



## Presenting the 3rd edition of the Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK



UKTS President Gabriel Theophanous with Chief Editor Dr Anne Yardumian

So far 2016 has been one of the busiest years ever for UKTS. As you will have noticed, this issue of TM is rather late - but we hope you will forgive us when we tell you about the labour-intensive, time consuming projects we have undertaken!

By far the largest and most important project was the publication of the 3rd edition of the Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK. These guidelines, which are used by doctors responsible for thalassaemia care in many overseas countries, were first produced in 2005. An updated version was published in 2008 after the introduction of the new oral chelator Exjade; but this new, 2016 3rd edition is completely new and has been rewritten from scratch. No fewer than 25 authors, all acknowledged authorities in their fields, contributed to the various chapters, which cover all aspects of thalassaemia care. The writing process began in January 2015 under the editorial supervision of Dr Anne Yardumian, Chair of the UK Forum on Haemoglobin

Disorders; and culminated on the 12th May 2016 when the new Standards were introduced at our national academic conference, presented in partnership with the UK Forum, at the Royal Society of Medicine in London. The conference was opened with a video message from Professor Dame Sally Davies, the government's Chief Medical Officer for England. Dame Sally (who also wrote a Foreword for the book) was kind enough to commend UKTS for their leadership role in producing the Standards and to confirm the Department of Health's strong support for the document. We were also honoured by the presence of Mr Panos Englezos, President of the Thalassaemia International Federation, who joined UKTS President Gabriel Theophanous in welcoming over 200 health care professionals from all parts of the UK to the conference. The UK Thalassaemia Society would like to thank Dr Claire Chapman (Retired, former Consultant Haematologist at Leicester

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### UNITED KINGDOM THALASSAEMIA SOCIETY

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# A word from our President



Dear friends,

Well – so far it has been quite a year for us at UKTS – if not the busiest, it has certainly been one of the busiest years ever for us. The first half of 2016 saw us simultaneously tacking a number of very important, labour-

intensive projects. The year started off with a bang, as we joined forces with the Sickle Cell Society to bid for a public tender contract with the NHS Screening Programme – and we were immersed in the complicated and confusing business of learning how to write a bid for a public tender (see page 6 for details). Thankfully our joint bid was successful and we are delighted to be working in partnership with our colleagues at the Sickle Cell Society, in what we hope will be the first of many joint ventures.

Many of our readers will be aware that we also sent out a comprehensive survey in 2016. This was a questionnaire sent to all those people on our database who have thalassaemia and who were aged 15 and over on 1st January 2016. The survey covered quality of life and social matters as well as medical treatment, along with space for respondents to enter their own thoughts and experiences. This survey yielded a vast quantity of useful information; which has been collated and is currently being prepared for publication. One very important aspect of the survey however

was that it provided quotations which we were able to use for another huge project – the publication of the 3rd, fully revised and updated edition of the Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK. As in previous editions, each chapter is started by a selection of genuine (anonymous) quotations from you, our readers. Many health professionals have told us that these quotations are so important because it reminds them that behind the science, the tables and the medical terminology are real people - people who don't only exist in the hospital unit but who have full lives, careers, families, all of which are affected by their treatment. So if a drug causes nausea and tummy pain, the person suffering that unpleasantness could be a mum or dad trying to get the children to school or a youngster who has to get off the bus several times on the way to work or college – not just a statistic. So let me thank each and every person who took the time and trouble to complete the survey. Which brings me to direct your attention to the page opposite – and to encourage all of you to contact the UKTS office to request your FREE copy of the latest Standards! As you will have read in the front page story, I and my fellow Trustees were proud and happy to be able to present the Standards to the medical community at our national academic conference at the Royal Society of Medicine on 12th May 2016 – truly a day to remember. Presenting the lifetime awards to Drs Yardumian and Wonke and my dear friend George Constantinou was

truly one of the most fulfilling tasks I have undertaken as President of UKTS.

Among the many proud moments UKTS has enjoyed in 2016 there is one very disappointing matter I have to mention; which is the cancellation of our AGM on the 3rd June. According to our constitution, for an AGM to take place we must have 21 paid-up members of the Society present; and despite letters, emails and reminders being sent to all our members (not to mention the desperate last minute phone calls on the night) we did not have enough members present to make a quorum. We can ill afford the waste of time and money; so in future we will be looking at alternative venues for the AGM, perhaps at a larger meeting. Nevertheless we have ploughed ahead and rescheduled the AGM for the evening of the 7th September – and this time hopefully the meeting will go ahead.

Finally, I have some news of my own to share with you but I don't want to spoil the surprise – all will be revealed on page 9. As you will see, 2016 has truly been a landmark year so far!

