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Thalassaemia Matters

WINTER 2019
ISSUE 132

In this issue...

Diabetes • Festivity fatigue • Blood donation

...and a whole lot more!

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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.

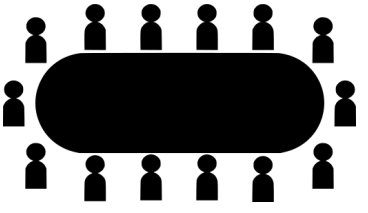
Please follow the link to donate to us:
https://www.paypal.me/teamukts

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.

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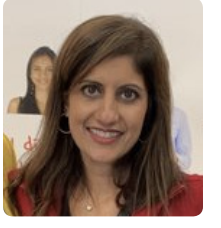
Letter from the Editor

Season's greetings and welcome to the winter 2019 issue of *Thalassaemia Matters.* Hopefully in amongst the festive chaos, you will get a chance to put your feet up with a mince pie and read this edition.

Christmas is a time when it's hard not to overindulge, but this can be risky if you have diabetes. In this issue, Dr Shah gives some really useful advice on how to keep your diabetes in check, whilst still fully enjoying the festive period. The holiday season can also be a time when we feel exhausted and overwhelmed with commitments. If this resonates with you, read Dr Eziefula's top tips for managing festivity fatigue. As we approach 2020, you may be thinking 'new year, new start' whether it be for your career, your health regime, the pursuit of a new hobby or something else. If that strikes a chord, turn to Yiannis Zambas's story for some serious inspiration. A perfect motivational boost!

We really appreciate the positive feedback we have had to the 'new look' magazine. Please do keep sending us your comments and any article suggestions that you may have for future editions. Enjoy the festive break and happy reading!

Neelam
Neelam Dongha



Message from the Chair

As 2019 draws to a close, it's a time to reflect on the year gone by. This year has certainly been a challenging yet rewarding year for us at UKTS. We organised several patient support groups throughout the UK; set up our very own All Party Parliamentary Group solely for thalassaemia; hosted our first National Thalassaemia Day which will now be celebrated annually; supported our members at the Infected Blood Inquiry; continued our partnership with the Sickle Cell Society for the NHS Screening Programme; engaged in new awareness campaigns; made four submissions to National Institute for Clinical Excellence (NICE) on new treatments that may be used to treat people with thalassaemia in the future; collaborated with the Department for Work and Pensions on Personal Independent Payment (PIP) for people with thalassaemia; were involved in the peer reviews being undertaken in thalassaemia and sickle cell around the UK, and so much more. As the UKTS is a non-government funded charity, I would like to take this opportunity to thank all of our sponsors and dedicated volunteers for their continued support throughout the year. UKTS is your charity and we would not be able to make a difference without your invaluable contribution.

On behalf of the team at UKTS, I would like to wish you and your families a happy christmas and a healthy and prosperous new year! We have lots planned for next year, so here is to 2020 and beyond!

Gabriel Theophanous

Meetings and events attended by the UKTS (September-November 2019)

September

9	Infected Blood Inquiry Update, Hepatitis C Trust
11	Bradford Patient Meeting, Manningham Clinic, Bradford
12	NHS BT meeting with CEO and Medical and Research Director
14	Education and workshop event, Friends of Sickle Cell and Thalassaemia, Cardiff
15	Cardiff Mela
16	Planning meeting, LGR Studios
16	Sickle Cell and Thalassaemia Counselling Competencies Meeting
17	Nursing Standards Interview on nursing education in thalassaemia
17-18	Meeting with TIF President, TIF Headquarters, Cyprus
18	Euro Genc TV interview
19	Meeting with Elizabeth Dormandy, Chair of Screening Group
19	Patrons' Quarterly Meeting
20	Meeting with Raleen Fernandes (Project Arise) and Iyamide Thomas (Sickle Cell Society) about screening
21	London Greek Radio Interview
23	Meeting with NHSBT CEO and Medical Director
24	Open coffee morning at UKTS to canvas public opinion on educational material (part of screening work)
26	Peer Review of Haemoglobinopathy Treating Centres - Barking, Havering and Redbridge Hospital NHS Trust
27	Peer Review of Haemoglobinopathy Treating Centres - Imperial College Hospital Trust, Hammersmith Hospital
30	UK Forum meeting

October

1	Peer review of Haemoglobinopathy Treating Centres - Cardiff and Vale Health Board
8	Delite Radio Interview
8	Meeting with officials from Vertex Pharmaceuticals Ltd
9	Planning meeting with Outreach Officials, North Middlesex Hospital
10	GG2 Diversity Conference
10	Mayor's meeting, Enfield Council
14	St George's Red Cell Celebration Day
16	Peer review of Haemoglobinopathy Treating Centres - Sheffield Children's Hospital
17	SCT Programme Advisory Board Meeting

(October continued)

18	BBC Asian Network Interview, Dilse Radio Interview
18	Volunteering at the Mayor of Enfield's Gala Ball
19	National Thalassaemia Day
21-23	Annual Sickle Cell and Thalassaemia Conference
22	UKTS General Meeting
28	Health Education England Meeting

November

1	STANMAP Conference and Annual General Meeting
4	Sickle Cell and Thalassaemia Counselling Competencies Meeting
6	Peer review of Haemoglobinopathy Treating Centres - Barts Hospital Trust, Royal London Hospital
7	Peer review of Haemoglobinopathy Treating Centres - Barts Hospital Trust, Newham Hospital, Whipps Cross Hospital
14	SCT Programme Advisory Board Meeting
15	Meeting with CEO, Asian Voice
19	Meeting with HDC and Silent Therapeutics
20	Peer review of Haemoglobinopathy Treating Centres - Homerton University Hospital
21	Planning meeting with Trustees
25	Peer Review Steering Group Meeting
27	Patient support group meeting at UKTS Office
29-30	TIF Board Meeting

Annual Sickle Cell and Thalassaemia Conference

From 21-23 October, UKTS hosted a booth at the Annual Sickle Cell and Thalassaemia Conference (ASCAT) which took place at Guy's and St Thomas' Hospital in London. At the event, UKTS provided literature (such as clinical standards for treating adults and children with thalassaemia) and support to national and international medical professionals. The UKTS also teamed up with Iyamide Thomas from Sickle Cell Society to provide information about parent stories and the benefits of identifying and referring at risk couples for early screening. UKTS would like to congratulate Professor Baba Inusa on his recent professorship! Professor Inusa is the founding father of ASCAT.

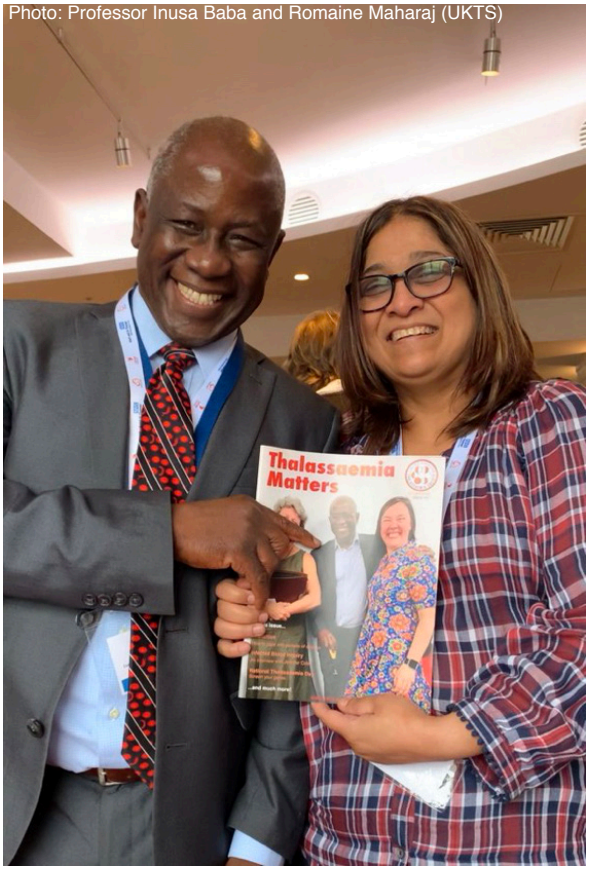


Photo: Professor Inusa Baba and Romaine Maharaj (UKTS)

Photo: Iyamide Thomas (Sickle Cell Society, Roanna Maharaj and Romaine Maharaj (UKTS)

Developing closer links with NHS Blood and Transplant

On 23 September UKTS met with the CEO of NHS Blood and Transplant (NHSBT), Betsy Bassis and Medical and Research Director Dr Gail Milfin, to discuss future collaboration between UKTS and NHSBT.

