THE RENZO GALANELLO FELLOWSHIP PROGRAMME 2022 (condensed/online training)

A Thalassaemia International Federation (TIF) educational programme in collaboration with the Joint Red Cell Unit of the Haematology Department of the University College London Hospital (UCLH)

OFFICIAL REPORT FOR THE TRAINING PERIOD

21 – 25 November 2022

Co-funded by
the Health Programme
of the European Union

Venue:

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

Course Leader/Co-ordinator:

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

Multidisciplinary team:

Distinguished medical specialists of the department and of across different relevant medical and scientific disciplines

Foreword

We feel extremely privileged and delighted to provide the official completion report of TIF's Renzo Galanello Fellowship Programme 2022.

The Renzo Galanello Fellowship Programme 2022 was offered to 5 successful candidates – medical doctors from Switzerland, Denmark, Greece, Egypt and Pakistan,– and it was delivered as condensed/online training between the 21st – 25th of November 2022 through the Joint Red Cell Unit, Haematology Department, University College London NHS Foundation Trust in London, UK under the leadership and co-ordination of Dr Perla Eleftheriou, Consultant Haematologist and the participation of distinguished medical specialists across different relevant disciplines.

Even though this year' s training was a condensed and virtual one, as an exception due to the COVID-19 pandemic and the subsequent challenges, it was extremely beneficial and valuable to the work of the physicians attending the course, towards strengthening the quality of healthcare provided to our patients in their countries.

We are greatly indebted to each one of the specialists involved 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.

We look forward to the next training period in 2023 for yet another unique training experience.

Sincerely,

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

Dr Androulla Eleftheriou
BSC, MSc, PhD
Executive Director, Thalassaemia International Federation

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 (physical)

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.

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21 – 25 November 2022

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

The Training Centre/The Course team

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/Course Co-ordinator: 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. Professor John Porter, MD, MRCP, FRCPath, Professor of Haematology
2. Professor John Malcolm Walker, Consultant Cardiologist
3. Dr Farrukh Shah, Consultant Haematologist
4. Dr Emma Drasar, Consultant Haematologist
5. Dr Sarah Trompeter, Consultant Haematologist and Paediatric Haematologist
6. Dr Nickolas Jackson, Consultant Haematologist
7. Dr Ben Carpenter , Consultant Haematologist
8. Dr Ryan Mullaly, Consultant Haematologist
9. Dr Kenneth Fung Cardiologist
10. Dr Julian Waung, Consultant in Diabetes, Endocrinology & General Internal Medicine
11. Dr Mary Petrou, Consultant Clinical Molecular Geneticist
12. Dr Ruth Anderson, Clinical Psychologist
13. Mr George Trandafir, Senior Staff Nurse, Apheresis
14. Mrs Helen Keane, Matron
15. Dr Christopher Dean, Paediatric Red Cell Clinical Nurse Specialist

The Training Programme

A wealth of information was provided to the fellows in the form of back to back comprehensive but interactive lectures held by haematology consultants, clinical psychologists, red cell specialist nurses, consultant cardiologists and consultant endocrinologist.

Training Schedule

TRAINING PROGRAMME (UK Time)