**Gabriel Theophanous**  
President, UK Thalassaemia Society

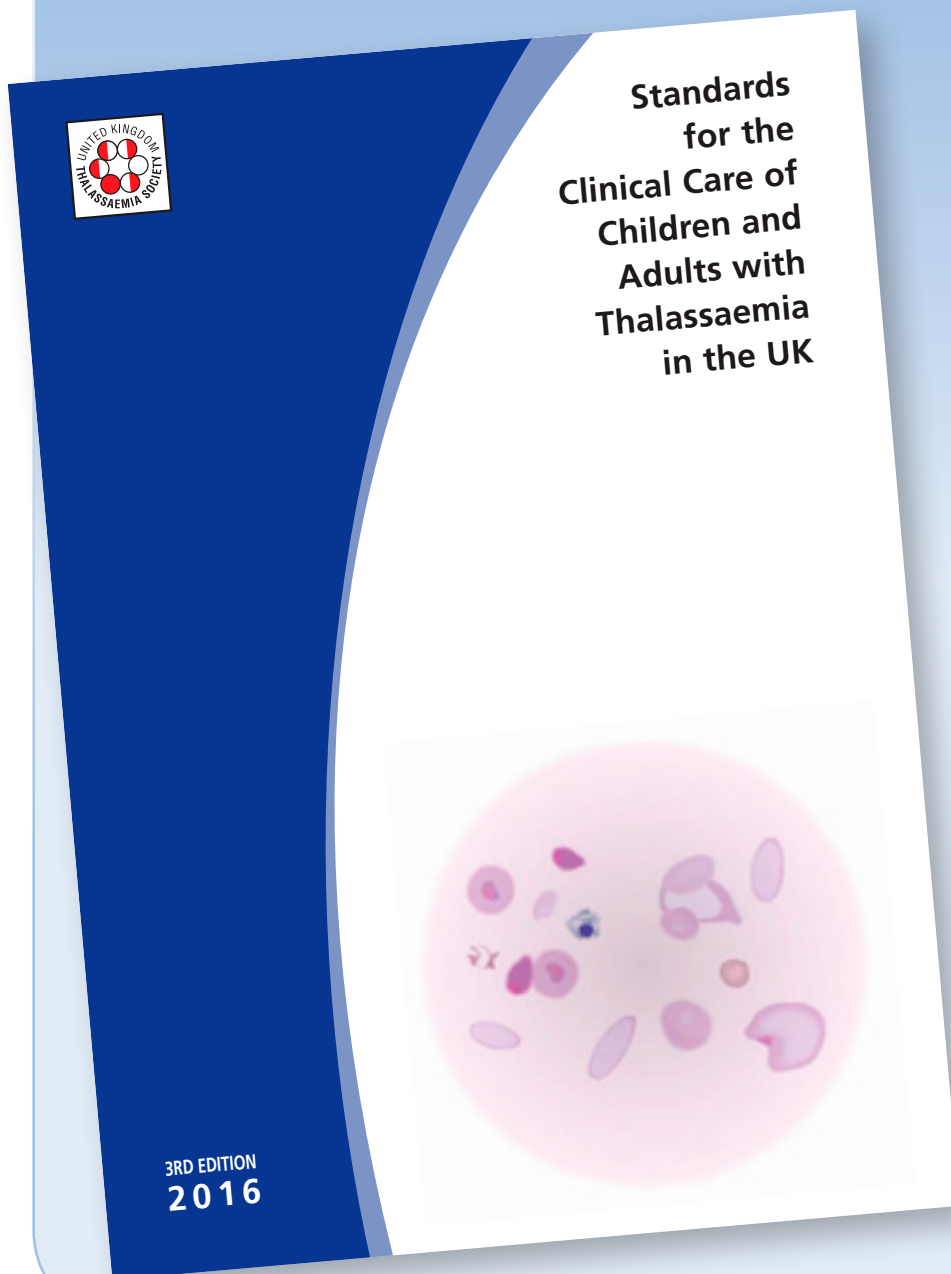
## Our Mission Statement

- To be the definitive source of information, education and research for those affected by, or working with thalassaemia.

## The UKTS Management Committee

<i>President</i> <b>Gabriel Theophanous</b>	
<i>Vice-President</i> <b>Romaine Maharaj</b>	<i>Treasurer</i> <b>Raj Klair</b>
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# Presenting the 3rd edition of the Standards For The Clinical Care of Children and Adults with Thalassaemia in the UK



Fully revised and updated  
new edition (May 2016)  
Available **FREE** from the  
UKTS Office to:

- Health Care Professionals (Doctors, Nurses and Associated Professionals) caring for people who have thalassaemia
- People affected by thalassaemia (Patients and Carers)

Order your copy by emailing  
**office@ukts.org** Or Call  
**020 2882 0011** TODAY!

Also available online at:  
**<http://standards.ukts.org>**





*Dr Beatrix Wonke accepting her award*



*Gabriel with George Constantinou*

Royal Infirmary) and Dr Farrukh Shah (Consultant Haematologist, Whittington Hospital) for their help on the conference organising committee; as well as all the speakers and chairs who gave up their time to help us make the conference a success. Thanks also to the committee of the UK Forum on Haemoglobin Disorders for their kind cooperation in allowing us to present the conference in partnership with their academic meeting programme.

Delighted as we were to welcome all the doctors and nurses to the conference, there were two very special doctors whose presence made the occasion memorable – Dr Beatrix Wonke and Dr Anne Yardumian. Dr Wonke has been enjoying her retirement, steadfastly refusing all invitations to take part in medical meetings since she left the Whittington Hospital in 2004; and we were aware of Dr Yardumian's impending retirement at the end of 2016. We therefore knew that it might be another ten years before we could get both doctors in the same room again, and decided that we could not miss the opportunity to bestow some very special UKTS awards.

At the end of the conference our President, Gabriel Theophanous, presented Dr Beatrix Wonke and Dr Anne Yardumian with crystal rose bowls engraved

with the UKTS logo and the inscription "Presented to ....with grateful thanks for your lifetime of dedication and outstanding contribution to the treatment of thalassaemia in the UK." Gabriel gave a moving speech about the careers of both doctors and how they achieved their legendary status in the thalassaemia community; finishing with "Dr Wonke and Dr Yardumian, we can never replace you, but your work will go on - through your colleagues and through us, your patients. We can never thank you enough for what you have done for our community. We honour you. On behalf of the UK Thalassaemia Society it is my great pleasure and privilege to present you with these awards, with grateful thanks from us all."

And finally, another presentation closed the conference – this time a very personal award from the UK Thalassaemia Society to our longest serving Trustee, George Constantinou. George was absolutely amazed when Gabriel presented him with an engraved crystal plaque – in fact we can safely say that this was the first time we can ever remember seeing George lost for words!

