheriou,
TIF Executive Director

University College London Hospitals 
NHS Foundation Trust



**THALASSAEMIA
INTERNATIONAL
FEDERATION**



THE RENZO GALANELLO FELLOWSHIP PROGRAMME

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THALASSAEMIA
INTERNATIONAL
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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, which took place in the 3-month period from 16 October to 15 December 2017 through the Joint Red Cell Unit of the Haematology Department of the UK University College London Hospitals (UCLH).

We are greatly indebted to the specialist team at the UCLH – members of TIF's International Expert Advisory Panel - for this invaluable contribution in the materialization of this effort as well as for their support to TIF's educational programme throughout the years, towards improving quality care standards for thalassaemia and other haemoglobin disorders across the world.

We look forward to the next training period in October 2018 for yet another unique training experience.

Sincerely,

Mr Panos Englezos
President, Thalassaemia International Federation
President, Cyprus Alliance for Rare Disorders
Honorary President, Pancyprian Thalassaemia Association

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

General Information

The Renzo Galanello Fellowship Programme is a new 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 in collaboration with the Whittington Hospital NHS Trust in London, UK, and is, with the support of Novartis Pharma, 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

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

As of 2015, 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 across different relevant disciplines.

The latest Renzo Galanello Fellowship Training Programme took place in the 3-month period from 16 October to 15 December 2017.

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 international fellows, as well as the opportunity to undertake clinical research and become familiar with how audit, peer review and multidisciplinary meetings are conducted and integrated into the services 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

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 (but time TBC): consultant-led ward round	8:30-1pm: Adult Red Cell Clinic (Dr Eleftheriou, Prof Porter) Or 9-1pm Genetic risk assessment/counselling clinic (Dr Mary Petrou)	Am: audit/projects Visit of apheresis/supportive 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 TO 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. I would encourage you to arrange between you a plan of when to visit which clinic (multidisciplinary wed pm clinic, Dr Petrou's clinic). You can get in touch with Dr Petrou to come up with a mutually convenient plan her email address is: mary.petrou@uclh.nhs.uk

The Candidates

A place in this year's Renzo Galanello Fellowship Training Programme was offered to four candidates:

1. Dr Maria Liza Naranjo from Philippines
2. Dr Sein Win from Myanmar
3. Dr Muhammad Ahmed D. Saeed from Iraq
4. Dr Ludi Dhyani Rahmartani from Indonesia

Sadly, Dr Saeed from Iraq withdrew his application due to family health issues and Dr Rahmartani from Indonesia was not able to attend due to unforeseen commitments.

Participants

1. **Dr Maria Liza Naranjo**, Doctor of Medicine, Paediatric Medicine, Fellow in Haematology, Hematology Consultant, National Children's Hospital (under the Department of Health), Coordinator, Thalassaemia Care Programme, Assistant Professor, St Luke's College of Medicine , Quezon Philippines
2. **Dr Sein Win**, MBBS in Medicine, Associate Professor/Senior Consultant Haematologist, Department of Clinical Haematology, Yangon General Hospital, Yangon, Myanmar

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 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.

Feedback from the Course co-ordinator Dr Perla Eleftheriou

"We had the pleasure and the privilege to accommodate two very skilled, competent and enthusiastic haematologists in the context of the Renzo Galanello Fellowship. I am referring to Dr Maria Liza Naranjo from Philippines and Dr Sein Win from Myanmar"

"As a whole, speaking on behalf of the whole Red Cell Haematology team, we enjoyed the presence of our two fellows and hope to continue the collaboration and networking further on"

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

"I am grateful for the opportunity to observe bedside and out-patient doctor- patient interaction, the importance of communication and patient engagement."

"Though my research skills have been rusty, the experience has made me reconnect with the importance of research to be able to share our own experiences and challenges with colleagues"

"I will always treasure the chance to interact with Prof. Porter, Perla, Sarah, Emma, Farrukh and the Red Cell Staff of UCLH and Whittington Thalassaemia Group who are all so accommodating, understanding, caring and passionate about their work"

"And most of all, the opportunity to interact with patients and listen to their stories. I am grateful that they have opened their lives to us"

"As a whole, the fellowship enabled me to have " front row seats" on how the multidisciplinary management to thalassaemia care is carried about which I plan to apply first at the National Children's Hospital – government children's hospital as a pilot site, including how to network to nearby community hospitals specially those that do not have access to a haematologist"

Dr Maria Liza Naranjo

"This TIF's education programme is a well-structured one. The objectives of the programme were very clearly defined before the programme started and were well informed to the candidates beforehand. I have got the great opportunity to learn every minute, every hour and every day throughout the two-months-course to improve healthcare of haemoglobinopathy patients in own country, Myanmar. It greatly improved my knowledge and opened my eyes towards holistic care in thalassaemia, sickle cell disease, other red cells disorders and iron-related problems."

