Summer 2019

THALASSAEMIA MATTERS

The magazine of the United Kingdom Thalassaemia Society

UKTS AMBASSADORS
Exciting new programme

INTERNATIONAL THALASSAEMIA DAY!
MPs and actors show support

MEDICAL ADVANCES
Luspatercept and gene therapy

UNITED KINGDOM THALASSAEMIA SOCIETY

Issue 130

Inform • Inspire • Support

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PrettyLit.

What is thalassaemia major?

Thalassaemia major is a serious, life-long, genetic blood disorder. People with thalassaemia major cannot make enough haemoglobin in their red blood cells. Consequently, they need frequent and regular blood transfusions throughout their lives. If left untreated, a child born with thalassaemiamajor would die in early infancy. In parallel, they also need chelation treatment to remove the excess iron that comes from regular blood transfusions. Iron overload is extremely harmful and can lead to organ damage and ultimately failure.

Every year, at least 75,000 children are born with thalassaemia major worldwide. The condition is prevalent in Mediterranean countries, the Middle East, Central Asia, India, Southern China, and the Far East as well as countries along the north coast of Africa and in South America. In the UK there are over 1,700 patients living with some form of thalassaemia in addition to over 300,000 thalassaemia carriers. With medical advances, most people with thalassaemia major who adhere to a rigid medical treatment regime, are able to manage the condition and live full lives. However, with better awareness and early screening, thalassaemia could be consigned only to history books.

What does the UKTS do?

UKTS aims to improve the lives of patients with the genetic blood disorder, thalassaemia by:

- providing a counselling support and information service to individuals and families affected by thalassaemia,
- producing specialist educational materials for patients, healthcare professionals and the general public,
- organising local and national events (e.g. training days, national medical conferences), and
- raising funds for research and life-saving equipment.

"Parts of your life will be different from others but don't let that stop you… don't let thalassaemia take over your life"

Thalassaemia patient, UKTS family conference: 2020 and beyond

Contents

Message from our Chair

Welcome to the summer 2019 issue of Thalassaemia Matters. I'm sure you will agree that this year has already seen a lot of changes for the NHS, fellow patients, families and the UKTS. We are now entering a phase of exciting new developments and whilst we are embracing the positive changes, we are looking ahead for ways to deal with the new challenges.

Our first major task for 2019 has been to try and engage more with all our patients across the UK. Towards this aim, we have launched our community group meetings and our ambassador programme. We have recently made amendments to our membership requirements which we hope will encourage everyone's participation. You can read more of the activities and projects undertaken by the UKTS in the magazine. There are lots of other articles too; advice from doctors, the latest medical updates on gene therapy and Luspatercept and some wonderful real-life stories.

I do hope you like the new look and format of the magazine and the team would love to hear your feedback.

Working together to 2020 and Beyond!
Gabriel Theophanous

Cypriot Wine Festival

UKTS hosted a stand at the Cypriot Wine Festival held in Lee Valley Leisure Centre on the 26th May 2018. The charity has been a part of the festival for a number of years, taking the opportunity to provide information on the condition as part of our outreach work. The Cypriot Wine Festival is known to be one of the largest Cypriot events held outside of Cyprus, providing a taste of Cypriot culture in the United Kingdom. Throughout this two-day annual event, visitors are treated to an assortment of Cypriot treats, namely, food, drinks and entertainment! It also provides an avenue for local businesses and the community's entrepreneurs to display and promote their products. The event is well attended by families from the various communities.

Roanna Maharaj and Ashkaan Bandoui

visitors to our booth


visitors to our booth with Katerina Loizi and High Commissioner for Cyprus.

UKTS wins best employer award

UKTS was delighted to be presented with the award for 'Best New Employer of the Year' by First Rung, a charity providing innovative and high quality learning and employment opportunities to young people since 1983.


Zahra Thornhill (trainee) and Romaine Maharaj


Roderik Nemes and Katerina Loizi

Media coverage

UKTS has been really busy raising awareness through different media channels. Board Member, Oddy Cooper and Dr Christos Sotirelis appeared on Hellenic TV (Greek) to talk about the condition and its effects, while Dr Bana Kayu and Zehra Gokturk appeared on Euro Genc (Turkish)TV. Recently, we were also featured in the following newspapers and radio stations: Parikiaki Newspaper, (Greek), Olay News (Turkish Newspaper), The Asian Online News and London Greek Radio.


Vasili Panayis (presenter), Dr Chris Sotirelis and Oddy Cooper

Zehra Gokturk, Dr Banu Kaya and Gul deniz(presenter)

Professor Allan Victor Hoffbrand honoured

The 'Sultan Bin Khalifa International Thalassemia Award' (SITA) Ceremony was held on the 12th April 2018 in Emirates Palace, Abu Dhabi. Professor Allan Victor Hoffbrand was the 2018 winner for 'Grand International Award' from the International category. Professor Hoffbrand has been hugely instrumental in the world of thalassaemia, both in the United Kingdom and abroad.

Professor Hoffbrand receiving his award (third from left).

UKTS Head Office refurbishment

Last year, the charity's head office in Southgate had a complete makeover. With its leaking ceiling and poor infrastructure, the office itself was in desperate need of refurbishment, having not been touched for over 20 years. There was a garage at the back of the office which was in disrepair, waterlogged and full of boxes of old documents. With the help of Oddy Cooper (the UKTS Treasurer), Romaine Maharaj organised the office refurbishment. The end-result was the creation of a suitable office space which is now fit to work in and host meetings. Bambos Charalambous, MP for Southgate, formally reopened the offices on the 2nd December 2018 with members and well-wishers of the society there to celebrate. On the same day, the AGM was hosted in the newly refurbished offices.

Cutting the ribbon.

Bambos Charalambous MP(pictured on the left) with the UKTS team

National Blood Week

National Blood Week ran from 10th-16th June 2019 and the theme this year was about connecting people. During the week, for the first time ever, NHS Blood and Transplant brought together the people who have received blood and their blood donors. There were some amazing stories that emerged which highlighted exactly why blood donors make such a difference. Every day, across England, 5,000 people give an hour of their time to save lives. However, more is needed and NHS Blood and Transplant is appealing for new donors at their local donor centres. They particularly need more of specific blood types (O negative and Ro sub type) as well as more male donors and more black donors. For more information visit www.blood.co.uk.

ASCAT 2018

The 2018 Annual Sickle Cell Disease and Thalassaemia (ASCAT) Conference, hosted by Guy's and St Thomas' Hospital, was held in London on the 22nd - 24th October 2018.This event was open to consultants and specialist psychologists, nurses, scientists and all relevant experts. The event provided information on the latest advances in clinical care, transition services and emerging new therapies, including updates for curative treatment options. Everyone attending had the opportunity to network with leading practitioners. The theme for the event was 'Sickle Cell Disease and Thalassaemia: Bridging the Gap in Care and Research to improve outcomes for patients living with the disorders. The meeting highlighted key basic science, clinical and translation research in haemoglobinopathies, including the mechanisms of chronic complications and end organ damage. UKTS was proud to be a part of this event, providing literature and information from our very own booth.

Iyamide Thomas (SCS) and Romaine Maharaj

UKTS updates its data protection policy

As many of you know, a new law was introduced that changed the way in which organisations can store people's personal details. This law came about because the European Union enacted the General Data Protection Regulation (GDPR).
This new law means that organisations, like ours, can only keep the personal details of people under certain, specified scenarios (such as when you sign up as a member). It also means that organisations should only record and keep information that is absolutely necessary. To reflect these changes, we have completely re-designed our membership form. It no longer asks questions that could be considered sensitive under GDPR, such as blood type or treating doctor. We are also deleting all unnecessary information that we have previously kept. We have updated our privacy policy to reflect all of these changes. Our privacy policy explains what information we are now holding and how we ensure that data is kept safe. You can find this document on our website, at the bottom of the home page. We're continuing to assess our policies and will keep you updated should we make any further changes in the future.

Nurse Emma Prescott wins Patient Choice Award

In September 2018, the Whittington Hospital held its annual hospital awards. The NHS Trust received a staggering 400 nominations for just 15 categories. With such stiff competition, we were thrilled that Emma Prescott, a specialist thalassaemia nurse, won the Patient Choice Award! Her nominator was our very own UKTS advisor Roanna Maharaj. Well done to the both of you!

Emma and Roanna at the award ceremony

NEWS

Shining bright: Emma's in the steps of Florence Nightingale

The Islington Tribune featured Emma and her award

Emma and Roanna

Here are some extracts from Roanna's heartfelt nomination letter:

"I'd like to nominate Emma Prescott, who tirelessly fights to ensure all patients receive the best possible care. Emma has been involved with the thalassaemia service at the Whittington Hospital in London since the beginning and I don't think she has even been properly acknowledged for her selfless work. I have yet to meet a more efficient Clinical Nurse Specialist. Emma dedicates her life and soul to thalassaemia!

As patients, we owe a lot to Emma, especially for having the option of weekend services. A few years ago, I became extremely unwell and started reacting to my blood transfusions. It was the first known case in thalassaemia in the world, and despite it being extremely new and unheard of, Emma never made me feel as if I was a burden despite all the changes we had to make to my rigorous treatment regime. She has always been calm, nurturing and genuine, traits that definitely follow in the footsteps of the great Florence Nightingale and Mary Seacole. It is always interesting to see how Emma approaches new patients despite age, sex or ethnicity and is always able to find common grounds to make everyone feel at ease and welcomed."

40th Anniversary gala dinner and awards ceremony

On Saturday 6th October 2018, UKTS celebrated 40 years of success by hosting a gala dinner and awards ceremony. The night recognised the fantastic people who have made a huge difference to the lives of thalassaemia patients and their families and in shaping what the UKTS is today.

The evening took place in London, at the prestigious Hilton Hotel on Park Lane, and welcomed over 300 people including patients, clinicians, internationally renowned figures in the world of thalassaemia and anyone else who wanted to be a part of a key moment in thalassaemia's history.

It was a wonderful night with a live Latin and salsa band entertaining throughout the evening. Forty awards were presented by our trustees. the ceremony recognised some of the people who truly made a difference and they are listed below:

Three previous presidents with trustees Anand and Ashkaan

Professors Pennell and Porter with awards

Matty Asante-Owusu
Matty is a nurse in the Thalassaemia and Sickle Cell unit at UCH. She was recognised for her dedication to patients.

Dr Vasili Berdoukas
Dr Berdoukas worked alongside Professor Modell on the development of pioneering thalassaemia treatments, organised the first ever meeting at UCLH and was one of the people responsible for the establishment of the UKTS.

Mary Christodoulou (Karsa)
Mary was one of the founding member of the society and opened up her home to parents for the first ever parent meeting held outside of a hospital. Sadly, Mary passed away earlier this year.

Dr Bernard Davis
Dr Davis trained in haematology at the Whittington Hospital. Dr Davis joined the consultant staff at the Whittington Hospital in 2001 and was part of the team responsible for the extensive work on desferal and the syringe driver pump.

Avraam Demetriou
Avraam first got involved with the society after finding out about the condition from his dental patients over the years. He was also actively involved in patient advocacy during the society's formative years.

Robert (Bob) Ficarra
Bob is one of TIF's founding members and has been on the board of directors since 1986. He has made many notable achievements in the world of thalassaemia.

