

# Thalassaemia Matters



SPRING 2020  
ISSUE 133

In this issue...

## CORONAVIRUS

What steps should you be taking?



and...

The importance of dental care • Yoga for mind, body and soul

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## What is thalassaemia?

Thalassaemia major is a serious, genetic blood disorder. People with the condition cannot make enough haemoglobin in their red blood cells and are dependent on regular blood transfusions throughout their lives. If left untreated, a child born with thalassaemia would die in early infancy. Thalassaemia developed as an evolutionary response to malaria which is why it mainly affects those coming from regions such as Asia and South East Asia, the Mediterranean, South America, the Caribbean, Northern and Central Africa and the Middle East. Whilst it was initially prevalent in these regions, due to the migration of communities over the centuries, anyone can be at risk. In fact, every year 75,000 babies are born with thalassaemia major worldwide. With better education of those at risk and more effective screening, this inherited condition could be eradicated.

Please follow the link to donate to us:

<https://www.paypal.me/teamukts>



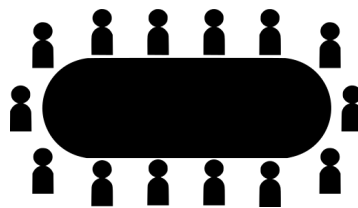
*Produces specialist  
educational material for  
patients and healthcare  
professionals*



*Provides counselling,  
support and  
information to patients  
and families*

## What does UKTS do?

*Organises national  
events including medical  
conferences, training days  
and support groups*



*Raises funds  
for vital medical  
research and life-saving  
equipment*



*Thalassaemia Matters* is produced (content - unless otherwise credited, interviews and design) by Neelam Dongha. If you would like to give feedback or make suggestions, please email [neelam@ukts.org](mailto:neelam@ukts.org).

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## Contents

### News and interviews

- 4 News
- 8 UKTS *Share Your Story* Campaign
- 10 Meetings and events attended
- 11 Changes to the UKTS Board
- 12 UKTS Festive Gala
- 16 The Renzo Gallenello Fellowship

### Special feature

- 20 Coronavirus: what you need to know

### Medical and support

- 30 Staying well during the COVID-19 lockdown
- 34 The importance of dental care

### Real-life stories

- 40 Smita Thakrar: yoga for mind, body and soul

### Supporter activities

- 42 Thank you to our supporters

## Letter from the Editor

As I write my letter from the editor, I can't help but think the world is a very different one to when I wrote the last letter. Not one of us could possibly have imagined what lay ahead for us all. And yet humans are amazingly resilient and the instinct to survive is strong, so we adjust and adapt to our new 'normal'.

If you want an excuse to avoid doing all the jobs that you now have time for - courtesy of lockdown, or you have had your fill of 'quality' family time, find a quiet corner and lose yourself in this issue of *Thalassaemia Matters*.

In light of the current pandemic, we have included an in-depth feature about coronavirus. Understandably, many of you are feeling anxious and have many questions and we hope this makes you feel more informed. Perhaps you are following the national trend with home exercise. We could all do with jumpstarting those happy hormones right now! Read Smita Thakrar's personal experience of yoga and you too will feel inspired to give it a go. There is an excellent article about how you can care for your teeth by dental experts Dr Kumar and Dr Cho with a handy printable factsheet for your own dentist. For a bit of escapism, we have coverage of our wonderful festive gala which harks back to a time when we could dress up and socialise - hopefully we will be back there soon enough.

There is so much more and as always, I welcome your feedback and ideas for future issues.

Stay safe and happy reading!

Neelam



## Message from the Chair



We are now facing one of the biggest health emergencies in our lifetimes and I am asking members and families to remain calm and stay as safe as possible throughout this period. UKTS is striving to continue to support members as much as possible. Towards this, an online meeting was recently scheduled with Dr Emma Drasar, Haematology Consultant, on hand to answer all questions. We intend to continue this and the other vital work of the society and would encourage members to continue contacting our team for any further information or concerns you may have.

I would like to take this opportunity to thank the outgoing trustees, following our recently concluded Annual General Meeting and formally welcome on our new team. It was particularly refreshing to note that more members are coming forward, pledging their support as they are happy with the additional work and support undertaken by the society, especially over the last two years.

We are looking forward to working with everyone once this pandemic is over so for now be safe, observe the restrictions being imposed towards restricting the spreading of the virus. We need to get through this together.

Gabriel Theophanous

## National Haemoglobinopathy Panel Meeting



UKTS attended the first ever National Haemoglobinopathy Panel Meeting on 13 February chaired by Professor Inusa Baba (pictured second from left in front row). It was extremely productive and we look forward to working together to create a system which will help patients, support healthcare professionals and deliver consistent care throughout England!

The meeting was attended by doctors, nurses and allied health professionals throughout England (some via teleconference), in addition to UKTS and Sickle Cell Society. UKTS was represented by Gabriel Theophanous (Chair) and Roanna Maharaj (Patient Advocacy Lead).

## SCREENING UPDATE

*As part of UKTS's work for the NHS Sickle Cell and Thalassaemia Screening Programme - together with our colleagues at Sickle Cell Society - we have been focusing on outreach work to raise awareness in the community.*

*We have designed posters to go up in GP surgeries and public spaces like community centres, and we were intending to disseminate these in the coming months. However, this has had to be put on hold during the coronavirus pandemic. We will also distribute copies of the Standards of Clinical Care of Children and Adults with Thalassaemia in the UK to GPs. Our standards are guidelines for for medical professionals treating patients with thalassaemia. The aim is to improve GPs' understanding of the condition and reinforce the vital need for early screening.*

*The planned distribution programme will resume once it is safe to do so. In the meantime, we would encourage all interested GP surgeries to contact us for additional information.*



**Infected Blood Inquiry Chair Sir Brian Langstaff has called for specialist psychological support across the UK for those infected and affected by infected blood and blood products. We wholeheartedly welcome this move. Thank you Sir Brian for continuing to champion patients' rights and we hope the government will respond and provide this much-needed service.**

## Prescription charges



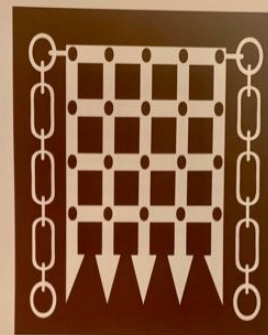
On 31 January UKTS attended the Prescription Charges Coalition (PCC) Planning meeting to continue our fight in abolishing prescription charges for people who live with long-term conditions in England. PCC is a coalition of 46 organisations who believe that people with long-term conditions in the UK should not have to pay for their prescriptions. The meeting was chaired and hosted by Parkinson's UK in central London and other societies present were Asthma UK, Behçet's UK, MS Society, UK National Rheumatoid Arthritis Society (NRAS) and Cystic Fibrosis Trust.

UKTS has been a long-standing member of this coalition as we believe people with thalassaemia should not pay for their prescriptions and we are eager to abolish these fees! As it stands in England, a person can only qualify for free prescriptions if: they have been diagnosed with one of a restricted list of conditions; are pregnant; are under the age of 16; or are 16-18 (and in full time education). Since then, a disappointing announcement was made by the government on prescription charges which means people with thalassaemia do not qualify for exemption. Moreover, pre-payment certificates and prescription charges will rise. Needless to say, we will continue to work with other members of the PPC to lobby government and have this outdated and unfair policy changed.



## Westminster Business Forum Policy Conference

UKTS attended the Westminster Business Forum Policy Conference on 21 January on disability in the workplace. The key speaker was Justin Tomlinson MP, Minister of State (Department for Work and Pensions). It was an opportunity to gain an understanding of the changes being introduced and also to raise and discuss issues that affect thalassaemia patients.



WESTMINSTER  
BUSINESS  
FORUM

## APPG for Thalassaemia

On 13 February, UKTS had a meeting for the All Party Parliamentary Group for Thalassaemia. Fifteen MPs (listed below) including Bambos Charalambous, Chair and Valerie Vaz, (pictured) attended to show their support and discuss issues pertinent to the thalassaemia community.

Bambos Charalambous MP  
 Cat Smith MP for Lancaster and Fleetwood  
 Chris Elmore MP for Ogmore  
 Chris Matheson MP for City of Chester  
 Fleur Anderson MP for Putney  
 Gary Streeter MP for South West Devon  
 Liz Twist MP for Blaydon  
 Mark Tami MP for Alyn & Deeside  
 Marie Rimmer MP for St Helens South and Whiston  
 Matt Western MP for Warwick & Leamington  
 Rosie Duffield MP for Canterbury  
 Rupa Huq MP for Ealing  
 Stephens Timms Labour MP for East Ham  
 Thangham Debonnaire MP for Bristol West  
 Valerie Vaz MP for Walsall South



Photo: Teresa Choudhary (UKTS), Valerie Vaz, MP and Romaine Maharaj (UKTS)



## THALASSAEMIA CONFERENCE & AGM

**Let's Learn, Challenge & Excel Together**

**THALASSAEMIA CONFERENCE & AGM**

**HELD AT: FRIENDS HOUSE, 173-177 EUSTON RD, NW1 2BJ**  
**SATURDAY 29th FEBRUARY 2020**  
**FROM 9.30am - 5pm**

**SPEAKERS:**  
 DR MALCOLM WALKER, CARDIOLOGIST  
 DR EMMA DRASAR, HAEMATOLOGIST  
 DR JULIAN WAUNG, ENDOCRINOLOGIST  
 DR CHINEA EZIEFULA, PSYCHOLOGIST

**PROGRAMME FOCUS:**  
 HEART HEALTH  
 NEW TREATMENTS  
 BONE DISEASE  
 COPING STRATEGIES  
 DWP/PIP

**PLEASE CONFIRM ATTENDANCE AS SEATS ARE LIMITED**  
**CONTACT THE UKTS BY EMAIL: [admin@ukts.org](mailto:admin@ukts.org) /**  
**PHONE 020 8882 0011**

**On 29 February this year, UKTS hosted a medical conference for patients. Over 100 patients attended with many more participating via a live feed. There were some excellent and informative talks by eminent experts with Q&A sessions. There was also a session on PIP and a discussion of the changing landscape. At the AGM, we were pleased to welcome Adam Christodoulou, Zehra Gokturk, Roanna Maharaj, Jon White and Zehra Gokturk Yiannis Zambas to the Board.**

**LIVE Q&A SESSION ON COVID-19 & THALASSAEMIA**

**UKTS invited all its UK members to an online patient discussion on 25 March to answer questions and address concerns relating to the current pandemic.**

**The issues discussed are included in the Coronavirus feature (pages 20-21).**



**MAYOR'S AWARD FOR UKTS CHIEF!**

UKTS Board members and staff were delighted that the Mayor of Enfield chose Romaine Maharaj as one of the inspirational women to be honoured with an award on International Women's Day, in recognition of her outstanding work to the thalassaemia community.



**Congratulations Romaine for your unflinching dedication!**



**On 3 March, Romaine Maharaj attended the final fundraising committee meeting with Kate Anolue, Mayor of Enfield. Thank you Counsellor for your dedication and commitment to thalassaemia, your other chosen charities and all those living in your borough. You have been a truly inspirational Mayor.**

# UKTS Share your story campaign

## UKTS BLOOD DONATION CAMPAIGN DURING COVID-19

*Roanna Maharaj (UKTS), featured on ITV news' coverage of NHS Blood and Transplant's newest campaign on why it is crucial for those who can safely donate blood to do so in this time of the coronavirus crisis.*

*UKTS is running its own campaign to encourage blood donation so please join many other thalassaemia patients and tweet your transfusion stories via our social media feeds.*



Roanna Maharaj needs blood transfusions every three weeks to stay alive. Credit: NHSBT/PA

Roanna Maharaj, 30, from Wood Green in London, has thalassaemia major and needs blood transfusions every three weeks.