"By attending the red cell clinic, paediatric clinic and general haematology clinic, my knowledge on management of red cell disorders expanded and consultants' conducts towards the medical and psychosocial benefits of patients could also be learnt. Their works are inspirations to me."

"I am very fortunate to have a chance to do a research project in such a biggest and the best red cell centre over the world under the supervision of well-known researchers, and am very much obliged to Professor Porter and Dr Eleftheriou for giving me such a wonderful opportunity. To do research project every day and night is my dreams forever. I hope the research project could be presented at a TIF meeting or published as a contribution to current knowledge on haemoglobinopathies."

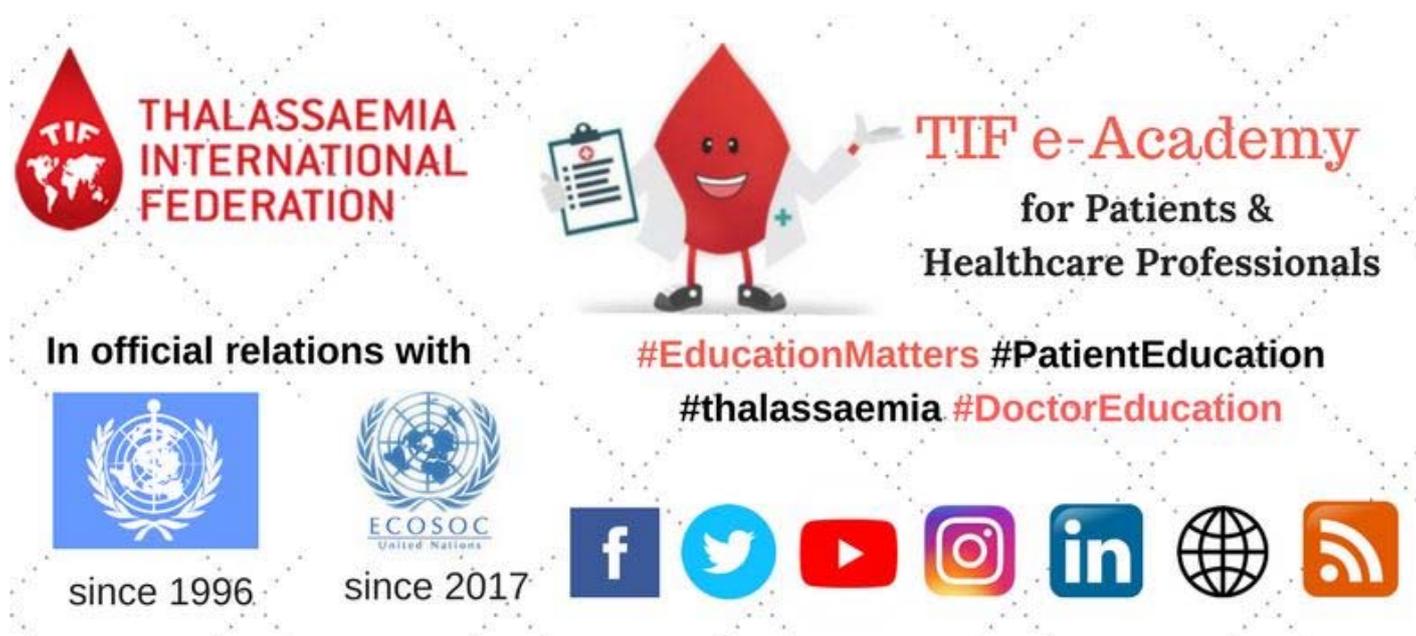
“Finally, I would like to send my words of thanks to executive board of TIF for allowing me to attend such a great course. The programme facilitated the acquisition of knowledge and gave a practical experience to me so that I can serve my thalassaemia patients and patients with other haemoglobinopathies better after completion of this unforgettable Renzo Galanello Training Fellowship Programme. I have decided to share my experiences and knowledge gain from this programme with fellow colleagues in my country and to try hard together with these colleagues to improve haemoglobinopathy care in Myanmar. I wish more and more candidates from Myanmar get the similar chance to expose to such an excellent programme in coming years to be able to form a group of haemoglobinopathy experts in Myanmar and strive for better haemoglobinopathy care in Myanmar.”

Dr Sein Win

Special thanks to the contributors

The Board of Directors of the Thalassaemia International Federation (TIF), TIF's Executive Director Dr Androulla Eleftheriou and TIF's Medical Director Dr Michael Angastiniotis, 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** and in particular Mrs Helen Cosgrove, for facilitating the admission of the candidates and their journey to the fellowship programme
- **Board of Directors, the President Mr Gabriel Theophanous and the staff at the UKTS, particularly Mrs Katerina Loizi** for facilitating and supporting this programme in as many ways as possible.





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.