Photo: Dr Gail Milfin, Betsy Bassis, Roanna Maharaj and Romaine Maharaj (UKTS)

Luspatercept gets FDA approval in the US

On 8 November Celgene Corporation and Acceleron Pharma Inc announced that the US Food and Drug Administration (FDA) has approved the use of Reblozyl (Luspatercept) to treat patients with a moderate to severe form of beta thalassaemia (patients have to meet certain criteria). Reblozyl is the first drug of its kind – erythroid maturation agent – to get FDA approval. It is an exciting step forward in the treatment of beta thalassaemia and it offers a whole new form of therapy. It works by assisting the development and maturation of red blood cells so that patients need fewer blood transfusions. So far clinical trials in Europe have been encouraging, so we wait to see if the European Commission will follow suit and grant approval.

Photo credit: Gerd Altmann for Pixabay

Thalassaemia education event and mela in Cardiff

On Saturday 14 September, Roanna Maharaj (UKTS) was invited to give an update on advances in treatment for thalassaemia and the current work of the UKTS, at a family education day hosted by Friends of Cardiff Sickle Cell and Thalassaemia at Butetown Community Centre in Wales. The event was mainly aimed at people and families with thalassaemia and sickle cell, in addition to medical professionals and commissioners. The meeting was a huge success and it was a great opportunity to educate families on the need to advocate for oneself. It was also a chance to strengthen ties and form new relationships with all who were present.

Photo: Rochelle Powell (Paralegal, Inquiry team) and Neelam Dongha (UKTS)

INFECTED BLOOD INQUIRY

On 17 October Andre Andreou provided evidence at the Infected Blood Inquiry on behalf of her husband Mario (read her story on page 18).

Media coverage

UKTS has been really busy in the last few months getting lots of media coverage to spread awareness of thalassaemia amongst those at risk and the public in general. By raising much-needed awareness of the condition, we can encourage people to get screened and thus help to eradicate this blood disorder. Here is what we have been doing…

Euro Genc TV

On 18 September, Roanna Maharaj and Didem Keles were interviewed live for the medical programme of Euro Genc Television (Turkish and Turkish Cypriot television channel). Both Roanna and Didem spoke about why early screening for thalassaemia is so important in the Turkish communities before couples decide to have children. Roanna also gave a personal account of what it is like living with beta thalassaemia major.

Photo: Gul Deniz in centre (Euro Genc TV) with Christine Koulas and Didem Keles (both UKTS)

Photo: Roanna Maharaj (UKTS) and Mick Brown

Delite Radio

Roanna Maharaj was on air on 8 October, at Delite Radio for the morning show with Mick Brown. She told Mick about our National Thalassaemia Day events and the need for us all to be screened.

London Greek Radio

On 21 September, Peter Polycarpou (UKTS patron), Roanna Maharaj, Christine Christodoulou, Koula Kanias and Katie Read were interviewed by Vasilis Panayis about the UKTS' National Thalassaemia Day and the early screening event which was offered to all members of the public for free on 19 October. The group spoke about the prevalence of thalassaemia amongst the Greek population. From our engagement with the listeners, we were shocked to learn that people thought thalassaemia was a thing of the past and it no longer affected the younger population as it did thirty years ago. As a result, people were not passing on this information to their children or grandchildren in the UK. It was great to be able to have the opportunity to correct the myths. On 26 September, Tonia Buxton (UKTS Patron) was later interviewed by Vasilis Panayis about National Thalassaemia Day.

Photo: Tonia Buxton and Vasilis Panayis

Photo: Vasilis Panayis and Roanna Maharaj

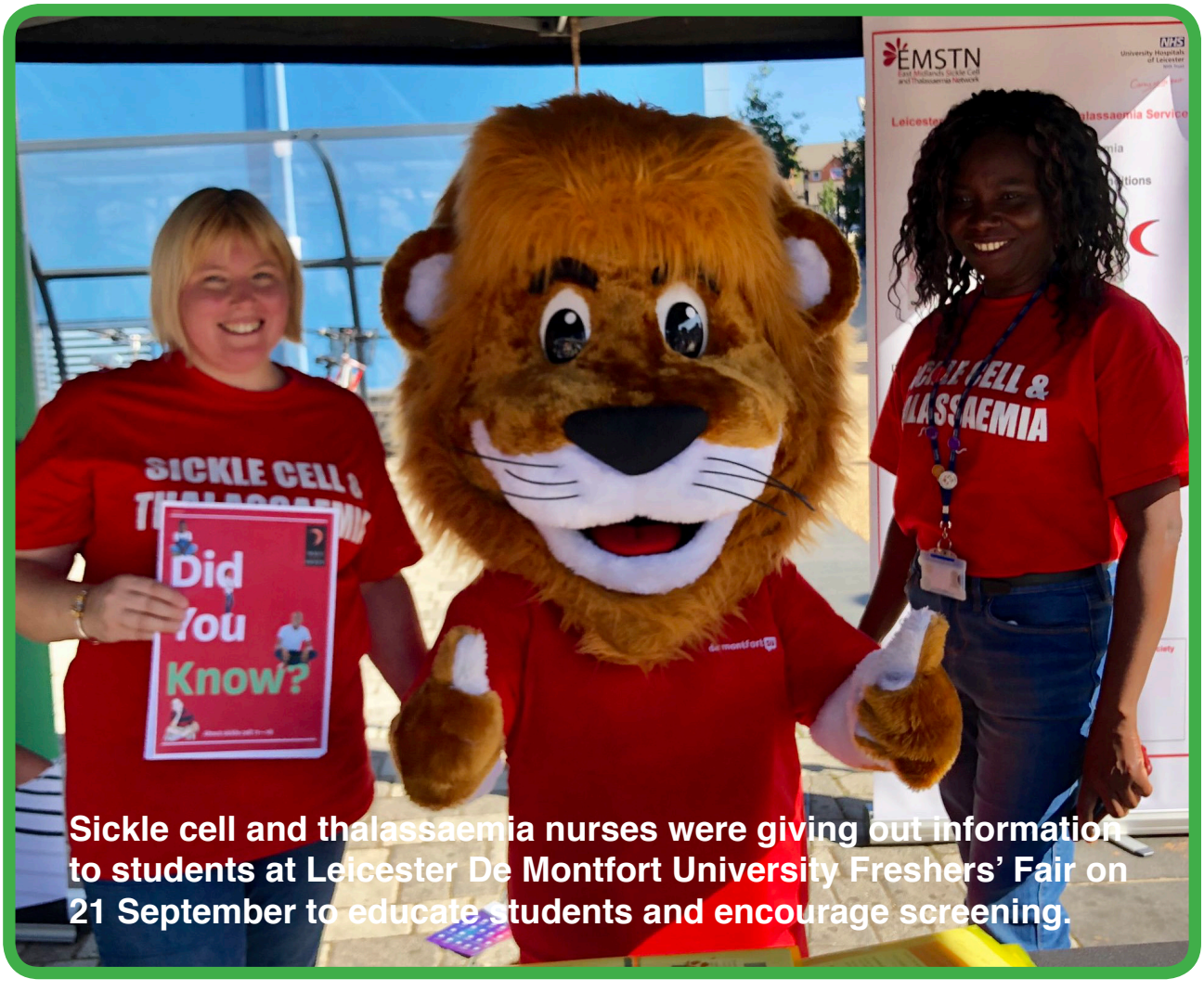
BBC Asian Network and Dil Se Radio

Roanna was broadcast again on 18 October, firstly on BBC Asian Network and then talking to Deep Rajah on Dil Se Radio. She highlighted the importance of blood donation and the shortage of BAME donors.

There was also coverage of our UKTS National Thalassaemia Day in various papers including the Sunday Mirror, Londra Gazette and Parikiaki News.

On 20 November UKTS were talking about the first National Thalassaemia Day on Hellenic TV.