"My body does not create enough haemoglobin to carry oxygen my body," she said.

"I've never taken blood donors and donation for granted, and this truer now more than ever.

"Right now, one of the most important things you can do to ensure we do not have another health crisis, is keep donating blood. Many people like me rely on blood donations to stay alive. Thank you to everyone who keeps donating as normal."



Following @BorisJohnson's announcement, we can confirm that blood donation is essential travel under the category of "medical need and helping a vulnerable person"

Blood donation saves lives. If you are fit and well, please #KeepDonating



You can still give blood during the lockdown!



"Hi, I'm Tanver & I'm 51 years young. I have #thalassaemia major & have relied on blood donations to live.

My family means the world to me & my only dream is to see them grow up & accomplish their dreams like every parent. Please donate!" @GiveBloodNHS



Michael from Scotland says Hi!

"For 28 years I have been receiving blood transfusions every 2-3 weeks to stay alive.

I have been able to live a full & healthy life due to the generosity of blood donors. Thank you!"

Donating blood is allowed during the #lockdown. @GiveBloodNHS



THANK YOU BLOOD DONORS SAVING LIVES

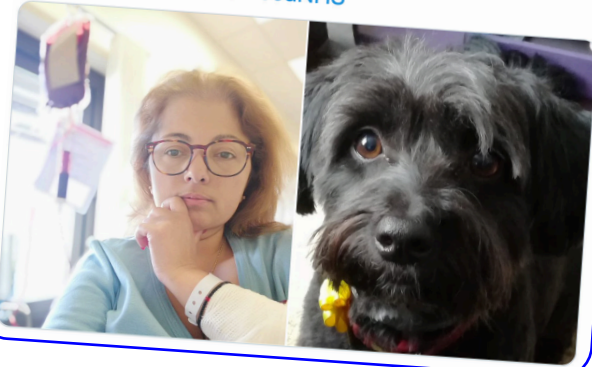


Hi All, I'm Azmat from Birmingham, I have beta [#thalassaemia](#) major & need 3 units of blood every 21-28 days.  
I would like to ask that if you can donate please donate. Your blood donations are a lifeline! I would like to say a big THANK YOU to all that has signed up! [@GiveBloodNHS](#)



Say HI to Christina from Essex!

Christina who has blood transfusions every 3 weeks said "I am grateful to blood donors for keeping me alive. Because of you I am able to work & enjoy being a mother to a very cute Doggie Oscar 🐾 I would like to say a huge THANK YOU!" [@GiveBloodNHS](#)



Meet Michael & his world from Bristol. Michael needs blood transfusions due to beta [#thalassaemia](#) major. His wife Tricia said "we are so worried about blood supplies during this crisis. Please, continue to give blood to save the amazing father of our 3 children." [@GiveBloodNHS](#)



Mum Amber says:

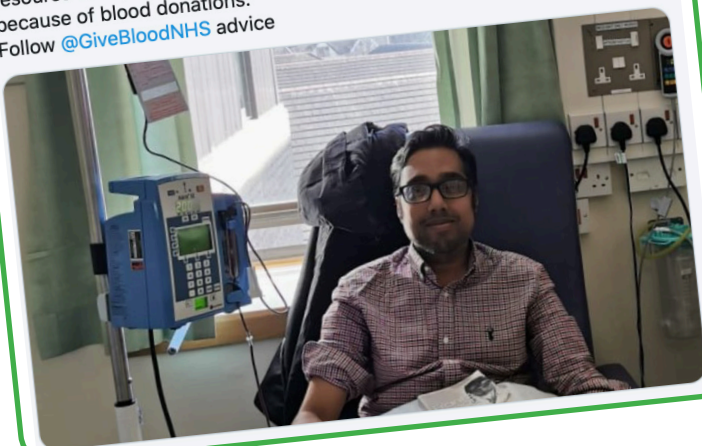
"Hi this is my daughter Maryam, who was born with [#thalassaemia](#) major. At only 9months old, she started having transfusions. Please continue to donate blood if you are healthy"

Follow [@GiveBloodNHS](#) guidance.



YOU TO ALL THE AMAZING DONORS - YOUR KINDNESS IS LIVES LIKE OURS...

Sajid from Wakefield says "During these challenging times, you may feel like you have little to offer. Let me tell you, you have the most precious resource of all; the ability to save a life by donating blood. I'm only alive because of blood donations."  
Follow [@GiveBloodNHS](#) advice



Happy 19th Birthday to our beauty Munirah!

Munirah relies on blood transfusions every 21 days to survive.

Munirah would not have been able to celebrate this milestone today had it not been for blood donors.

Please donate blood if you are well! We need you!

[@GiveBloodNHS](#)



## Meetings and events attended by the UKTS (January-March 2020)

### January

- 8 Meeting with AMG
- 9 Meeting with HCD
- 10 Meeting with Bambos Charalambous MP
- 13 SCT Counselling Competencies - Working Group meeting
- 15 Screening Patients Advisory Group
- 21 Westminster Business Forum policy conference: disability in the workplace
- 22 Peer review, London North West
- 24 Meeting with officials of PHE- screening review
- 27 Haemoglobinopathy CRG meeting
- 30 Teleconference with Celgene
- 31 Teleconference with Vertex
- 31 Prescription Charge Coalition meeting

### February

- 4 Mayor's Fund Raising Committee meeting
- 4 Peer Review, Nottingham
- 5 NHS BT Steering Group meeting
- 6 NHSBT next blood donation campaign forum
- 6 Peer review, Oxford (Paediatric Services)
- 9 Giants (fundraising group) event
- 11 Visit to Job Centre re PIP assessments
- 12 All Party Parliamentary Group AGM
- 13 National Haemoglobinopathy Panel meeting
- 17 BDB post-workshop teleconference
- 17 Planning meeting Mr Khanji – outreach work for patients in India
- 20 Meeting with Bluebird Bio
- 24 PIP interview representation
- 24 Haemoglobin Disorders Peer Review Programme - Steering Group Meetings
- 28 Orthodox Easter Celebrations within the Metropolitan Police Service (MPS)
- 29 Patients Conference and AGM

### March

- 3 Mayor's Fund Raising Committee Meeting
- 5 Peer review, Bradford
- 6 Mayor's Award Event
- 7 Mayor's Spring Ball
- 9 UK Forum for Haemoglobinopathy Disorders
- 9 SCT Counselling Competencies Working Group meeting
- 17 Welfare rights and social policy issues – teleconference for PIP
- 25 Zoom patients meeting to discuss Covid-19
- 26 Covid-19 discussion forum

## CHANGES TO UKTS BOARD

At our AGM on 29 February, we were pleased to welcome Yiannis Zambas, Roanna Maharaj, Adam Christodoulou, Jon White and Zehra Gokturk to the Board. Thank you to Rahmatullah Mohammed and Raj Klair - for your dedication over the years. The new Board is as follows:



Gabriel Theophanous  
*Chair*



Anand Ghattaura  
*Vice Chair*



Yiannis Zambas  
*Treasurer*



Oddy Cooper  
*Secretary*



Adam Christodoulou  
*Assistant Treasurer*



Roanna Maharaj  
*Assistant Secretary*



Jon White



Ashkaan Bandoui



Zehra Gokturk

# UKTS festive gala

Imagine... the glamour of Strictly Come Dancing, entertainment worthy of Broadway and prizes to die for...all under one roof! Yes, we are talking about the UKTS Festive Gala that took place at The Hive in London on 7 December. What an amazing night! Not only was it a fantastic way to kick off the festive season, it also raised £15,228 of much-needed funds for the charity.

After a cocktail reception and brief introduction to the condition by UKTS trustee, Roanna Maharaj, the entertainment kicked off in earnest with an exhilarating dance performance by dance troupe, IGotSole, followed by stand-up comedienne Fiona Allen. We were delighted to have well-known TV and radio celebrity, Chris Tarrant OBE, as our Guest of Honour for the evening and we really appreciate him giving his time to attend and host the event voluntarily.

The real showstopper had to be Mike Osman who made everyone do a double-take when he walked out in all his orange glory, as none other than, Donald Trump.

With the trademark fake tan, bouffant blond hair, voice and mannerisms down to a tee, he was the spitting image of the US president. He was absolutely hilarious and even Melania would have struggled to tell them apart!

The evening went seamlessly and whilst it may have appeared effortless, that is not the case. Planning and organising began a whole year in advance and we have one person in particular to thank for this, our UKTS trustee, Oddy Cooper. She worked tirelessly to ensure the evening was a huge success, and it was all done on a voluntary basis. Thank you to this amazing lady!

We would also like to extend our appreciation to all the individuals and companies who donated prizes for the auction. Thank you so much - it makes such a difference. And there really were some amazing prizes. At UKTS, we all had our eyes on the amazing 7-night, all-inclusive package at Veligandu Island Resort & Spa in the Maldives. Thank you Crown Company Maldives for such a generous donation.



Photo: Oddy Cooper, Chris Tarrant, prize-winning guest and Mike Osman



Photo: Roanna Maharaj (UKTS)

Photo: Chris Iarrant, OBE



Photo: Dance troupe, IGotSole



Photo: Mike Osman as Donald Trump!



Photo: Anthea Couppas



**We would also like to thank all those who so generously donated the wonderful auction prizes:**

**Prize: 7-night all-inclusive package at Veligandu Island Resort & Spa, Maldives  
Donated by: Crown Company Maldives**

**Prize: Autographed boxing gloves  
Donated by: Hughie Fury and Joseph Parker**

**Prize: Two-night stay at luxury Columbia Beach Resort in Cyprus  
Donated by: Columbia Beach Resort**

**Prize: Three course dinner for 4 with wine at the exclusive Arts Club  
Donated by: The Arts Club**

**Prize: Three-night stay at the Four Seasons Hotel in Cyprus  
Donated by: The Four Seasons Hotel**

**Prize: Spice Girls Autographed Programme  
Donated by: Spice Girls**

**Prize: Rowan Atkinson Autographed Picture  
Donated by: Rowan Atkinson**

**Prize: Two Bosch Tassimo Coffee Machines  
Donated by: Suzy Robinson**

**Prize: 3-night accommodation at Amathus Beach Hotel, Limassol, Cyprus  
Donated by: Cyplon Travel Palmers Green**

**Prize: A Chocaholic afternoon tea for 2  
Donated by: London Hilton Hotel Park Lane**

**Prize: Tottenham Hotspur 2001/2002 shirt autographed by team and match tickets  
Donated by: Tottenham Hotspur and Tony Franks**