Overall the 12th May 2016 was a landmark day for UKTS. A national conference entirely devoted to the treatment of thalassaemia patients, the publication of a completely up to date set of clinical standards; and finally, three special UKTS awards for people who have devoted their own lives to improving the lives of people with thalassaemia. No-one in our thalassaemia community has been untouched by their work - the clinical skill and discernment of Dr Wonke and Dr Yardumian; and the relentless campaigning of George Constantinou, whose dedication to the cause of thalassaemia will never be surpassed, nor will it be forgotten by his friends at the UK Thalassaemia Society.

The full programme of the conference can be downloaded from the "Academic Meetings" section of the website of the UK Forum on Haemoglobin Disorders [www.haemoglobin.org.uk](http://www.haemoglobin.org.uk)

The Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK can be downloaded here: <http://standards.ukts.org>.

# UKTS Runs for Fun on International Thalassaemia Day!

By Tina Bhagirath

On Sunday 8th May 2016 UKTS Trustee Tina Bhagirath organised a Fun Run at Upton Park in Berkshire in celebration of International Thalassaemia Day.

The walk was attended by some familiar faces from previous years, but we were delighted to be joined by a greater number from the local community and to gain some new supporters. It was a lovely day, with children and adults alike walking the 5k to mark the occasion.

The Fun Run was a great success, attracting walkers whose ages spanned three generations! Bringing fun to our supporters was an achievement in itself; as well as being a vehicle to spread the message of our work. We were able to bring awareness of thalassaemia to a new area and to a community where knowledge and awareness of thalassaemia was scarce, despite being densely populated with the South Asian community. It was great to have a presence in Upton Park on this special day, when we made many new friends and visitors, who engaged with us and took away information on thalassaemia and the work we do at the UKTS.

Tina's cousin, Anita Rullay from Wolverhampton, was supporting the Fun Run for the second consecutive year. Anita had set up a Justgiving page and raised £395 for the Society in 2015. Smashing her previous record however, Anita raised an amazing £542 in 2016! All of us at UKTS would like to thank Anita for her marvellous effort and her continuing support in this event.

Thanks also go to Slough Borough Council for their support in allowing UKTS to hold the walk in Upton Park – and last but not least, love and thanks to all the walkers who made the day such a success! I hope we can build on this success and have an even bigger event in 2017.

**Watch this space for more information on next year's event - save the dates 7th & 14th May 2017!!!**



*Fun Run organiser Tina Bhagirath with her father*



*Tina presents medals to our young supporter Jena Khan*



*... and our youngest walker Aaqib age 3*





## UKTS partners the Sickle Cell Society in new project

As our regular readers will be aware, UKTS has worked with the NHS Sickle Cell and Thalassaemia Screening Programme (NHSSCTSP) since its inception in 2001. This work has been ongoing and has covered a number of different aspects including: representing the interests of people affected by thalassaemia on the NHSSCTSP Steering/Advisory Group and all sub-groups, sourcing service user representatives for NHSSCTSP events and consultations and very importantly, working with the Programme on public engagement. Since 2009 UKTS and the Sickle Cell Society have received financial support from the Programme for our contribution to the public engagement work. This has helped to raise awareness of thalassaemia to many thousands of people over the years; and has included the production of our film *Thalassaemia – your life, your choice, your test* (available in English and Urdu, free from the UKTS office).

However in recent years the NHS and Public Health England have been through radical restructuring programmes; and these have led to widespread change and reorganisation. One of the new procedures introduced is that of public tendering for any work carried out on behalf of the National Screening Programmes. Hence, at the beginning of January this year the NHSSCTSP published a public tender for a project entitled *“Tender for managing public and service user engagement/consultation to support the NHS Sickle cell and January Screening Programme”*. This meant that, for the first time, UKTS and the SCS would be competing with other organisations to obtain the contract to carry out this work. As the two national Societies representing people affected by thalassaemia and sickle cell, we and our colleagues at the Sickle Cell Society were confident that we were the best people for the job; and agreed to join together in writing a partnership bid with the Sickle Cell Society as the lead applicant and UKTS as partners. However, writing public tender bids is a complex and difficult process, very time-consuming as we soon found out! UKTS

being a very small organisation with no finance department or employees trained in bid writing (such as are permanently employed by the larger charities) it was most definitely the steepest learning curve we have had to negotiate for some time! Most of January 2016 was taken up by our efforts and we were all very relieved when we finally sent in the bid in time for the end-of January deadline. Thankfully the time was not wasted as in February we learned that we had been successful in winning the contract, which started with the new financial year on 1st April 2016 and is planned to run for two years. The new project will focus on:

- improving the timeliness of antenatal screening
- developing and publicising a timely pathway for known carrier couples to access prenatal diagnosis
- improving performance on various aspects of newborn screening, transition into care and data collection

The NHSSCTSP offers screening for thalassaemia to all pregnant women. According to the standards of the Programme, this offer of screening must be made by the time the woman is 10 weeks pregnant. If the woman is diagnosed as a carrier, the offer is then made to test the baby’s father. If the couple take up these screening offers and are found to be both carriers (a “couple at risk”) they are offered counselling and prenatal diagnosis (PND). The standard is that PND should be performed by the time the woman is 12 weeks and 6 days pregnant. Unfortunately in too many cases the standards regarding timeliness are not being met which restricts the opportunity of the couple to exercise informed choice. The project will be looking at pathways into antenatal care and trying to identify any barriers which prevent the targets from being met.

Of course, there are some couples who know in advance of their pregnancy that they are at risk; from having had an earlier child or sometimes from having chosen to be tested before starting a family. Sometimes these couples have already decided on how they wish to proceed – some may choose to decline screening from the outset; however there are others who know that they wish to have PND. Statistics show that even where a couple

has expressed the wish for PND very early in pregnancy, often they are still not receiving the test until later than the 12 weeks 6 days standard. There are a numbers of reasons for this, among them are the fact that maternity services operate differently in various parts of the country and have their own protocols and guidelines. However it should be possible to create a specific pathway for those couples who request PND at the outset to ensure that they meet no obstacles; and one of the objectives of the project is to design such a pathway. In view of this, we will be consulting women who have had children in the last five years so that we can record their experiences of the antenatal screening pathway, and find out what choices they were given and at what stage of their pregnancy.