Pany Garibaldinos
(awarded posthumously)
Pany was one of the first patients to celebrate his 60th birthday in 2017. A dynamic advocate, he served on the Board of Trustees for many years.

Professor Allan Victor Hoffbrand
Professor Hoffbrand's research led to new revolutionary treatment for thalassaemia. He helped develop Deferiprone in 1987.

Mahesh Kotecha
Mahesh joined the society after his son was diagnosed in 1985 and served as president from 1985 to 1989. He managed to pull together a team of volunteers who went on to raise over £1million pounds to fund research on the first oral chelator.

Karen Madgewick
Karen is a blood specialist and worked alongside Dr. Yardumian for most of her career. She is loved by all her patients at the North Middlesex hospital for the care, commitment and support she gives to everyone.

Katerina Loizi-Read
Katie has been involved in the society for over 35 years. She served as a board member before taking the position of administrator at the UKTS. She is a shining example for all thalassaemia

Niamh Malone Cooke
Niamh has been with the thalassaemia unit at the Whittington for over 10 years and always goes above and beyond for her patients.

Francis Mate-Kole
For the past 15 years Francis has provided the best possible care for all of his patients at the North Middlesex Hospital.

George Michael
(awarded posthumously)
George was a financial supporter and patron to the society for over 10 years.

TIF award being presented by our Chair Gabriel

Gabriel, Dr Spino and Professor Modell

Gabriel and Nishel Theophanous

Dr Nitin Lakhani
Dr Lakhani joined the society from 1990 as president and served until 2000. He was instrumental in raising much needed funds towards the Asian awareness campaign.

Sandy Brody
Sandy has been an outstanding thalassaemia nurse at the Whittington Hospital for over 20 years.

Elaine Miller
Elaine joined the Society in 2002 and was the first point of contact for anyone wanting to get in touch with the society. She worked extensively on the NHS Sickle Cell & Thalassaemia Screening Programme.

Zainab Rasul
Zainab has worked tirelessly to support and educate her community. She organises annual conferences and events for her patients and community.

Professor Bernadette Modell
Professor Modell was instrumental in developing effective treatment for thalassaemia major. She has also helped to extend programmes for the treatment and prevention of haemoglobin disorders to many parts of the world.

Dr Christos Sotirelis
Chris has been representing the thalassaemia community, tirelessly advocating on behalf of EURORDIS and Rare Diseases. He has also been involved in the development of a number of surveys regarding patient quality of life within the thalassaemia community.

Koula Kanias
Koula has been involved with the society from a very early age. She can be depended upon to support any activity being planned at the society.

George Constantinou
George was one of the founding members of UKTS and has been a tireless campaigner on behalf of thalassaemia. He is also serving on the board of Thalassaemia International

Professor Dudley Pennell
Professor Pennell has led many international projects introducing CMR (cardiac magnetic resonance) techniques across the world. This aims to increase life expectancy and quality of life for patients dealing with thalassaemia.

Thalassaemia International Federation
Panos Englezos and his team were congratulated for their contribution towards the cause over the period.

Part of the North Middlesex Hospital team with their guests

Costas Paul
Costas took the role of public relations officer back in 1976 and worked with volunteers and board members up until 2004, on fund raising and awareness campaigns. He made an amazing contribution to the thalassaemia community during his time with the society.

Emma Prescott
Emma has been fundamental in evolving the services provided to patients and their families. She was instrumental in setting up the first ever thalassaemia clinic, providing updates at many conferences and delegation visits. Emma recently won the Whittington patient's choice award.

Photis Papaiacovou
Photis is one of the founding members of the society and served as president for a year. He continues to be an active participant in most of the meetings.

Dr Farrukh Shah
Dr Shah is actively involved in clinical research in iron chelation. She has worked as a medical advisor to the UKTS and has contributed to both the UK thalassaemia and sickle cell national guidelines in relation to iron chelation.

Michael Michael
Michael was the first patient to step into the president's role from 2000-2010. He has also served on the Board of Directors for TIF for several terms. He has been to many countries on delegation visits in order to improve patient care.

Costas Kountourou
(awarded posthumously)
Costas, a patient himself, lobbied continuously on behalf of the patients and was loved by all. He served on the Board of Trustees for many years.

Professor John Porter
Professor Porter is head of the joint Red Cell Unit for University College Hospital and the Whittington Hospital. His research has focused on the treatment of thalassaemia, particularly in relation to iron overload and the mechanisms of iron chelation. Professor Porter has served as a scientific advisor to the UKTS and TIF.

Dr Paul Telfer
Dr Telfer is a consultant haematologist at the Royal London Hospital. He has been an advisor to the UKTS and actively involved in various publications produced by the society over the years. Paul has been nominated by his patients for the dedication and support extended to all under his care.

Roanna Maharaj with Niamh Malone Cooke

Ashkaan Bandoui, Zainab Abbas and Yianni Zambas

Dr **Mary Petrou**
Dr Petrou is a consultant clinical molecular geneticist and the head of the Haemoglobinopathy Genetics Service at UCLH. Mary is an advisor to the UKTS, The Sickle Cell Society and the Thalassaemia International Federation.

Dr Anne Yardumian
Dr Yardumian has been revered as one of the most caring doctors, always there for her patients. She has been an advisor to the UKTS, actively involved in various publications produced by the society over the years.

Dr Andrew Robins
Dr Robins has been a consultant paediatrician at the Whittington Hospital since 1995. He ensures that there is a smooth transition from the paediatric clinic to the adult unit.

Dr Beatrix Wonke
Dr Wonke was introduced to thalassaemia patients in 1978. She has worked tirelessly alongside Professor Modell to provide the best possible care for all patients. She earned the reputation of being a pioneer in the thalassaemia communityand was recognised with an OBE in 2004 for her work in thalassaemia.

Phedias Soteriou
A policeman by profession, Phedias worked alongside Mahesh and Avram to highlight the condition, as well as to raise much-needed funds for life-saving equipment and drug development.

Dr Michael Spino
Dr Spino recently received the humanitarian of the year award from Cooley's Anaemia Foundation, for jointly spearheading the research that brought a life-saving drug to patients around the world.

Dr Fernando Tricta
Dr Tricta founded the first Brazillian treatment centre for children with thalassaemia. He joined the ApoPharma team and, alongside Michael Spino, fought to ensure that all patients across the world have access to this life-saving drug. Fernando is loved by patients and families all over the world.

Dr Malcolm Walker
Dr Walker has nearly 40 years of clinical experience as a physician and a cardiologist. Dr Walker is recognised globally in specialist areas of cardiovascular medicine, including the cardiovascular effects of thalassaemia; the cardiovascular consequences of iron overload; and the cardiovascular effects of cancer and its treatment.

Politicians and actors support International Thalassaemia Day!

New APPG for thalassaemia

Wednesday 8th May 2019 was International Thalassaemia Day and supporters from around the world were busy raising awareness of the condition to mark this special day for the global thalassaemia community. It was a particularly special day for our UK charity and all of its members, because an All Parliamentary Party Group (APPG) was created for UKTS, to represent all those living with the condition.

Members from our charity were invited in to the Houses of Parliament to speak to MPs about this serious, genetic blood disorder. Bambos Charalambous, MP for Enfield Southgate, led the way for fellow MPs to raise awareness of thalassaemia and was voted Chair of the APPG. Officers for the group will be duly elected. Working together with UKTS, the APPG will provide a valuable platform to discuss the different challenges faced by patients, their families and medical professionals in the field.

(L-R) Neelam Dongha, Oddy Cooper, Romaine Maharaj, Bambos Charalambous MP, Roanna Maharaj, Cllr Stephanos Ioannou and Andrew Credgington.

The following 29 MPs attended the meeting, learnt about the condition – especially the importance of pre-conception and antenatal screening – signed our banner and then tweeted messages of support.

MPs	Constituency
Bambos Charalambous	Enfield South
Jonathon Ashworth	Leicester South
Tracy Brabin	Batley and Spen
Preet Kaur Gill	Birmingham Edgbaston
Ruth Jones	Newport West
Tony Lloyd	Rochdale
Cat Smith	Lancaster and Fleetwood
Eleanor Smith	Wolverhampton South West
Maggie Throup	Erewash
Craig Tracey	North Warwickshire
Pat McFadden	Wolverhampton South East
Fiona Bruce	Congleton
Catherine West	Hornsey and Wood Green
Andrew Rosindell	Romford
Norman Lamb	North Norfolk
Chi Onwurah	Newcastle Upon Tyne
Annaliese Dodds	Oxford East
Khalid Mahmood	Birmingham, Perry Barr
Mark Menzies	Fylde
Dennis Skinner	Bolsover
Barry Gardiner	Brent North
John Hayes	Lincolnshire
Alberto Costa	South Leicester
Martin Vickers	Cleethorpes
Stephen Crabb	Pembrokeshire
Ed Milliband	Doncaster North
Tanmanjeet Singh Desi	Slough
Matt Rodda	Reading East
Alison Thewliss	Glasgow Central

Bambos Charalambous MP

Mr Charalambous said, "I am delighted to be Chair of the APPG for such an important cause, one that resonates with many of my own constituents." Romaine Maharaj, Executive Director of UKTS added "It is great to have the support of Bambos and the other MPs. We want to reach out and support all those living with and affected by this serious condition. With increased understanding of thalassaemia among the general public and in particular amongst high-risk groups, this condition could and should be consigned to the history books."

Eleanor Smith MP

Dennis Skinner MP

Alberto Costa MP

John Hayes MP

Andrew Rosindell MP

Matt Rodda MP and Tan Dhesi MP

Preet Gill MP

Barry Gardiner MP

Maggie Throup MP

Norman Lamb MP

Alison Thewliss MP

Jon Ashworth MP

Cat Smith MP

Anneliese Dodds MP

Ed Milliband MP

Tracy Brabin MP

Tony Lloyd MP

Pat McFadden MP

Craig Tracey MP

Bollywood stars spread the word…

Meanwhile, across the globe famous Bollywood stars got in on the act! Partth Thakur, an Indian national with thalassaemia and the founder of The Wishing Factory galvanised a number of stars to show their support and spread awareness to their fans by posts on social media. Famous names included Hrithik Roshan, Abhishek Bachchan, Farah Khan, Anil Kapoor, Arjun Kapoor, Soonakshi Sinha, Huma Qureshi, Kunal Kapoor and Ayushmaan Khurrana.

Soonakshi Sinha

Soonakshi Sinha posted a video for her 15m followers in which she said "Please have a thalassaemia test done before you conceive a child so that you do not transfer this disease to your future generations. It's something that needs to be controlled."

Asian Today newspaper featured a story about International Thalassaemia Day. Whilst we are really pleased with these awareness-raising achievements, we will strive to do more so that ALL those who might be affected by thalassaemia fully understand the condition.

Meet the UKTS patrons

UKTS is delighted to have the support of four well-known patrons who are working hard to raise awareness of thalassaemia and promote the work of the charity.

Ms. Tonia Buxton

Tonia Buxton is a Greek Cypriot television presenter and author. She is the host of the Discovery Channel Travel & Living show; My Greek Kitchen and is also the author of several publications. Although extremely busy balancing her career and family life, Tonia is determined to support the charity in raising awareness of the inherited disorder.