Photo: Patron Tonia Buxton, Roanna Maharaj, Oddy Cooper (UKTS) and interviewer Vasilis Panayis



Sickle cell and thalassaemia nurses were giving out information to students at Leicester De Montfort University Freshers' Fair on 21 September to educate students and encourage screening.

NHS Blood Donation

"I don't know whose transfused blood I've received over the years but as I far as I am concerned, every blood donor saved my life! I'd like to say a huge thank to the real superheroes of this world!

I live because you give."

NHS Blood and Transplant interviewed Roanna Maharaj. They are sharing her story on their social media channels and in their publications, to encourage blood donation from BAME groups. Read their article here.

Roanna Maharaj, 30, from Wood Green in London, needed blood from nearly 250 people over two years to stay alive. Roanna has thalassaemia, a rare blood disorder that affects the production of haemoglobin. She's had blood transfusions all her life to help control her symptoms, but during her most severe spell she received more than 248 units of red blood cells.

The haematologists who were treating her, said her blood requirements were the highest for any patient with thalassaemia in the UK.

"My case was frequently discussed with leading thalassaemia and blood transfusion specialist haematologists in the UK and abroad," Roanna said. Her illness was so bad she became virtually housebound. "I was given a zimmerframe to help me walk indoors. I remember being so exhausted and in so much pain I'd have to take a break during a shower and sit down. On some days it was even difficult to feed myself. I could only watch television, look at my pictures, listen to music, and think back to happier times.

Blood donors are amazing. They are giving somebody like me a chance at life. A chance to experience things like graduations, marriage, children and everything between.The doctors have struggled to find matched blood for me before because there are not enough black and Asian donors. I hope that by sharing personal stories like mine it inspires more black and Asian people to donate."

DONATE A LIFE-SAVING GIFT THIS CHRISTMAS...

GIVE BLOOD

Blood donors are always needed over the busy festive period.

Go to www.my.blood.co.uk where you can register and book an appointment to get started.

GG2 Diversity Conference

We were invited by Shailesh Solanki, Executive Editor at Asian Media Group, to attend their annual GG2 Diversity Conference. Asian Media Group is a highly successful company; it owns a number of leading publications, including Eastern Eye, Garavi Gujarat, Asian Trader, Pharmacy Business, Asian Hospitality as well as the Asian Rich List and GG2 Power List.

BBC presenter, Clive Myrie, hosted the conference and set the tone by saying: “We need to harness the power of diversity.” You couldn’t feel anything but inspired and upbeat after hearing talks by some of the UK’s most influential figureheads. The common theme of the day was the power of cognitive diversity; companies that utilise teams of people from a variety of backgrounds achieve optimal results.

Photo: Neelam Dongha (UKTS) in front of the AMG titles

There were some excellent speakers and Salman Amin (CEO, Pladis) explained: “Cognitive diversity and inclusion is not only the right thing to do, it is also the smart thing to do.” Matthew Syed (Broadcaster, Writer and Thought Leader) went on to say: “Cognitive diversity is set to become a key source of competitive advantage for corporations, political institutions and even societies.”

Disability issues

Jay Muthu (Vice President, Global Talent and D&I, Monster) gave a brilliant talk about disability and raised the point that it often gets left out of diversity and inclusion discussions or is simply sidelined as a strand of diversity. Jay, a wheelchair user himself made everyone laugh when he said: “People are really afraid of disability. I’m just as normal as you. Sometimes a bit more normal than you.”


Photo: Jay Muthu (Monster) and Roanna Maharaj (UKTS)

Marianne Waite (Director, The Valuable 500 Campaign), made the thought-provoking point that we need to think of disability in a different way. “We are all temporarily abled but with age we can all possibly become disabled so we need to think about that.” For this reason amongst many others, the consensus was that disability needs to be high on the corporate agenda.

Mental health

Shamil Thakrar (Co-Founder, Dishoom) gave an inspirational talk about how his company makes the mental health of his staff a high priority. They take a whole person viewpoint and look at the physical, mental and financial health of their employees. This is more than just an empathetic approach – it actually makes good business sense when you consider that a quarter of the UK population have mental health issues. It is not surprising then that Dishoom was ranked 19th in the Sunday Times survey, 100 Best Companies To Work For, in 2019.

Festivity fatigue:
top tips for physical and emotional self-care

by Dr Chinea Eziefula

Christmas is around the corner, so are you feeling festive or are you feeling fed-up and fatigued? Have you noticed yourself having any of the following thoughts recently: "It's cold, dark and miserable outside!", "I don't feel up to doing much today", "I need a rest, I'm feeling exhausted", "I don't want to let anyone down but I just don't feel up to it today". If the answer is yes, then you are not alone.

Photo credit: Pixabay

Although this is supposed to be the festive season, sometimes we can feel anything but festive. Especially when: exhaustion kicks in; we have financial pressures; we feel alone or isolated; we haven't got friends or family around us; we have said goodbye to loved ones who have died; we feel overwhelmed with health problems; or when we feel burdened by lots of demands from the different people in our lives – be it work colleagues, friends or family. It can be hard to be festive and upbeat. It can be hard to feel alone. It can be hard to say no to other people's demands on our time and energy. It can be hard living with a chronic illness that others do not fully understand – a recurrent theme over the years in my work with people who have chronic, life-long physical health conditions.In preparation for this piece, I've spoken with fellow psychologists and the Whittington haematology team. I asked them: "How do you cope with the winter months, festivity fatigue, exhaustion and trying to do too much?" and "What might you say to the individuals that you care for who might be experiencing similar things around this time of year?" Here are some of our top tips for doing something about 'fed-up and fatigued' feelings during this period.

Dr Chinea 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.

Self-care and health management

"Keep up with the green vegetables and salad even though all you might want to eat is potatoes! Take your vitamin D – your bones need it and there is very little sunshine available. Moods can be low during the darker months – think of some treats to keep spirits up".

"Try your best to stay on top of your medications, appointments and general health. Try not to ignore any warning signs that you are doing too much."

"Think about establishing a regular outing or activity over a period of 2-3 months and then review how it's going after month 1 – do you need to do less or more of other things in order to keep this activity? Or do you need to do less or more of the new activity?"

Keeping on top of usual self-care routines and health management can be challenging when the days get shorter. Time feels like it is flying by and energy or mood levels dip at this time of year. **A good diet and regular routine** (using paper or electronic diaries!) can help to maintain structure and hold in mind all of your important health-related tasks.

Also, definitely think about rewarding yourself when you have been able to stick to a routine – **rewards can be encouraging and motivating** – so think about something you would really like and promise it to yourself on the condition that you can stick to a planned routine or activity that you have set for yourself.

It is also important to think about how to **involve others in supporting you with any healthy routines;** can you try something new with a group? For example, consider a 'greens day' or 'greens hour' (green vegetables, juices, salads) with friends and family so that you can try healthy diet changes together.

Boundaries and assertiveness

"I try to stay boundaried with work and what I am doing over Christmas. Lots of people stress over buying presents, seeing everyone and cooking which can make Christmas feel like a burden rather than time to take a break. Find things that are genuinely nurturing to you at this time of year; cancel if you need to do less or say no to things that just feel too much, but still make sure you have some nice plans for yourself that feel important."

"Try to avoid the desire to spend time completely on your own."

"Notice if you are comparing yourself to your friends or people around you who don't face the same challenges as you; don't rush things or push yourself too hard."

"Having a support network helps! Make efforts to make friends and seek support (for example, from support networks or social groups). Reach out and ask for help when you need it."

"Let employers know what you need to support you at work. Find out about work practices that can help you – for example, can you change your working hours to be more flexible? Can you work from home? Get advice about talking to employers from charities like UKTS and Remploy or talk to your haematology team about this."

Clear boundaries and assertiveness are key components for communicating effectively with the people around you about what you need or how they can help you while you manage the effects of a health condition. This is especially important during the festive season when you might have many requests from people around you, or when you might just want to have some time to recover from the challenges of the year that is ending.

Assertiveness can be defined as an open style of communicating respectfully about your needs and self-disclosure can be defined as the act of expressing and sharing your needs with others. Unsurprisingly, lack of assertiveness and low levels of self-disclosure are related to less satisfaction with support from friends, family and others which is also known as 'social support' (Anders and Tucker, 2005). Similarly, less help-seeking from social support networks is linked to poorer emotional and physical wellbeing when living with a health condition (Rini et al., 2016).