MONDAY 21 November	TUESDAY 22 November	WEDNESDAY 23 November	THURSDAY 24 November	FRIDAY 25 November
08:00 - 08:15 Introduction ***Dr Perla Eleftheriou***	**09:00 - 10:00** Role of clinical physchology in haemoglobinopathies ***Mrs Ruth Anderson***	**09:00 - 16:30** UK Forum on Haemoglobin Disorders – 54th Academic Meeting	**08:15 - 09:00** Novel treatments in thalassaemia ***Prof John Porter***	**08:15 - 09:00** Liver Disease in Sickle Cell Disease ***Dr Emma Drasar***
08:15 - 09:00 Presentation by each fellow **(SEE BELOW NOTE 1)**	**10:00 - 11:00** - Role of CNS in haemoglobinopathies - UCLH Red cell service structure and IT system *Red Cell CNS*		**09:00 - 10:30** Sickle cell Disease in Children ***Dr Christopher Dean***	**09:15 - 10:15** Pulmonary hypertension in sickle cell disease ***Dr Kenneth Fung***
09:00 - 10:00 Thalassaemia management in adults ***Prof John Porter***	**11:00 - 12:00** Bone disease in thalassaemia ***Dr Julian Waung***		**14:00 - 15:00** Genetic counselling in Haemoglobinopathies ***Dr Mary Petrou***	**10:30 - 12:30** Basic Haemoglobinopathy diagnostics ***Dr Nickolas Jackson***
13:00 - 14:00 Manual Red Cell Exchange Protocol ***Ms Helen Keane (Matron)***	**14:00 - 14:45** Apheresis service ***Mr George Trandafir***		**15:30 - 16:30** Chronic complications in Sickle Cell Diasease ***Dr Perla Eleftheriou***	**12:45 - 13:45** The model of a thalassaemia unit ***Dr Farrah Shah***
14:15 - 15:00 Sickle Cell Disease management in adults ***Dr Perla Eleftheriou***	**15:00 - 16:00** Iron chelation in thalassaemia ***Dr Farrah Shah***		**16:45 - 17:45** HSCT & Gene therapy in Haemoglobinopathies ***Dr Ben Carpenter***	**14:00 - 15:00** Interesting cases Thal &SCD ***Dr Ryan Mullaly***
15:00 - 15:45 Haemoglobinopathy service structure in England ***Dr Emma Drasar***	**16:00 - 17:00** Transfusion in Thalassaemia and SCD ***Dr Sara Trompeter***			**15:00 - 16:00** Novel treatments in SCD ***Dr Perla Eleftheriou***
	17:00 - 18:00 Cardiac Disease in Thalassaemia ***Prof Malcolm Walker***			**16:15 - 17:17** **Case discussion by each fellow** **(SEE BELOW NOTE 2)**

NOTE 1: The fellows are requested to present a few slides to introduce themelves and share information about the centres they work at, their role, the unmet needs of their centres and the reason they were
NOTE 2: The fellows are requested to present one clinical cs from their centres that is complex and needign a second opinion/imput

The Candidates

The Renzo Galanello Fellowship Programme 2022 (condensed/online training) was offered to five candidates:

1. **Dr Cesare Medri**, Resident Doctor of Hematology, Inselspital, Bern, Switzerland

2. **Dr Nina Toft** , Consultant Haematologist, Department of Heamatology, University Hospital Rigshorspitalet, Denmark

3. **Dr Philippos Klonizakis**, Consultant Heamatologist, Thalassaemia Unit, Aristotle University, Hipppkration General Hospital, Thessaloniki, Greece

4. **Dr Fadwa Said Abdelazim**, Associate Professor Clinical Pathology (Hematology) and specialist Clinical Heamatology, Cairo University, Egypt

5. **Dr Muhammad Naveed**, Assistant Professor in Paediatric Medicine, University College of Medicine, University of Lahore, Pakistan

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.

Feedback from the course leader/course co-ordinator Dr Perla Eleftheriou

"It is with great pleasure that I can confirm that we conducted a very successful virtual Renzo Galanello Fellowship week which took place 21 -25 November 2022 through University College Hospital in London (UCLH), in collaboration with the Whittington Hospital in London and TIF".

"Despite the virtual nature of the fellowship this year, I am pleased to say that with the enthusiasm of the fellows, our team and the excellent organisational skills of the TIF office, the fellowship was successful"

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

"The program highlighted the value of a multidisciplinary approach for Thalassemia patients, so I will try to implement effective collaboration with different medical specialties"

"Overall, this was a highly educative programme"

"Coming from a place where no Thalassemia-center is available, I particularly appreciated the non-hematological expertise"

"It goes without saying, that the hematologists, with their theoretical knowledge and their practical know-how were also cardinal and extremely interesting. Thank you for your hard work and the amazing opportunity"

"The trainers displayed their high expertise in their respective field"

