UNITED KINGDOM
Thalassaemia SOCIETY
matters
DECEMBER 2015 ISSUE NUMBER 126
...continuing the fight against thalassaemia

UKTS wins prestigious 2015 SITA award for Thalassaemia Society of Excellence

19th November 2015 will be recorded as a momentous day in the history of the UKTS. In a glittering ceremony held at the Emirates Palace, Abu Dhabi, UKTS was awarded the Sultan Bin Khalifa International Thalassaemia Award for Thalassaemia Society of Excellence. This award is presented biennially by the H.H Sheikh Sultan Bin Khalifa Al Nahyan Humanitarian & Scientific Foundation (SITA), to a "thalassemia patient/parent Society that has significantly contributed towards improving the quality of life of patients with thalassemia." The award was presented by His Highness to George Constantinou, Secretary of UKTS. (George was deputising for our President Gabriel Theophanous, who had travelled to Abu Dhabi to collect the award but was prevented from doing so by a last-minute illness requiring him to be hospitalised. Thankfully Gabriel has made a good recovery and is now back to fighting fitness.)

Gabriel was able to take part in the ceremony by submitting a short video message, in which he stated "It is my great honour as President of the UK Thalassaemia Society, to accept the Sultan Bin Khalifa International Thalassaemia Award for Thalassaemia Society of Excellence; on behalf of all my fellow Trustees past and present. I am humbly conscious of those who have gone before me who have made such valuable contributions to the wellbeing of thalassaemia patients, not only in the UK but everywhere in the world… On behalf of all the members of the UK Thalassaemia Society, I would like to say how very proud and grateful we are to have been considered worthy of the great honour you have bestowed upon us. Our heartfelt thanks to the Chief Patron of the Sultan Bin Khalifa Thalassaemia Award, His Highness Dr Sheikh Sultan Bin Khalifa Al Nahyan, the Chairman His Highness Sheikh Zayed Bin Sultan Bin Khalifa Al Nahyan,

Dr Mahmoud Taleb Al Ali, Chairman of the General Secretariat Committee of SITA;

and the members of the Higher Scientific Committee - the Chairperson Dr Androulla Eleftheriou, Professor Dimitris Loukopoulos and Professor Suthat Fucheroen."

Supreme Chancellor of the Foundation His Highness Dr Sheikh Sultan Bin Khalifa Bin Zayed Al Nahyan presents the award to UKTS Secretary George Constantinou. Also present are Chairman Dr Mahmoud Talib Al Ali, Dr Androulla Eleftheriou & Mr Panos Englezos

From SITA's press release – The H.H. Sheikh Sultan bin Khalifa Al Nahyan Humanitarian & Science Foundation is interested in employing scientific research to improve people's lives. Thalassemia and the sickle cell diseases are among the challenges facing a large segment of society. It imposes a certain lifestyle on patients and limits their productivity. We are working to turn the Sultan bin Khalifa International Thalassemia Award to an integrated platform for best practices and most successful experiences that could improve the quality of the lives of patients and their families. This year, the Sultan bin Khalifa International Thalassemia Award received more than 400 entries, all of high quality, which needed additional efforts from the scientific committees and the arbitrators to select the winners."

We are delighted to report that University College of London Hospitals received the international award for Clinical Centre of Excellence (see page 4); and Dr. Yuanhan Mo from the UK received the Scholarship for Translational Research in Thalassemia.

For the full press release please see https://www.wam.ae/en/news/emirates/1395286992280.html

CONTENTS

UNITED KINGDOM THALASSAEMIA SOCIETY
A Charity Organisation
Registration Number: 275107
19 The Broadway
Southgate Circus, London N14 6PH
Telephone: 0208 882 0011 • Fax: 0208 882 8618
Email: office@ukts.org • www.ukts.org

A word from our President

Dear friends,

Well what a busy year it has been! I can hardly believe that the festive season is fast approaching and in a few short weeks we will be into 2016 – where does the time go? The second half of 2015 has been action packed – take a look at the "events and meetings" section on page 14 to get an idea of all the various projects and work streams we have on the go; and you will see that our work is by no means confined to office hours – we are out there at weekends raising awareness of thalassaemia whenever possible.