**Prize: 2-night accommodation at St Raphael Resort and Marina, Cyprus  
Donated by: St Raphael Resort**

**Prize: Freddie Ljungberg's autographed shirt  
Donated by: Freddie Ljungberg**

**Prize: Two VIP Tickets to see Harry Styles live in concert  
Donated by: Fulwell 73 Production Co**

**Prize: Two VIP tickets to the BROS tour 2020  
Donated by: Fulwell 73 Production Co**





**Prize: VIP Party Bus Experience**  
**Donated by: Heeru Malkani**

**Prize: Autographed Framed Picture of Freddie Flintoff**  
**Donated by: Neil Caisley and Maxine Langley**

**Prize: A collection of antique cigarette football cards.**  
**Donated by: Neil Caisley and Maxine Langley**

**Prize: Two VIP passes to Jack Whitehall UK tour 2020**  
**Donated by: Fulwell 73 Production Co**

**Prize: Golf Lessons with Keith Wood, personal coach to Sir Nick Faldo**  
**Donated by: Keith Wood**

**Prize: 2-night accommodation at Cleopatra Hotel**  
**Donated by: Cleopatra Hotels**

**Prize: 18 holes of golf for 2 adults at Shendish Manor**  
**Donated by: Shendish Manor**

**Prize: Distinctive Destinations Ltd Travel Voucher £100.00**  
**Donated by: Distinctive Destinations Ltd**

**Prize: Gift Voucher Worth £50.00 at Hob Salons**  
**Donated by: Hob Salons**

**Prize: A suit from Harry Brown London**  
**Donated by: Harry Brown**

**Prize: All-new Amazon Fire 7 Tablet**  
**Donated by: Photocopiers Direct Limited**

**Prize: Limited edition photo of Muhammad Ali A1 (framed)**  
**Donated by: Christina Jansen**

**Prize: A three-course meal for 2 with wine at London Hilton Park Lane**  
**Donated by: London Hilton Hotel, Park Lane**

**Prize: Dinner Voucher for £75.00 at Odos Mediterranean Kitchen**  
**Donated by: Odos Mediterranean Kitchen, Barnet**



# The Renzo Gallenello

If you attended the National Thalassaemia Day at the UKTS office back in October or the Christmas Gala night, then you may have met with two lovely young doctors, George and Wolfgang, who were over in the UK for The Renzo Gallenello Fellowship – a two-month training programme. We spoke to George and Wolfgang to find out what makes them tick, what they learnt on their London visit and their future aspirations...

Where did you grow up and where do you live now?

**George:** I was born and raised in a small city called Kozani, in Northern Greece. When I was 18, I relocated to Thessaloniki, the second largest city in Greece. I have been living there ever since (with just a few breaks) but I try to visit my home town as often as possible!

**Wolfgang:** I grew up in an outer district of Vienna and I am currently living in the heart of beautiful Vienna.

What made you decide to study medicine and where did you study?

**George:** I have always found science, the study of nature and understanding how the human body works particularly fascinating. When I was at school, I was one of those children that found the classroom more interesting than the playground! Moreover, I have a huge interest in genetics and I have always thought that it is the key to understanding the basis of many diseases and finding new therapies. So, I have tried to combine my interest in both. I studied at the Medical School of the Aristotelian University of Thessaloniki, graduated in 2007 and then I specialised in Clinical Pathology Laboratory Medicine at Papageorgiou Hospital in Thessaloniki. In 2016 I embarked upon a postgraduate Masters in Molecular Biology and Genetics at the Democritus University of Thrace, and I am currently completing my thesis on gene therapy for haemoglobinopathies.

**Wolfgang:** I started to imagine myself as a doctor during my social service at the Red Cross when I was 18 years old. Later on, it became clear to me that this was my dream job. I studied medicine at the Medical University of Vienna and I did part of my practical training in Western Austria. I also undertook an Erasmus placement in Milan.



Photo: (from left to right) Dr Ethan Troy Barnes, Dr Porter, Staff Nurse Nina Gorman, George and Wolfgang



# Fellowship

Where do you work and what do you specialise in?

**George:** Since 2016 I have been working at the Blood Center within the Blood Bank Department of AHEPA University Hospital of Thessaloniki.



nd Wolfgang

I am a Clinical Pathology Laboratory Medicine Consultant. My work involves all aspects of blood banking, such as blood donor selection, post-donation testing, blood products' inventory management, pre-transfusion testing, transfusion reaction workup, platelet apheresis donations and so on.

**Wolfgang:** I am currently a resident physician in paediatrics in the Outpatient Department for Haematology, Oncology & Immunology at St Anna Children's Hospital in Vienna. My main focus is on non-malignant blood diseases in children and this is ultimately what I want to specialise in. During my studies at the Medical University of Vienna, I developed a special interest in haematology and participated in extracurricular seminars, followed by internships in specialised institutions. I was very fortunate to learn from Professor Sillaber, whose enthusiasm for non-malignant blood diseases was a great inspiration for me.

What are your hobbies?

**George:** My main hobby is travelling and I try to travel abroad as often as possible. I have been to most European countries so far, so my goal for the future is to cross the Atlantic! I love sightseeing and getting in touch with the history and culture of other countries. Other hobbies include reading (both literature and scientific magazines), watching football, listening to music (mostly electronic) and watching movies.

**Wolfgang:** I find my balance through swimming after work and meditating. If I have some free time, I enjoy reading journals about history and whenever possible, I love to travel.

You have just spent two months in the UK for training as part of the Renzo Galanello Fellowship. Please tell us more about this.

**George:** The Renzo Galanello fellowship is a programme organised every year by Thalassaemia International Federation (TIF). TIF sponsors between two and four physicians per year, working in the field of haemoglobinopathies in their countries, to be trained at the Joint

Red Cell Unit, Haematology Department of the University College London NHS Foundation Trust, under the supervision of Professor John Porter and Dr Perla Eleftheriou. The programme also includes training in other locations, such as the Whittington Hospital, other departments at UCLH and the Chenies Mews Imaging Centre.

### What did you do and what did you learn?

**George:** We covered all aspects of care for patients with thalassaemia and sickle cell disease. We attended various clinics: the haematology clinic; the genetic counselling clinic; and other specialised clinics (clinical trials, paediatric, cardiology, hepatology, endocrinology/diabetes, rheumatology). Furthermore, we attended the thalassaemia/SCD clinic and visited the Thalassaemia Unit at Whittington Hospital. We also had educational visits to the Chenies Mews Imaging Centre, where we observed the Ferriscan examination process, and the Colindale Blood Center. Last but not least, we worked on a small genetics project in the laboratory under the guidance of Dr Mary Petrou at the Halo Building, where we studied certain genetic polymorphisms in thalassaemia patients. The results of this study will probably be announced in the future at a scientific conference or in a journal.

**Wolfgang:** We were mainly based at the Joint Red Cell Unit team of Professor Porter at the UCLH. In addition to the clinics mentioned by George, we also attended the multidisciplinary team meetings and joined the ward rounds where we mainly saw patients having crises (complications of their sickle cell disease).

### Has it changed the way you practise medicine now?

**George:** It has certainly given me a more global perspective on the disease, patients' populations and the resources and experience available in other countries. I have the privilege of living in a country with a high level of expertise and experience in thalassaemia. However, my

experience in the UK has made me realise how important it is to conduct more large-scale genetic studies and I am trying to work towards this goal.

**Wolfgang:** Through this training my understanding of haemoglobinopathies increased enormously and I am much more aware about their complexities. I got a much broader view on the many aspects involved in the treatment of patients with haemoglobinopathies. It was very important for me, as a resident physician in paediatrics, to see how the conditions present in many patients, especially when they grow old. It reinforced just how important it is for me to convince parents to take the appropriate steps when their children - the patients - are still in their youth.

### How would you describe the overall experience?

**George:** I would characterise the overall experience as a very educational, enlightening, useful, pleasant and memorable once-in-a-lifetime experience! I was trained by highly respected international experts at state-of-the-art facilities, and I also enjoyed staying in the international metropolis that is London!

**Wolfgang:** It was a great honour to receive training in such a renowned environment. I very much appreciated the warm hospitality of all members at the Joint Red Cell Unit and it has been amazing to see such a high standard of clinical care for patients with haemoglobinopathies. Seeing treatment at the forefront of clinical development in this field was probably the most exciting aspect for me.

### How did you find living in London? Is it what you expected?

**George:** It was my first visit to London and the UK and for that matter, so I wasn't sure what to expect. I felt overwhelmed by the size and diversity of the city. The crowded underground was always hectic, but what I found really interesting was that there are so many people of different ethnic and cultural backgrounds.

It makes it very easy for a foreigner like me to adapt and be part of his new environment. Moreover, there are so many tourist attractions that one can never run out of sightseeing and entertainment options. In my opinion, living in London can be very expensive and hectic, but also a lot of fun!

**Wolfgang:** At the beginning, I had to adapt to the speed of the city, the crowds and the unpredictable weather! But after a few days, I really started to love the many opportunities London provides and the great spirit of the city. I had visited London a few times before the fellowship but living here for two months gave me a completely new view of the city. What I really enjoyed was meeting many open-minded people with great ideas and views who are focused on solutions rather than problems.

**What did you think of the UKTS events you attended (National Thalassaemia Day, Gala night)?**

**George:** I enjoyed both events. The UKTS National Thalassaemia Day was very important

for raising awareness and getting people tested. Perhaps, in the future, you could attempt seeking permission and funding to host it at a more central location in the city and reach out to a wider audience? The gala night was very entertaining, and the charity money raised was very important as well.

**Wolfgang:** With regard to the National Thalassaemia Day, I think it is especially important in a city like London with its history of migration. Creating more awareness about the disease is a fantastic thing and being able to test oneself in such an uncomplicated manner is very beneficial.

We enjoyed the gala night very much and I really want to congratulate the UKTS for organising a really great event.

**Anything else you would like to add?**

**George:** I would like to thank TIF for selecting me for this amazing opportunity, as well as the UKTS for all the invaluable help and support! I will treasure this wonderful experience forever!



# CORONAVIRUS:

With the current global coronavirus crisis, many of you will be feeling anxious about what it means for you or a loved one with thalassaemia. In this article, we try to explain what the coronavirus is, what the health authorities are advising and to provide guidance through these testing times. On 25 March, UKTS invited all its members to a live online Q&A session with Consultant Haematologist, Dr Emma Drasar. We are extremely grateful to her for taking the time to facilitate this meeting, despite her already overloaded schedule. We have included information from that session and also from the various health authorities, so hopefully this will all help to make you feel more informed.