At the moment newborn babies are screened for sickle cell disorder and the sickle cell carrier state via the “heel prick” test given to new babies when they are a few days old. The current test does not diagnose thalassaemia carriers and nor does it give a diagnostic test for clinical forms of thalassaemia; however it does alert the health care professionals to the fact that there are anomalies in the baby’s blood and this leads to further, specific diagnostic tests being carried out. So although thalassaemia is not a specific element of newborn screening, in practice babies who have clinical forms of thalassaemia are diagnosed at a very early stage and are entered into the care of a paediatrician / haematologist by the time they are 3 months of age. It is of course essential that all affected babies are diagnosed, entered into care and entered onto the National Haemoglobinopathy Registry as early as possible; so that the baby’s health can be monitored and we have a complete picture of how many thalassaemia patients are registered with each hospital.

Any comments or queries about antenatal or newborn screening can be sent directly to Public Health England via the screening helpdesk [phe.screeninghelpdesk@nhs.net](mailto:phe.screeninghelpdesk@nhs.net).

*Although this the focus of our partnership work with the Screening Programme is no longer about raising awareness of thalassaemia in the general public, UKTS will of course continue to work hard in this area. See article on page 13 about our new employee Maserat Lal.*

# NHS Blood and Transplant appoints new Medical and Research Director



*Gail Mifflin, Medical and Research Director*

Dr Gail Mifflin has been appointed as Medical and Research Director at NHS Blood and Transplant. She will take up the post on 1st June.

Dr Mifflin qualified from Cambridge University and trained in haematology in Nottingham and Yorkshire. She joined NHS Blood and Transplant in 2010 having previously worked as a Consultant Haematologist at the Royal Free Hospital and then UCLH Foundation Trust where she specialised in treating patients with red cell disorders. During this time she worked for three years at South East London Strategic Health Authority alongside her clinical career where she gained experience in management and leadership.

Since 2012 she has been an Associate Medical Director at NHS Blood and Transplant. In her current role she has worked closely with the University of Cambridge to establish the National Institute of Health Research (NIHR) Blood and

Transplant Research Unit in Donor Health and Genomics.

In her new role she will lead the Clinical Directorate and will be responsible for the Governance framework and clinical governance systems across NHSBT. She will also oversee research and development, acting as the interface with research bodies, including universities and Public Health England. In doing this she will ensure evidence is provided to shape national and international health care policy in respect of transfusion and transplantation medicine and science.

Dr Mifflin said, "I feel enormously privileged to be taking on this role. I am looking forward to working with a great team to do what we do best - saving and improving lives by providing a safe supply of blood, organs and tissues. We already work to the highest clinical standards and I will build on these wherever possible. Delivering a world class Research and Development programme that improves patient outcomes is equally important to me."

Welcoming the appointment NHS Blood and Transplant Chief Executive, Ian Trenholm, said: "I am delighted to appoint Gail to this key role in our organisation. Patient and donor safety is a key priority for us. Ensuring patients have confidence in the blood, organs and tissues they receive through us is vital, as well as ensuring the wellbeing of our donors who make our life saving and enhancing work possible. In addition, Gail will lead our clinical and research response to the opportunities provided by new therapies and help us establish our role in the exciting fields of cellular and regenerative medicine."

Dr Mifflin replaces Dr Lorna Williamson who retires on 31st May.

NHS Blood and Transplant is crucial to the NHS delivering blood and blood based therapies across England and north Wales; organ donation and supply services for the whole of the UK; retrieval and storage of other tissues like skin and bone and a range of specialist therapeutic blood products and related services.

# Blood transfusions abroad – what you need to know

By Dr Farrukh Shah, Consultant Haematologist, Whittington Hospital



Dr Farrukh Shah

We are very fortunate in the UK to have one of the safest blood supplies globally. The reason blood transfusion in the UK is safe and of the highest quality is because we have worked extremely hard

over many years to ensure that the quality of the blood is good.

The primary reasons for this are that we have:

**1. Voluntary unpaid donors**

This means that people give their blood for free and the altruistic nature of the donation means that the blood donor is highly likely to be healthy. Donors complete health questionnaires prior to collecting blood to ensure they are in good health.

**2. Processing**

Blood in the UK is filtered after collection and is processed according to strictly regulated international criteria.

**3. Testing**

All blood donations are extensively tested using the best available tests to allow for the earliest possible detection of any blood-borne infections, that is, infections that are transmissible by transfusion. In reality, this means that the period when an infection could pass via a blood donation to the recipient is very small for both HIV and hepatitis C. If a person donates their blood, the tests can detect HIV if the person has been infected as recently as \*\*\* days ago; and HCV \*\*\* days ago. This is known as the “window period”.

4. Blood transfusion laboratories in the hospital where you receive your transfusion can match blood carefully for your blood groups; and if you have an antibody the laboratory will ensure you get blood that is negative for that antibody.

In many parts of the world such as countries in Africa, the Americas and in the Asian and South East Asian subcontinent, blood donations come from a number of sources, including paid donors and family member donations. Depending on the centre in which you are being transfused, you could be at risk of catching an infection such as hepatitis C, HIV, malaria and other blood borne infections. HIV and hepatitis C infections are still being transmitted by blood transfusion in many parts of the world due to the lack of adequate screening and the financial Malaria transmitted during a transfusion in a patient with no spleen can be fatal.

Many centres do not test the donor blood groups sufficiently so you could only be getting blood for the main blood group A,B,AB or O and D. This means that if you have had antibodies for the other blood groups you could have a serious transfusion reaction which might be life threatening or make it difficult to transfuse you in future.