In this issue there are a couple of items I want to bring to your attention – on page 3 you will see an announcement that we are about to send out a survey at the beginning of 2016. Please don't let this opportunity to have your say go by – we need your comments and feedback so we can lobby for better services – give us the evidence we need to work on your behalf. On page 9 we have an update from the Nepal Thalassaemia Society, further to the disaster appeal we helped NTS to launch in issue 125 – what a wonderful, heart-warming response from the UK thal community! We are so proud of all our members who have rallied round to support our "thalassaemia family" members in need – thank you to each and every one of you who has sent a donation. And this issue we have a fantastic "patient news" section - I never fail to be amazed and inspired by the sheer determination and courage of my fellow thals. Don't forget, if YOU have a story you would like to share with our readers we would be delighted to hear from you!

And finally, 2015 has culminated in the most wonderful accolade we have ever received as a patient organisation – the Sultan Bin Khalifa International Award for Thalassaemia Society of Excellence. Receiving the news that we had won the award was one of the proudest moments I have had as President of UKTS – but I know that I speak for my fellow Trustees and our staff members when I say that our first thoughts were of gratitude to the early pioneers of the Society. It is thanks to them that the Society has such an impressive list of achievements dating back to the 1970s. We all strive continuously to keep up their good work and rise to every new challenge.

Next year in 2016 the UK Thalassaemia Society will be celebrating its 40th anniversary; and I will be approaching my 40th birthday. So much has already changed for thals in the UK within my lifetime; and I am planning to be around for a very long time to see many more advances!

Wishing you a wonderful holiday season and a very happy New Year in 2016.

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

President Gabriel Theophanous	
Vice-President Romaine Maharaj	*Treasurer* Raj Klair
Secretary George Constantinou	*Assistant Treasurer* Tina Bhagirath
Assistant Secretary Anand Singh Ghattaura	*Committee Member* Pany Garibaldinos

COMING SOON:

Survey – have YOUR say about YOUR services

One of our most important ongoing projects is the production of the 3rd edition of the *Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK*. We have a writing group of eminent clinicians who are updating the document and in some cases writing new chapters. Part of the process which informs the Standards is the views of the people directly affected by them – you, the people who spend a significant portion of your lives dealing with thalassaemia and its many aspects.

We are therefore asking all our readers to note that in January 2016 we will be circulating a survey, to be answered by all people who have thalassaemia who have reached the age of 15 or over by the 1st January 2016. The survey will be sent by post and a pdf copy which can be printed out will also be circulated by email. Reply paid envelopes will be provided. The survey will cover different aspects of thalassaemia treatment and will include space for your own comments and observations. UKTS will be including quotations directly taken from what you tell us in your comments and opinions (in the surveys) in the new Standards; and the data produced will give us a clear and up to date picture of how people with thalassaemia view the quality of their treatment. The survey will be anonymous so you can feel free to be absolutely honest in your responses.

Make your point – it is essential that we in the thalassaemia community take every opportunity to make our voices heard. For example, when UKTS asks about "out of hours" transfusion facilities to make life easier for working people, we are used to being told by management "There's no demand for it". If we are to counter this kind of argument, we need evidence from our members on this and all the other issues which affect people who have thalassaemia.

Nobody likes to fill in forms and it is easy to think "I don't have the time", "other people will do it" or "I can't be bothered" – but if we – the thal community - can't be bothered why should we expect other people unaffected by thalassaemia to care about the quality of our services? So when the survey hits your doormat, don't throw it in the bin or put it aside where it will be forgotten. We are planning to send out close to a thousand surveys. If only a couple of hundred are returned it implies that the vast majority are satisfied with their care and want nothing better. **Do you want better?** If so, complete the survey and return it to UKTS without delay and give us the evidence we need to lobby effectively for better and more accessible services.

TIF honoured by WHO

L-R George Constantinou, TIF Executive Director Dr Androulla Eleftheriou and President Mr Panos Englezos

We are extremely proud to announce that the prestigious Dr Lee Jong-wook Memorial Prize has been granted to the Thalassaemia International Federation (TIF) for its outstanding global contribution in the field of public health. The award ceremony was held during the 68th World Health Assembly (68th WHA) on 21 May 2015, in Geneva.

The prize was received by Dr Androulla Eleftheriou, TIF Executive Director. Mr. Panos Englezos, TIF President and Mr. George Konstantinou, Assistant Secretary of the TIF Board of Directors were also present at this formal occasion.

TIF's success through the years since its establishment in 1987, undoubtedly underlines and demonstrates the significant impact of patients/ parents' organisations can have on the promotion of policies and programmes, disease specific, but also health oriented ones.