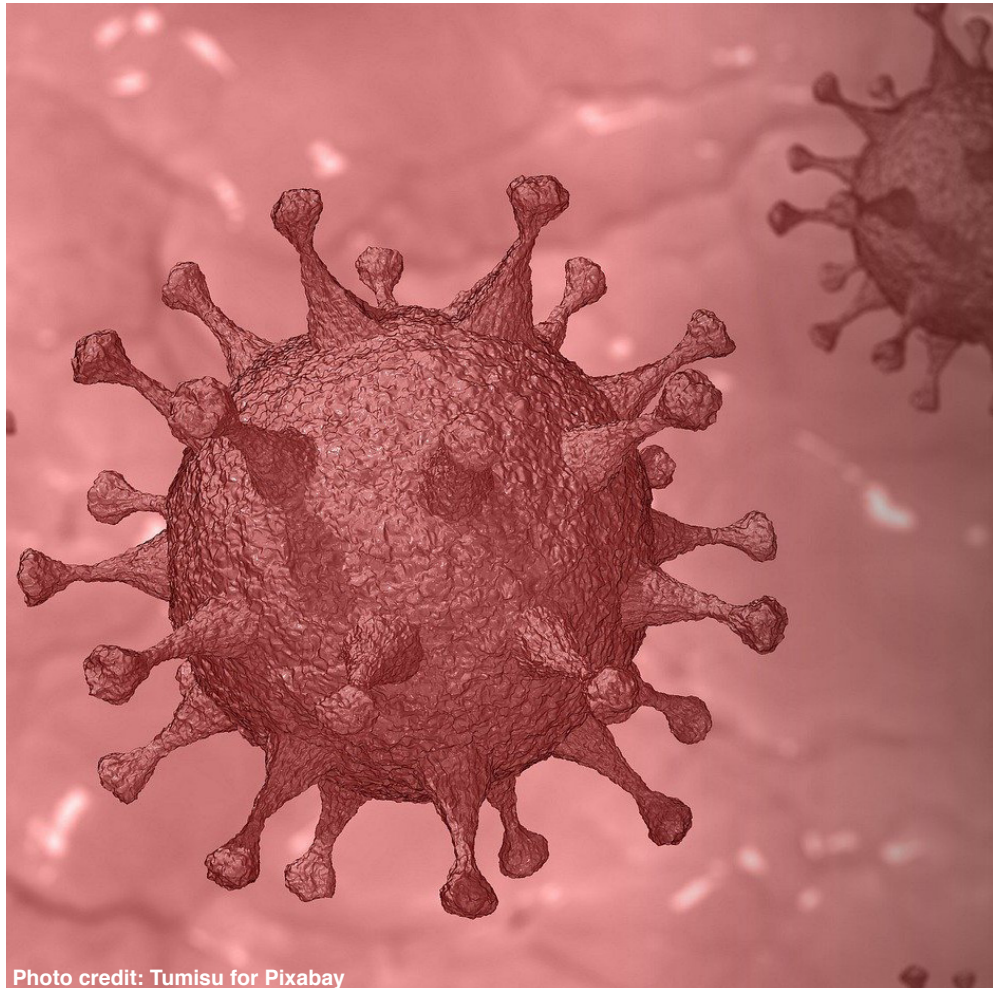


Photo credit: Tumisu for Pixabay

Coronavirus disease (COVID-19) is an infectious respiratory disease caused by a newly discovered coronavirus. It particularly affects the upper airways and lungs. At present, there is no evidence to suggest that people with thalassaemia are more at risk of catching it compared to others. In 80% of cases so far, people experience mild symptoms and recover fully. However, we all need to be stringent about minimising the risk of infection to ourselves and to others, whilst also being vigilant for spotting signs of infection early.

# What you need to know



## *Correct at time of publication*

These are unprecedented times. Never in our lifetimes have any of us experienced anything like the global pandemic that we are now faced with. As a consequence, medical experts are in unknown territories facing unknown entities. This makes it extremely difficult for them to know what action should be taken. It also means that as each day uncovers new challenges, medical advice and guidance has to be adjusted accordingly. So please bear in mind that the information provided here was relevant at the time of publication, but may since have changed significantly. If guidance from the health authorities is different to that provided within this article, UKTS is not accountable. Please continue to check the links to get the most up-to-date and accurate information.

COVID-19 first appeared in Wuhan, a city in China, in December 2019. Coronaviruses are zoonotic, meaning that they can be transmitted from animals to people. Investigations are ongoing as to how this virus originated and spread but early hypotheses suggest it may be linked to a large seafood and animal market in Wuhan, with the possibility that it was transmitted to humans from bats.

*Coronaviruses are named for their appearance: Under the microscope, the viruses look like they are covered with pointed structures that surround them like a 'corona' - which means crown in Latin.*

## How does this coronavirus compare to past respiratory epidemics?

The 1918 Spanish Influenza – or the H1N1 virus – remains the most devastating flu pandemic in modern history. The disease swept around the globe and is estimated to have caused 50-100 million deaths. A virus was also behind the 2009 swine flu outbreak, thought to have killed as many as 575,400 people. Other major influenza outbreaks include Asian flu in 1957, which led to roughly 2 million deaths, and Hong Kong flu, which killed 1 million people 11 years later.

### Previous coronaviruses

There are many different kinds of coronaviruses. Some of them can cause colds or other mild respiratory (nose, throat, lung) illnesses. Other coronaviruses can cause more serious diseases, including severe acute respiratory syndrome (SARS-CoV) and Middle East respiratory syndrome (MERS-CoV). In 2002-03, the SARS virus rapidly spread across 29 countries, infecting more than 8000 people and killing about 800. The MERS-CoV epidemic appeared in Saudi Arabia in 2012, with people experiencing similar symptoms to SARS-CoV but with a higher mortality rate of 34%. Unlike SARS-CoV, which spread quickly and widely, MERS-CoV has been mainly limited to the Middle East.

## How contagious is COVID-19?

By the end of January this year, the new coronavirus had been declared an international public health emergency by the World Health Organisation (WHO). Whilst COVID-19 appears to be less severe than SARS-CoV or MERS-CoV with a better recovery rate, it is spreading more quickly and more widely, and scientists are unable to predict how it may mutate. Estimates of the mortality rate have ranged from below 1% in younger people to over 3% among those who are elderly or have underlying health conditions. Any data is unreliable however in the absence of widespread and accurate testing for COVID-19. For example, if people have only mild symptoms or are asymptomatic (have it but show no symptoms) and it is not recorded, then this makes the mortality rate appear worse.

Since the virus was first detected in China in December, outbreaks have been confirmed in more than 200 countries and territories around the world. There have been more than 1.8 million cases of coronavirus globally and over 111,000 fatalities. As a point of comparison, seasonal flu typically has a mortality rate of less than 1% and is thought to cause about 400,000 deaths each year throughout the world. In the UK, there have been over 84,000 reported cases of COVID-19 and over 10,000 deaths. Get updated statistics [here](#).

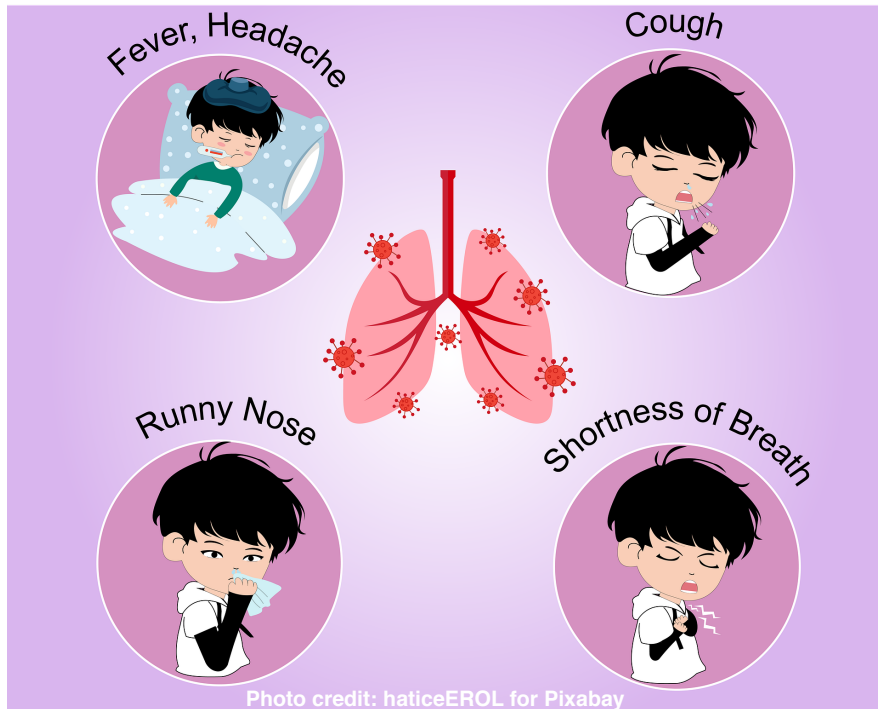
## How is coronavirus spread?

Scientists are not fully clear how Covid-19 is spread. However, it is believed that like cold and flu bugs, the virus is spread via droplets when a person coughs or sneezes. The droplets land on surfaces and are picked up on the hands of others and spread further. Germs can live on surfaces for several hours. People catch the virus when they touch their infected hands to their mouth, nose or eyes. There is some debate about whether the disease is airborne – there is no evidence for it yet, but that could change. Airborne viruses linger for a longer period of time than those spread by droplets and can also be spread in air conditioning and ventilation systems. The current advice is that the disease can only be spread by close contact – defined by Public Health England as spending more than 15 minutes within two metres of an infected person.

***It follows that the best possible course of action you can take is to follow the government advice and stay at home. The other single most important thing you can do to protect yourself is keep your hands clean, by washing them frequently with soap and water or an alcohol-based hand-sanitising gel.***



## What are the symptoms?



According to the NHS, the two main symptoms of Covid-19 to look out for are:

- a high temperature - over 37.8 °C, and
- a continuous cough.

Some patients may also have breathlessness, fatigue, a runny nose, sore throat, nasal congestion, aches, pains and diarrhoea. Some people have reported losing their sense of taste and smell.

The positive news is that about 80% of people who get Covid-19 only experience mild effects – about as serious as a common cold – and recover without needing any special treatment.

The WHO estimate that one in six people become seriously ill. Older people, and those with underlying medical problems like cardiovascular disease, diabetes, chronic respiratory disease, and cancer are more likely to develop serious illness.

As this is a viral pneumonia, antibiotics are of no use. The antiviral drugs we have against flu will not work, and there is currently no vaccine. Recovery currently depends on the strength of the immune system. However, there are many ongoing clinical trials evaluating potential treatments. Whilst work to develop a vaccine is accelerating, it is unlikely to be available until next year.



# How can I protect myself and others?

It starts with your hands. Please wash your hands frequently with soap and water or an alcohol-based solution.

**1 HANDS**




Be READY to fight #COVID19  
www.who.int/COVID-19

FIFA World Health Organization

Cover your nose and mouth with a bent elbow or tissue when you sneeze or cough. Dispose of tissue immediately and wash your hands.

**2 ELBOW**



Be READY to fight #COVID19  
www.who.int/COVID-19

FIFA World Health Organization

Avoid touching your face, particularly your eyes, nose or mouth to prevent the virus from entering your body.

**3 FACE**

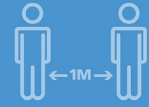


Be READY to fight #COVID19  
www.who.int/COVID-19

FIFA World Health Organization

In terms of social interaction, take a step back. Stay at least one metre distance from others.

**4 DISTANCE**



Be READY to fight #COVID19  
www.who.int/COVID-19

FIFA World Health Organization

If you feel unwell, stay home. Please follow all instructions provided by your local health authorities.

**5 FEEL**



Be READY to fight #COVID19  
www.who.int/COVID-19

FIFA World Health Organization

FIFA, the international governing body of football, and the World Health Organization (WHO) have teamed up to combat the coronavirus (COVID-19) by launching a new awareness campaign led by world-renowned footballers, who are calling on all people around the world to follow five key steps to stop the spread of the disease. Twenty-eight players are involved in the video campaign, which is being published in 13 languages. The “Pass the message to kick out coronavirus” campaign promotes five key steps for people to follow to protect their health in line with WHO guidance, focused on hand washing, coughing etiquette, not touching your face, physical distance and staying home if feeling unwell.