Mr. Kypros Kyprianou

Kypros Kyprianou is Group Chief Executive for the Theo Paphitis Retail Group, including brands Ryman, Robert Dyas, Boux Avenue and London Graphic Centre, all of which are owned by retail entrepreneur and businessman Theo Paphitis. Kypros has a degree in Actuarial Science from City University and is a qualified banker, having gained this whilst spending the first 13 years of his career at the Bank of Cyprus, UK. In 2004, Kypros left the Bank to join Theo Paphitis' Group as Commercial Director. A leap into the unknown has been very rewarding for Kypros, with retail acquisitions, disposals, a start-up and growing existing businesses all featuring in his time at the Group. Today the Group has a combined total of around 350 stores, E-commerce sites and 4,200 staff, serving more than 28 million customers a year.

Kypros' main passion away from work is football, being Chairman and now a trustee of the community's leading youth football club, Omonia Youth FC for over a decade. Kypros is married to Fanoulla and has three sons. He is a committed supporter of the society and in helping to raise awareness of the society across his network.

Ms. Nina Wadia

Nina Wadia is a British actress, known for playing Zainab Masood in the BBC soap opera EastEnders, Mrs Hussein in the Open All Hours and for starring in the hit BBC Goodness Gracious Me. Additionally, Wadia played an important role in the Hindi-language romantic comedy Namaste London. Her most recent role was in Disney's new movie 'Aladdin' which is showing in theatres across the UK.

Nina is also committed to supporting the various campaigns spearheaded by the society towards raising awareness of the condition and the fact that it is a genetically inherited disorder which can be prevented.

Mr. Peter Polycarpou

Peter has starred in the world's most successful musicals of all time and his acting career is now in its 40th year. Amongst numerous other roles, he was the Phantom in Sir Andrew Lloyd Weber's Phantom of the Opera. More recently in 2018, he played Ahmed Qurie in OSLO for which he was nominated for an Olivier award. He has had various TV roles but is most famous for playing Chris Theodopoulopoudos in Birds of a Feather and even today it is shown on TV. Peter is a director of The Royal Theatrical Fund and also teaches in schools, colleges and universities across the UK.

Peter has supported UKTS for over 25 years and now as a patron he is keen to hear about all aspects of the new medical research currently being undertaken. He is particularly excited about the huge advances in gene therapy and feels they offer real hope to patients with thalassaemia.

Introducing our newest board member: Oddy Cooper

We are delighted to introduce our newest UKTS board member, Oddy Cooper. Since joining the Board of Trustees as Treasurer last year, she has been an invaluable asset to the team. Capitalising on her professional interior design background, she helped to plan and manage the total revamp of the charity's head office in Southgate. Not only did she volunteer her designer skills to create the new office design, she also sourced and negotiated a lot of the fittings and fixtures at amazing rates (generously donating some herself). The office has been totally transformed! Oddy also assisted in organising our amazing gala night (See pages 8-11) and is busy planning the next one, so if you haven't already, add Saturday 7th December to your diary. For those of you who follow us on social media, you will see Oddy has represented the charity at numerous events and meetings. In this interview, we find out what makes her tick and her hopes for the charity…

Where does the name Oddy come from?

Oddy is short for Odysoulla, a Greek name deriving from Odyssey and chosen by my father. He was adamant that he wouldn't follow the Greek tradition of baptising his baby with a Saint's name. In fact, he threatened the priest if he didn't approve, he would baptise me himself!

Do you work, and if so, what do you?

I started my career making curtains and home furnishings and this led to me becoming an interior designer. Since getting involved with the charity last year, I have had less time for this as I am attending meetings on behalf of UKTS. I also do floristry for events and am tending to focus on that more now.

Any interesting clients?

Through a recommendation, I ended up furnishing Sharon Osbourne's offices and she liked our work so she went on to commission us for her house in Amersham. Ozzy Osbourne was away at the time but would phone home and sometimes I would answer which led to some interesting calls where I would say "Hi Ozzy, it's Oddy." To which he would reply, "No, I'm Ozzy" and it would all get very confusing...

Oddy with husband Chris

Three words that describe yourself?
Stubborn, honest and outspoken.

What do you do to unwind?
I love gardening.

What skills do you bring to your role at the charity?

Creativity, commitment, determination and transparency.

What do you think are the charity's strengths?

I think UKTS is a strong lobbying body. Romaine and her small team are incredible and do amazing things with limited resources.

What do you think are the biggest challenges the charity faces?

Being able to raise sufficient funds to continue to do the vital work. Also getting the right people to do the right things.

How did you get involved with UKTS?

My son Stephen, who has thalassaemia, is 40 years old now. Over the years I sent in donations and received newsletters from UKTS. Last year I received a call out of the blue from UKTS asking if I would help with the planned refurbishment of the office. They had got my details from letter headed paper that I had sent in with a donation! I became more and more involved in the charity and I was then asked if I would like a role on the Board. Given that I am a parent of a child with thalassaemia, I felt it would be a good thing to do.

In an ideal world, what would you like the charity to be doing in five years time?

I would obviously like the charity to continue to support thalassaemia patients. But whilst the issues of transfusions and iron chelation are well-managed, I would like us to address the other issues that patients often have to deal with. For example, diabetes, osteoporosis, pain management and heart-related issues. I would like for us to make the lives of patients with thalassaemia to be functional and comfortable. I also think global awareness is very important. I don't want to hear that children in Nepal are dying because they do not have access to proper medical treatment or that they are dependent on the generosity of a few individuals.

What has being a parent of a child with thalassaemia taught you?

Patience. I don't just mean with that in regard to raising a child with thalassaemia, but in all aspects of life. I used to be a very impatient person, so I sometimes wonder if this was a lesson I had to learn. It has also taught me to question things as I have always had to advocate for my son.

As a parent of a child with thalassaemia, what advice can you give to a parent who has just received the same diagnosis for their child?

Do your own research and don't be scared to question everything. You have to advocate on behalf of your child until they are old enough to do it for themselves. Also, I would advise them to get involved with UKTS. The charity organises patient support groups, conferences and many more events where you can learn really useful information and also meet others who are going through similar experiences.

Sons Stephen and Nicholas.

Place you would most like to visit and why?

I feel a real connection with Italy, I love the language, the food and the style. I would love to really explore it properly.

Oddy's Daughter Marianna and grandaughter Isabella

What is your greatest achievement, personal or professional?

Personal? Definitely my three kids and my 11-year old grand-daughter Isabella. Professionally, it is creating things that make people happy.

Thank you for a really interesting interview. One last question, if you could interview anyone in the world, who would it be and why?

Elvis Presley. I don't know why! And Princess Diana, to ask what she thought of the current monarchy and the chance that Camilla could be Queen! In all seriousness, I'm sure Diana would be very proud of her boys.

Romaine Maharaj takes the helm at UKTS

Romaine Maharaj will be a familiar face to many of you, having been actively involved with UKTS for many years; firstly, as a volunteer and then serving on the UKTS Board of Trustees from 2010 to 2018. Last year, she made the momentous decision to walk away from a job she loved, within the diplomatic community, to take the position of Executive Director at UKTS.

Whilst her Caribbean accent might lead you to believe she is laidback and slow-paced, Romaine is anything but these things! In fact, since taking the helm at UKTS, she has been extremely proactive and accomplished a great deal. Moreover, she is totally dedicated to the charity – leading her small team towards various achievments, some of which are:

Office refurbishment

One of the first things she chose to tackle was the office itself. Although in dire need of a makeover (the antiquated plumbing included outdoor toilets), other pressing matters resulted in this being put on hold for almost 20 years. She is particularly proud of this achievement as it also resulted in her meeting Oddy, who jumped in and rendered much needed guidance and help. The results of the refurbishment are still being commented on by visitors and passers-by.

Internal operations

The team resolved some long-standing banking issues, upgraded the computer and IT system and implemented operating procedures which led to numerous cost-savings.
The database has been updated so that UKTS now has email contact details for almost 200 more members.
GDPR has been updated in line with current regulatory requirements.

Events

Previously, based on the small staff, there was generally one event per year; either patient-focused or a medical conference. Last year, the charity organised two really successful patient conferences, one in Leeds and the other in London (see pages 32-33).

Additionally, to recognise the 40th anniversary of the society, a gala event was planned and executed with huge cost savings.

Patient Support

- As a follow-up to the two patient conferences, the charity recently introduced patient support group meetings. A team from UKTS travelled to Birmingham along with specialist doctors to collaborate with patients, offer support and better understand their needs.

- An Ambassador Programme has also been launched, whereby 'ambassadors' will be trained and represent the charity across the UK. They will assist the society where possible with the organisation of local events within their communities and be another point of contact for patients in their region.

- The charity has been working with patients to understand the changes to PIP claims. Representation has also been made on a governmental level to highlight some of the issues needing to be addressed with regard to the application process and treatment of our patients.

Funding

Some of the funding efforts are covered throughout the magazine but here are a few examples:

- Gift aid claims were processed for five years leading to an additional income of £8,900.00

- The 2019 London Marathon saw an increase in runner participation and fundraising.

- The charity secured a Breaking Down Barriers grant for £5,000.

Awareness-raising

The charity has been fortunate in attracting the interest of some prominent dynamic individuals who have since agreed to become patrons for the society. They have already been actively participating with the team towards making a real difference in the lives of patients and families.

The charity has also significantly stepped up its social media presence, helping to raise much-needed awareness of the condition.

Several television and radio interviews were arranged and articles on the work of the society featured in multiple newspapers and websites.

Other projects

- After discussion and a subsequent presentation at the launch of the Infected Blood Inquiry in September 2018, the charity was invited to become a core participant. The charity called for those directly affected by the contaminated blood scandal to get a fair hearing during the inquiry while working with its members and families towards supporting the inquiry itself.

- UKTS was also invited to participate in the review of the nursing midwifery standards of care and was able to ensure that relevant information on thalassaemia was included.

- The NHS Screening Programme (jointly run with Sickle Cell Society) is progressing well with a current focus on early diagnoses.

- Although every attempt was made to produce regular newsletters, the issue with staffing and manpower only allowed annual publications. Following repeated requests from members, the team was increased to facilitate the production of quarterly issues of the publication.

- Peer reviews – UKTS continues to be a part of the reviews, ensuring that centres treating thalassaemia are following national guidelines.

- APPG: a brand new All-Party Parliamentary Group was recently registered for thalassaemia, to specifically address the unique issues affecting our patients.

Launch of UKTS Ambassador Programme

Exciting new voluntary role

We are recruiting volunteer ambassadors to spread the word about the work of our charity and to support patients in their local areas. UKTS is dedicated to supporting patient and families of the thalassaemia community. We support over 1,200 people a year across the UK by providing much needed advice and guidance. We want more people in all communities to know about us and we want to raise vital funds to continue supporting those who need it most.

Our ambassadors will work as part of a regionally based network and the role will involve:

- inspiring people to support the charity,
- raising awareness about what we do, and
- increasing the charity's geographical reach to support more patients

What would we like our ambassadors to do?

- Liaise with patients, families and groups in the area,
- organise local fundraising events, ensuring that all donations and expressions of interest in fundraising and volunteering are passed back to the fundraising team,
- deliver engaging talks about the work of the charity at award evenings, dinners and fundraising events using presentation materials and literature supplied by the charity,
- use social media to contribute to the online presence of the society, and
- signpost patients to the necessary support.

Would YOU like to be an ambassador?