There are times when discomfort or feelings like guilt, 'feeling bad' or frustration show up when trying to assert or share our personal feelings and needs with others. This is because we all have many rules and expectations about how we think other people should behave. Rules often start with a 'must', 'should' or 'ought to' and we tend to apply such rules to ourselves too, sometimes with a distinctly harsh, critical tone. When we feel like rules that are important to us are violated or our expectations are left unfulfilled, difficult feelings may rise to the surface including anger, frustration, disappointment and guilt. Such feelings can be directed towards other people or sometimes they can be directly inwardly, towards ourselves.

Photo credit: needpix.com

During the festive season and at other times of the year, it is important to notice and recognise if any of your own rules or expectations are coming up; for instance, rules about the importance of respecting and meeting the needs of particular friends or family members. Sometimes such rules can stop you from also nurturing or looking after yourself, while you focus on tending to the needs of others. Or such rules can lead to a distancing from people around you if you are left feeling disappointed, frustrated or exhausted by others.

If these feel like familiar patterns to you, then consider taking some actions to develop and assert boundaries and express to those around you what you might need from them in order for them to help you. Below are some ideas about how to go about this:

1. **Pace yourself and avoid overcommitting**. Instead, try to come up with compromises or negotiations about what you have time for and, if you struggle to do this by yourself, then ask other people to help you think about this too. Don't automatically give in to guilty feelings – feel free to cancel or say no to things that might mean over-extending yourself. Try to problem-solve, scale back and be creative where you can about how and when you can commit your time and energy. It is possible to put boundaries in place while still being connected to the people you love and care about. For example, this could entail scaling back on social engagements but keeping family commitments because that feels most important to you. Or it might mean opting to spend some time alone (5-10 minutes) when you are at a family event because you committed to go but in fact wanted some quiet time to yourself too that day.

2. **Consider how you communicate with the people around you about your decision-making or plans**. There are three common styles of communication: passive, aggressive or assertive (Raskin, 1994). The following qualities have been shown to be common assertive traits that can help people lead fulfilled lives: (i) being able to say 'no' when needed, (ii) talking openly about personal needs and desires and (iii) being able to talk openly about (positive and negative) personal feelings (Lazarus, 1971; cited in Peneva and Mavrodiev 2013). Suppressing and withholding feelings is associated with increased tension and can have a negative impact on wellbeing (Gross and John 2003) so rather than taking a passive approach to communicating your needs, consider ways you can be more open about why and how you might be taking a breather from certain social activities or requests. Seek support from work-based support services if you need help to communicate your needs at work.

3. **Think about the best ways you can make use of your support networks** and share this information with the relevant people in your network. By doing this, the people around you will know how best to support you and you can feel well-supported by your support network. Try to identify the people who can help you with different challenges. For instance, where can you go or whom can you talk to when you need emotional support and you would like to feel heard or listened to? Who or what is the best source for practical advice and support? Who or what can help you take your mind of worries and distract you with something fun or funny? Who can help you to notice when you are starting to feel exhausted by social activities? Is there anything you can suggest they do to alert others or help you get some rest?

If you would like more guidance on developing skills in assertiveness and communicating your needs then consider working through the following online self-help modules on this: https://www.cci.health.wa.gov.au/Resources/Looking-After-Yourself/Assertiveness

Physical activity

"Do a 'good deed' like sharing some advice with others or signing up to a cause that feels important to you. You might feel lighter or good in some way for having made a difference to someone else or by focusing on an important issue."

"For me physical activity is the best mood-booster. Cycling gives an unbeatable feeling of freedom. Take up some form of physical activity or schedule this into your time. You could cycle to work and back. If not work, then try to get up early and go for a cycle to a park, café or to see a friend. Even when you start out feeling like the dark and cold is too miserable. As long as you have the right clothes, you'll feel better when you get back."

Cycling is just one way of being active. Physical activity is any movement of your body and muscles that requires energy (Department of Health, 2011). You don't have to take up structured exercise like going to the gym or cycling regularly to be physically active; you could simply take up activities like doing housework, going shopping, walking or other active hobbies. Physical activity can reduce stress and anxiety (Stonerock et al., 2015), increase positive moods such as alertness and enthusiasm (Pascoe et al., 2011) and improve health, such as reducing blood pressure (Rowley et al., 2018) and improving bone health (World Health Organisation, 2003). As little as 10 minutes of physical activity a day has been found to improve energy levels, fatigue and mood (Hansen et al., 2001) and some form of physical activity is actively encouraged for people with physical health problems (Rowley et al, 2018).

Physical activity can be a challenge for some people with thalassaemia due to possible problems with inflammation, low haemoglobin, and iron build-up in the heart. Also there are people with thalassaemia who struggle with body pains (lower back, bones, joints) and struggle to be active as a result (Oliveros et al., 2013). The 2016 UK standards for the clinical care of children and adults with thalassaemia highlight the importance of physical activity for people with thalassaemia while recognising the potential challenges due to complications resulting from the condition; regular exercise within one's capacity is recommended. This means that physical activity is promoted for people with thalassaemia too.

Physical activity can improve heart health, (Rowley et al., 2018) reducing the likelihood of developing secondary problems such as diabetes or improving health outcomes for those already living with diabetes (WHO, 2003). It can also mitigate the effects of osteoporosis alongside good diet, vitamins/supplements and monitoring (UKTS, 2016; WHO, 2013). Although you may feel tired or low in energy due to your thalassaemia, what we know is that physical activity can increase energy levels and has positive health benefits so if you can do something active even for just ten minutes at a time, then that is a good start and you can build from there.

Consider using NHS apps (Active10) or a GP exercise referral scheme to help you get going and see https://www.nhs.uk/live-well/exercise/ for more information. For some individuals with pain affecting the bones, muscles or joints then it may be helpful to see a physiotherapist for help to become (more) active, however you can also visit the NHS website mentioned above for advice on adapted exercises for people living with health problems. Please always seek advice from your haematology team before commencing any rigorous exercise regimens.

These are just a few ideas about how to manage 'festivity fatigue' but general tips on managing thalassaemia-related fatigue throughout the year are welcome! If you have your own 'top tips' that you would like to share then please do get in touch with me [Dr Chinea] by by emailing the UKTS magazine editor, neelam@ukts.org.

Photo credit: Len Williams, geograph.org.uk/p/5237739

Diabetes, thalassaemia and the festive period

by Dr Farrukh Shah, FRCpath

Diabetes is a disease that develops when blood glucose (sugar) levels are higher than the normal range. Blood sugar levels are controlled by a hormone called insulin which is released from an organ called the pancreas. The pancreas is easily damaged by iron overload and patients can then develop diabetes as a result of this. Damage to the pancreas is avoidable if there is good control of iron overload and patients are fully compliant to medication. Patients should have a glucose tolerance test every year or monitoring of fasting blood glucose and random glucose, in order to check for diabetes.

Diabetes is a commonly encountered endocrine complication in thalassaemia patients; approximately 10% of thalassaemia patients have diabetes. There are several ways in which patients with thalassaemia may be affected:

1. Patients may have impaired glucose tolerance and are therefore pre or peri-diabetic but do not require any treatment for this. In the majority of patients, their blood sugar levels are well controlled with simple dietary measures. This situation is often observed when someone has poor adherence to their chelation therapy regime. However, it is a reversible stage which can normalise with good chelation therapy. Some patients with this may simply be genetically predisposed to type 2 diabetes and are identified early as the glucose tolerance test is done annually.

2. Patients may have non-insulin dependent diabetes, treated with tablets. The predisposing factors for this type of diabetes are:
   - The patient has a genetic predisposition to type 2 diabetes,
   - The patient has a high Body Mass Index (BMI), is of Asian origin and /or has high blood pressure.

3. Patients who have insulin-dependent diabetes and are treated with a variety of insulin regimes.

If you are diabetic, you should be under regular monitoring by the diabetes team. The control of blood sugar is best measured using the fructosamine test. The test for HbA1c that is generally used to test for diabetes is unreliable for patients with thalassaemia, as this indicator is diluted down by the blood transfusions. Diet-controlled diabetics or pre-diabetic patients need to be as careful as patients who are on medication for control of their diabetes, to avoid very high blood sugar levels.