*Please note that the UK Government states that we need to keep a minimum distance of 2 metres from other people outside the home.*



## Lockdown measures and social distancing

Since 23 March the government has placed the UK into a ‘lockdown’ with drastic new measures in the fight against the coronavirus outbreak. Boris Johnson said: “When we reduce our day-to-day contact with other people, we will reduce the spread of the infection” and so we must stay at home and keep away from others – social distancing. You will only be able to leave your house for one of these four reasons: shopping for necessities; once a day for exercise; medical need or providing care; and travelling to or from work (if you can't work from home). All non-essential shops are closing, except food shops, pharmacies, corner shops, hardware stores, petrol stations, pet shops, post offices, banks, newsagents and shops inside hospitals. Parks will remain open, but gyms including outdoor gyms, playparks, all places of worship except for funerals will shut. All gatherings of more than two people are going to be banned except for people from within the same household. These measures will be in place for three weeks and will then be reviewed. Police now have the power to issue on-the-spot fines if you breach these rules. Find out more [here](#).



## Shielding

The latest government guidance strongly advises people with serious underlying health conditions to rigorously follow shielding measures. Shielding is a measure to protect people who are clinically extremely vulnerable by minimising all interaction between those who are extremely vulnerable and others. The NHS is directly contacting people with these conditions to provide further advice. If you think you fall into this category but have not been contacted, please get in touch with your GP or haematology team.

You are strongly advised to stay at home at all times and avoid any face-to-face contact for a period of at least 12 weeks from the day you receive your letter. Visits from people who provide essential support to you such as healthcare, personal support with your daily needs or social care should continue, but carers and care workers must stay away if they have any of the symptoms of coronavirus.

Shielding also means that if you live with others, you must take social distancing measures *within* the home: keep 2 metres away from them; minimise time in shared spaces; toilets must be cleaned after each use; eat separately in your own room; use your own towel; don't share a bed; use a dishwasher if possible. While the rest of your household are not required to adopt these protective shielding measures for themselves, they should stringently follow the social distancing rules when outside.

To learn more about shielding and see the list of conditions categorised as extremely vulnerable, click the following [link](#).

## What if I get symptoms?

### Self-isolation

If you have any symptoms of coronavirus, you and your family must self-isolate. To prevent the spread of the virus, the NHS asks that you do not go to your GP, pharmacy or hospital. Stay at home. You can use your own garden if you have one. If you need food or medicine, order them online if possible, or ask a neighbour or friend to drop them off at your home for you.

If you are worried, visit the 111 NHS Coronavirus website <https://111.nhs.uk/covid-19/> to find out what to do. Call 111 if you cannot get help online and let them know you have COVID-19 symptoms and thalassaemia. If you need urgent medical help, call 999.

If you live with someone who has symptoms, you'll need to self-isolate for 14 days from the day their symptoms started. This is because you may have it but it can take 14 days for symptoms to appear.

If more than one person at home has symptoms, self-isolate for 14 days from the day the first person started having symptoms.

If you get symptoms, self-isolate for 7 days from when your symptoms start, even if it means you're self-isolating for longer than 14 days (and only when your temperature has returned to normal).

If you do not get symptoms, you can stop self-isolating after 14 days.

### After self-isolation

You still need to stay at home when you finish self-isolating, but you can then follow the lockdown rules like everybody else and go out for essential trips such as buying food or to exercise once a day.

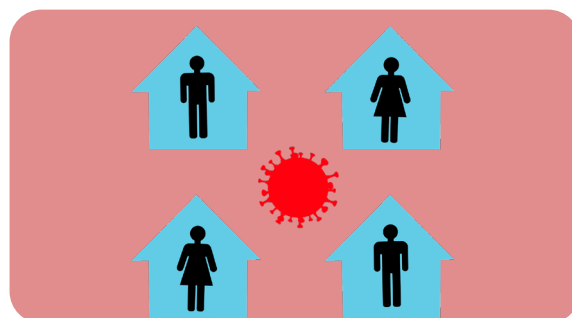


Image: Mohamed Hassan from PixaBay

# I have thalassaemia..

Understandably, here at UKTS, we have received an overwhelming number of phonecalls and emails with questions from many of you at this extremely worrying time. Until now, this coronavirus feature has focused on the issues that affect the population as a whole but in this section, we look at some of your concerns about how COVID-19 may impact you or a loved one with thalassaemia. Here are some of your common concerns and our responses.

## Risks

Thalassaemia is not generally associated with respiratory conditions. However, patients with thalassaemia may have other health issues - for example, relating to the heart, lungs and the immune system. Because of these additional issues, thalassaemia patients may be at greater risk of complications if they contract COVID-19. It is therefore extremely important to follow the stringent hygiene protocol (washing hands regularly and so on) and observe strict social distancing rules.

## Blood transfusions

We have been asked at UKTS by a number of you if the coronavirus can be transmitted via blood. The medical professionals we have spoken to are confident that this is not the case. Their advice is to continue with your transfusions as you would normally do, unless of course you suspect that you may have the virus. In that case, contact your haematology team immediately (remember to stay at home) to let them know. They will give you the necessary guidance, for example, they may advise you to stop your chelation medication if you have a fever.

There is also the issue of what to do if you are self-isolating as a member of your family has COVID-19. This varies between the different haematology units. Please contact them and follow their advice. Many units have set up a separate isolation area where you can have your blood transfusion without the risk of potential contamination of others. Do please check with your team if this situation arises.

## Shielding

Following the shielding advice issued by the Government, the Haemoglobinopathy Coordinating Centres/Clinical Reference Group for Haemoglobin Disorders issued a statement to help thalassaemia patients understand if they should fall within this 'extremely vulnerable' group. You can see the full statement by clicking the following link:

<https://ukts.org/heads-up/coronavirus-information/>

The two main types of thalassaemia patients in this higher risk group that need to 'shield' are:

**(1) Patients with iron overload.**

(T2\* <15 ms, previous or current impaired LV function or other cardiac complication related to thalassaemia, severe iron overload LIC >15 mg/g DW or ferritin >3000 mg/L)

**(2) Patients who have had a splenectomy AND have another risk factor** for complications, in other words another health condition, such as diabetes.

Patients in these groups are at higher risk of a more severe form of the disease and that is why they are being asked to follow shielding advice. If you have not had a letter telling you that you are in this 'extremely vulnerable' category, but think that you are, please contact your haematology team or GP for clarification.

# ..what does it mean for me?



Photo credit: [www.oxfordhealth.nhs.uk](http://www.oxfordhealth.nhs.uk)

## Blood supply

Some of you have expressed concern that blood supplies may dwindle during the crisis. NHS Blood and Transplant have ramped up their public appeal for blood donations and are carefully monitoring the supply situation, but there is little evidence to suggest this will happen at present. The experience in other countries who are further ahead in the COVID-19 cycle than the UK, have not had any real issue with blood supply. If the situation does arise that blood stocks do decrease, then it has been suggested that patients may have to accept older units. That is not the case for now, however.

It is important to note that people are allowed to go out to donate blood during the lockdown. It follows that the best thing we can do is to encourage friends and families to donate blood at this critical time. At UKTS, we have a campaign to encourage patients to share their transfusion stories to encourage more people to donate (see pp8-9) so please post your transfusion stories to our social media channels.

## Flu and pneumonia vaccines

Whilst there is no clear evidence they will give any additional protection against COVID-19, if you are entitled to the flu and pneumonia vaccines, it may be worth having them if you have not already done so. Phone your GP to arrange to have them administered but please do not worry if you cannot have them (some practices have shortages) – as mentioned, there

is no evidence that they provide any additional protection against coronavirus. A flu jab is given yearly and the pneumonia vaccine is generally administered every five years (although there are situations where only a one-off vaccination is required).

## Paracetamol

There has been some debate about whether ibuprofen can exacerbate the effects of coronavirus but there is currently no strong evidence that this is the case. Having said that, until we have more information, take paracetamol to treat the symptoms of coronavirus, unless your doctor has told you paracetamol is not suitable for you. If you are already taking ibuprofen or another non-steroidal anti-inflammatory drug (NSAID) on the advice of a doctor, do not stop taking it without checking first. In addition to ibuprofen, other examples of NSAIDs are diclofenac (volterol) and naproxen.

In fact you should continue with your regular medication regime unless your medical team has told you otherwise.

## Splenectomy

As already mentioned, but just to be very clear, if you:

- have beta thalassaemia
- have had a splenectomy AND
- have another underlying condition then you may fall into the higher risk category and need to 'shield'. If you have not had a letter telling you that you are in this category, but think that you are, please contact your haematology team or GP for clarification.

*Please note that this information is correct at the time of publication. We will post regular updates, if advice changes, to the UKTS [website](#). Check also [www.nhs.uk](http://www.nhs.uk) and [www.who.int](http://www.who.int)*

# How to boost your immune health

## Eat a healthy diet

We all know that what you eat is closely linked to your health. Eating foods high in antioxidants, such as vegetables and fruits, will boost your overall health and evidence shows there are significant health benefits to getting at least 5 portions of a variety of fruit and vegetables every day. The 5-A-Day campaign is based on advice from the World Health Organization (WHO), which recommends eating a minimum of 400g of fruit and vegetables a day to lower the risk of serious health problems.



The anti-inflammatory properties in nutrient-dense foods, like dark leafy greens, berries, salmon, and sweet potatoes, help build up your immune system's defences. Studies also show that zinc - which can be found in foods including pumpkin seeds, spinach, oysters, nuts and beans - has powerful immune-boosting and protective effects. Also stay hydrated.

## Get regular exercise

Adults should aim to be physically active every day. The NHS recommends that you do at least 150 minutes of moderate intensity activity a week or 75 minutes of vigorous intensity activity a week. You should also do strengthening activities that work all the major muscles (legs, hips, back, abdomen, chest, shoulders and arms) on at least two days a week. This may not be possible for everyone, and any activity is better than none. Whilst our exercise regimes have been disrupted by the current lockdown measures, there are plenty of online exercise classes you can join. Many of them have live sessions (for example, Joe Wicks at 9am on Youtube or 1RebelUK via Instagram) so you can feel like you are in a class with other people. One of the many beneficial side-effects of exercise is that it reduces stress, also on our list of immune-boosting priorities.

## Get enough sleep

A solid night's sleep is essential for a long and healthy life. According to the NHS, most of us need around 8 hours of good-quality sleep a night to function properly – but some need more and some less. What matters is that you find out how much sleep you need and then try to achieve it. Exercising and eating well will have the likely knock-on effect of helping you sleep better, which is a bonus because a tired body is more susceptible to bugs.



## Stop smoking

Don't smoke or use tobacco. If you do, quit now.

## Limit how much alcohol you drink

If you were thinking of drinking your way through the coronavirus crisis, you will have to come up with another plan! Heavy drinking depletes our immune cells.

## Manage stress

Stress hormones such as cortisol can compromise immune function. See Dr Chinaea's fact-filled article (page 30) for advice on how to reduce stress levels and maintain mental and physical health.

## Financial and employment concerns

If you have concerns about your employment rights or finances, you should seek expert advice from ACAS (helpline: 0300 123 1100). The Money Advice Service also has some helpful [information](#) on different situations. The government explains what employers should do for their employees [here](#).