The empowerment of patients and parents across geographic, cultural, religious, social and linguistic borders and their transformation into equal partners with national and international health bodies in their journey has been our major success and will continue to constitute the main focus of work.

TIF was privileged to be working in official relations with WHO since 1996 promoting and contributing to many of its programmes, disease specific and public health ones, as an important pillar of its activities.

TIF's Board of Directors and the global haemoglobinopathy family across 63 countries worldwide express their most sincere appreciation to those who have shown confidence and have recognised its impact and value clearly reflected through the receipt of this prestigious award.

We express our continued and full commitment not only to keep but to strengthen the momentum across the world in many ways through enhancing our contribution to the relevant programmes of WHO.

#RealLifeVampire – fun social media campaign reaches international thal community

Tom Koukoulis, serving "Interview with the Vampire" realness!

Those of our readers who are active on social media may have seen our social media campaign #RealLifeVampire during October 2015 – this was our first foray into social media campaigning and was quite a bit of fun; mainly intended to appeal to younger members of the thal community and see how many people we could reach using Facebook, Twitter and Instagram. We were amazed and thrilled to find that the campaign reached over 10,000 people; and attracted vampire selfies from as far afield as the Philippines, the Maldives, Australia and Canada! We are planning more campaigns during 2016 so if you're not already following us on Twitter or Instagram, make sure that you follow us @UKThal today!

Many thanks to our online team leader Tina Bhagirath and our co-opted committee members Amit Ghelani for the professional portrait photography and Tom Koukoulis, who is our resident social media expert and who ran the campaign on Facebook, Twitter and Instagram.

UKTS Trustee George Constantinou presents at EHA 2015

L-R George, Professor Dame Sally Davis, Dr Androulla Eleftheriou

Many of our readers will be familiar with George Constantinou, a founder member of UKTS and our longest serving Trustee. The words "expert patient" do not even begin to do justice to George, who can give most haematologists a run for their money when it comes to discussing thalassaemia and it's treatment! George, who is Secretary of the UK Thalassaemia Society and Assistant Secretary of TIF, was asked to give a presentation at the annual congress of the European Hematology Association (EHA); which took place in, Vienna, Austria from 11 - 14 June 2015. George's presentation **Access to quality healthcare: challenges and successes – the UK experience** was given on 13th June and to an audience of eminent haematologists which included Dr Androulla Eleftheriou, Executive Director, Thalassaemia International Federation and Professor Dame Sally C Davies, Chief Medical Officer and Chief Scientific Advisor to the Department of Health.

Congratulations to UCLH on winning the 2015 SITA award for Clinical Centre of Excellence

The winning team – medical and nursing staff including Consultant Haematologists Sara Trompeter, Bernard Davis and Professor John Porter

Consultant Haematologist Dr Perla Eleftheriou joined the UCLH team in Feb 2015

The Joint Red Cell Unit, University College London Hospital has been awarded the 2015 Sultan Bin Khalifa International Thalassaemia Award for Clinical Centre of Excellence. This service, under the leadership of Professor John Porter, has long enjoyed an international reputation as a centre of excellence for thalassaemia treatment and research. UKTS congratulates all the staff of the service on the award and their outstanding contribution to thalassaemia care in the UK.

Trust, confidence and voluntary organisations

No-one who follows the news could have failed to notice the number of stories about charities which have emerged in 2015; and the vast majority of these were far from flattering. It would not be surprising if many people had decided not to donate to charity at all given the shocking picture that has been painted – of chief executives who earn 6-figure salaries travelling the world first class, swanning around the UK in chauffeur-driven Bentleys and enjoying perks such as free housing, private education for their children and in one case, even their own private massage therapist!

In addition to financial profligacy, there has been justifiable concern about charities which have adopted unethical and overbearing fundraising methods, such as targeting vulnerable people, for example elderly donors who have been pressurised by telephone calls asking for donations. In many cases the contact details of these donors have been obtained from other charities selling their donor lists on for profit.

While there may be a few charities which behave in this manner however, for the vast majority of us the truth is very different. The Charity Commission publishes a Register of Charities every year; and the latest figures from 30 September 2015 show that there are 164,889 registered charities in the UK. Of these only 2,074 charities – or 1.2% - are in the highest income bracket, earning over five million pounds per year. The same figures show that 87.8% of charities earn less than £500,000 per year – needless to say, UKTS falls emphatically within this 87.8%! Very small charities like UKTS are understandably unhappy that, thanks to the wrongdoing of a few – who in many cases have chief executives earning well in excess of UKTS' total annual income – public trust in charities has never been lower. We have therefore set out below some of our policies in case any of our members should have concerns regarding the confidentiality of their information etc.