Photo credit: Silviarita for Pixabay

Here are some steps to take to ensure you keep well over the festive period.

For insulin-dependent patients:

1. Ensure you have enough medicines and testing supplies.
2. Keep to your normal routine with carbohydrate counting and insulin ratios, look at boxes and packets to make sure you are assessing correctly.
3. Remember to give correction doses if your sugars are high pre-meal, if you are using insulin.
4. Remember to be careful with alcohol. A lot of alcoholic drinks contain carbohydrates but you might not need to take your usual mealtime amount of insulin to cover them, because you are more likely to get a hypoglycaemic episode. If you are drinking and going dancing, then the risk is higher and you should test more frequently. Make sure people you are with know you are diabetic and there is a risk of hypoglycaemic episodes, and also what to do if you have one and cannot help yourself. The risk of hypoglycaemic episodes last for up to 24 hours so keeping a close eye on your sugars and symptoms is important.

For patients using oral medication or no medication (to manage their diabetes):

1. You need to make sure you have enough medication to last you over the festive period.
2. Keep to your normal routine with the medicines.
3. Be sensible about your meal choices and aim for lower carbohydrate and lower fat alternatives. For example, opt for turkey without the skin, single cream instead of double, custard with skimmed or semi-skimmed milk.
4. Be careful about alcohol especially if you are taking sulphonylurea-type drugs such as glibenclamide, gliclazide, glipizide, tolbutamide and glimepiride as there is an increased risk of hypoglycaemic episodes.
5. Take some exercise such as going for a walk, checking out the sales at the shopping mall, going dancing to help burn off the extra calories and also to help control the blood sugar levels.

Wishing you all a happy festive season!

Dr Farrukh Shah is a Consultant Haematologist at Whittington Hospital NHS and University College London Hospitals.

Infected Blood Inquiry: time to be heard

Whilst many patients with thalassemia and their families have been directly affected by NHS treatment with infected blood, so far not many have come forward to provide witness statements.

The Inquiry Chair, Sir Brian Langstaff, reads every statement provided to the Inquiry. On 1 November, Sir Brian explained that he is particularly interested in receiving statements from people with thalassaemia. This is because the Inquiry aims to provide a full picture of what happened and this picture will not be complete without that evidence.

It is understandable that people hesitate to spend time focusing on distressing things which happened to themselves or their family. The Inquiry recognises this and has developed different ways to contribute so you can choose the best way for you. We explore the different options here.

Talk to an intermediary

Some people told the Inquiry that because of social stigma they would not be able to provide a witness statement in the usual way. This led Sir Brian to introduce the option of speaking with complete confidentiality to one of the three 'intermediaries'. The intermediaries meet the individuals who request this service and then write reports for the Inquiry.

These reports do not identify the different people they have spoken to but summarise common experiences and themes. This can also be a good option for anyone who does not have a great deal of information about what happened to a family member.

The Chair will read the intermediaries' reports, and they will be published alongside other evidence, helping to paint an accurate overall picture of what happened. You can find information about the intermediaries at https://www.infectedbloodinquiry.org.uk/news/inquiry-launches-innovative-way-collect-evidence and if you would like to use this option, please speak to the Inquiry Team on freephone 0808 169 1377, or email contact@infectedbloodinquiry.org.uk.

Complete the witness statement yourself

If you don't feel comfortable talking to someone face-to-face, you may prefer to draft your witness statement yourself. The Inquiry will send you a witness statement form which you complete and post back to the Inquiry office. A member of the Inquiry staff will then liaise with you via email (or phone if you prefer) in order to finalise your statement. A member of UKTS staff can assist you in filling out the form, just call or email the UKTS office.

Complete a witness statement with a member of the Inquiry Team

You can give a witness statement to a member of the Inquiry at a place of your choice, where you feel comfortable:

- A member of the Inquiry staff can visit you at your home,
- You can go to the Inquiry's offices in central London (Fleetbank House) to have your statement taken, or
- Your statement can be taken at the UKTS office in Southgate, or another location that you prefer.

You can have a family member or friend (or a member of the UKTS team) to support you while you give your statement.

Anonymity

Whether you complete the witness statement forms yourself or give your statement to a representative of the Inquiry, the Inquiry can anonymise any identifying information to ensure your identity is protected.

If you think you might like to make a statement, or even if you just want to find out more, visit https://www.infectedbloodinquiry.org.uk/evidence-and-public-hearings and click the link '*Form to express interest in providing evidence*' where you can download the form.

Real-life stories

Gina Halwani and Andre Andreou both lost loved ones with thalassaemia, as a result of them being given infected blood. They both made the decision to provide witness statements but did it in different ways. Gina did it from her home with a member of the Inquiry whilst Andre Andreou gave evidence at the Inquiry at Fleetbank House.

Gina Halwani

Gina's brother, Costas Kountourou, passed away after contracting liver cancer. When Gina first heard about the Inquiry, she was adamant she did not want to provide a witness statement. However, her sons encouraged her to tell their uncle's story. They told her that it was the right thing to do, not just for him but for all the others who suffered like he did. A member of the Inquiry team visited Gina at her home to take her witness statement. We spoke to Gina about how she found the experience. She told us that, whilst it was difficult to recount what had happened with Costas, she felt glad that she did it. She commented that it was a relief to be able to tell his story and she felt like she was seeking justice for him. Gina also said that the person from the Inquiry was very approachable, kind and sympathetic.

Andre Andreou

On Thursday 17 October, I [Neelam Dongha] attended the witness hearing for the Infected Blood Inquiry. I listened to Andre Andreou talk openly about her family's experience after her husband Mario, a thalassaemia patient, contracted Hepatitis C as a result of being given contaminated blood. Andre was incredibly brave and her honest and heartfelt account gave a real insight into the harrowing times the family went through during Mario's illness.

Throughout the hearing, Andre kept saying: "It wasn't about me, it was about him," but this is not the case; it was and still is about the whole family, as all of their lives were affected. It was truly heartbreaking to hear how they all suffered. But this is exactly why you need to come forward if you too have been affected by infected blood. This is Andre's story.

"Mario was treated at Queen Elizabeth Hospital until he was twelve years old and then he moved to the care of the North Middlesex Hospital. When I got together with Mario in 1993, he was very funny, energetic and bubbly. He was someone who loved socialising and he really enjoyed working for Warner Films in the city.

Photo: Mario Andreou

He told me he had Hepatitis C and said it was an infection in the liver that he had caught through his blood transfusions. He said it could be dangerous but with treatment it would go away. I don't think that Mario understood the seriousness of his illness.

When he started the medication (Interferon), it had a huge impact on Mario's physical *and* mental health. The side-effects of the drug were very nasty. It totally changed his personality and his outlook on life; he became very fragile and very depressed. He lost weight and was always shivering and sweating. He would be wiped out, sometimes hallucinating. He was often very angry and the fact that he had been given tainted blood really upset Mario.

He lost everything: his self-esteem, his self-respect and his confidence.

He was a very sick man and in 2001 he was medically retired from work. He developed so many other health issues including osteoporosis and two collapsed vertebrae. He was taking anti-depressants but they were not working. At the back of his mind, I think he knew he was going to die.

Mario didn't want people to know he had hepatitis C or thalassaemia. There used to be a lot of ignorance about thalassaemia, as if it were the plague. Back then in Cypriot society, it was a taboo thing. There was a cultural stigma attached to hepatitis C too and he was worried how people would react. This further added to Mario's isolation and led him to feel suicidal at times. He lost everything: his self-esteem, his self-respect and his confidence.

It had a huge emotional impact on me and my two daughters. I was working so hard to make ends meet whilst raising the kids at the same time. Financially it was very hard, so whenever I could I would do overtime.