Key things you should know are:

- Check your employment contract for policy on sick leave, Statutory Sick Pay, paid holiday leave and other types of caring/emergency leave.
- If you are normally entitled in your contract to Statutory Sick Pay, and you are off-sick or self-isolating due to coronavirus in your household, you should still get sick pay from the first day of absence.
- If you are on a zero hours contract, you may still be entitled to sick pay if you have done some work for the company. Check your [eligibility](#).
- If you have a relative who is ill, or your children's school is closed, your employer must give you time off. But they only have to pay you if this is in your contract.
- If you don't get Statutory Sick Pay, for example because you're self-employed or your earnings are too low, you may be able to claim other benefits.
- If you're a contractor, freelancer or similar (in gig-economy work) then speak to your current company - some are offering sick pay or compensation.
- If you claim [Universal Credit](#), the rules around minimum income will be relaxed for the duration of the outbreak of coronavirus.
- If you claim Employment and Support Allowance (ESA), you will be able to claim from day one, instead of day eight.
- If you're worried about the impact of coronavirus on your finances, speak to your bank, mortgage lender and utility bill companies - some are offering support to their customers during this time.
- If you are shielding this may help you discuss it with your employer: [www.111.nhs.uk/isolation-note](http://www.111.nhs.uk/isolation-note)



### THANK YOU!

We could not have expressed it better ourselves than Devesh Thakkar (pictured far right), did in his recent tweet. In amongst all the doom and gloom, we have seen some amazing acts of kindness in recent weeks. Please join us in a virtual clap for carers - to say thank you to all the NHS staff who are risking their lives each day to protect and care for us. Let's help them by staying at home. Thank you too to all the other key workers!

We stand to show our support to our front line staff in the #nhs after spending the day having my much needed blood transfusion and continuing receiving exceptional care despite being so stretched. We love you all and thank you. #ClapForCarers #StayHomeSaveLives #innhswetrust



*DISCLAIMER: All the information found in this article is provided in good faith, but we do not provide any warranties whatsoever, nor assume any legal liability or responsibility whatsoever, for the accuracy, completeness or usefulness of any of the information supplied. We do not endorse and are not in any way responsible, and have no legal liability, in respect of the URLs, titles and/or contents of any other site or information source referenced from this article.*

# Staying well during the COVID-19 lockdown

by Dr Chinae Eziefula

In this article, I try to provide some valuable psychological advice to you for staying well during this time. With the current coronavirus crisis, it can be a very scary and uncertain time, especially for those with long-term health problems such as thalassaemia whereby you still have to arrange and receive ongoing blood transfusions or treatments for your condition while also being encouraged to stay at home or to shield. It can be additionally difficult if you have parents, a partner and/or children to care for as well as following all of the guidance and taking care of yourself and your health.

As I mentioned in the talk I gave at the UKTS Medical Conference on 29 February 2020, we all have different reserves for coping with challenges – we all have different sized ‘stress buckets’! A pandemic like COVID-19 is a very significant challenge with lots of stress taps and our buckets are different sizes. It follows that we all have different ways of coping to relieve the stress in our buckets and deal with COVID-19 overspill.

**Stress-vulnerability** Whittington Health **NHS**

Imagine overall coping like this:  
We all have a unique "stress bucket", it's size (how vulnerable we are) depends on many things we cannot always control.  
What fills our buckets up include life experiences, stressful ones...

Overwhelmed (overflow!)  
Getting stressed (filling up)  
Relaxed (coping well)

**Stress-vulnerability** Whittington Health **NHS**

We **cannot** change size of the bucket (our vulnerabilities).

Overwhelmed (overflow!)  
Getting stressed (filling up)  
Relaxed (coping well)

**Stress-vulnerability** Whittington Health **NHS**

We **can** develop ways to cope with the things that fill our buckets.  
We **can** develop ways to help us drain our buckets (outlets, drains) through support networks, emotional self-care and seeking help with emotional problems from professionals.

Overwhelmed (overflow!)  
Getting stressed (filling up)  
Relaxed (coping well)

**Below are some simple tips and information to help anyone with thalassaemia to cope during the lockdown:**

- 1. Seek out practical support and help with shopping and groceries so that you don't have to leave the house to do this yourself, where possible.**

You may have friends or family who can shop for you and drop items off for you or there are a number of NHS/ non-NHS volunteers offering this type of support locally. If you are in the 'extremely vulnerable' category then consider registering with the Government for support with your shopping and your local council will offer you specific support with your shopping: <https://www.gov.uk/coronavirus-extremely-vulnerable>

## Get coronavirus support as an extremely vulnerable person

Register if you have a medical condition that makes you extremely vulnerable to coronavirus. For example, you'll be able to ask for help getting deliveries of essential supplies like food.

If you're not sure whether your medical condition makes you extremely vulnerable, register anyway.

You can register yourself, or on behalf of someone else.

[Start now >](#)

### Related content

[Coronavirus \(COVID-19\): what you need to do](#)

2. **Think about how you can get prescriptions delivered to your home.** Ask your pharmacist, haematology team or thalassaemia nurse specialist about this.
3. **Make inquiries with your haematology team/ nurse specialist about your blood transfusions.** You maybe be able to ask about changes to the frequency or if there is any other help on offer with this. If you have to travel to your blood transfusions then attempt to do so using your own personal vehicle, ask a friend or family member to regularly drive you, or arrange for hospital transport to collect you and drop you off.
4. **Continue to look after your health in all ways possible.** This includes taking up regular, daily exercise at home, creating a routine for yourself at home with regards to activities and meals, eating healthily and minimising snacking, continuing to ‘attend’ any virtual or telephone outpatient appointments that may have been arranged for you. Don’t let your health routines slide because this will keep you healthy and well during this important time.
5. **Look after your emotional wellbeing too.** This includes taking regular breaks if you are working from home and/or caring for parents, a partner or young people. Also making time for yourself and doing a ‘self-care check in’ – you can ask yourself: “What is one kind thing I can do for myself today?” Or promise to spend 15-30 minutes doing something nice for yourself.

Here are some other ways of looking after your emotional wellbeing:

- **Create a daily routine for your time at home.** Have regular wake/ sleep/ meal/ break/ social (virtual) interaction times. Plan what you’d like to achieve each day (eg, work tasks, housework), include planning for fun activities like watching television, listening to music/ radio/ a podcast/ a TED talk, gardening, cooking, reading, physical activity, playing games, chatting to a friend on the phone or to a family member you share your household with.
- **Find interesting things to do online.** For instance online museum tours: <https://artsandculture.google.com/partner?hl=en> or the National theatre are offering free theatre showings online via their YouTube channel at 7pm on Thursdays !  
Visit the theatre on Thursdays here: [National Theatre on Thursdays](#)
- **Introduce mindfulness meditations into your day.** Here are some examples:  
15-minute guided meditation- <https://www.youtube.com/watch?v=fz57mdSPgMI&t=1s>  
12 free guided meditation websites - <https://www.heromovement.net/blog/free-guided-meditation-resources/>  
Sounds and thoughts mindfulness meditation -<https://soundcloud.com/hachetteaudiouk/meditation-5-sounds-and-thoughts>  
Mindful movement meditation - <https://soundcloud.com/hachetteaudiouk/mindful-movement-meditation>  
Mindful breathing - <https://soundcloud.com/icoperelaxationexercises/sets/relaxation-and-meditation-exercises>  
Other free mindfulness meditations: <http://franticworld.com/free-meditations-from-mindfulness>
- **If mindfulness or meditation is not for you then that’s ok! Try a relaxation exercise instead.** Here are some examples:  
Diaphragmatic breathing - <https://www.youtube.com/watch?v=BckGYBfN5e0>  
Relaxation and breathing exercises - <https://www.headspace.com/work/covid-19>  
Calm natural sounds - <https://www.calm.com/>

- **Take up learning something new:**  
**Learn a language for free with Duolingo** - <https://www.duolingo.com/>  
**Learn to write a song/ create music** - <https://www.bbc.co.uk/bitesize/topics/z3dqhyc/articles/zrx3vk7>  
**Access a range of free online courses here** - <https://www.open.edu/openlearn/free-courses/full-catalogue> and <https://www.futurelearn.com> and <https://thecrashcourse.com/>  
**Take up an Inspiring Digital Enterprise Award (iDEA) challenge** - <https://idea.org.uk/>  
**Learn to program your own interactive stories, games, and animations** here- <https://scratch.mit.edu/about> and <https://blockly.games>
- **Keep active!**  
 Visit the Sports Health England website for various home work-based workouts - [https://www.sportengland.org/stayinworkout#get\\_active\\_at\\_home](https://www.sportengland.org/stayinworkout#get_active_at_home)  
 Also visit the NHS website for workouts: <https://www.nhs.uk/oneyou/for-your-body/move-more/home-workout-videos/>  
 Consider *mindful yoga* -  
 Down Dog app (free until May 2020) - <https://www.downdogapp.com/>  
 Yoga Nidra app - <https://apps.apple.com/gb/app/yoga-nidra-relaxation-lite/id444707986>  
 Youtube videos - ([https://www.youtube.com/watch?v=\\_pYoDdUijY8](https://www.youtube.com/watch?v=_pYoDdUijY8) or [https://www.youtube.com/watch?v=PEImyy\\_kwN0](https://www.youtube.com/watch?v=PEImyy_kwN0))  
 Join The Body Coach Joe Wickes' daily PE sessions - <https://www.youtube.com/channel/UCAxW1XT0iEJo0TYIRfn6rYQ>
- **Don't spend too much time watching the news** – think about other ways to manage or think about the COVID-19 situation – **Dr Russ Harris**, author of *The Happiness Trap* offers tips on how to 'FACE COVID' and respond effectively to the Coronavirus situation - click here [Face COVID19](#)

**Dr Ruth Marks**, clinical psychologist in haematology from North Middlesex University Hospital says: “reduce stress with plenty of down time especially in the evening whilst winding down for sleep. Try to limit yourself to two or three news updates a day only and make sure that these are from trusted sources such as GOV.UK and the UKTS website. As far as you are able, avoid looking at news reports in the evenings, wind down by watching or reading something entertaining or by talking to friends, have a warm drink rather than alcohol. These steps will help to promote sleep and a good night's sleep can help to boost your immune system. *If you find yourself worrying a great deal, remind yourself that you are an expert in your health condition and you know how to look after yourself, remind yourself that worrying thoughts are just thoughts not facts and thoughts will pass.* Bring yourself into the present moment where everything is calm, noticing everything around you and slow your breathing. Then, when you are ready, carry on with what you were doing.”