- UKTS keeps a database of contacts which includes people who have thalassaemia, carers, health professionals and other supporters. Some of these people are members but not all. Regardless of whether or not a person is a member of UKTS, the Society has an invariable policy of confidentiality; under which all contact details on our database are for UKTS communication purposes only. These details will never be disclosed to any other party or organisation. UKTS may, from time to time, agree to send out materials, e.g. questionnaires, on behalf of researchers; but any materials of this kind are handled by the UKTS office staff only and researchers are not given access to the UKTS database or any other records.
- The same policy of confidentiality applies to donors. UKTS will never disclose the contact details of any donor to any other party or organisation. UKTS may occasionally, with the donor's permission, publish a newsletter article thanking a donor. Needless to say, the wishes of donors who prefer to remain anonymous are always respected.
- UKTS does not solicit donations by means of "cold calling" and does not purchase lists of contact details from any other organisation.
- All UKTS Trustees are volunteers and receive no remuneration or benefits in kind. In common with other people who attend meetings at the request of the Society, Trustees may receive occasional reimbursement of out-of-pocket expenses such as (standard class) travel expenses. Any and all such expenses are declared in the Society's accounts. It should be additionally noted that UKTS Trustees pay their own expenses if they wish to attend international conferences, e.g. TIF conferences (with the exception of official TIF Board members representing the UK – a maximum of 2 people). The UKTS constitution forbids any person immediately related to a paid employee of the Society from becoming a Trustee of the Society (i.e. any person related by blood, marriage or adoption). Similarly, no person immediately related to another Trustee may be elected to the management committee.
- Occasionally a Trustee or a business connected to them may be able to offer services to the Society at very preferential rates. This is a common practice among charities and Charity Commission guidance states that there is nothing untoward about such payments provided that the Trustees agree the payment is in the charity's best interests and reasonable for the service provided. UKTS has a conflict of interest policy which ensures that any such payments must be recorded and declared in the accounts.
- Each registered charity must submit an annual return form and a copy of their accounts to the Charity Commission each year. UKTS has never failed to submit an annual return together with a copy of the Society's fully audited accounts. These are a matter of public record and can be viewed on the Charity Commission website https://www.gov.uk/government/organisations/charity-commission

CHARITY COMMISSION

We hope the above will go some way towards reassuring our members that we take the issue of ethical behaviour very seriously. If any of our members have any queries regarding our policies please feel free to contact the office.

SHOT blood safety report 2014

The latest SHOT (serious hazards of transfusion) report was published on 27th June 2015. Below are some excerpts from the report summary. *To any reader who would like to see a copy of the SHOT report summary, or indeed the whole report, please contact the UKTS office.*

Blood and blood component transfusion in the UK is very safe with a small number of adverse incidents in relation to the number of components issued and transfused. In 2014 (January to December) the total number of reports made to SHOT was 3668 and 3017 were analysed for the Annual Report (others were incomplete or withdrawn). The total number of reports made to the Medicines and Healthcare products Regulatory Agency (MHRA) was 1110 of which 764 were serious adverse events (errors in 97.8%) and 346 were serious adverse reactions. The proportion of SHOT reports where errors were the underlying cause was similar to 2013, 77.8% (2346 reports). Acute transfusion reactions (allergic/febrile) were the most common pathological reactions. The cumulative data (18 years) can be viewed on the website, www.shotuk.org

Transfusion-transmitted infections: No bacterial transmissions have occurred since 2009, but there were two near miss events in 2014 where Staphylococcus aureus was isolated from platelet packs. These were detected initially by visual inspection and are a reminder of the importance of this and rapid reporting to the Blood Service so that associated packs can be withdrawn. One hepatitis E transmission to two recipients was reported. This is not currently screened for by the Blood Services.

New guidance which may be useful for people affected by thalassaemia

In the past UKTS has been informed that some hospitals have used the SHOT recommendations as an excuse for refusing to consider offering any "out of hours" transfusion facilities. Further to lobbying from UKTS (with help from Dr Anne Yardumian, Chair of the UK Forum on Haemoglobin Disorders) the following paragraph is new and contains a reference to patient groups who require regular transfusion. Of itself this will not solve our problems with out-of-hours; but at least the needs of people with thalassaemia are being recognised.