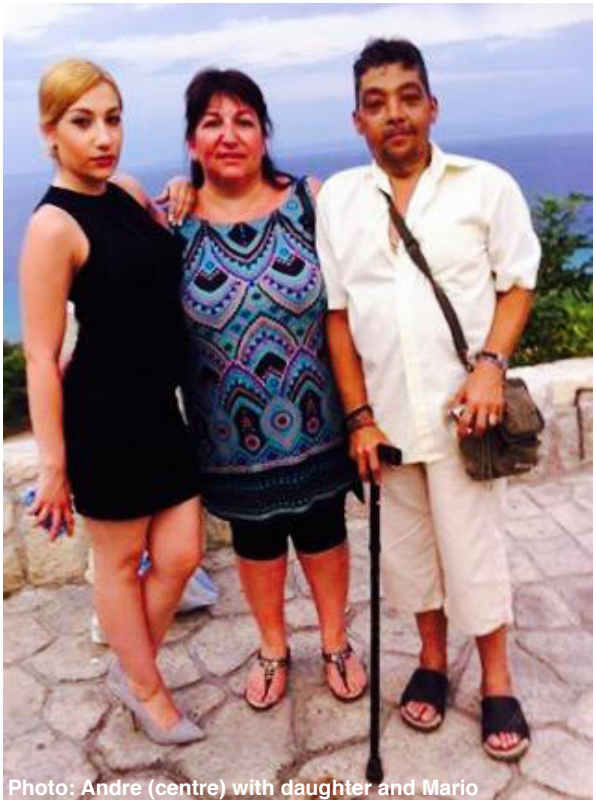


Photo: Andre (centre) with daughter and Mario

Mario was on Interferon for almost 12 years before the doctors said that his liver had cleared. But then, in 2016, Mario was diagnosed with liver cancer. He had surgery and we thought he was doing well. However, by Christmas that year, his stomach became bloated and his legs started to swell up. After more tests we were told in March the following year that the cancer was back. Mario asked for his prognosis and was told he had six months to live. The news killed him and he died just three weeks later. He was only 52. My hope is that over time this Inquiry will give us the answers and justice."

A psychotherapist's perspective

Demi Andreou is Andre's sister-in-law (married to Mario's brother) and she works as a psychotherapist. She gave us her professional insight into the psychological impact that Mario's illness had on the family.

"Having a person with thalassaemia in the family is all my husband ever knew growing up. Watching a sibling undergo regular blood transfusions and injecting desferal on a daily basis was his norm. However, despite all this he watched his brother persevere and try to lead as normal a life as he could; working, socialising and having a witty, larger than life sense of humour. All this unfortunately changed once he was diagnosed with hepatitis C. The 12-year course of therapy took a real toll on Mario both physically and mentally.

As a family they watched and noticed this change happening before their eyes. Mario lost his work, his enthusiasm but also in time, his personality. They watched him develop depression, my husband and his family stood by quite helpless. Watching his brother from afar deal with such a condition – along with the depression and change of personality that followed – evoked feelings of helplessness, frustration, guilt and anxiety; these being just a few of the emotions experienced.

My husband often felt moments of guilt that he was the healthy child in the family. These feelings of guilt themselves led to depressive thoughts and depression. Depression has to be managed and recovery comes from the person alone, only they can take that step to help themselves feel better. Being a compassionate listener is what I could offer as a psychotherapist.

Watching his brother then finally pass away was a trauma in itself; the last few weeks were particularly difficult. The helplessness became even more present, withdrawing and becoming detached from what he was witnessing. This was a defence mechanism to what was happening and can be quite normal for someone who is grieving. Two and a half years on and the trauma is being relived through the Inquiry. However, there is optimism in how this will end and then the real recovery for family members can begin."

My hope is that over time this Inquiry will give us the answers and justice.

Photo: Sir Brian Langstaff and Andre Andreou

Infected Blood Inquiry team

Alice O'Connell, a member of the Infected Blood Inquiry team and three of her colleagues also attended the UKTS National Thalassaemia Day. Their aim was to raise awareness among the thalassaemia community about the work they are doing to represent all those who have suffered as a result of contaminated blood. They were keen to engage with people who have been affected and encourage them to provide evidence. We wholeheartedly support them and strongly urge you to share your story with them (remember you can choose to do it with complete confidentiality).

Hepatitis C Trust

The charity Hepatitis C Trust is a fellow core participant in the Infected Blood Inquiry. Samantha May, a Hepatitis C Trust helpliner, attended our National Thalassaemia Day to raise awareness about this very serious condition. She acknowledged that there is a stigma around Hepatitis C which prevents people from wanting to get tested. She herself has had hepatitis C and urged people who may be at risk to be tested. She said: "On the helpline we hear from people in their 50s, 60s, 70s and 80s who had blood transfusions before 1991 and received contaminated blood. They are phoning us because they have only just received a diagnosis of hepatitis C. The problem is that it can remain symptomless for many years. If you get tested, we can save lives because if we find the undiagnosed people, they can get the right treatment." If you would like to get in touch with Samantha in total confidence, you can email her at samantha.may@hepctrust.org.uk

Yiannis Zambas: follow your dreams

Yiannis is a driven, successful young man with beta thalassaemia intermediate. He chose to share his story with us in order to encourage fellow patients to take on challenges and pursue the career paths that they enjoy. His positive and balanced outlook is inspiring.

"I was first diagnosed with beta thalassaemia when I was two years old. My parents can vividly recall that period, when doctors had to conduct a series of tests to determine which form of thalassaemia I was born with. I was officially diagnosed with beta thalassaemia intermediate, a less clinically severe form of thalassaemia. It is characterised by lower haemoglobin levels (7-10 g/dl) but without the need for regular blood transfusions.

In terms of my background, I was born in Cyprus in 1991 and I have two siblings; an older sister and a younger brother. No other member of my family has beta thalassaemia. I was fortunate to grow up in Cyprus, a country – which along with the UK and a few other countries – is a world leader in terms of healthcare provision and treatment of thalassaemia-related conditions.

Growing up with beta thalassaemia intermediate, I had to contend with a weaker-than-normal immune system and lower haemoglobin than other boys my age. Since my diagnosis at the age of two years old, my medical routine has involved a periodic visit to the Nicosia thalassaemia specialist doctor for check-ups and taking some daily supplements. Fortunately, I haven't had the need for a blood transfusion to this day. Despite experiencing some medical complications while growing up,

Photo: Yiannis Zambas

looking back I can say that my condition did not prevent me from having similar experiences to other children. The only limitation was an extensive participation in sports activities, but I always tried my best to take part in sports as much as I could, and I regularly go to the gym nowadays. Upto now, I have found that some physical exercise from a young age, combined with healthy nutrition and a positive attitude to

life really has helped me manage my condition.

At 28 years old, my treatment hasn't changed much. I'm currently monitored at University College London Hospital on a regular basis. I try to maintain a healthy lifestyle and strike the right balance between working hard, exercising but also taking time to rest and enjoy time with friends and family.

Photo: Yiannis with his mum

At the age of 18, I left Cyprus for the UK, to begin a degree in Accounting & Finance at the University of Manchester. In my final year of studies, I received a job offer from Deloitte LLP London, a global consultancy firm, to work in their Audit department for three years whilst at the same time being sponsored by the company to study for my Chartered Accountancy qualification. I have to admit, at the beginning I was a bit hesitant to take this opportunity. London is a fast-paced city, and the work environment can be demanding. Nonetheless, accepting the job and taking on this challenge is probably the wisest choice I've made in my life so far. My employer was very understanding regarding my condition, and with some work adjustments, I was able to perform well in my job, contribute to my team's success, pass my exams and obtain my professional qualifications.

After completing my three years in the Audit department, I decided to take on a new challenge; about two years ago I joined the Mergers and Acquisitions team within the Corporate Finance department of Deloitte. Whilst it is definitely a more demanding and fast-paced job, I'm really enjoying my current role. I do find it challenging at times, but I ensure that I communicate any issues with my team and try to maintain a good balance between work, rest and leisure.

As a thalassaemia patient living in London, what really excites me is the ongoing innovation in the medical treatments for thalassaemia and the pivotal role that London medical centres are playing in this transformation. I've been closely following the development of various thalassaemia medical treatments including erythroid maturation agents, gene therapies and gene-editing solutions. In fact, last year I took the decision to participate in a clinical trial for Luspatercept for intermediate patients, which is currently ongoing.

I'm confident that in the near future, patients will have a number of potential options to alleviate symptoms or fully treat beta thalassaemia. I feel very optimistic about the

future as medical breakthroughs continue at pace but also as society – including our fellow citizens, communities and the government – are becoming more and more aware about thalassaemia, and more measures are taken to ensure that fellow patients receive the treatment they need in the UK and abroad.

