

Thalassaemia International Federation (TIF)

**THE RENZO GALANELLO
FELLOWSHIP PROGRAM
2016**

OFFICIAL REPORT FOR THE TRAINING PERIOD

03 OCT – 30 NOV 2016

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,



Supported by



**Compiled by Dr Androulla Eleftheriou,
TIF Executive Director**

Foreword

We feel extremely privileged and delighted to provide the official completion report of the last TIF – Renzo Galanello Fellowship which took place between 3rd of October – 30th of November 2016 through the Joint Red Cell Unit of the Haematology Department of the University College London Hospital (UCLH) in the UK.

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

Furthermore, we are indebted to Novartis Pharma who supports this fellowship as well as to all the medical specialists and health care professionals who have contributed to this initiative.

Looking forward to the next training period in October 2017 for yet another unique training experiences.

Sincerely yours

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.

Dr Michael Angastiniotis
Medical Advisor, Thalassaemia International Federation

General Information

Thalassaemia International Federation (TIF) has launched, in the context of its educational programme, in 2013 a new initiative; A fellowship program, the Renzo Galanello Fellowship Programme, in honour of the late Professor Renzo Galanello, a pioneer in the field of thalassaemia research and management.

This programme has been initially developed in collaboration with the Whittington Hospital NHS Trust in London, UK, with the support of Novartis Pharma. This is part of TIF's Educational Programme and is offered to physicians, specialists in the field of haematology, paediatrics or internal medicine. In our effort however to widely spread this fellowship and collaborate with other reference centres as well, the training is offered, as from 2015, through the Joint Red Cell Unit, Haematology Department of the University College London NHS Foundation Trust in London, UK under the supervision and coordination of Professor John Porter, Professor of Haematology and Dr Perla Eleftheriou, Consultant Haematologist.

TIF is aware that in many countries there is a lack of trained medical staff and as result, healthcare of haemoglobinopathy patients is less than optimum in many countries rudimentary. This need is partially due to a general poorer interest in haematology circles for non-malignant haematological disorders but also because these disorders are regarded as rare and as such are not given priority or integrated into national strategies or programmes. Policies for rare and chronic disorders are suboptimal or inadequate in many countries and health policy interest is diverted to other health 'priorities'. Improving knowledge towards holistic care in thalassaemia and sickle cell disease has been a TIF priority since its establishment and this need has no geographical boundaries.

Improving policies for the prevention and management of these disorders, constitutes a vast and invaluable contribution towards the health and quality of lives of our patients and towards national, regional and international public health and social burden; Since these diseases are polyorganic in nature, have lifelong dependency on blood and are genetic in aetiology, bear considerable medical, public health and social repercussions in addition to the economic ones.

DURATION: Two (2) months

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

As from 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 of Professor John Porter, Professor of Hematology and the course co-ordinator Dr Perla Eleftheriou, Consultant Hematologist with the participation of distinguished medical specialists across different relevant disciplines.

The recent Renzo Galanello Fellowship Training Programme was held between 3rd of October – 30th of November 2016.

The Centre

The Joint Red Cell Unit of the Haematology Department of the University College London Hospital (UCLH). The centre through its work, research and published data is considered as a Reference Centre for haemoglobin disorders at the national and international level.

- 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.

The Training Programme

The aim of program was to provide to the selected international fellows the clinical training and the opportunity to undertake clinical research and become familiar with how audit, peer review and multidisciplinary meetings are conducted and integrated in the services for holistic care offered 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

A pre and post written assessment was submitted by the candidates

RENZO GALANELLO FELLOWSHIP TRAINING PROGRAM

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)	8:30-1pm: Adult Red Cell Clinic (Dr Eleftheriou, Prof Porter)	Am: audit/projects 2pm onwards: Cardiology clinic (Dr Walker)	Audit/projects	9-11 am Ward round
pm	2-5 pm: Paediatric clinic (Dr Trompeter)	1-3 pm: MDT 3-5pm ward round	4-8pm: Multidisciplinary Evening clinic (Prof Porter, Dr Eleftheriou, Dr Davis)	Audit/projects	Apheresis unit (after 11 am)

- Aim of program: 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.