"I have received significant information on novel treatment of both thalassaemia and sickle cell diseases"

"Following this training, I hope to spread the knowledge and have more cooperation with the TIF"

"Well organized and interaction with us. Very kind and interesting speakers"

"Participation and interaction were encouraged"

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, Dr Perla Eleftheriou** for her 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

1. Professor John Porter, MD, MRCP, FRCPath, Professor of Haematology
2. Professor John Malcolm Walker, Consultant Cardiologist
3. Dr Farrukh Shah, Consultant Haematologist
4. Dr Emma Drasar, Consultant Haematologist
5. Dr Sarah Trompeter, Consultant Haematologist and Paediatric Haematologist
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8. Dr Ryan Mullaly, Consultant Haematologist
9. Dr Kenneth Fung Cardiologist
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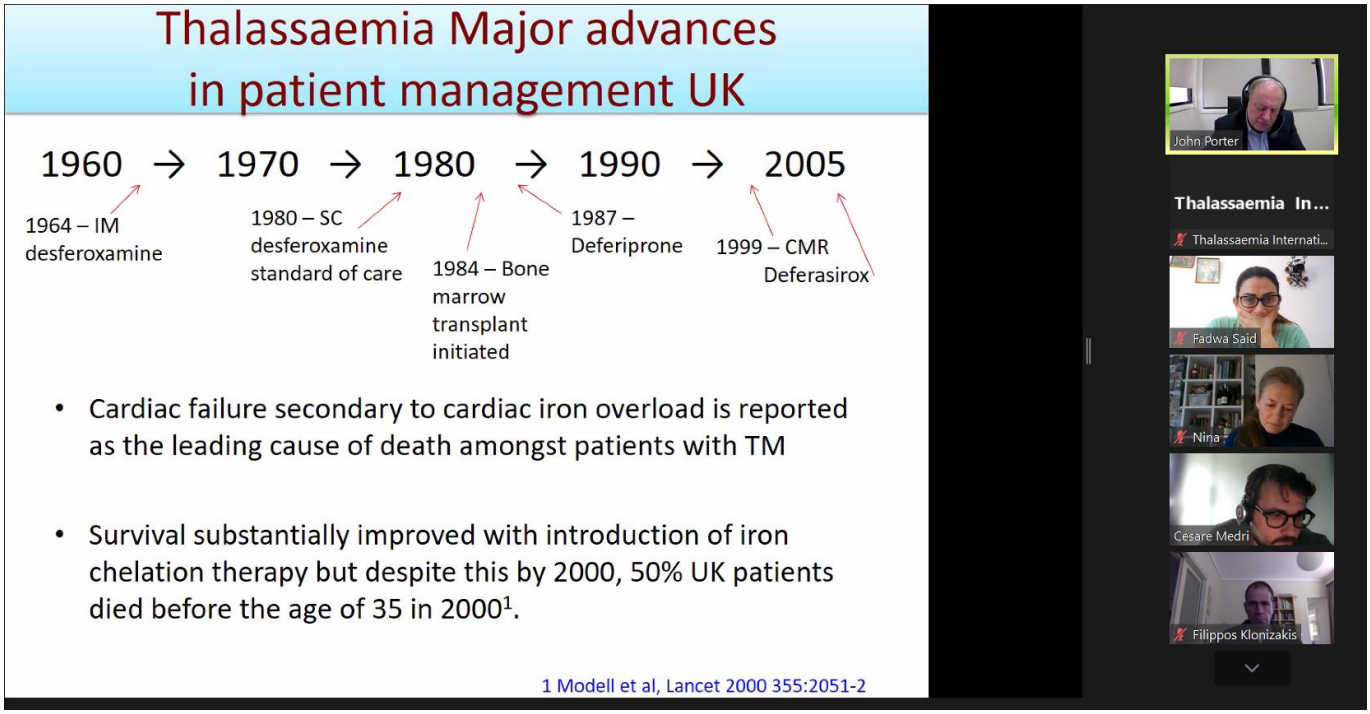
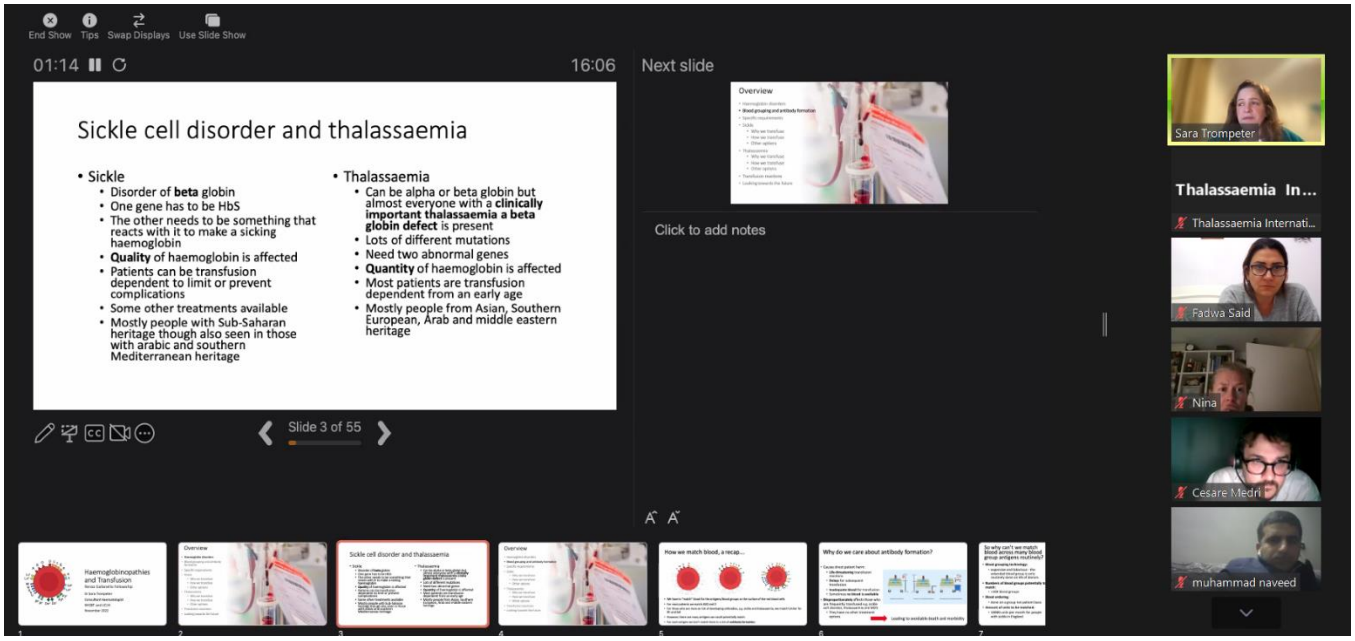
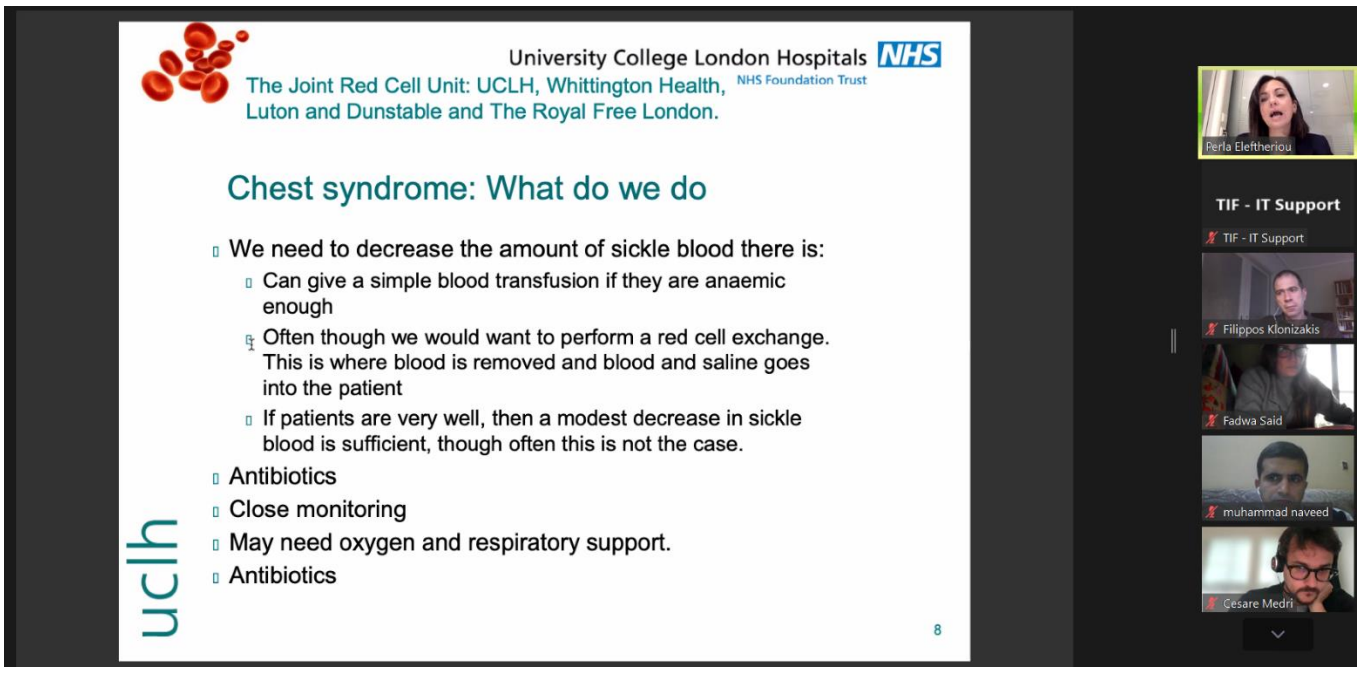
12. Dr Ruth Anderson, Clinical Psychologist
13. Mr George Trandafir, Senior Staff Nurse, Apheresis
14. Mrs Helen Keane, Matron
15. Dr Christopher Dean, Paediatric Red Cell Clinical Nurse Specialist