"I try to maintain a healthy lifestyle and strike the right balance between working hard, exercising but also taking time to rest and enjoy time with friends and family."

Photo: Yiannis with friends

My main motivation for getting involved with UKTS is to interact with children with thalassaemia and their parents, to inspire and motivate them to pursue their goals and dreams. Today, with the extended care available, organisations like UKTS and a more general awareness, every child with beta thalassaemia can and should be encouraged to experience life as any other child would. I look forward to the opportunity of participating in more of the great events organised by UKTS and interacting with other fellow members."

Special feature: National Thalassaemia Day

On Saturday 19 October 2019, UKTS held its first-ever National Thalassaemia Day!

The charity invited the general public to come into its Southgate office and have free testing (via a simple blood test) for thalassaemia, sickle cell trait and hepatitis C. In addition to screening for these conditions, people could have a fibroscan to test their liver function.

There were also representatives from NHS Blood and Transplant (NHSBT) conducting blood tests so that people could immediately find out what blood group they belonged to. NHSBT and UKTS were delighted that more than 35 people registered on the day to become donors.

It was a hugely successful day with lots of people walking in to be tested. Moreover, it was a fantastic way of raising awareness of thalassaemia among the general public.

Also attending were: the Mayor of Enfield, Kate Analou; MP for Southgate, Bambos Charalambous; David Burrowes; four members of the Infected Blood Inquiry; and Samantha May from Hepatitis C Trust.

Aside from the screening, it was a great opportunity to educate people about these conditions.

Photo: Oddy Cooper (UKTS), Mayor Kate Analou and UKTS patron Kypros Kypyrianou

The colour theme is obvious from the photos...we wanted to paint the town red! In fact, we obtained council approval to use the roundabout opposite the offices to set up a stand, where we could hand out out information leaflets to passers-by and tell them about the free testing on offer.

UKTS is incredibly grateful to Kypros Kyprianou and the Theo Paphitis Charitable Trust for generously sponsoring the event. Thank you to our amazing patrons: Kypros again and Peter Polycarpou for supporting the event in person; and Peter and Tonia Buxton for the media coverage. Huge thanks to the nurses, doctors, genetic counsellors and psychologists who so kindly gave their time. Lastly, thank you too to all the volunteers who helped and to the local shops that supported the event.

Before the testing began, UKTS Chair, Gabriel Theophanous, welcomed everyone and explained the different tests being offered. UKTS patron, Peter Polycarpou, then gave an important message: “Thalassaemia is a very serious disease but one that can be prevented by knowing your carrier status. It is extremely important to find out before you think about having a baby. I urge you to be screened. That would be an enormous help to you, your family and your offspring.”

Peter was followed by fellow patron, Kypros Kyprianou, who explained how he came to be involved with the charity. He described how he met a bright, intelligent young woman at a party and was impressed by her positive outlook and personality. He then discovered she had thalassaemia and was bowled over by the intense and harsh treatment she had to endure in order to keep her alive. That was our very own UKTS voluntary staff member, Roanna Maharaj! Kypros said it was because of her that he had been inspired to join UKTS as a patron. He spoke about UKTS and said: “You are great people doing great things. I’m proud to be a patron.” UKTS is incredibly grateful to Kypros for generously sponsoring the event.

Photo: UKTS patron Peter Polycarpou

Photo: MP Bambos Charalambous (fourth from left) with UKTS trustees, staff members and volunteers

UKTS Executive Director, Romaine Maharaj, stressed the importance of the day and said a special thank you to the nurses for giving up their Saturday to work voluntarily for the charity. With that, the testing began.

Later in the day, Mayor Kate Analou said a few words. She remarked: “I am a retired midwife and have delivered many babies. I have seen the devastating effects of thalassaemia so I know what people are going through. Screening is crucial.”

Gina Halwani also paid tribute to her late brother Costas Kountourou, a much-loved and inspirational thalassaemia patient. The date of the event had been set to commemorate the 10-year anniversary of his passing. Gina said: “This is the happiest and the saddest day for me. I feel so honoured that the day has been launched in Costas’s honour. I would also like to remember all the other thalassaemia patients that have passed.” In the evening Gina hosted a small get-together for close family and friends to remember her brother.

Christina Terry-Christodolou, a patient with thalassaemia said: “This is a fantastic event and the amount of support has been overwhelming”.

Over 70 people were tested for the various conditions and of those, the following results were detected: probable alpha thalassaemia trait – 21%; probable beta thalassaemia trait – 9%; sickle cell trait- 3% and normal – 67%. There were no positives from those that were screened for Hepatitis C but the fibroscans (liver) did show up some abnormalities. Some 54 people were fibro-scanned: one was cirrhotic and five others had abnormal results. All these people were given mini consultations with Dr Ghosh to discuss the result and advised to see their GPs. They were then given forms with the results on and relevant contact details for any follow-up questions that their GPs may have.

The day was a huge success on many levels: raising awareness and educating people about the condition; encouraging people to spread the word and get tested for thalassaemia; and bringing the community together. We have been asked to run more testing days like this in other areas across the UK so watch this space!


Photo: Nurse Clare Smith and Dr Indrajit Ghosh (fibroscan team)


Photo: David Burrowes and Gabriel Theophanus (UKTS)

Photo: Clinical Nurse Specialist Rachel Brown with her partner


Photo: Kypros Kyprianou (UKTS patron) being tested

oto: Peter Polycarpou (UKTS patron) being tested

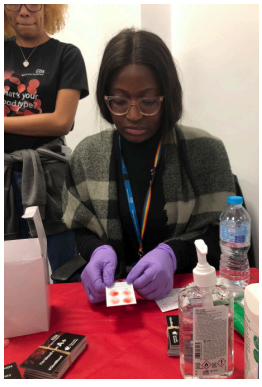



Photo: Christina Terry-Christodolou (left) with friends

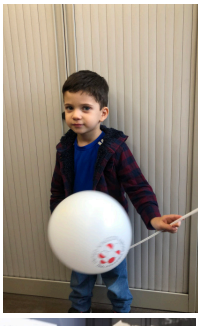


Photo: Dr Georgios Kaltsounis, Francesca Belli and Dr Wolfgang Novak


Photo: Gina Halwani (right) with Alice O'Connell, Infected Blood Inquiry Team (centre) and friend


Photo: Roanna Maharaj (UKTS) and Parth Thakkur (The Wishing Factory, India)

Photo: Dr Chinea Eziefula, Neelam Dongha (UKTS), and Ninga Kankinza (clinical psychologist trainee)


Photo: Infected Blood Inquiry team members


Photo: Priya Desai (UKTS) with Clinical Nurse Specialist Nkechi Anyanwu and granddaughter

In memory of Chris Fassis

Sadly, Chris Fassis passed away on 5 June 2019. Chris had thalassaemia and had been a trustee of UKTS over the years. To mark and honour Chris's passing, his previous employer: Cypriot Elderly and Disabled Group and Day Care Services (CEDG), decided to make a donation of £8,000 to UKTS. We are extremely grateful to Savvas Charalambous (Chair) and the management committee at CEDG for this hugely generous gesture which will help fund UKTS activities next year.

Photo: John Constantinou (far right) and his daughter Niki (next to him) at the UKTS National Thalassaemia Day presenting the cheque to Chris's family members

Chris's manager John Constantinou attended UKTS's National Thalassaemia Day and presented Chris's family with the donation cheque for UKTS. John told us about the work of CEDG and also what Chris was like to as a work colleague.

"CEDG was set up to prevent isolation amongst the Cypriot, Turkish and Greek communities. It provided a venue where they could meet regularly to discuss problems, get advice, guidance and translation support if necessary. CEDG started operating full-time with GLC funding in 1984 and rented the Cypriot Centre to run the daycare service for the elderly clients until its closure on 30 September 2019 (due to financial reasons). At its peak, it had 24 members of staff with 8 minibuses servicing 55 clients.