It is also very important to avoid family member donations especially from first degree relatives (children, parents, brothers and sisters) as blood from these donors can result in a life threatening complication that leads to the bone marrow failing (transfusion associated graft versus host disease).

If you are going away on holiday and want to stay for a longer period of time, you may need a blood transfusion aboard. If possible, you should avoid being transfused abroad unless it is in a country with a highly regulated and controlled blood supply. It is really important that you discuss your plans with your healthcare team - how long you plan to be away and in which city and country you would like to be transfused. It is possible to be transfused safely abroad, but you may need to travel to a centre that we recognise as providing a safe transfusion service. That centre may be in the city and country you are going to be visiting, or may be in a country near where you are visiting, so you may need to travel to have the transfusion. You will probably need to pay for the blood transfusion and you must make sure you have health insurance to cover you

for any complications.

It is often helpful to give a planned itinerary to your doctor if you are travelling around in any part of the world for a longer period of time and if you will need transfusions on a number of occasions during the trip. We can try to work around this to ensure that your blood is given in safe centres even if you are travelling to remote places. Before you travel you should obtain a letter from your UK doctor which details your transfusion requirements including how much, how often, as well as what type of blood transfusion (washed, irradiated etc.), major and minor blood groups and antibody history as well as your medical history. If we know your plans in advance we will try to get in touch with the doctors in the centres we are recommending for transfusion and the local team will then be expecting you around the transfusion episode. This often makes it easier for both yourself and the medical team at the local centre to ensure you have a safe and good experience.

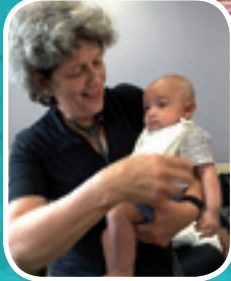
Thalassaemia should not limit your enjoyment of life and you should be able to do everything you would like to do, but because you need blood transfusions every few weeks you must plan your adventures around them. Therefore, to ensure you have a good time when you are abroad and are safely managed, talk to your medical team about your plans. Get a medical and transfusion history from your doctors before you travel and a letter for the local doctors at the centre where you plan to be transfused. The UKTS staff will also try to help you by finding out information etc. Before you leave the UK you should have a detailed plan for around your blood transfusions and the contact details of the centre you will be transfused in. We will try our best to help you by finding out as much information as possible - but please help us to help you by telling us about your plans as far in advance as possible. Gathering information and organising medical care can take time; so please don't spring it on us at the last minute!



## Twintastic news from our President!

We certainly weren't kidding (no pun intended!) when we said that the first half of 2016 had brought some momentous events to our "UKTS family"! For UKTS President Gabriel Theophanous and his wife Nishel, 2016 has brought the most wonderful and welcome miracle into their lives, with the arrival of their twin sons Zac Ayrton and Luca Senna. The babies were born at University College of London Hospital on 14th April 2016. Zac (left) weighed 6.1 lbs and Luca (right) 4.4 lbs – says the proud father "They each have their own distinct personalities - Luca is smaller but definitely cheekier!"

To Gabriel, Nishel and their families – massive, twintastic congratulations from all of us on the safe arrival of your gorgeous little boys.



*The twins accompanying their proud father for a transfusion at the North Middlesex Hospital; and meeting Dr Anne Yardumian*

## Another double baby celebration for the Nawaz family in Coventry!



29 year old Naheed Nawaz (who has beta thalassaemia major) gave birth to her little son Aadam Faruq on the 24th March 2016. Little Aadam was born weighing a healthy 6lbs 4oz at the University Hospital of Coventry & Warwickshire. Naheed and her husband Saleem, who were married on 1st November 2014, were over the moon at the arrival of their little miracle. Equally overjoyed are Naheed's brother Shehzad (who also has beta thalassaemia major) and his wife, who are expecting their first

baby at the end of August 2016. We all send our very best wishes for the safe arrival of Shehzad's first child and hope to have another beautiful baby picture in the next issue of TM. All of us at UKTS congratulate Naheed, Shehzad and their respective spouses; and thank them for showing the world that thalassaemia need not be a barrier to family life.

# Nepal Thalassaemia Society Update

By Wendy Pinker



*Our heroic nurse who was transfusing during the earthquake*



*It was with much excitement that my son Taal and I prepared to visit our wonderful blood transfusion clinic in Kathmandu again this year. Now the clinic has been open for 7 years it was Taal's seventh time to visit!*

As our plane loomed in over the city of Kathmandu the devastation of the enormous 7.8 magnitude earthquake that hit in April last year was clear to see. Taal and I had left Nepal just 5 days before the earthquake hit and we were left feeling deeply sad, shocked and helpless sitting in our safe home in the UK. Unable to fly back I decided that I would launch an appeal to raise funds for families that I know who were worst hit losing

everything, their homes, belongings and livestock.

With the help of my very dear friend Elaine Miller of the U.K. THALASSAEMIA SOCIETY we raised £20,000 in just 4 weeks. The donations just kept rolling in and it was clear to see that the people of Great Britain

have a very deep love and respect for the Nepali people. It was deeply touching and sincerely humbling to talk with people I have never met before but who were eager to help out both financially and physically.

Having sent out an emergency sum of money immediately last April to help families buy tarpaulins, kitchen equipment, clothing and bedding it was time to come back and make a much clearer assessment of how the funds we raised should be utilized. We spent our first week here in Nepal visiting such families.

Then came our eagerly awaited visit to the blood transfusion clinic. Everyone was so excited to see us. We were adorned with flowers and gifts and as always the tears fell uncontrollably down my face. I spend so much of my time in the UK raising funds and giving presentations about my work that when I finally arrive my heart is just so overcome with emotion. This place is so deeply etched in my heart. It really is a wonderful gift and great inspiration in my life.

The children were all so much bigger and looking healthier than I had ever seen

them look before. It was clear that their regular blood transfusions were starting to take effect. Due to some very kind donations we have also been able to give a limited amount of chelation treatment to some of children in greatest need.