If you are:
- a confident individual who is passionate about the society's cause,
- have existing links and networks within the wider community,
- have good communication and organisational skills,
- are able to work on your own initiative, and
- are willing to ask the audience to support the charity through fundraising or volunteering, then please get in touch with the UKTS team for an informal chat about the role or to register your interest.

How much time commitment is involved and how we will support you?

We expect a minimum of three hours per month and a minimum of one year commitment to the role, due to the investment of time and resources in recruiting, training and supporting you as an ambassador. We want to make sure that all ambassadors feel equipped to carry out this role confidently and effectively, and so the UKTS team will support you in a number of ways:

- a welcomemeeting which will be 1:1 with one of the team or in a group with other ambassadors if recruited at the same time,
- an induction pack containing presentation materials, information leaflets, fundraising materials and tips,
- regular contact with the fundraising team to provide updates on the society and its work, and to offer any advice or guidance relating to your role,
- liaison with ambassadors working in other regions to share ideas and information.

Expenses and codes of conduct

We will reimburse any agreed out of pocket expenses incurred when carrying out this volunteer role in line with the society's volunteer expenses policy. In addition to the specific tasks outlined in this role, ambassadors are required to operate within the society's relevant policies and guidelines.

We already have some Ambassadors signed up and rearing to go! We will be featuring their profiles in the next issue of the newsletter…

The barriers to employment and the potential adjustments

Maria Cajucom did an internship, working with Professor Simon Dyson and Dr. Maria Berghs on a study of thalassaemia and employment. She reports their findings.

A short study conducted in conjunction with the graduate champion internship at De Montfort University and part of a larger study funded by the Disability Research on Independent Living and Learning (DRILL) explored the different challenges faced by people with thalassaemia major in activities, work and employment. As employment is an integral part of everyday life, adjustments ought to be made by employers, fellow colleagues, recruiters and service providers such as the NHS to provide a better working environment and opportunities for people with thalassaemia major.

The study found that obtaining time off work for treatment and other appointments is the greatest challenge in employment. Therefore, hopes for more flexible working hours to overcome this issue were significantly expressed by many participants of the study. Tiredness, fatigue, pain and mobility issues were also frequently mentioned as significantly challenging whilst working. Some participants suggested that a blue badge and access to car parking would help with the mobility issues that they experience. These are largely caused by pain and fatigue, which is particularly bad closer to the time of blood transfusions. Disclosure was also an issue that was often raised; whether in the phases of job seeking or during employment, participants were weary of whether to disclose their condition to employers as they felt less likely to get the job with the need for multiple days off for treatment and appointments. Others felt tired of repeatedly explaining the condition yet still feeling misunderstood by colleagues and employers.

This was one participant's response, "We are, I suppose all individuals with this condition, some worse off than others…I feel there are quite a few issues that affect most patients. They probably don't realise it but the most important is mental health. When your haemoglobin yo-yos up and down, I find it can be quite a battle with my state of mind. It's scary that pre-transfusion you can feel so negative and pessimistic and post-transfusion very optimistic and positive about everything. This then makes dealing with the everyday pain I endure and even just interacting with people quite a struggle at times."

Employment is necessary in everyday life and need not be a struggle for anyone with thalassaemia. With simple adjustments, and some additional support the work environment may be improved providing safe, comfortable and fair opportunities for work for people with beta-thalassemia major. In fact, many people with thalassemia have already shown perseverance despite difficulties and have gone on to lead successful, long-lasting and meaningful careers in a range of different fields.

The study found that obtaining time off work for treatment and other appointments is the greatest challenge in employment

Thoughts, feelings and thalassaemia

It is natural for us all to feel low at times, especially when you are living with a chronic condition like thalassaemia. Dr Chinea Eziefula explores some of these psychosocial issues and signposts the support services available.

There is a strong relationship between what you think, how you feel and what you do. As the philosopher, Rene Descartes said "We do not describe the world we see, we see the world we can describe."

A lifelong condition like thalassaemia can have a significant impact on your view of yourself, the world around you and your future. In turn, this can then affect the emotions you might feel (for example, sadness, guilt, regret, anger, frustration or worry) and how you cope and respond to these thoughts and feelings. The complications of managing medical treatments and changes in health while also trying to deal with the ups and downs of life are commonly reported by many patients and their families.

Living with thalassaemia can affect self-esteem, confidence and general mood. It is very common for people with thalassaemia to feel worried, stressed and/ or low in mood at one time or another, depending on what is happening around them in their lives or related to their condition. These are normal emotional responses to dealing with the challenges of living with a chronic illness. Some people with thalassaemia report being able to cope with these feelings in their own ways and others find it helpful to talk to their specialist haematology team about how to get help and support with these feelings from healthcare professionals. Everyone is different and it is okay to ask for help – that is what your haematology team is there for.

Your mind is part of your body too and asking for help with how you might be feeling because of the challenges of living with thalassaemia is okay.

How to get help

Haematology psychologist:

Ask your specialist nurse or consultant about what type of help is available to you to help you with the thoughts and feelings that come with thalassaemia. It may be that there is a psychologist within your haematology team to whom you can be referred for a consultation. With the psychologist, you can discuss therapy options to help you understand and deal with any challenging thoughts, feelings or situations linked to living with thalassaemia.

Other support services:

Whilst not all haematology departments in the UK will have a psychologist as part of the team, your consultant or specialist nurse should still be able to advise you on how to access psychologist support. Alternatively, they may direct you to community-based support groups and services. Your nurse may even suggest peer-to-peer support where they put you in touch with another patient who is experiencing similar feelings. There is always the option to speak to your GP about what support is available to you.

IAPT services:

You can also consider looking for support via a local improving access to psychologist therapy (IAPT) service using the following link (https://www.nhs.uk/ServiceSearch/Psychological%20therapies%20(IAPT)/LocationSearch/10008) . Most IAPT services accept self-referrals meaning that you can refer yourself online or by phone. Alternatively, you can be referred by any healthcare professional including your GP or **your haematology team.**

UKTS:

If you are struggling to get help with any of these issues, you can call the UKTS office and they will try and direct you to the support you need. In the future, UKTS is planning to run group support sessions at their office in Southgate. If you are interested in attending these, please express your interest by emailing info@ukts.org.

Dr Chinea Eziefula is a Clinical Psychologist and the Haematology Psychology Service Lead at Whittington Hospital. She will be writing a regular piece for our quarterly magazine, so if you have any particular psychology-related topics that you would like her to write about, please send us your suggestions at info@ukts.org.

Dr Chinea Eziefula

European conditional approval for gene therapy to treat thalassaemia

On the 3rd June 2019, Bluebird Bio announced that it had received conditional marketing approval from the European Commission for Zynteglo, its gene therapy for beta thalassaemia.

Initially, patients will have to meet certain criteria to be eligible for the therapy but trials could expand its use in the future. Through its gene therapy, Bluebird Bio is confident that patients will achieve transfusion independence. In other words, the effects of their one-time gene therapy treatment would be permanent with patients no longer needing transfusions.

Simple answers to common questions (*more indepth information in our next issue*)

What exactly is Gene Therapy?

Gene therapy is a is technique thats uses genes to treat genetic conditions. The therapy aims to replace mutated or non functioning genes which causes disorders with a healthy copy of the gene.

In the case of thalassaemia, the production of the protein haemoglobin (the part of the red blood cell that carries oxygen) is affected. Gene therapy aims to correct a person's genetic code so that they can produce haemoglobin successfully.

What is the process of gene therapy?

1. Patient is given G-CSF(granulocyte colony stimulating factor) to move from the bone marrow to the blood.
2. Patient's stem cells are then collected from the blood by a process called apheresis.
3. The collected stem cells are then sent to the laboratory to be corrected.
4. The corrected cells are then inserted into a viral vector (which acts as a vehicle). The viral vector cannot cause infectionas it's genetic code is removed.
5. The corrected cells are then transfused into the patient (after the patient receives a short course of chemotherapy. This is to ensure that only the corrected cells are replicated).
6. The corrected cells then produce the desired protein: haemoglobin.

Will having chemotherapy affect my ability to have children?

Yes, however there are many ways which can help you have children in the future:

- egg retrieval
- ovarian tissue freezing
- sperm collection

Luspatercept: under the spotlight

Dr Shivan Pancham, Consultant Haematologist at Birmingham City Hospital, explains the science behind Luspatercept, the drug being clinically trialled for patients with thalassaemia.

Current treatments for thalassaemia for the majority of patients consist of blood transfusions and iron chelation treatment to remove the iron that builds up from the transfused red cells. Bone marrow transplantation is available for a minority of patients due to the toxicity of the procedure and lack of suitable donors. Emerging therapies for thalassaemia are agents to improve haemoglobin (such as Luspatercept) and gene therapy.

What is Luspatercept and how does it work?

The genetic changes in thalassaemia result in reduced haemoglobin production and premature death of the early red cells. The bone marrow which makes red cells is expanded due to ineffective production of red blood cells (RBCs). Various signals control the maturation of RBCs. Some of these signals block the later stages of RBC development; one group of these signals is called the transforming growth factor beta (TGF-beta) family. Luspatercept acts as 'trap' for this group and allows development and maturation of RBCs.

What is the evidence that Luspatercept works?

Luspatercept was investigated in a clinical trial (BELIEVE) to look at the effect on haemoglobin, transfusions and side effects. The study was conducted at various centres in Italy and Greece. The study was conducted in various stages and the results were published in January 2019. Some 64 adult patients were enrolled, 33 were non-transfusion-dependent (mean haemoglobin less than 10g/dL) and 31 were transfusion dependent receiving more than four units of RBC in eight weeks. Patients were on the trial for an average of 428 days (21-768).

One half of the patients with non-transfusion-dependent thalassaemia who received the higher doses of Luspatercept had increases in haemoglobin of 1.5g/dL. The majority (80%) with transfusion dependent thalassaemia developed a 20% reduction in transfusions. Better responses were seen in patients who had higher doses of Luspatercept. Some patients had an improvement in levels of liver iron.

How is Luspatercept administered?

As a subcutaneous injection every three weeks.

What are the side effects?

The most frequent were bone pain, headaches, myalgia, arthralgia, musculoskeletal pain, back pain, and injection site pain. These tended to be more noticeable in the first eight weeks of treatment.

How will Luspatercept be used?

Luspatercept will be used along with other treatments for thalassaemia. The hope is that the improvement in haemoglobin will result in fewer transfusions, lower iron levels and will make patients feel better.

Outstanding questions?

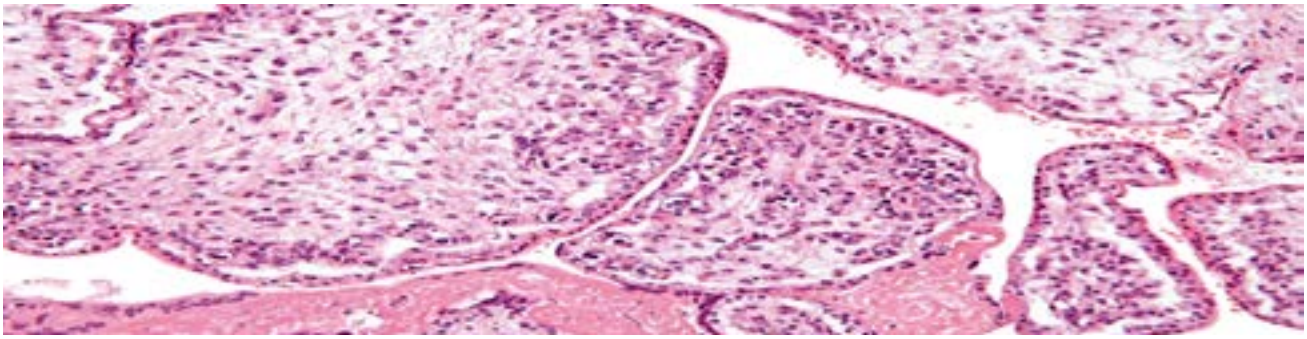
Further studies are always needed with any new treatment. Areas such as the safety profile, the impact on iron chelation, use in paediatrics and which patients will get the most benefit from Luspatercept will need to be determined.