"Recommendations are not rules and should be interpreted according to the individual patient needs. The recommendation concerning transfusion at night has been updated. Some patients have been denied transfusion at night when it was essential, and there are some patient groups where regular transfusion is required and this can be scheduled to minimise time lost from education and employment."

Resonance Health Media Release

St Mary's Hospital celebrates 1000 FerriScans from Perth to Paddington!

22 September 2015

St Mary's Hospital has become one of the first hospitals in Europe to reach a milestone of providing 1000 FerriScans (the Gold Standard MRI for measuring Liver Iron Concentration) for children and adult patients. Celebrations were held to mark the achievement and the collaboration between Australian-based Resonance Health Ltd and St Marys, London Paddington. The Imperial Trust set up the FerriScan MRI service four years ago to optimise iron monitoring and reduce the need for liver biopsy in patients.

The FerriScan MRI technology, developed at the University of Western Australia has become the Global Gold Standard for measuring liver iron concentration and has replaced the need for liver biopsy in many patients.

Patients are scanned locally on validated MRI machines in the hospital and then data is sent electronically to Resonance Health in Perth, Australia where it is analysed using unique processes under rigorous quality standards. The FerriScan Liver Iron Concentration reports are available within 2 days.

Dr Alavi, Consultant Paediatric Radiologist who leads the team providing the FerriScan service at St Mary's said: 'We aim to incorporate the very best diagnostics into care pathways for haemoglobinopathy patients and those at risk of iron overload. The introduction of FerriScan has significantly improved health outcomes and the excellent collaboration with Resonance Health to provide 1000 patients with access to optimised monitoring is certainly something to be celebrated."

Celebrations were presided over by Dr Alavi and Lead Haematologist, Dr Josu De La Fuente who instigated the service

Dr Josu de la Fuente (holding plaque) stands on the right of UKTS Administrator Katerina Loizi-Read

and runs one of the largest paediatric Haemoglobinopathy clinics in the country. The certificate was presented by Melanie Baxter, Global Marketing Director, Resonance Health and the event attended by representatives from four patient societies; the UK Thalassaemia

Society, The Sickle Cell Society, The Hereditary Haemochromatosis Society and the Diamond Blackfan Anaemia (DBA) Society who have all advocated access to FerriScan in the NHS for patients. FerriScan is currently available at 30 hospitals in the UK and used at over 220 centres globally. St Marys is a centre of excellence in iron monitoring, and has provided more FerriScans to children than any other hospital in Europe over the past four years

TIC-TOC: An Update from Dr Amna Abdel-Gadir

– see article on page 7 issue 125 of TM – "The Heavy Iron Load of the Heart"

Dear UKTS members

I would like to take this opportunity to share with you some exciting developments in my research on the use of MRI in the diagnosis of iron overload as described in the previous edition of Thalassaemia Matters. I recently visited a Red Cross Hospital in Bangkok, Thailand that serves as a referral centre for thalassaemia patients, to set up the TIC-TOC (Thailand and UK International Collaboration in Thalassaemia utilising an Optimised Ultrafast CMR Protocol) project.

The management of thalassaemia major in Thailand differs greatly to that in the UK. Due to financial constraints, patients receive on average 1 unit of blood every 2-3 months, and their pre-transfusion haemoglobin runs between 6-7 g/dL. Chelation therapy is available, but cost also plays a large role in the availability of desferrioxamine and deferiprone. Iron loading status is assessed with ferritin measurements alone, which is not a reliable indicator of iron loading in the heart and liver. In this setting the aim of TIC-TOC was twofold: firstly, to demonstrate that ultrafast MRI scans can provide immediate diagnoses of iron in the heart and liver whilst keeping costs at an affordable minimum; and secondly, through multiple visits, teach the ultrafast technique to the developing world, training local teams to create diagnostic algorithms that can translate into a national clinical thalassaemia service.

Under the guidance of Professor John Porter, Dr Malcolm Walker and Professor James Moon, with help from the Bangkok Thalassaemia Society (see picture below), and with funding from the Rosetrees Trust (due to end December 2015) we were able to perform and immediately analyse over 120 T2*/T1 MRI scans in 2 days. Results were available before the patient had left the scanner room! This was the first time the patients had an MRI scan performed despite all having raised ferritin levels ranging from 800 to over 18,000µg/L. Each scan was performed in less than 6minutes including analysis time, and enabled us to diagnose severe liver iron loading in 90% of the patients and iron in the heart in 20%. The MRI scans also diagnosed previously undetected abnormalities that required urgent medical attention and treatment. As a result, patients who had participated in TIC-TOC now have individually tailored and intensified treatments to remove the iron.