The clinic is run solely by the funds that I raise in the UK. Without these funds the children would deteriorate very quickly. My clinic partner, Durga Pathak (in Nepal) works incredibly hard to ensure that the running costs are kept to a bare minimum. He gives up a great deal of time to this cause running here there day after day with not a rupee of remuneration.

Treatment at our clinic is free for every child who registers with us, giving the chance of life to those who would otherwise not be able to afford it. A very high percentage of the population of Nepal live in poverty – we think we know poverty in the UK but believe me, there is no comparison. Nepal has no health service, so even the most basic of medical care is unobtainable unless it can be paid for - a privilege that many cannot afford. Durga and I are deeply passionate about what we do and it is our lifetimes work to ensure that the clinic continues.

## NTS most recent news

I am very proud to announce that after months of planning NTS is now a registered charity in the UK. With effect from 30th June 2016 we are registered with the UK Charity Commission under registration number 1167957. I am deeply honored to have Elaine Miller (of UKTS), Susan Powell and Karen Holley as my fellow trustees. Together we make a very strong and well skilled team.

We have great hopes for NTS's future and hope to be able to create a more





secure and stable future for all the children we support.

Over the coming months a new website is being made with a just giving page and of course we will now be eligible to register for Gift Aid giving us an extra 25% on all donations. We also plan to send out more regular newsletters and communications. You can see our current website and new website in the future at [www.nepalsts.org.uk](http://www.nepalsts.org.uk) Please bear with us over the next few months as we develop the website – we are planning to put up lots of pictures so that all our kind supporters can see for themselves how all the children are getting on.

It is our hope that now we are registered we will be able to secure enough regular monthly standing order donations to cover the £10,000.00 per year running costs of the clinic – which would be a dream come true. It is a very small sum indeed compared to what would be required to treat 125 children in the UK! But a little money goes a long way in Nepal and every penny given by our generous supporters helps to keep a precious child alive.

Watch this space for more updates and let me say again, the thalassaemia children of Nepal send the most heartfelt and grateful THANK YOU to their friends

and supporters in the UK thalassaemia community.

With love and best wishes, Wendy

**A monthly £10.00 donation pays the transfusion costs of a child, keeping them alive and giving hope and encouragement to their parents.**

**Nepal Thalassaemia Society Bank Account Details**

Account Name: Nepal Thalassaemia Society  
 HSBC Account Name: 71463209  
 Sort Code: 40 47 34  
 Email Wendy: [wendy@nepalsts.org.uk](mailto:wendy@nepalsts.org.uk)

## UKTS congratulates Mohammed Bachani – our friend in Kenya



*Mohammed Bachani*

Some of our long standing members might remember seeing previous *TM* articles featuring our young friend Mohammed

Bachani from Kenya. Mohammed, who has beta thalassaemia major, came to the UK in 2002 for a bone marrow transplant at Birmingham Children's Hospital. Unfortunately however, the transplant was unsuccessful and Mohammed has remained transfusion dependent. Now aged 18, Mohammed attends the Aga Khan hospital in Mombasa for his thalassaemia treatment. He is transfused every 3 weeks and uses a Desferal pump. The health system in Kenya requires Mohammed's family to replace every unit of blood that is given to him by finding another person to donate an equal amount. In addition, they must pay fees for every transfusion, blood

test and prescription that he requires. Mohammed visited the UK with his parents this summer, during which he had some medical checkups; and also found time to pop into the UKTS office to visit our staff.

Mohammed is a devoted student and has won the highest honours for his academic achievements. To the delight of his proud parents Ayoob and Femina, he plans to study medicine in future. Says Mohammed "The reason I want to become a doctor is to help other people, especially those less fortunate who are unable to afford high medical bills." Many congratulations to Mohammed for his outstanding performance; and very best wishes for the future.



# Punjab Proposes Screening Programme for Pregnant Women



*A midwife consulting with a patient in the Punjab*

Under a new initiative for prevention and control of haemoglobinopathies the government of the Punjab has decided to screen all pregnant women for thalassaemia and sickle cell disease. A proposal for antenatal screening, staff training and increased public awareness has been included in the Punjab's State Programme Implementation Plan for 2016-17; to be proposed to the Union Government for approval. Vini Mahajan, the Punjab's Principal Secretary for Health

and Family Welfare announced that, in addition to the screening proposals, there are plans in place for improving referral and diagnosis, blood transfusion services and chelation therapy in government health institutions.

Many of our UK thalassaemia community have family links with the Punjab; and we all join them in welcoming this excellent news.

## office news

# Blood and Organ Donation: Saving Lives in Black and South Asian Communities

On 11th May 2016 NHSBT held a Parliamentary Reception to highlight the fact that we need more blood and organ donors from the BAME community. The event took place at the House of Commons and was attended by MPs from all parties; as well as representatives from the voluntary sector. UKTS was represented by our Assistant Treasurer Tina Bhagirath, who was pleased to meet Virendra Sharma MP, a long-standing supporter of the work of NHSBT.



*Tina pictured here with Virendra Sharma MP*



*Mr Sharma showing his support for NHSBT*

# UKTS welcomes new staff member Maserat Lal



Mas (left) raising awareness in Bradford

My name is Mas and I live in Leeds. I started working part-time for UKTS in December 2016, mainly to help Elaine (UKTS National Coordinator Elaine Miller) with awareness events. This was a new role, and when I started it was to find places and community centres where UKTS could go and give a talk about thalassaemia to the general public. In theory this sounds easy enough doesn't it? Not so!! First off there is a challenge of actually finding a place. With the advances in modern technology you would think this was fairly simple; and if you have an organisation's name it is. If however you are trying to find somewhere that would be suitable for you to go and give a talk to - a class or to a group - it is not so simple finding these!