Next Steps?

The company is currently seeking approval in the US with the FDA.

Parvovirus infection

Consultant haemotologist, Anne Yardumian tells us why parvovirus can affect people who have thalassaemia, sickle cell or other red cell breakdown anaemias ('haemolytic anaemias').



Parvovirus B19 causes a common childhood illness known as 'fifth disease', a mild rash illness with fever. Adults can get infected with parvovirus B19, too. It can spread from person to person by 'droplets', when the person coughs or sneezes. Therefore, it can commonly affect several members of a family at the same time. People tend to get infected with parvovirus B19 more often in late winter, spring, and early summer. Mini-outbreaks of parvovirus B19 infection occur about every three to four years. Other much less common symptoms of parvovirus B19 infection include painful or swollen joints, more common in adults. The virus is usually self-limiting, and mild, and once a person has had the infection, they will then remain immune to further episodes in the future.

However, it is important and can cause some additional problems for people with long term red cell conditions. This is because the virus causes the bone marrow to 'switch off' production of red blood cells. Less often, production of white blood cells (which fight infection) and the platelets, or clotting cells, can also be dampened down.
In most people, the red cells last about three months in the blood, and so the marrow production halting for a few days doesn't matter, and doesn't cause any significant fall in the blood level, or anaemia. However, in conditions such as sickle cell disease and non-transfusion dependent thalassaemia, also haemoglobin H and other haemolytic anaemias, maintaining the usual blood level depends on the marrow making red cells at a much increased rate, to make up for those that break down in the circulation.

For example, in sickle cell anaemia the red cells may last only about ten days in the circulation, so if the bone marrow stops making enough to make up for the breakdown for even a few days, the blood level or haemoglobin can fall and the person can become more severely anaemic.

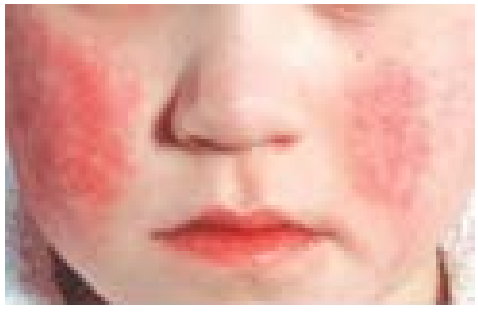
When you have a blood test, we often check not just for the total numbers of red cells, white cells and platelets, but also for the numbers of newly produced or young red cells – these are called 'reticulocytes'. If your haemoglobin has fallen for any reason, your bone marrow normally responds by increasing its output of red cells to make the numbers up again. If your low blood level is caused by this parvovirus infection, however, the bone marrow can't respond by making additional red cells and the reticulocytes in the blood will be low. This combination will often cause your nurses and doctors to question whether you have parvovirus **infection and there is a simple blood test to check if you have (looking for the IgM antibody to the virus).**

If the blood level falls unduly – and how low a level you can safely tolerate depends on how old you are and any other medical problems you may have, so there is no 'one size fits all'… – you may need a simple 'top-up' transfusion to keep the levels up until your own bone marrow starts up making red cells again, usually after about 5-10 days. Sometimes, more than one transfusion may be necessary, if the blood levels continue to fall after the first. Your team can predict when you are recovering and not likely to need further transfusions once the reticulocyte count picks up.

There is no specific treatment for the infection, and currently no vaccine which could prevent it. But do not worry! The infection seldom causes problems other than the temporarily worsened anaemia, which can easily be managed with red cell transfusion.

SO – if you or your child have one of these red cell conditions, then:

- try to avoid having contact with anyone known to have the infection.
- If you have had contact, be watchful for any symptoms, which might include fever or rash, or you / they just may start feeling more tired than usual and looking pale.
- If you have these symptoms, or if you are in any doubt, contact your usual red cell paediatric or haematology team, and tell them you think you may have parvovirus infection and they will do the necessary checks, and continue to monitor and give any treatment you require.



Joint APPG pushes for improvements to PIP and changes to the Nurses Curriculum to include training for nurses

UKTS and Sickle Cell Society(SCS) jointly shared responsibility for the All-Party Parliamentary Group for Sickle Cell Disease (SCTAPPG) and Thalassaemia. In 2018 we worked together on two main projects, one on Personal Independent Payments (PIP) and the other on nurses' curriculum / inclusion of training on both conditions.

Following an APPG meeting in June 2018, where we presented a report, with evidence on the failures of the PIP system for people living with sickle cell and thalassaemia, we were invited to meet with the Secretary of State for DWP – Esther McVey MP, her Minister Sarah Newton MP and senior representatives of the Department of Works and Pension (DWP) providers of the PIP system. The Chair of the SCTAPPG Diane Abbott MP was also present at the meeting.

It was a very constructive meeting with DWP officials acknowledging that action should be taken on the main recommendations contained in our report:

1. Assessors require training and education on sickle cell and thalassaemia

2. Equality Impact Assessment on PIP form 2 which is completed by applicants

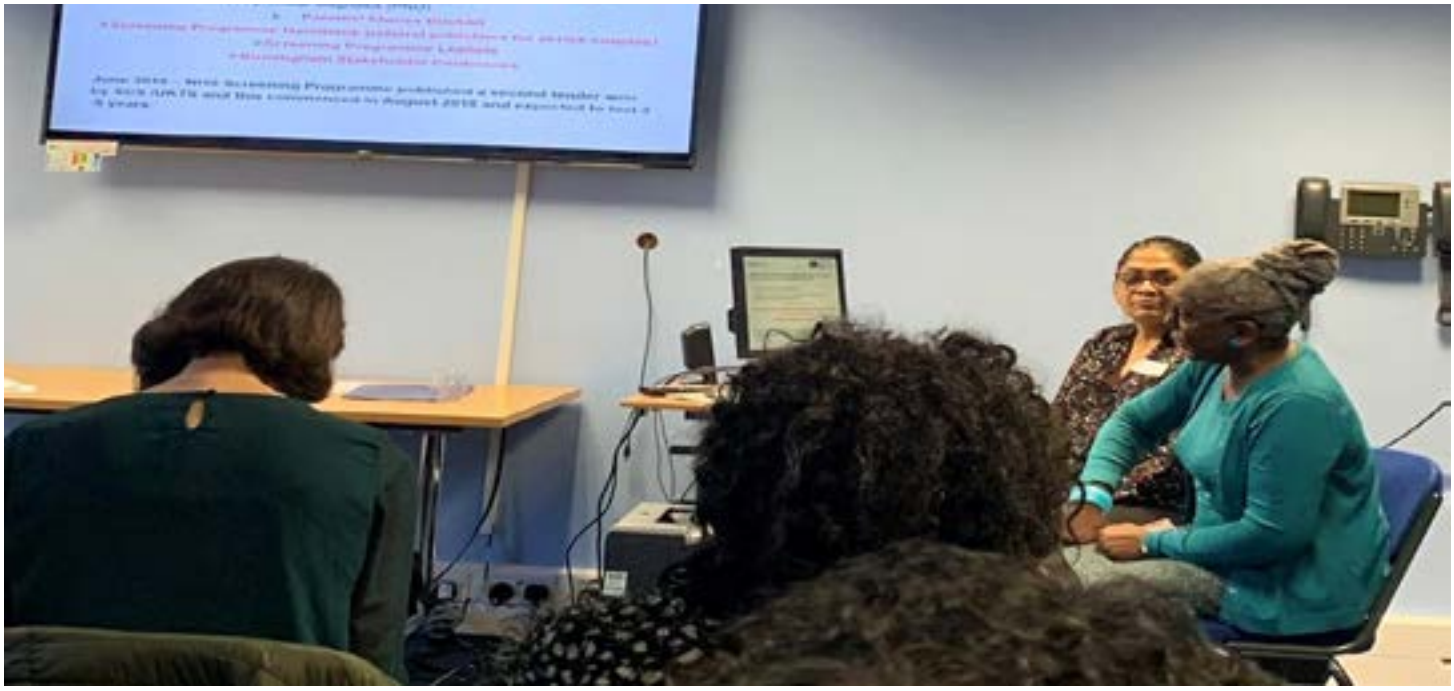
We have had several meetings with the officials from the DWP officials to date and will work alongside them towards creating a specialist training programme for their front line staff. We are hopeful that our continued collaboration will equip the assessors with sufficient knowledge on both conditions to properly assess the applicants and make the experience less stressful for everyone.

Nurses Curriculum

SCTAPPG published a report on the lack of representation that thalassaemia and SCD have in pre-registration nurses and midwife education. The report "I'm in Crisis" was presented in Parliament on the 20th November 2018 and included information and results of a survey circulated to 197 students, from nine nursing and midwifery schools and faculties. It was reported that the majority of participants responding did not have any formal training on thalassemia or sickle cell nor did they feel confident enough to nurse anyone with either condition. The recommendation was that Approved Education Institutions should incorporate thalassaemia and sickle cell into all components of training by working alongside professional bodies and charities. The report also provided recommendations on the way forward. Meetings have been scheduled with the Nursing Medical Council and Health Education England for further discussion.

The joint APPG with Sickle Cell Society has been a hugely fruitful collaboration. However, we felt the time was right for us to set up an APPG solely for thalassaemia (see p12), in order to deal with the specific issues that affect people with thalassaemia. We would like to thank all our colleagues at Sickle Cell Society for our co-working efforts and we wish them every success in the future.

An update on the joint NHS Screening Programme



Romaine Maharaj and Iyamide Thaomas presenting at a STANMAP meeting recently.

As most of you already know, we have been working alongside the Sickle Cell Society for our NHS Screening Contract. For the contract we are partnered with Ms Iyamide Thomas, a dynamic individual with years of knowledge and experience. Iyamide has been working alongside our team for a number of years and our joint collaboration has successfully managed the huge workload associated with this project to bring about outstanding results. Together, the parent stories booklet and other pertinent publications were produced.

This year we will be concentrating mainly on supporting the work of the Screening Programme and the Newborn Outcomes System (NOC) which supports the referral of babies and families with thalassaemia and sickle cell disease as soon as the baby is diagnosed.

A new electronic system has been developed to flag the results of the 5-day heel prick test (newborn blood spot screening) currently done on all new babies. Newborn blood spot screening involves taking a blood sample to find out if your baby has 1 of 9 rare but serious health conditions. Once diagnosed, the results are automatically forwarded to the clinician responsible for the child. This is particularly important as it ensures that the parents are referred for counselling earlier and the child gets access to treatment immediately (penicillin and so on).