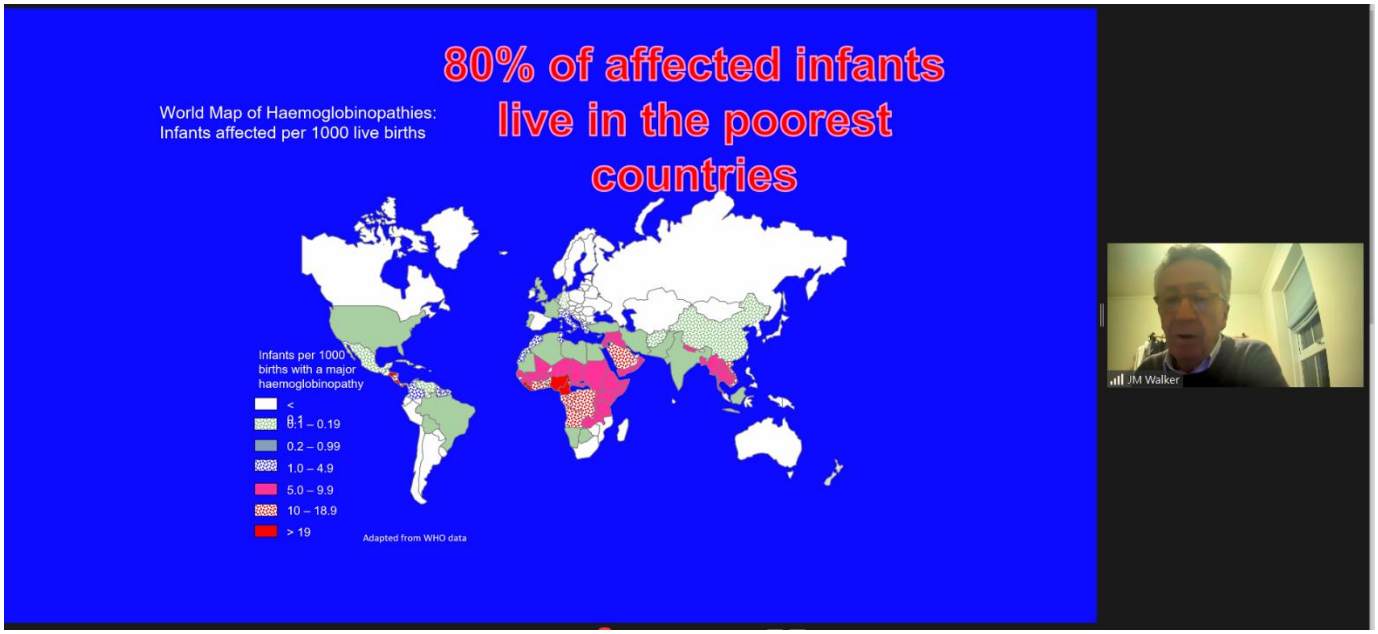
- **TIF's Officer, Mr Rawad Merhi** for the technical administration and support