- **Make time to play games and puzzles either alone, with children/ friends/ partners or other family members** - <https://www.natgeokids.com/uk/category/play-and-win/games/> or <https://www.sporcle.com/>
- **Listen to a TED talk** <https://www.ted.com/> or a podcast



- **If you have a garden and children or young people, consider some adventure activities that involve the outdoors with them -**  
<https://www.woodlandtrust.org.uk/blog/2020/03/kids-nature-activities-self-isolation/>
- **Visit websites that focus on how to promote good wellbeing:**  
Mind Charity - <https://www.mind.org.uk/information-support/coronavirus-and-your-wellbeing/>  
Mental Health Foundation charity - <https://www.mentalhealth.org.uk/publications/looking-after-your-mental-health-during-coronavirus-outbreak>  
British Association for Counselling and Psychotherapy - <https://www.bacp.co.uk/news/news-from-bacp/2020/28-february-coronavirus-anxiety-how-to-cope-if-you-re-feeling-anxious-about-the-outbreak/>  
Happiful Magazine - <https://happiful.com/coronavirus-ways-to-help/>  
World Health Organisation coping with stress poster - [https://www.who.int/docs/default-source/coronaviruse/coping-with-stress.pdf?sfvrsn=9845bc3a\\_2](https://www.who.int/docs/default-source/coronaviruse/coping-with-stress.pdf?sfvrsn=9845bc3a_2)  
World Health Organisation helping children to cope with stress poster - [https://www.who.int/docs/default-source/coronaviruse/helping-children-cope-with-stress-print.pdf?sfvrsn=f3a063ff\\_2](https://www.who.int/docs/default-source/coronaviruse/helping-children-cope-with-stress-print.pdf?sfvrsn=f3a063ff_2)

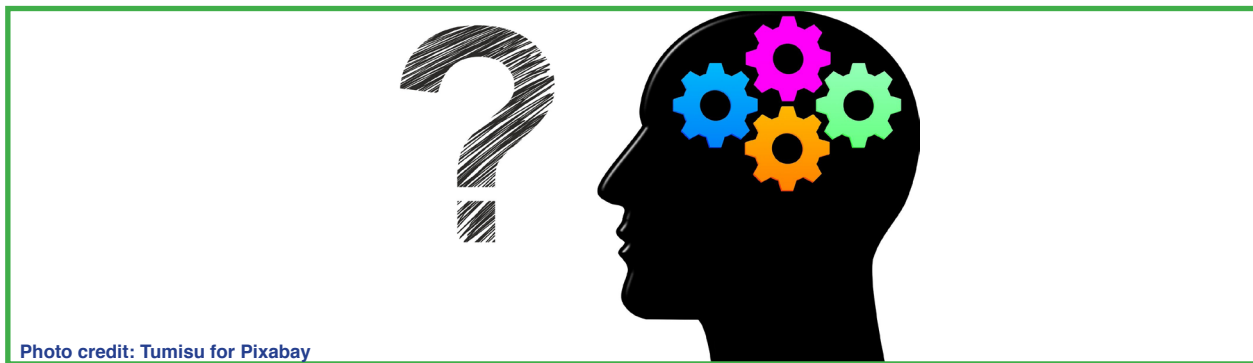


Photo credit: Tumisu for Pixabay

- **Ask if you feel you need more help!** Ask your haematology team if you feel you need some psychological support or help during the COVID19 pandemic – Also consider contacting your local Improving Access to Psychological Therapies service <https://www.nhs.uk/service-search/find-a-psychological-therapies-service/> (Please note that some services are offering reduced services or suspended services during the COVID-19 pandemic, however some services are offering brief psychological support for people who are in the ‘**vulnerable**’ and ‘**extremely vulnerable**’ groups. For example this is on offer in iCope Camden and Islington psychological therapies service in London: <https://www.icope.nhs.uk/>).

I hope you have found this range of coping tips and techniques helpful! They only work to help you relieve the COVID-19 related stress in your bucket if you use them so please make sure you do and remember the advice from Dr Ruth Marks – you are an expert in your health condition and you know how to look after yourself. Take care and stay safe for now and seek advice from your haematology team – be sure to let them know if you have any issues or concerns during this time.

Wishing you all the best for now!

*Dr China Eziefula is a Clinical Psychologist and the Haematology Psychology Service Lead at Whittington Hospital. She writes a regular piece for our quarterly magazine, so if you have any particular psychology-related topics that you would like her to cover, please send your suggestions to [neelam@ukts.org](mailto:neelam@ukts.org).*



# The importance of dental care

by Dr Navdeep Kumar and Dr Hana Cho

Most of you will already know how important it is to look after your teeth when you have thalassaemia. However, many of you have told us that your dentists are not always as clued up as you would like them to be when it comes to understanding the specifics of thalassaemia. We asked Dr Navdeep Kumar, a specialist dental consultant with extensive experience in treating thalassaemia patients to prepare a factsheet that you can hand over to your dentist. If you are one of those who dread visiting the dentist, hopefully this will make it easier for you. It is absolutely vital that you maintain regular visits to your dentist so please do use this helpful aid - see pages 38-39. The message from Dr Kumar and Dr Cho (co-author) is very clear: prevention is better than cure.

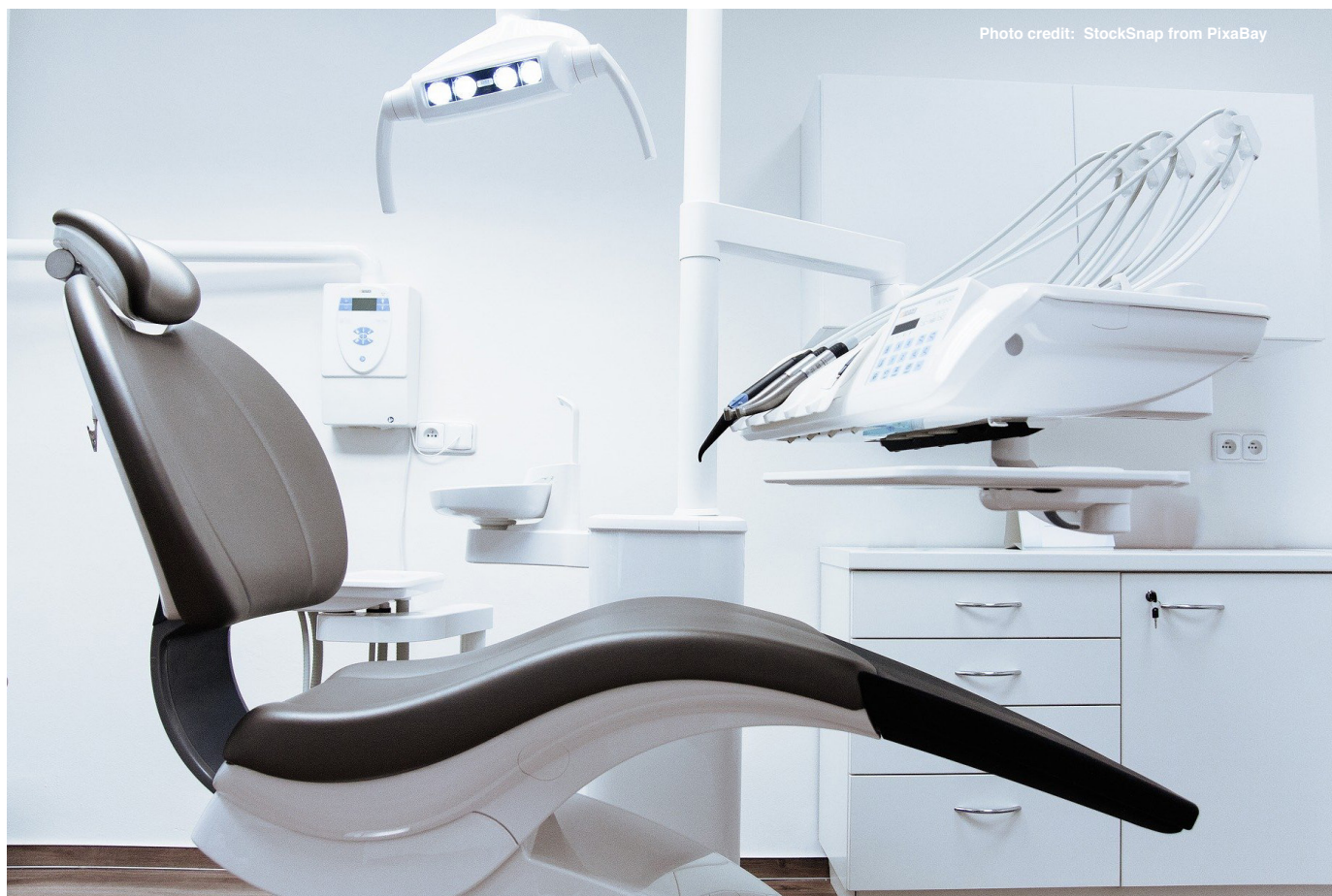


Photo credit: StockSnap from Pixabay

## Thalassaemia and the dentist

In the United Kingdom, thalassaemia predominantly affects people of certain ethnic origins (Mediterranean, Asian, Middle Eastern and African). As a result, many dentists may not have experience in treating a patient with this condition. Fear of the unknown may be associated with a reluctance to provide anything other than basic dental care. Indeed, many general dentists may prefer to refer these patients to either the community dental services, or to hospital-based specialised dental units (special care dentistry, paediatric dentistry, oral surgery), especially when extractions of teeth are required. When dental treatment is provided, the dentist may not be fully aware of the impact of thalassaemia on dental management, and so may not liaise with the haematologist when appropriate.

### Oro-facial features

Many oro-facial (meaning to do with the mouth, jaw and face) features have been described in thalassaemia, and are shown in the table below:

Feature	Reason
Enlargement of the upper jaw	Bone marrow expansion
Migration and spacing of upper anterior teeth	Changes to bones of the face
Varying degrees of malocclusion (overbite, open bite)	Changes to bones of the face
Painful swelling of salivary glands and dry mouth	Iron deposits
Reduced salivary protection	Reduced immunoglobulin A (IgA) in saliva
Sore or burning tongue	Folate deficiency
Pale gums and mucosa (lining of the mouth)	Anaemia
Discoloured gums	Iron deposits
Delayed dental development	Physical growth delay
Discoloured teeth with short crowns and roots	Iron deposits
Higher rate of dental decay	Multiple reasons; see under 'dental decay'
'Chickenwire-like' appearance of tooth bearing bone on radiographs	Bone marrow expansion

## Dental decay

Studies have shown that patients with thalassaemia have a higher rate of dental decay. There are many reasons which contribute to this. Changes to the amount and protective quality of saliva can result in dry mouth, which increases the chance of getting dental decay. Patients may have difficulty accessing regular dental care or may be reluctant to attend if they feel the dentist does not understand their condition. However, it may also be because patients are more concerned with the potentially serious medical complications of thalassaemia, and hence pay less attention to their teeth. Financial and time constraints may also contribute.

Although the higher rate of dental decay means that there is an increased need for fillings, care may only be sought at a late stage when individuals experience pain and try to access emergency dental services. In this situation, the dental decay is often advanced, with the risk of infection and abscess spreading into the tissues of the face and neck. Unfortunately, as a consequence of late presentation, dental extractions may be more likely to be provided than fillings, leading to individuals losing more and more teeth.

## Dental care

Dental care should be delivered as a coordinated team approach, ensuring close liaison between the dentist, the haematologist, and where appropriate, the paediatrician. The involvement and treatment provided will depend upon the severity of thalassaemia.

Dental care is provided on a shared care basis. Most patients with thalassaemia can receive routine dental treatment under local anaesthesia from a local general dentist. This means that routine check-ups and treatments are mainly provided by the local general dentist, but referral may be required to specialist services in the community or hospital dental services. This will be for specific courses of treatment, such as extractions if the patient receives regular blood transfusions. Another example is dental treatment under general anaesthesia. This

should be avoided due to the risks associated with underlying anaemia. When general anaesthesia is absolutely necessary, it should be carried out as an inpatient procedure, with the patient admitted under joint care with the haematology team. After completing treatment, the patient will be discharged to the local dentist for continued care. The dental specialties may include paediatric dentistry, special care dentistry (adults above the age of 16), or oral surgery. The dentist or doctor can refer the individual to these services.

Some individuals who have additional medical conditions or needs, may be seen by the community dental services for regular check-ups and treatments. It is important to be registered with a local dentist; either general dentist or community dentist.