Then there is the challenge of getting a foot in through the door. As many of you thals will know, you know what happens when we say the word thalassaemia? Thal-a-what?? is the reaction we get. This part actually helps in my defence, and so I introduce UKTS and thalassaemia and for the most part, I get a good reaction - people seem very keen. I leave them my details. They assure me they will get in touch with me. And then nine times out of ten, nothing happens! Sometimes this is due to the bureaucracy of an organisation,

sometimes because of the stresses in the organisation and workplace and sometimes... maybe they just don't think it's important enough or I have no idea why. Don't get me wrong - it's not all doom and gloom. Sometimes I have come across wonderful, caring people who completely understand what it is I'm trying to do because they've actually never heard of thalassaemia. And so they can instantaneously think yes this is worth spending a little

of their time in taking it forward. I've had organisations where I have phoned one day and a few days later we're actually at an event or at a class giving a talk. I've had people that have heard and said that they will get in touch with me and they do! I met one such person at the first health mela that I attended in Bradford with Elaine. I arranged to talk to her group of women at a coffee morning and she subsequently got me in to an ESOL (English as a second language) class as well. But for the most part I have to phone, I have to email, I have to chase up and then if I'm incredibly lucky I can eventually get into the organisation. Once there, everything is fabulous but the work involved in getting there is something that we UKTS members don't see. I have been a member for over 25 years, but I never realised what a difficult job it is trying to raise awareness of thalassaemia!

In addition to being a long-standing member, I have been involved with UKTS unofficially in one way or another for over 15 years. My living up north and UKTS being down south has limited my involvement in large part until now. UKTS held and continues to hold a special part in my heart and life. I have been lucky enough to know some incredibly fabulous people who were part of this

organisation and some who still are, and I am privileged to call some of them my friends. They were and are my inspiration and (...if I remain here long enough lol...) I hope to have achieved a fraction of the reaction that they inspired in me. And it's rather scary that I am actually part of and representing this awesome organisation!

I believe that those of us who have thalassaemia have a responsibility and a duty to our own communities to do whatever we can to raise awareness of the condition. Raising awareness is important on so many levels. The more we speak out openly and publicly about having thalassaemia, the more everyone can see that we are normal people living normal lives, not a bunch of sad invalids worthy only of pity. Too many people still suffer from this kind of stigma and here in the UK in this day and age it is completely unnecessary. And that is down to us and how we present ourselves - if we don't challenge it head on with those people in our communities who judge us, then we reinforce that impression. We cope with so much more than "normal healthy" people and I honestly believe we are definitely stronger than them! Secondly, we need to increase public knowledge so that people who may be carriers understand that they can request a blood test before they start a family; and have the opportunity to learn about thalassaemia - rather than, as happens all too often, getting a terrible shock when they are expecting their first baby. So - all you thals out there - help us to raise awareness so that all our lives and the lives of future children with thalassaemia will be that bit easier. Do you know of any local organisations, faith or community groups, health events, educational events? We can come along and give talks, hold discussion groups, man information stalls - just let us know and we'll do our best to be there. You can contact us by emailing [office@ukts.org](mailto:office@ukts.org) or by telephoning the office on 0208 882 0011.

# Recent Events & Meetings

Those who attended meeting on behalf of the UK Thalassaemia Society are: Gabriel Theophanous *President*, Romaine Maharaj *Vice-President*, George Constantinou *Secretary*, Tina Bhagirath *Asst. Treasurer*, Elaine Miller *National Coordinator*, Katerina Loizi-Read *Office Administrator*, Maserat Lal *Office Assistant*, Tom Koukoulis *patient member*

## Acronyms

APPG – All Party Parliamentary Group for Sickle Cell & Thalassaemia  
 GAUK – Genetic Alliance UK  
 HCC – Hepatitis C Coalition  
 NEBATA – North of England Bone Marrow and Thalassaemia Association  
 NHSBT – NHS Blood & Transplant  
 NSC – National Screening Committee  
 RDMCC – Roald Dahl Marvellous Children's Charity  
 RDUK – Rare Diseases UK  
 SCTSP – NHS Sickle Cell & Thalassaemia Screening Programme  
 SCS – Sickle Cell Society  
 SHCA – Specialised Health Care Alliance  
 TIF – Thalassaemia International Federation  
 UKFHD – UK Forum on Haemoglobin Disorders

- 12 Jan 2016 – meeting with SCS to discuss joint bid for SCT public engagement contract *Romaine Maharaj, George Constantinou, Elaine Miller, Tom Koukoulis*
- 25 Jan 2016 – SCTSP newborn information governance & clinical advisory group meeting, Guy's Hospital *Elaine Miller*
- 25 Jan 2016 – meeting with Dr Elizabeth Dorman to discuss joint bid for SCT public engagement contract, Guy's Hospital *Elaine Miller*
- 27 Jan 2016 – medical presentation by Dr Vasili Berdoukas, UK Thalassaemia Society
- 1 Feb 2016 – APPG teleconference, *Elaine Miller*
- 4 Feb 2016 - peer review of haemoglobinopathy services, North Middlesex Hospital *Elaine Miller*
- 8 Feb 2016 – NHSBT stakeholder interview *Elaine Miller*
- 9 Feb 2016 – Health mela, Girlington