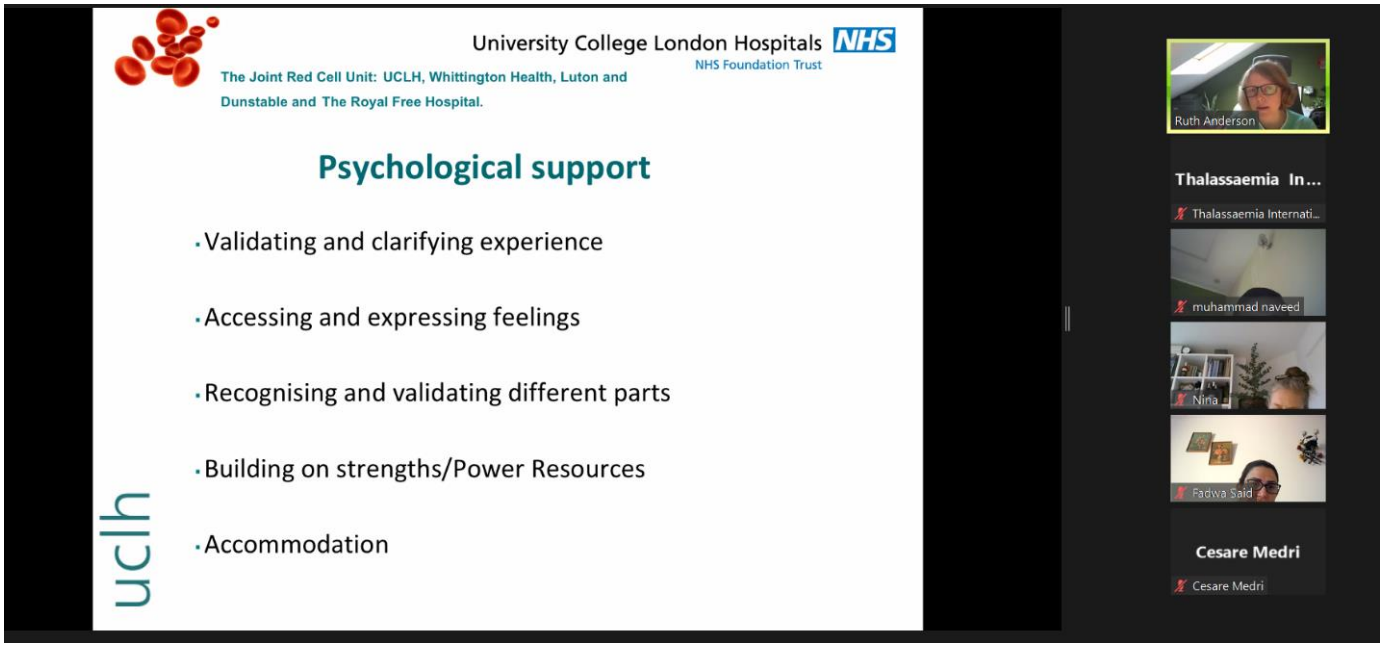

Perla Eleftheriou
TIF - IT Support
TIF - IT Support
Filippos Klonizakis
Cesare Medri
Fadwa Said
Kenneth Fung
muhammad naveed
Nina
Dr Androulla El...
Dr Androulla Eleftheriou
Mary Petrou
Mary Petrou