Chris had worked as a full-time employee at CEDG since 1984. He initially began as a volunteer but after three months, a post was created for him as a carer and outreach worker. Chris's role was to engage with clients; this might involve taking them to various appointments and advocating on their behalf, acting as an interpreter, or even simply socialising with them. Chris was very popular and a real team-player. He was very cheeky and had a great sense of humour. He always had a lot of

banter going on with the clients, especially as he was a Chelsea supporter. In addition to Chelsea, Chris's other passion was collecting antique glass. His nickname was Napoleon because of his height! He was so committed to his job that he undertook an Open University degree in Health and Social Care. He was very bright and sharp. In fact, he could be like a 'little pitbull' because he liked to challenge and debate work procedures."

Photo: Chris Fassis

Photo: Pany with Chris

Pany Mardapittas, Chris's cousin, paid a moving tribute to his beloved cousin.

"My cousin Chris...where do I start? Chris was my first cousin, my best man at my wedding and my best friend. We were just like brothers. Ever since I opened my eyes, Chris was around. We were so close. He was my 'go-to-guy', I would tell him things and shared so much with him. He must have heard them time and time again but never got bored and always gave me time to bend his ear. Chris was a larger than life character. He wasn't the quietest person in the family...I must have got that from him! Through the years, we had many good times, with a few lows thrown in too. He was always there for me. Chris, my cousin Helene and our very good friend Jim were my rocks when my mum passed away.

Anyone who knew Chris would say he was lively, loving, caring and someone who would always go the extra mile. All my life, I can honestly say he didn't moan or complain about his condition which is amazing considering what he and many others have had to go through and endure all their lives.

Chris, I love and miss you so much. I know a big part of me has gone with you. I hope you are keeping them all entertained and on their toes up there."

Chris's Aunt, Frosoulla Knell lived with Chris when he was growing up (between the ages of 8-23). She said he had a very good nature, was very generous and never complained about his condition. He was always willing to help others and had a very kind soul. Chris's cousin Evi and her husband Dr John Ioannou told us how Chris is dearly missed. They said that despite his thalassaemia, Chris was full of life, funny and cheeky.

In April, Chris was interviewed as part of a red cell project at UCLH. The following are Chris's words.

"At 60 I'm the oldest person with thalassemia major at UCLH – although sometimes I feel like I'm 160! I was born in Paddington in July 1958 to Greek parents who came over to England in the late 1950s. They found themselves, without extended family, managing a small child with a medical condition. I was diagnosed at Monks Park Clinic at 18 months, having my first blood transfusion shortly afterwards, and was treated at Paddington Green Children's Hospital, St Mary's and then at Barts until arriving at UCLH.

Having been asked to leave Wembley High School for spending an excessive amount of time in the photography lab (and nowhere else), I moved to Alperton High School. I gained a City and Guilds qualification in Photography at college and worked for a food photographer, then worked full-time in electrical retail before retraining to become a carer. Despite setbacks, I gained a degree in health and social care and I am now able to add the letters BSc to my name.

When I first arrived at UCLH I was still an angry young man but soon learnt that in order to fit in within my newfound home, I had to start thinking of others. I moved quickly from irresponsible to responsible, so much so that for the past 10 plus years, I co-run the red cell patient group with my fellow patients.

The greatest threat to our health is infection because most of us thalassaemics don't have spleens (they were removed) and therefore no first line of defence. I've had episodes in my life which have caused me to face my mortality – most recently suffering atrial fibrillation which is usually controlled by medication.

For me, the service at UCLH is probably the best in the land because all my needs and concerns are addressed with a sense of immediacy. It's reassuringly person-focused and our doctors and nurses identify the necessary procedures, treatments and care to halt any advancement of decline and are committed to our health and well-being."

Marathon 2020: Meet Julien and Ward

The 2020 London Marathon is panning out to be a source of real excitement for UKTS. In our last issue of *Thalassaemia Matters*, we featured Professor Valdir de Andrade Braga who had been busy fundraising for the charity. We would now like to introduce two more runners, Julien Morrut Selesse and Ward Stepman, who between them have already raised a staggering £6,000! This has surpassed anything previously achieved by former marathon runners for UKTS. We are incredibly grateful to them both for their fundraising efforts, which will go towards funding the patient support groups planned in 2020.

Julien and Ward are work colleagues, both working for Biobest Group. Julien is an agricultural engineer and lives in France whilst Ward is a sale manager whose home is in Austria. Both have previous running experience; Julien has done trail runs of over 55km with a 3,500m elevation and Ward has done several half marathons and trail runs of over 50km with a 1,500 elevation.

Julien has a strong personal connection to thalassaemia; his wife Sabha Bandoui has thalassaemia trait and her brother – Ashkaan Bandoui, our very own UKTS board member (Assistant Treasurer) – has thalassaemia major. As a consequence, Julien is well aware of the impact the condition has on a patient's daily life. This is why he encouraged his colleague Ward to join him and support UKTS too.

In fact, Sabah is also running the marathon for UKTS so it will be a real friends and family affair!

The date for the marathon is 26 April 2020 so put it in your diaries NOW and come along and join us in cheering on Julien, Ward and the rest of our amazing runners! It is thanks to the efforts of people like Julien and Ward that we are able to provide the services we do. Well done and thank you to Julien and Ward. Good luck to all our runners!

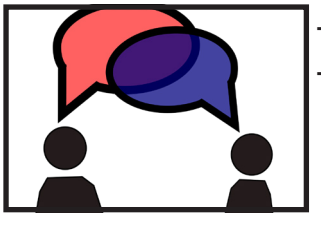
THANK YOU!

We would like to say a really BIG thank you to the following companies for their generous donations this year:

Theo Paphitis Charitable Trust
ApoPharma
Celgene
Bluebird Bio
Vertex Pharmaceuticals
Leigh Day Solicitors

Their support is invaluable to us in our work to support the thalassaemia community.

We have lots more being planned for 2020; patient support groups, medical conferences, research programmes, to name but a few. Our overriding aim is to support you - our patients - so it is really important that we hear what your concerns and issues are, in order to provide the right services for you. Please do call or email us with your suggestions.



Tell us what you think about this issue of Thalassaemia Matters. Email the editor Neelam Dongha on neelam@ukts.org

Would you like to share your story? Or do you have any article ideas that you would like to suggest for future issues of Thalassaemia Matters? We would love to hear from you. Please do email the editor with your comments and suggestions.

United Kingdom Thalassaemia Society

-STANDING ORDER MANDATE-

Help us to help you by supporting YOUR Society
-Every £1 is precious!

Please Support The UK Thalassaemia Society
by Making a Monthly Donation

To the Manager [Name of Your Bank]	
Address:	
City:	Postcode:

Please Pay: NatWest, 12 The Broadway, Southgate, London N14 6PL

For the credit of: UK Thalassaemia Society, Registered Charity No:275107
Sort Code: 51-50-00 Account Number: 64949362

The sum of: £2.00 ☐ £5.00 ☐ £10.00 ☐ Other ☐ £_____ (amount)

On the_____ (day) _____ (month) _____ (year)

And thereafter every month until further notice and debit my account accordingly.

Signed:	Date:
Signed:	Date:

I would like tax to be reclaimed on my donation under the **Gift Aid Scheme**. I am a UK tax payer and pay an amount of income tax and/or capital gains tax at least equal to the tax that can be reclaimed on my donation.

YES ☐ NO ☐

Data Protection

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

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

YES ☐ NO ☐

Please contact us if you have any queries. When completed, please return form to the UKTS office (see below). We will then send this form on to your bank.
Thank You for your valued support.

UK Thalassaemia Society, 19 The Broadway, London N14 6PH
Charity Registration Number: 275107
TEL. 020 8882 0011 www.ukts.org

United Kingdom Thalassaemia Society

-Membership Sign Up-

Being a member gives you: Regular newsletters to keep you up to date on national developments, Invitation to our events, right to vote at our AGM to decide how the society is run, join the UKs largest community of people affected by thalassaemia

Personal Details

Title (Mr/Ms/Dr):

First Name(s):

Surname:

Address:

Postcode:

Occupation:

Ethnic Origin: (Optional)

Contact Details

Telephone (home):

Telephone (work):

Mobile:

Email:

Are you a (please tick where appropriate):

Patient: ☐ Parent: ☐ Organisation: ☐

Health Care Professional: ☐ Other (Please state): _____

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

Patient's Names:

Date of Birth:

Gender you identify with:

Type of thalassaemia (Major, intermedia etc):

Hospital where treated:

Important: 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.

All details and information will be kept on our files. It will not be made available to 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:** ☐

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