The system being introduced is linked to the National Haemoglobinopathy Registry (NHR), and it is vital that the parents and families are aware of the importance of the registry itself. One of our tasks will be to ensure that this information is shared with all our members and interested families.

The societies will also be working together to create handbooks or parents' guide for both conditions. While we will be working to create separate handbooks, this will be done as a joint project as some of the information included will be similar to both conditions. We are pleased to report that we have the support from most of our consultants for this project.

Both charities are looking for volunteers for the focus and support groups so please get in contact with either of them, if you are interested.

Infected Blood Inquiry

UKTS is one of the charities that has been appointed as a core participant of the Inquiry. Since the hearings have got underway, there has been widespread news coverage of the devastating impact to many people's lives from the contaminated blood.

UKTS Presentation:

In September 2018, UKTS consultant Roanna Maharaj presented on behalf of UKTS at the preliminary hearings of the Infected Blood Inquiry which took place at Church House in Westminster, London.
She said "According to the National Registry of Haemoglobinopathy, there are some 1,000 people living with thalassaemia major in the UK. Of these, 23% contracted hepatitis C as a result of being given contaminated blood in the 1970s and 1980s." On behalf of all thalassaemia major patients, she urged the inquiry for a full and thorough investigation into why and how this atrocity was allowed to happen.

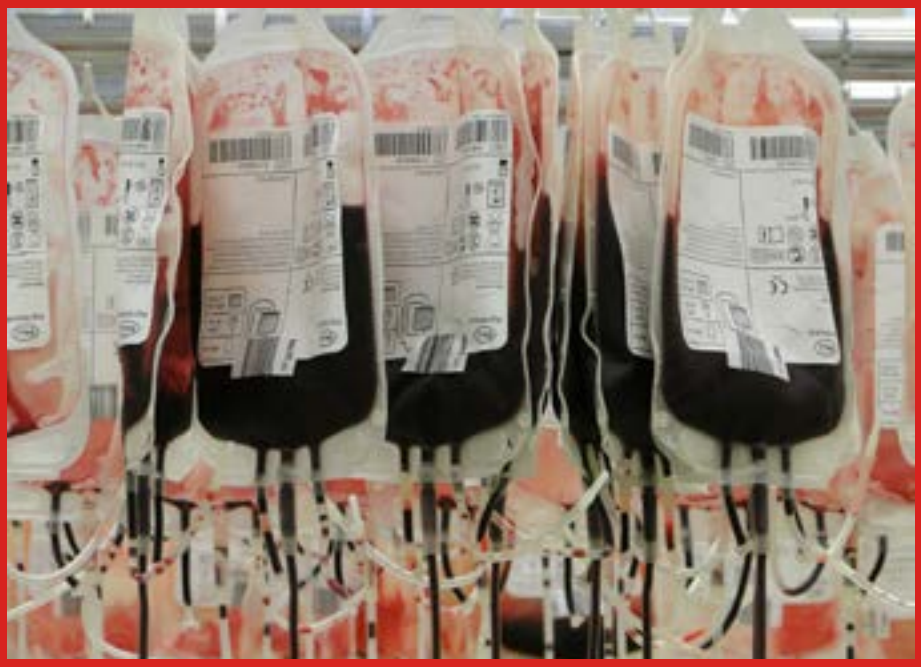
(You can watch Roanna's full presentation on our social media channels).

Inquiry update

In April this year, the Inquiry began the process of gathering evidence by hearing witness statements from infected and affected people. These began in London but hearings will continue across the UK at venues in Belfast, Leeds, Edinburgh and Cardiff. This process is expected to last a few months but the schedule is regularly updated and can be viewed at:
www.infectedbloodinquiry.org.uk

What is the Infected Blood Inquiry?

During the 1970s and 1980s, it is estimated that some 4,000 people with blood disorders were infected with hepatitis C and over a quarter of these were also infected with HIV, the virus that leads to AIDS. Over 2,000 have since died. The Inquiry will examine why men, women and children in the United Kingdom were given infected blood and/or infected blood products; the impact on their families; how the authorities (including government) responded; the nature of any support provided following infection; questions of consent; and whether there was a cover-up.



When the Inquiry was formally launched in July 2018, Sir Brian Langstaff, Chair of the Inquiry said, "What is difficult to comprehend is the sheer scale of what happened. The numbers of people, both adults and children, from all walks of life who were infected by Hepatitis viruses, or HIV, from clotting factor or transfused blood runs into thousands. At least as many more – including partners, children, parents, families, friends or carers – have been affected. This may have happened principally in the 1970s and 1980s, but the consequences persist today with people continuing to feel the mental, physical, social, work-related and financial effects. Many of the people infected and their families have battled for years to understand what happened and how they have been treated since. I aim to put the people who have been infected and affected at the heart of this Inquiry. I am determined to get to the truth and where necessary will use the Inquiry's power to compel witnesses to explain their actions."

Infected Blood Inquiry Contact details:
Tel: 0808 169 1377
Email: contact@infectedbloodinquiry.org.uk
Address: Fleetbank House,
1st Floor, 2-6 Salisbury Square,
London EC4Y 8AE
Twitter: @bloodinquiry
Website: www.infectedbloodinquiry.org.uk

Support for *those affected*

The Inquiry is funding a confidential support service for anyone affected by treatment with infected blood or blood products. This is run by a team from the British Red Cross who have been working with the Inquiry since September 2018. If you feel distressed by the coverage of the Inquiry, you can contact the confidential support service directly by calling 0800 458 9473.

As a core participant for the inquiry, UKTS would like to urge those patients and families who were infected or affected with contaminated blood to come forward and share your stories. Please note that this can be done in person or via a third party as we respect your privacy.

Why we need to share education in haemoglobinopathies

More needs to be done in terms of educating medical professionals about thalassaemia and other blood disorders. Giselle Padmore-Payne is the Roald Dahl Transition, Senior Clinical Nurse Specialist and Team Lead for Adult Haemoglobinopathies at King College London. She describes how her team is striving to achieve this through their accredited study days.

It is an established fact that there is a lack of education for pre-registered and post-registered nurses and allied health care professionals around haemoglobinopathies. In the report launched at the All Party Parliamentary Group for Sickle Cell & Thalassaemia 'I'm in Crisis', it states that "following a number of damming reports about poor care and management of people with SCD and avoidable deaths occurring in the NHS, the first specialist centre was established in Brent in 1979. Since then there has been major improvement in scientific research and advances in treatment and knowledge of these conditions. Several specialist centres have evolved in the last four decades".

Furthermore, the outcome of a survey conducted (Dr Chakravorty, et al, 2018) in conjunction with the Picker Institute published that patients with SCD "report of staff's lack of knowledge, skill and competence and negative attitude to the patient group culminating in provision of inadequate and poor healthcare".

Giselle Padmore-Payne

Patients interviewed stated:

"The help at [certain hospitals] has been good. I avoid some because of the lack of knowledge and care provided there." (Picker 2015:12)
"Adults and parents appeared to have less confidence in the knowledge of the emergency healthcare staff, reporting that 21% and 17% respectively did not know enough about sickle cell disorder relative to only 5% of children." (Picker 2015:18)

In spite of recent published data showing why education is required for professionals who provide care for patients with such a specialised condition as SCD, unpublished data from patients with thalassaemia has also shown that the same standard of care is also required. It has been my mission to improve the standard of care delivered to patients with both SCD and thalassaemia, through education that is accredited by the Royal College of Nursing (RCN) with health care professionals who are experts in the field delivering the necessary presentations, as well as patients having the opportunity to share their experiences.

As discussed with Gary Bridges, our Haemoglobinopathies Psychologist, feedback from a psychological perspective from an anonymous patient suggested "a patient would feel misunderstood and not valued and demotivated if they thought a nurse or a doctor did not understand their health condition; or they could feel frustrated and angry if they think the health professional should know; or even anxious and worried if they are concerned about them not treating them correctly. Or maybe a combination of all three". It depends on the way the patient interprets it and their own individual circumstances and personality. We do have open access for our patients to discuss such matters with the team and others in peer support groups.

At King's College Hospital, I am very fortunate to have a team dedicated to improving patient standards of care. We work coherently between the paediatric team and adult team and we enhance the patients' experience and quality of life by sharing our knowledge and expertise with others. Over the last two years, we have educated 236 nurses, doctors and allied health care professionals from across departments that range from Emergency Department, Paediatrics, Haematology Wards, General Medical Wards, Surgical Wards, Liver, Renal, ITU, Pharmacy, Antenatal Wards, - community teams and Outpatient Departments with the now accredited 'Sickle Cell and Thalassaemia Study Day', which is being hosted as part of the South Thames Sickle and Thalassaemia Network (STSTN)

Over the last two years, we have educated 236 nurses, doctors and allied health care professionals from across departments.

This year the study days will be hosted at King's College Hospital and Guy's Hospital sites. As part of the course, I have created Sickle Cell and Thalassaemia Workbooks for both paediatrics and adults. The workbooks are based on documents such as the National Standards of Care for Children and Adults with Sickle Cell and the Royal College of Nursing (RCN) competencies 'Caring for people with Sickle Cell Disease and Thalassaemia syndromes'. The workbooks are intended for use by all attendees who provide care for patients with haemoglobinopathies, ensuring that participants have information that is useful and can act as a reference guide – reminding them of the important steps of providing safe and effective care.

I would like to thank all members of the King's College Hospital haemoglobinopathy team, South Thames Sickle and Thalassaemia Network (STSTN) and members of the inter and multi-disciplinary teams, as well as our sponsors of the training days. We thank the attendees for raising awareness, improving knowledge and skills towards delivering the best possible care for our patients. Lastly, we thank our patients for sharing their experiences.

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Summary of current management systems for Haemoglobinopathies in the United Kingdom

Dr. Emma Drašar explains how NHS England is changing the way that services for people with haemoglobinopathies and rare anaemias are organised and funded in the UK.

Dr. Emma Drašar

In the past, specialist centres self-identified which meant that there were a range of sizes and distributions across the UK. This led to some areas having a high density of specialist centres, whereas in others there was less access to care for patient. Haemoglobinopathy care is directly funded by NHS England but this relies on health care trusts correctly 'coding' and applying to NHS England for money.

Over the past year, NHS England has been trying to make access to specialist services more equal across the country by incentivising trusts to join up in networks of specialist centres and smaller centres to make sure that all patients have access to good care. As a result of this, all the specialist centres have to reapply for that designation.

Only specialist centres will now receive the direct funding from NHS England and will distribute this to local centres. To be a specialist centre you have to meet a certain set of criteria, in particular the number of doctors, nurses and psychologists that are trained in haemoglobinopathy as well as special services for patients (for example, availability of transfusion).

If the trusts don't meet these criteria then there is the potential for NHS England to withdraw funding and give it to another centre which does meet the criteria. Targets have been set for compliance with guidelines, availability of scans and so on and these will be audited.

Certain trusts will be designated Haemoglobinopathy Coordinating Centres (HCC) and they will have oversight of the specialist centres and make sure that they are toeing the line! The HCCs will also organise an on call so that 24/7 there will be a haemoglobinopathy expert available on the end of a phone if someone becomes unwell and the local team has questions or needs management help.

There is also going to be a National Haemoglobinopathy Panel formed which will be comprised of experts to discuss complex patients or treatment decisions. Hopefully this will all lead to an improvement in patient care across the country and mean that there are enough doctors and nurses to keep the services performing well into the future.