Thalassaemia Major advances in patient management UK
1960 → 1970 → 1980 → 1990 → 2005
1964 – IM desferoxamine
1980 – SC desferoxamine standard of care
1984 – Bone marrow transplant initiated
1987 – Deferiprone
1999 – CMR Deferasirox
• Cardiac failure secondary to cardiac iron overload is reported as the leading cause of death amongst patients with TM
• Survival substantially improved with introduction of iron chelation therapy but despite this by 2000, 50% UK patients died before the age of 35 in 2000[1].
1 Modell et al, Lancet 2000 355:2051-2
John Porter
Thalassaemia In...
Thalassaemia Internati...
Fadwa Said
Nina
Cesare Medri
Filippos Klonizakis


End Show
Tips
Swap Displays
Use Slide Show
01:14
16:06
Next slide
Sickle cell disorder and thalassaemia
• Sickle
• Disorder of beta globin
• One gene has to be HbS
• The other needs to be something that reacts with it to make a sicking haemoglobin
• Quality of haemoglobin is affected
• Patients can be transfusion dependent to limit or prevent complications
• Some other treatments available
• Mostly people with Sub-Saharan heritage though also seen in those with arabic and southern Mediterranean heritage
• Thalassaemia
• Can be alpha or beta globin but almost everyone with a clinically important thalassaemia a beta globin defect is present
• Lots of different mutations
• Need two abnormal genes
• Quantity of haemoglobin is affected
• Most patients are transfusion dependent from an early age
• Mostly people from Asian, Southern European, Arab and middle eastern heritage
Slide 3 of 55
Click to add notes
Sara Trompeter
Thalassaemia In...
Thalassaemia Internati...
Fadwa Said
Nina
Cesare Medri
muhammad naveed


University College London Hospitals NHS
NHS Foundation Trust
The Joint Red Cell Unit: UCLH, Whittington Health, Luton and Dunstable and The Royal Free London.
Chest syndrome: What do we do
We need to decrease the amount of sickle blood there is:
Can give a simple blood transfusion if they are anaemic enough
Often though we would want to perform a red cell exchange. This is where blood is removed and blood and saline goes into the patient
If patients are very well, then a modest decrease in sickle blood is sufficient, though often this is not the case.
Antibiotics
Close monitoring
May need oxygen and respiratory support.
Antibiotics
uclh
8
Perla Eleftheriou
TIF - IT Support
TIF - IT Support
Filippos Klonizakis
Fadwa Said
muhammad naveed
Cesare Medri


80% of affected infants live in the poorest countries
World Map of Haemoglobinopathies:
Infants affected per 1000 live births
Infants per 1000 births with a major haemoglobinopathy
< 0.1
0.1 – 0.19
0.2 – 0.99
1.0 – 4.9
5.0 – 9.9
10 – 18.9
> 19
Adapted from WHO data
JM Walker


University College London Hospitals NHS
NHS Foundation Trust
The Joint Red Cell Unit: UCLH, Whittington Health, Luton and Dunstable and The Royal Free Hospital.
Psychological support
Validating and clarifying experience
Accessing and expressing feelings
Recognising and validating different parts
Building on strengths/Power Resources
Accommodation
uclh
Ruth Anderson
Thalassaemia In...
Thalassaemia Internati...
muhammad naveed
Nina
Fadwa Said
Cesare Medri
Cesare Medri


Fadwa Said
Thalassaemia International Federation
Kenneth Fung
Filippos Klonizakis
Nina
muhammad naveed
Nick Jackson
Cesare Medri

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.