Other considerations may need to be taken into account in the following instances:

- If a patient has had a splenectomy, they may be at greater risk of infection following any invasive dental procedures (such as extractions or deep scaling); as such, antibiotics may be prescribed to reduce the risk.
- With repeated blood transfusions there is an increased risk of bleeding due to heparinisation and a slightly greater risk of carriage of blood-borne viruses (Hepatitis C / HIV).
- Cardiomyopathy (heart disease due to effects of iron deposition) – there is a higher risk of stress to the heart.
- Medication-related side-effects – medication-related osteonecrosis of the jaw.

The most important principle of dental care is that prevention is better than cure. It is therefore extremely important to keep teeth and gums in as clean and healthy a state as possible by brushing teeth twice a day with a medium-textured small-headed toothbrush. Alternatively, an electric toothbrush can be used, and the dentist will be able to advise which ones are suitable. A fluoride toothpaste is recommended to reduce the risk of dental

decay. Regular check-ups are essential to ensure that problems can be picked up at an early stage and treated before acute infections arise. Individuals with thalassaemia who present with acute dental infections and abscesses should be treated at the earliest opportunity, especially if they have had a splenectomy. If the person is not registered with a dentist, they should seek emergency dental care from the local emergency dental services (call NHS 111) or hospital so that antibiotics can be prescribed until suitable care can be arranged. Alternatively, their general medical practitioner may be able to assist.

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## Summary

**It is important that both dentists and people with thalassaemia understand the implications of this condition on oral and dental health. The key to management is the prevention of oral disease. It is essential to visit a dentist regularly, so that any problems can be detected and managed early.**

Dr Navdeep Kumar is a Consultant in Special Care Dentistry at UCLH, an Honorary Senior Lecturer at UCL and a Divisional Clinical Director at Royal National ENT and Eastman Dental Hospital.



Dr Hana Cho is an Academic Clinical Fellow in Special Care Dentistry at UCLH.



# THALASSAEMIA FACTSHEET FOR DENTISTS

## What is thalassaemia?

Thalassaemia is a group of genetic conditions that affects haemoglobin formation. The haemoglobin is abnormal and can result in anaemia. Depending on the globin chain affected, it is classified into two main types: beta and alpha. These can be further subcategorised into minor, intermedia and major. The medical management depends on the severity of the condition.



Image: Mohamed Hassan from PixaBay

This factsheet has been produced by dentists for dentists! It provides a summary for the dental management of patients with thalassaemia. Please print it, photocopy or tear it from this magazine and hand it to your dentist.

What are the dental implications?

The table opposite provides treatment guidance.

## When should I refer the patient?

- Patients should be managed on a shared care basis.
- Most patients can be seen by a general dental practitioner for routine examination and non-invasive dental treatment.
- If the patient is transfusion-dependent and requires invasive dental treatment, such as extractions, refer to either community dental services or hospital dental services (Paediatric Dentistry, Special Care Dentistry or Oral Surgery depending on availability) for a course of treatment.

	Risk Assessment	Details	Treatment Modification
<b>Medical</b>	Chronic anaemia	<input type="checkbox"/> Fatigue <input type="checkbox"/> Poor motivation <input type="checkbox"/> Oral manifestations of anaemia	<input type="checkbox"/> Consider tolerance to dental procedure <input type="checkbox"/> If sedation / GA required arrange pre-operative assessment
	Infection	<input type="checkbox"/> Due to splenectomy, immune abnormalities, iron overload, severe anaemia <input type="checkbox"/> Bacterial and fungal	<input type="checkbox"/> Manage infections early and more aggressively – consider prescription for oral antibiotics <input type="checkbox"/> Consider post-operative antibiotics (liaise with haematology team)
	Transfusion	<input type="checkbox"/> Patients with thalassaemia major +/- intermedia receive regular blood transfusion	<input type="checkbox"/> Confirm whether patient receives regular blood transfusions <input type="checkbox"/> Avoid treatment on the same day <input type="checkbox"/> Time dental appointment within 1 week of transfusion <input type="checkbox"/> Consider referral to community dental service or hospital dental services for invasive dental procedures
	Blood-borne viruses	<input type="checkbox"/> Transfusion-transmitted infections: - Hepatitis B, C, G - HIV	<input type="checkbox"/> Follow cross-infection control protocol <input type="checkbox"/> Confirm status of infection and management <input type="checkbox"/> Check for presence of liver cirrhosis – caution when prescribing drugs, bleeding risk (pre-operative blood test may be required)
	Cardiomyopathy	<input type="checkbox"/> Due to iron overload <input type="checkbox"/> Risk of increased stress to the heart	<input type="checkbox"/> Assess degree of cardiac involvement; liaise with medical team <input type="checkbox"/> Minimise stress / anxiety for the patient
	Depression	<input type="checkbox"/> Poor motivation, tolerance, acceptance, fatigue	<input type="checkbox"/> Consider tolerance to dental procedure <input type="checkbox"/> Adapt treatment plan accordingly
<b>Dental</b>	Malocclusion	<input type="checkbox"/> Enlargement of maxilla due to bone marrow expansion / hyperplasia <input type="checkbox"/> Spacing of maxillary incisors	<input type="checkbox"/> May require orthodontic intervention
	Medication-related osteonecrosis of the jaw (MRONJ)	<input type="checkbox"/> Antiresorptive drugs for osteoporosis - Oral or intravenous bisphosphonates - Denosumab	<input type="checkbox"/> Follow SDCEP guidelines on MRONJ (2017)*
	Caries	<input type="checkbox"/> Xerostomia (iron deposits in salivary glands) <input type="checkbox"/> Reduced salivary IgA <input type="checkbox"/> Higher levels of salivary <i>Streptococcus mutans</i> <input type="checkbox"/> Poor motivation	<input type="checkbox"/> Follow PHE toolkit for prevention (2017)**
	Periodontal disease	<input type="checkbox"/> Short crowns and roots <input type="checkbox"/> Splenectomy <input type="checkbox"/> Poor motivation	<input type="checkbox"/> Regular monitoring and maintenance

\* Scottish Dental Clinical Effectiveness Programme (SDCEP) (2017). Oral Health Management of Patients at Risk of Medication-related Osteonecrosis of the Jaw

\*\* Public Health England / Department of Health (2017). Delivering better oral health: an evidence-based toolkit for prevention.

# Yoga for the mind, body and soul

Yoga has been a way of life for Smita Thakrar from the tender age of seven. In this article she tells us how it is a holistic approach to health – not only keeping her physically strong but also nourishing her mind and soul.

With the current coronavirus pandemic, we are all looking at ways to stay fit and healthy – physically and mentally. Maybe it's time to follow Smita's example and give yoga a try.

My name is Smita. I'm a yoga teacher based in London and have been teaching for over 19 years. My first experience with yoga was when I used to copy my grandad's yoga practice when I was just 7 years old. From that young age I began attending regular classes. Becoming a yoga teacher was initially to deepen my practice but I realised quickly that I wanted to share my passion and teach others. Yoga is now an integral part of my life and an essential part of my wellbeing. Yoga, for me, is a practice for the mind, body and soul.

Firstly, the physical practice of yoga that focuses on the body, also known as Asana, is what our first thought of yoga may be. My personal practice is a strength-based movement practice taking into account biomechanics. I also add resistance training into my daily routine.

For people with thalassaemia in particular, Asana, along with resistance training is an ideal form of practice as it builds bone density, benefits our posture, joints, and circulation. It is ever so important to keep moving our bodies by stretching and strengthening.



Photo credit: Karen Arnold for Public Domain Pictures

**“Yoga is an essential part of my wellbeing.”**





Photo credit: Karen Arnold for Public Domain Pictures

The second element of yoga which is often forgotten about is the mind. Breath practices, known as Pranayama can be the quickest and easiest way to change our state of mind. If you are feeling anxious and overwhelmed try and close your eyes. Simply take 10 slow breaths, (work your way up to 28 breaths). Focus and feel each breath. Hopefully, after this, the mind feels clearer and calmer, perhaps open for more creativity. For those of us with thalassaemia, breath practices will also help oxygenate our bodies, help with circulation and detoxification.

Finally, yoga is also for the soul. This simply means connecting to our true self through meditation and mindfulness. It is a practice that helps us stay in the present moment, without judgement. It can help lower stress and pain and can help us focus. In this day and age of constant stimulation, this can help disconnect from the outside world and benefit our mental

health. It helps create space in our minds and in our lives. It does however require patience and persistence. For people with thalassaemia, I find that visualisation techniques can help. Try sitting upright, slow your breath with 28 slow breaths and begin visualising a clear heart or liver with less iron and your body full of vitality and energy. Obviously don't stop your chelation.

The yoga community is ever expanding with a large variety of classes available locally and also online. There are so many styles of yoga and I'm sure you will find a style that fits your personality and needs. If you are new to yoga I would recommend you find a class local to you. Once you become confident you can practice on your own or online yoga sites.

If you have any questions please feel free to contact me. You will find more details of my classes on [www.yogabalance.co.uk](http://www.yogabalance.co.uk)

## A BUDDING STAR!

When we wanted a young person to feature in our video for the festive gala, we asked our patient member Maria Couppas if her seven year old daughter, Anthea, would like to take part. She agreed and did a fantastic job, talking about how her mum has thalassaemia. Maria posted the video on her social media accounts and asked for donations to UKTS. Together, they raised an incredible £590. Well done and thank you so much!



## THANK YOU FOR BEING GIANT-HEARTED

UKTS attended the AGM of the Giants Group of London in February and delivered a short presentation about thalassaemia and why screening for the condition is so important. Roanna Maharaj (UKTS) highlighted the importance of passing this information down to the younger generations as it is imperative that they are tested. UKTS plans for 2020 were discussed, amongst them the need to increase the visibility of thalassaemia amongst parliamentarians and the government as a whole. The Giants president presented a staggering £1000 to UKTS for which we are incredibly grateful. We would also like to say a heartfelt thank you to two very special people, Nilesch and Mina Raithatha (pictured with Roanna and Romaine), for their continued and unfailing support over the years.





## United Kingdom Thalassaemia Society -Membership Form-

All members receive regular email updates to keep informed about national developments and our events.  
Full members also have the right to vote at our AGM to decide how the society is run. (T&C apply).  
Join the UKs largest community of people affected by thalassaemia

### Personal Details

Title (Mr/Mrs/Ms/Dr/etc):

First Name(s):

Surname:

Address:

Post Code:

Occupation:

Ethnic Origin (optional):

Membership Type: Full (£2 per month with voting rights)  Ordinary (Free without voting rights)

### Contact Details

Telephone:

Mobile:

Email:

### Are you a (please tick where appropriate):

Patient:  Parent:  Organisation:

Health Care Professional:  Other (Please state): \_\_\_\_\_

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

Patient's Names:

Date of Birth:

Type of thalassaemia (Major, intermedia etc.):

Hospital where treated:

**Important GDPR requirement: We can only keep your details if you give us permission. Please tick yes if you would like to receive any further contact from us.**

Data will be kept on our files and only accessed by UKTS staff. It will not be shared with anyone outside of the UKTS.

I agree for my personal details to be held by the UKTS and for the UKTS to use these details to contact me about their work and issues relating to thalassaemia.

Yes:  No:

Signature:.....

UK Thalassaemia Society, 19 The Broadway, London N14 6PH  
Charity Registration Number: 275107  
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**Then display your picture on your window for your neighbours to see!**

**Competition closes on May 4th and winners will be contacted on May 8th!**