School, Bradford *Elaine Miller & Mas Lal*

- 18 Feb 2016 – awareness meeting with Muslim Chaplain, University of Leeds *Elaine Miller & Mas Lal*
- 29 Feb 2016 – awareness event, Royal Holloway University of London *Katerina Loizi-Read*
- 8 March 2016 – awareness meeting, International Womens Day event, Bangladeshi Community Centre, Leeds *Mas Lal*
- 9 March 2016 – peer review Steering Committee teleconference *Elaine Miller*
- 10 March 2016 – awareness event, Girlington Community Centre, Bradford *Mas Lal*
- 15 March 2016 – awareness meeting at Chandos Medical Centre, Leeds *Mas Lal*
- 17 March 2016 – SCT Public Engagement meeting, Skipton House, London *Elaine Miller*
- 20 March 2016 – awareness event, Lahore Community Centre, Harrow *Katerina Loizi-Read*
- 22 March - SCT Public Engagement meeting, Skipton House, London *Elaine Miller*
- 11 April 2016 – Blood donor selection committee, Richmond House, London *Elaine Miller, Tom Koukoulis*
- 12 April 2016 – SCTSP Advisory Group meeting *Elaine Miller*
- 14 April 2016 – awareness presentation, Leeds Grand Mosque *Elaine Miller, Mas Lal*
- 20 April 2016 – awareness presentation, Leeds Bangladeshi Community Group at Shantona, *Mas Lal*
- 22 April 2016 – Patient Group meeting at Roundhay Road Surgery, Leeds *Mas Lal*
- 5 May 2016 – SCT Public Engagement teleconference *Elaine Miller*
- 11 May 2016 - Parliamentary Reception, NHSBT Blood and Organ Donation: Saving Lives in Black and South Asian Communities *Tina Bhagirath*
- 12 May 2016 – UKTS/UKFHD national academic conference, Royal Society of Medicine *UKTS Trustees and staff*
- 17 May 2016 – meeting at Roundhay Road Surgery, Leeds *Mas Lal*
- 18 May 2016 – SCT Public Engagement meeting, Skipton House *Elaine Miller*
- 23 May 2016 – West Midlands Paediatric Haemoglobinopathy Network meeting

*Mas Lal*

- 27 May 2016 – GP awareness day, Freezywater Health Centre *Katerina Loizi-Read*
- 3 June 2016 – Training day for school nurses, Hertfordshire Regional College *Elaine Miller, Katerina Loizi-Read*
- 13 June 2016 – UKFHD teleconference meeting *Elaine Miller*
- 20 June 2016 - SCT Public Engagement meeting, Skipton House *Elaine Miller*
- 28 June 2016 – NHSBT Stakeholder Day, London *Tina Bhagirath*
- 3 July 2016 – UKTS AGM (cancelled due to lack of quorum)
- 7 July 2016 - SCT Public Engagement meeting, Skipton House *Elaine Miller*
- 15 July 2016 – ED education module development meeting with Keyopps, Birmingham *Elaine Miller*
- 15 July 2016 – awareness presentation at Asian Women's Support Group, Huddersfield *Mas Lal*
- 18 July 2016 - Blood donor selection committee, Richmond House, London *Elaine Miller*
- 21 July 2016 – awareness at St Martins Surgery Leeds, coffee morning drop in, *Mas Lal*
- 22 July 2016 – stakeholder interview for Bristol Blood & Transplant Research Unit, University of the West of England, Bristol *Elaine Miller*
- 26 July 2016 – meeting at GP's, St Martins Surgery, Leeds *Mas Lal*
- 26 July 2016 – meeting at GP's, Roundhay Road Surgery, Leeds *Mas Lal*
- 28 July 2016 – SCT Public Engagement teleconference *Elaine Miller*
- 5 August 2016 – meeting with Swedish Orphan Biovitrum, Sheffield *Elaine Miller*
- 10 August 2016 – awareness presentation, Belgrave Neighbourhood Centre, Leicester *Mas Lal*
- 10 August 2016 - SCT Public Engagement teleconference *Elaine Miller*
- 12 August 2016 – awareness presentation, Heckmondwike/Batley *Mas Lal*
- 18 August 2016 - West Midlands Paediatric Haemoglobinopathy Network meeting *Mas Lal*
- 18 August 2016 – SCTSP newborn outcomes information & clinical governance telecon *Elaine Miller*





**Tired of the hassle of writing cheques / renewing your membership every January? Give as little as £2 per month and your membership will renew automatically!**

**Please Support The UK Thalassaemia Society by Making a Monthly Donation**

**STANDING ORDER MANDATE**

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.

Name(s) of account holder(s) to be debited:  
Account Number:  
Sort Code:

Signed  Date   
Signed  Date

Your Address:  
Tel Number:  
Email Address:

*giftaid it*

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. *Please tick.*

YES  NO

**Please call 020 8882 0011 if you have any queries. When completed, please return to:  
UK Thalassaemia Society, 19 The Broadway, Southgate Circus, London N14 6PH  
We will then send this form on to your bank.**

Thank you for your valued support.



# membership application form

**UK Thalassaemia Society, 19 The Broadway, London N14 6PH  
Charity Reg No. 275107**

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

If you however do not wish your details kept on our computers please tick this box

### Your Personal Details

Title (Mr/Mrs/Miss/Ms/Other):

First Name(s):

Surname:

Address:

Post Code:

Occupation:

Ethnic Origin:   
*(Optional)*

### Contact Details

Telephone:  *Home:*

*Work:*

Mobile:

Fax:

Email:

### Are you a:

- Patient  Parent/Relative  
 Healthcare Professional  Association  
 Other (Please state)

### Membership Required *(please tick)*

- ANNUAL (£10.00)  LIFE (£100.00) *(Please make your cheque payable to U.K.T. Society)*

### If you are a patient or parent of a patient please complete the section below

Patient's Name(s):

Date of Birth:

Sex:  Male  Female

Type of thalassaemia: *(e.g. Major, Intermedia, Haemoglobin H etc)*

Hospital where-treated:

Address:

Consultant's Name:

Consultant's Telephone:

GP's Name:

Address:

Telephone:

### Blood Transfused *(please tick)*

- Whole  Washed  Frozen  Filtered

### Chelation *(please tick)*

- Desferal  Deferiprone  Desferal & Deferiprone

Transfusion Frequency:  Units received at each transfusion:  Blood Type:

**OFFICE USE:** Date Paid \_\_\_\_\_ Receipt No. \_\_\_\_\_ Approval Date \_\_\_\_\_