Dr. Drašar is a consultant haematologist at the University College Hospital London and Whittington Hospital. She is also the North Central Haemoglobinopathy Network Lead.

Family conferences in Leeds and London

In 2018, UKTS held two family conferences across England, in order to be more accessible to our members. The conferences were held on Saturdays; March 10th (London) and April 11th (Leeds) and were completely patient driven.

The conferences were chaired by Roanna Maharaj, a beta thalassaemia major patient with professional graduate training on the psychological aspects of haemoglobinopathies. The social media desk and question and answer segments were managed by the Vice-Chair of the UKTS, Anand Ghattaura, a beta thalassaemia major patient with a professional background in brand, marketing and communications for one of the Big-4 accountancy firms. Each conference included a panel of two presenting doctors who also took part in the patient discussions and debates held later in the day.

In London, Dr. Paul Telfer (Consultant Haematologist at the Royal London Hospital and Senior Lecturer at Queen Mary Medical School) presented on 'new developments in treatment' while Dr. Emma Drašar (Consultant Haematologist at the Whittington Hospital and University College Hospital in London) presented on 'living long and looking good'.

In Leeds, Dr. Emma Drašar presented on 'new developments in treatment' which was followed by Dr. Christine Wright (Consultant Haematologist at Birmingham City Hospital) who presented on 'living long and looking good'.

The 'living long and looking good' presentation promoted the importance of taking iron chelation treatment as prescribed. Not only was damage to internal organs discussed – from not following a rigid chelation regime – but also the visible effects to organs, such as the skin being affected by becoming darker and more pigmented.

The presentation entitled 'new developments in treatment' focussed on the current trials that are underway in the UK for Luspatercept (the haemoglobin-increasing drug) and gene therapy.

The latter half of the conferences focussed on the psychological aspects of living with thalassaemia, which was followed on by many discussions and debates.

The second part of the morning session focussed on patients' stories where we were heard some incredible and deeply inspiring life stories - which we hope will be featured in future magazines.

The conferences were a huge success and we intend to organise more for next year. We would like to say a huge thank you to all the doctors and patients for taking their time to present at our conferences and to all our members and the health care professionals who attended the meetings.

Photis, Chriso and Maria Papaiacovou

"A very inspirational and informative conference and an opportunity to bring all thalassaemia groups together and share issues and concerns."
Nighat Basharat, NHS EPIC link worker

"UKTS have given me a lot of support. Recently they had a conference and it was really great because there were other thalassaemia patients at the event. It is really important to have that relationship, those connections with other people that have thalassaemia, because it's reassuring and you learn about the latest treatments."
Meliz Toros, thalassaemia


Meeting in London

"The conference was beneficial to my general knowledge and it's given me a better understanding. I met some great people who shared their life experiences of living with thalassaemia. But it also made me much more appreciative about the iron chelation we have nowadays compared to the Desferal gun." Qadeer Akhtar, thalassaemia patient

Same But Different

Our member Meliz Toros was invited to take part in an exciting project by 'Same but Different', a not-for-profit organisation who use the arts to give a greater voice to those affected by disability and rare diseases. Below is the blog by Meliz that is featured on their website.

"I have beta thalassaemia major which is a blood disorder that reduces the production of haemoglobin. Haemoglobin is the iron-containing protein in red blood cells that carries oxygen to cells throughout the body. Every three weeks, I have to have a transfusion of three units of red blood cells which takes all day. Because of the excess blood, and the excess iron in the blood, I need to then have regular medication to get the iron out of my system.

I was diagnosed pretty late, at three years old. My mum said I used to cry a lot when I was younger and there was never really a reason. I then started to get jaundiced and my eyes and skin started to go quite yellow. It was then that I was diagnosed.

Having this condition really affected me when I was younger. I used to take a lot of time off school for doctors' appointments, hospital appointments, transfusions, blood tests and just through being tired in general. It really affected me academically and since then has caused issues with employment as I still need to take a day off for transfusions every three weeks. Not all employers are sympathetic or understand why it is essential.

Because of the transfusions, it is recommended that I keep my iron intake low so I don't eat too many foods that are naturally high in iron, like watermelon, spinach and broccoli. I have also been told that it might help to drink black tea when I eat meals as it reduces iron absorption.

In my family I'm the only one with the full blown illness. I have six siblings and some of them do have a thalassaemia trait as both my parents are carriers. If both parents are carriers of thalassaemia, they have a one in four chance that their child will be born with thalassaemia, one in four chance that their child will have nothing (neither the trait nor the illness) and then it's a two in four chance that their child or offspring will be carriers, so it's quite a high percentage.

One of the hardest aspects of the condition for me is the tiredness. My back also sometimes throbs because of where the bone marrow is trying to produce more blood cells when I am due for a transfusion. It really impacts on so many aspects because I am often too tired to socialise and that can really affect some of my relationships.

UKTS have given me a lot of support. Recently they had a conference and it was really great because there were other thalassaemia patients at the event. It is really important to have that relationship, those connections with other people that have thalassaemia, because it's reassuring and you learn about the latest treatments. Awareness is so important. I think this project by 'Same but Different' is fantastic."

If you would like to find out more about Same But Different visit their website: https://www.samebutdifferentcic.org.uk/

Meliz at home

Meliz Toros

"One of the hardest aspects of the condition for me is the tiredness. It really impacts on so many aspects because I am often too tired to socialise and that can really affect some of my relationships."

"UKTS have given me a lot of support. Recently they had a conference and it was really great because there were other thalassaemia patients at the event."

I'm a 'Thalley' from the Valleys

In this article, Dimitri tells us about his experience growing up with thalassaemia in Wales and gives an inspiring message to others living with the condition.

"Hello everyone! My name is Dimitri Azzopardi, usually known to my friends as Dim for short. As you may have guessed from my name, my family are from Greece originally. Although I love the beautiful land of my ancestors, I myself was born in Wales, another beautiful country but unfortunately the climate isn't quite so sunny!

As most of you will know, even today Wales is a country which has very few thalassaemia patients; and when I was born 38 years ago, nobody – including my family – had any idea what was in store. I was eventually diagnosed with beta thalassaemia major at the age of two, after a lot of 'trial and error' trips to the doctors. It was quite a shock for my parents as it would be for anybody. Back in the 1980s, treatment was nothing like as advanced as it is today; people were still dying very young and to get a diagnosis of thalassaemia was devastating. Having said that, I am sure that we were no different to other families in that it was not me but my parents who bore the brunt of the worry and stress at that time. Like all children, I just accepted my life for what it was, only as I got older did I start to realise that I was different and other kids didn't have to go to hospital for blood transfusions.

Luckily for me, my family lived close to Cardiff which has a large, modern hospital. Today, all these years later, Cardiff is the only hospital in Wales which treats thalassaemia patients – there aren't many of us 'thalleys' in the valleys! When I was young I used to have my transfusions staying overnight in hospital and my mum always used to stay with me. One vivid memory from when I was a child comes from when I was about eight years old, a nurse was attempting to put up a unit of blood for me when she accidentally pierced through the actual plastic of the bag and blood started running everywhere! Looking back, I suppose she was worried about getting into trouble for wasting the blood because she actually got out a sticking plaster and tried to patch it up. My mum however was having none of it and she wouldn't let her bring the compromised blood anywhere near me. I still think about it and I am glad mum stuck to her guns but it just shows you what could have happened if she hadn't been with me.

Dimitri (centre)

In fact, I have a great deal more than that for which to thank my mum. She was always very encouraging when I was young. Like a lot of young boys I was very keen on sports and mum never tried to put me off – her attitude was always 'try it and see how you get on'. I played most sports as a youngster and to this day my favourite hobby is playing roller hockey, I play for my team which is the Cardiff Bay Crossbones. As anyone who has seen any kind of hockey on TV will know, it is a very physical game and not for the faint-hearted. Thalassaemia is left behind in the dressing room and believe me, I give as good as I get!

My team-mates, friends and colleagues know I have thalassaemia, it doesn't bother me to talk about it and I have never encountered any problems because of it. It's there, but I don't see it as the most important thing about me or make an issue of it and nor does anyone else. Actually, in a way I think it makes me stand out from the crowd!
Speaking of standing out, I should mention one of my other favourite hobbies… tattoos! I have a lot of them, they are all special to me and I enjoy spending time thinking about what I will have done next and
where to put it!

When I'm not playing roller hockey, planning or having tattoos, I love watching films and spending time with my family – especially if it involves enjoying my mum's Greek cooking! I know everyone thinks their mum is the best cook in the world but honestly, I have never had food in any restaurant that bears comparison with hers. Family is the most important thing in the world to me and the other person who has been a major influence in my life and has given me tremendous support over the years, is my sister Sofia – she's not a bad cook either! As for my career, I do cost administration for a civil engineering company. The job suits me very well and I really appreciate my employers' understanding in allowing me to take the day off when I need a transfusion.

When I look at my life today, on the whole I am satisfied. I look after myself pretty well these days although like most people with the condition, I did go through a rebellious phase. Let's face it, youngsters always think they're the first ones ever to go through teenage angst but we've all been there. I think I was about fifteen when I started kicking off at my mum, threatening not to do my treatment and generally behaving like an immature jerk.

Dimitri Azzopardi during a game


Dimitri's Sister & Mother

I'll never forget her response, she said "You have two choices, you can grow up and do your treatment or you can just be selfish and don't bother. It's up to you." Those words hit home and I realised just how much time and effort mum had put into keeping me healthy over the years and how selfish it would be to throw all that in the dust because I couldn't be bothered. Her words have stayed with me over the years and if ever I felt like lapsing they are still there at the back of my mind, As I said, I am pretty good these days (my doctor might be reading this LOL).

Speaking of which, I get on very well with the doctors and nurses in Cardiff, they are a great team and very dedicated. I appreciate everything they do to keep me as fit as I can be. Of course, it helps that thalassaemia treatment has improved greatly over the years, oral chelating medicines have made life so much easier and transfusions too are quicker and easier than they used to be. All in all, I have a good life, and I am going to keep on being myself and enjoying life for many years to come. If I had a message for young people with thalassaemia, it would probably be the same message I would give to any young person: be who you want to be, do what you want to do and don't let your own negative thoughts stop you from trying anything. Have a go – you just might surprise yourself!"

A daughter's story

Maria Read gives us an insight into what life was like growing up with a parent who has thalassaemia.

"My name is Maria Read and I am 21 years old. I am the daughter of thalassaemia beta major patient, Katerina Loizi. This article will hopefully present another side to living with thalassaemia and how children of patients deal with the indirect effects of the condition.

Katerina with young Maria

I don't think there was a precise moment when I realised mum had thalassaemia, it was just always there in the background. Looking back, I guess it didn't really affect my life when I was growing up because my mum always shielded me from any pain she was going through. When I was younger, I can remember her going to hospital once a month for quite a few hours, but I didn't fully understand why she had to go so often. Seeing her in and out of North Middlesex Hospital did make me wonder what she had to go through and how it must have affected her physically and mentally.

The effects of thalassaemia, whether it be at the hospital or at home, are something that my mum deals with daily. The condition takes a toll on her body and it is hard for me to see as a daughter, as I cannot control or prevent it. Most organs are seriously affected by thalassaemia, so she has had a number of medical complications to deal with.