NOTES:

- 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.
- 2) This up until now has been Tuesday and Friday mornings, but is now subject to change.
- 3) Haemoglobinopathy Genetic Counselling clinics with Dr M. Petrou take place Tuesday mornings (9-1pm) . You are encouraged to visit at least 2 of these
- 4) during your stay (1 fellow at a time of each clinic)
- 5) The thalassaemia evening clinics on Wednesdays are multidisciplinary: services provided simultaneously: haematology, Clinical psychology, diabetology,
- 6) cardiology, fertility, osteoporosis. You are encouraged to observe the practice across all the disciplines.
- 7) TCD paediatric clinic every 3 months with Dr S. Trompeter
- 8) Audits/projects and their deadline will be decided and allocated at the start of the fellowship
- 9) There will be a pre and post- written assessment.
- 10) All clinics (except paediatric) , take place at the McMillan Centre, 4th floor, haematology outpatients
- 11) The paediatric clinics take place at Elisabeth Garrett Anderson Hospital, in the lower ground.
- 12) You will be informed about any other relevant meetings as needed.
- 13) Professor Porter’s research lab is situated on Huntley street and you can make arrangements to visit the lab under his supervision.

The Candidates

This year's Renzo Galanello Fellowship Training Programme was offered to four candidates:

1. Dr Shruti Kakkar from India
2. Dr Mostafa Mohamed Embaby Ahmed Abd El-Majeed from Egypt
3. Dr Muhammad Ahmed D.Saeed from Iraq
4. Dr Ahmad Mohamed Abd El Latife from Palestine

Sadly, due to entry visa difficulties, Dr Saeed from Iraq and Dr El Latife from Palestine were not able to join the programme.

Participants

1. **Dr Shruti Kakkar**, MBBS in Medicine, MD in Paediatrics, Fellowship in Hemato-oncology, Assistant Professor in Department of Pediatrics, Dayanand Medical College and Hospital, Ludhiana, Punjab, India
2. **Dr Mostafa Mohamed Embaby Ahmed Abd El-Majeed**, M.B.Ch.B in Medicine and Surgery, M.Sc in Pediatrics Medicine, M.D. in Pediatrics, Lecturer (Consultant C) of Pediatrics, Assiut University, Faculty of Medicine, Egypt.

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 honorable Associate members of TIF. In this context, these medical specialists are entitled of 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 the policies related to better health and quality of lives of patients with haemoglobin disorders and how TIF could support.
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, competed and enthusiastic haematologists, Dr Kakkar from India and Dr Abdelmajeed from Egypt. We are looking forward to receive their feedback following their training on how this fellowship changed their practice. Our vision is for this fellowship programme to lead to more experts in the field with the ultimate aim to improve the standards of care at the centres where thalassaemia patients are treated"

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

"I am extremely fortunate and obliged to the executive board of TIF for giving me such a wonderful opportunity."

"It was an absolute pleasure to observe the consultants' interaction with the patients in this clinic. The discussion involved not only the red cell disease but the entire medical and psychological makeup of a patient."

"I would like to mention my sincerest regards to Professor Porter and Dr Eleftheriou for their time and effort. Their dedication towards the patients with red cell disorder is infectious. I do find myself a changed person both personally and professionally."

Dr Shruti Kakkar

"The objectives of the training were clearly defined... "

"... the content was organised and easy to follow.. "

"the trainers were knowledgeable about their training topics and very well prepared"

"The hospitality, the whole team behave the fellows in an excellent manner"

"I hope that this training will help to improve the standard quality of care for our thalassaemia patients"

Dr Mostafa Mohamed Embaby Ahmed Abd El-Majeed

We were also delighted to receive the below good news from Dr Abd El-Majeed following his training:

"A new lab was opened few weeks ago in our hospital specified for hemolytic anemias. The staff members in that new lab propose to make genotype for all our thalassaemia patients. Also, we started process of detection of patients who are not chelated (not covered by health insurance) and provision of chelation for them either by governmental support or by donations"

Special thanks to the contributors

The Board of Directors of 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:

- **Novartis Pharma** for financially supporting the materialisation of this programme
- **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.
- **The 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
- **The administration department of the ULCH** for facilitating the admission of the candidates and their journey to the fellowship programme
- **The President, the Board and the staff at the UKTS** for facilitating the financial aspect of the 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