However, with treatment, the complications are something that, over the years, have been a lot easier to manage and are less severe. This gives me, as a daughter, some peace of mind.

My mum has always taken care of me and been there when I needed her. She has led a normal life so growing up, the condition hasn't had a negative impact on my life. Being a carrier of thalassaemia, I am more aware of how thalassaemia can be prevented and how we can stop babies from being born with the condition.

Katerina and Maria a few years later

The blood donors and blood donation in general are the main reasons why my mum is still here today. In fact, thalassaemia has inspired me to become a blood donor, so we can continue to support people with thalassaemia and also other blood diseases. The treatment progression of thalassaemia has come a long way over the years and has therefore changed the way patients live their lives day to day. I am proud to say that, at 59, my mum is now one of the oldest patients living with thalassaemia in the UK.

If you would like to share your experience of living with a family member or partner who has thalassaemia, please email info@ukts.org. We would love to hear from you.

Katerina, Dr Yardumain and Maria at a recent function

London Marathon 2019

The London Marathon took place on 28th April this year and our six runners did us proud. Together they raised almost £12,000 for the charity so we would like to say a HUGE thank you to them all! Meet our runners and hear their personal motivations for running, why they chose to support UKTS and how they felt after. Once again, thank you to our 2019 marathon runners.

Sarah and Ellen

Sarah Ellen Hammond
Time taken to complete: 6.12.07
Position: 15996
Amount raised: £2,210.00

"With my 40th birthday fast approaching, I decided the London marathon would go on the bucket list. 26 miles through the streets of London. Run, walk or crawl we will cross that finishing line and get our medals whilst raising money for a very worthwhile charity."

Ellen Mary Jones
Time taken to complete: 6.12.07
Position: 15994
Amount raised: £3,636.94

"Started with couch to 5k with sweat pouring off me and now we enjoy running. So good for the mind, soul and body. Having watched it practically every year from our living rooms, Sarah and I decided the London Marathon was the only one we wanted to do."

Would you like to run for the charity in the London Marathon 2020?

It's a wonderful chance to focus on getting really fit while supporting a truly worthwhile cause. Nothing but a win-win! If you are interested in taking part or would like more information, please contact us at info@ukts.org. We already have two runners signed up for next year and will be featuring them in upcoming issues of the magazine.

Marios

Marios Vasiliou
Time taken to complete: 4.55.12
Position: 19062
Amount raised: £523.75

"As I started running years ago I never imagined I would be able to run a marathon. But most important is that this time I am not running for myself, the medal, the travel to London or a personal best which are important but to help and raise money for charity. UKTS gave me this rare opportunity to run this great race and I feel grateful and honoured."

Left to right: Laura, Carmien and Emma before the race

UKTS supporters

Emma Kolaru

Time taken to complete: 4.27.14
Position: 6671
Amount raised: £2,566.25

"I am running the marathon with two friends, Carmien Gharbaoui and Laura Samsonovaite. Completing the London Marathon has been on my bucket list since my late teens/early 20s (which is probably when I should have run it!).

UKTS has funded research which has changed the lives and prognosis for patients nationally and internationally. Any donation you can afford will contribute to the society's valuable work as well as make each of my miles that much more meaningful and keep me going over the next four months!"

This was Emma's response after the race. "I did it! Thank you for sponsoring me, you are truly generous and amazing. Knowing how much we raised kept me going during some really challenging periods yesterday. I'd like to keep up the running but right now my body needs to recover! Thank you so much."

Laura Samsonovaite

Time taken to complete: 5.35.20
Position: 13777

"I've always been someone who loves taking on a challenge in my life. So when I was presented with the opportunity to run the London Marathon I couldn't resist. I am very excited to have been accepted to run the 2019 London Marathon by the UK Thalassaemia Society."

Andrew and Romaine at the start

Carmien Gharbaoui

Time taken to complete: 5.27.02
Position: 13,112
Amount raised: £1,258.75

"I am raising funds for this cause as I have a friend with thalassaemia and wasn't aware of its potentially debilitating effects. As thalassaemia is a little-known disorder, I am keen to do whatever I can to raise awareness of it."

Left to right: Emma, Laura and Carmien after the race with their medals

Soul Night

A huge thank you to Koula Kanias, Christine Christodolou and Adam Christodolou for organising a fabulous Soul Night on behalf of UKTS. The event took place at The Venue in Cockfosters on 2nd March 2019 and was sold out weeks in advance. Performances by the famous 'Lovers Rock Sisters' Janet Kaye and Carol Thompson, supported by DJ Tas – provided the evening's entertainment. There was unanimous agreement from all those who attended that it was a fantastic night of fun, with everyone singing and dancing the night away.Not only was it fun, but they raised an amazing £2713.00 for the charity. Huge thanks to all those who donated raffle prizes too, your generosity makes a real difference.

From left to right; Maria Neo, Christine Christodolou, Stavroulla Averkiou, Carol Thompson and Koula Kanias during the performance

St Andrew the Apostle Greek Orthodox School

St Andrew the Apostle Greek Orthodox School in Barnet raised £316.50 for UKTS from their non-uniform day. Thank you to all the pupils and staff, not only for your fantastic fund-raising efforts but also for helping raise awareness on thalassaemia.

United Kingdom Thalassaemia Society

On 6th June, The School Council was visited by representatives of the United Kingdom Thalassaemia Society. The representatives, Romaine Maharaj and Cllr Stephanos Ioannou came to thank our students for raising money for their charity and to explain what the students needed to know about Thalassaemia. Below is an account of the visit from one of Year 7 students.

'When we gave the Thalassaemia group their cheque we discussed all the issues with today's society including how there aren't enough people supporting charities that are trying to raise awareness. The representatives Romaine Maharaj and Cllr Stephanos Ioannou, were extremely pleased with the amount of money our school had raised and we agreed to do another event to support a different charity in the future."

Anastasia Kitiou Y7T

Romaine Maharaj receiving the cheque with Cllr Stephanos Ioannou .

Ambassador Jatinder Singh Karir (right) with cheque

Lions Club

On May 11th 2019, UKTS was invited to the 6th Annual Charter celebration of the Lions Club of Mercia in Coventry. The charity was presented with a staggering donation of £1,001. We are extremely grateful to the Lions for their exceptional fund-raising work and look forward to working jointly with them on future awareness campaigns.

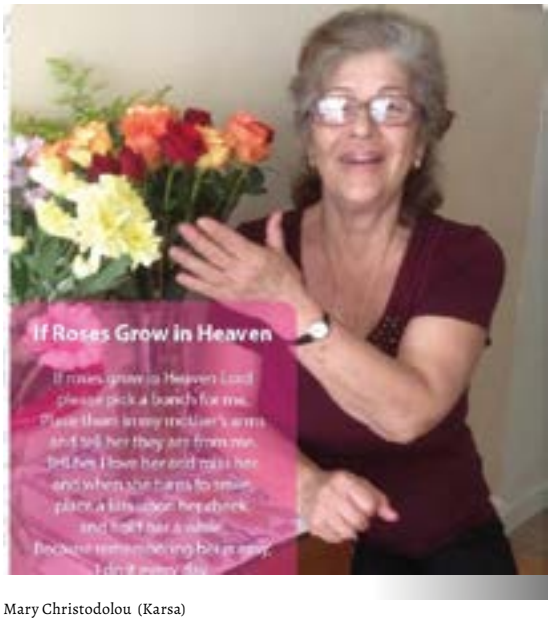
Giants

In February this year, we received the very generous donation of £501 from the London group, Giants, at their dedication service to their founder Nana Chudasama. Thank you, we really appreciate your support.

From Left to right Nilesh Raithatha, Roanna Maharaj, Mina Raithatha, Romaine Maharaj, President Kirti Bathia, Mr Bathia

In memory of loved ones

We are sad to announce that Mary Karsa (Christodoulou) – a founding member of the UKTS and one of the special parents honoured at our gala awards – passed away on 4th April, 2019. Mary was instrumental in laying the foundations for the charity. In fact, the first ever UKTS meeting was held at her home. We would like to thank her family for their amazing donation of £500 in memory of this wonderful lady and we wish them support at this difficult time. We hope they find some comfort in the knowledge that Mary's legacy to thalassaemia will live on.



Mary Christodolou (Karsa)

To honour the recent passing of her grandmother, Kacey Curtis asked for donations to be made to UKTS. Her grandmother, Zishan Adam, sadly lost her son, Cezar, to thalassaemia when he was only 21 years old. The loss affected her and the family deeply. Our condolences and wishes go out to Kacey and the rest of the family. Thank you for thinking of us and raising an amazing £540 for the charity.

Zishan Adam

Cezar Adam

Dates for your diary

• We will be running a patient support group in Bradford soon. Please check the website and our social media to see when it will be held.

• Calling all footy fans…our patron Kypros Kyprianou is planning a charity football match at Harringey Borough FC. The date will be announced soon.

• The wonderful team who organised the last soul night are planning another one. So if you missed out, watch this space to hear when it will be and how to get your tickets.

• It may be June, but before you know it the festive season will be upon us and you really don't want to miss the social event of the year…***so get your tickets now!***

UKTS would like to thank all those who contributed articles and stories to this magazine. We hope you enjoy reading it and would really love to hear your feedback. Please email us at info@ukts.org with your comments and any suggestions for future issues.

Would you like to share your experience of thalassaemia with other readers?
If so, please do get in touch and you could appear in one of our next issues! On that note, look out for our Autumn issue which will be packed full of more features that aim to inform, inspire and support the thalassaemia community.

Also, please note, our patients no longer have to pay membership fees. We took this decision because our priority is for everyone with thalassaemia to have full access to our services. Obviously as a charity we depend on donations, so if you are a patient and are happy to continue to pay for membership, please let us know. If you would like to become a member, please complete the form on the back page. If you would like to make a donation to the charity please use the following link https://www.paypal.com/paypalme2/teamukts

United Kingdom Thalassaemia Society
-Membership Application Form-

Your Personal Details

Title (Mr/Mrs/Miss/Dr):	
First Name(s):	
Surname:	
Address:	
Postcode:	
Occupation:	
Ethnic Origin:	
(optional)	

Contact Details

Telephone (home)	
Telephone (work)	
Mobile:	
Email:	

Are you a (please tick where appropriate):

Patient ☐ Parent ☐

Health Care Professional ☐ Association ☐
Other (Please state)

If you are a patient or parent, please complete the section below:

Patient's Names:	
Date of Birth:	
Sex: Male Female Prefer not to Say	
Type of thalassaemia(e.g. Major, intermedia, Haemoglobin H etc.):	
Hospital where treated:	

ALL DETAILS AND INFORMATION WILL BE KEPT ON OUR COMPUTERS AND WILL REMAIN IN THE OFFICE. YOUR INFORMATION WILL NOT BE MADE AVAILABLE TO ANYONE OUTSIDE OF THE UKTS.

I AGREE FOR MY PERSONAL DETAILS TO BE HELD ON THE UKTS COMPUTERS AND REMAIN AT THE UKTS OFFICE AND BE ONLY ACCESSED BY UKTS OFFICIALS. I UNDERSTAND THAT I CAN HAVE MY PERSONAL INFORMATION REMOVED WHENEVER I WISH.

YES ☐ NO ☐

UK Thalassaemia Society, 19 The Broadway, London N14 6PH
Charity Registration Number: 275107
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