Members of the Bangkok Thalassaemia Society with the UK and Thai medical teams leading the TIC-TOC project.

We worked closely alongside the Thai group (Cardiologists, Haematologists, and Radiologists), and due to the success of TIC-TOC they have set up a clinical service using the ultrafast scanning method to assess iron loading.

My long-term aim is to continue working with and caring for thalassaemia patients in the UK and across the globe. The experience TIC-TOC has given us has been truly humbling, but also educational. We have learnt about thalassaemia and seen the extreme effects it has on the human body when not adequately treated or managed - something we are fortunately no longer encountering here in the UK. I have told many patients who attend Dr Walker's clinic at UCLH about TIC-TOC, and the support the UK thalassaemia patients have voiced for this project to help improve outcomes for their thalassaemia families worldwide has been overwhelming. We are returning to Thailand twice a year for the next 3 years to continue working alongside our Thai colleagues to involve more patients in TIC-TOC. Our next trip is planned for February 2016. This project will then move onto other countries in the developing world introducing ultrafast MRI scanning to improve their patients' prognosis and quality of life.

Based on what we have achieved so far, I have been shortlisted for the SCMR Early Career Award 2016 for initiating, organising, and conducting this project. I look forward to presenting what has been achieved thus far at this international meeting in Los Angeles, USA, and I hope to encourage others to adopt TIC-TOC in their centres.

I hope this is only the beginning!

Kindest regards

Amna

Spotlight on thalassaemia and the need for Asian blood donors

Dr Rekha Anand, Consultant in Transfusion Medicine, NHS Blood and Transplant

Thalassaemia is the most common inherited single gene disorder in the world. Scientists and public health officials predict that thalassaemia will become a worldwide issue in the next century. In England, Beta thalassaemia major (BTM) is thought to affect around 1,000 people, with an estimated 214,000 carriers. It most commonly affects people of Cypriot, Indian, Pakistani, Bangladeshi and Chinese origin. In the UK, 8 out of 10 babies born with BTM have parents of Indian, Pakistani or Bangladeshi ancestry.

Thalassaemia and the blood supply

NHS Blood and Transplant (NHSBT) collects approximately two million units of blood each year from 1.4 million blood donors. Hospitals in England and North Wales need around 7,000 units of blood every day to treat patients with a range of health issues. The 2011 census data estimate that 2.5% of the English and Welsh population are of Indian descent. Over the last decade that equates to a 25% increase in the number of the population of Indian descent.

Some blood groups are more common than others. For example, 25% of South Asians have one of the major blood types, group B, whilst only 9% of West Europeans have blood group B - but this is only part of the story. There are over 300 hundred different blood types. Environmental factors, geographic factors and ethnic history have a direct influence on the presence of antibodies and antigens in the blood and therefore, directly affect blood type.

Treatment for thalassaemia

The treatment of patients with thalassaemia involves giving blood transfusions every 4 to 6 weeks throughout their lives. In the case of patients like these, who need a long term transfusion programme (i.e. require a lot of blood over a long period of time) it is beneficial for them to receive blood that is as similar as possible to their own. Patients that receive repeated transfusions are more likely to develop antibodies and require blood that is matched to their particular type. The best match is invariably from a donor who comes from a similar ethnic background.

NHSBT currently has around 14,000 blood donors from the Indian population, who made nearly 15,000 donations last year. Indian donors make up 25% of all blood donors from the Black and Minority Ethnic (BME) communities on the Active Donor Base (donors who have donated within the last two years). Since 2009 NHSBT has increased the amount of Indian donors by approximately 2,000 donors.

However, relatively low donor numbers is a problem for the Indian community. This can only be fixed by increasing the number of people that become donors, and making best use of the ongoing help and support of the blood services. NHSBT has a loyal number of donors from the Indian community, and this number is growing all the time. More donors are always needed, which is why NHSBT has a specific marketing group, the "Inclusivity Marketing Group", which focuses on the increasing the number of BAME blood and organ donors. Through targeted recruitment campaigns and direct engagement, this group works to remove the barriers that divide blood donation and the Indian community.

UKTS says -

Do you have a loved one who has thalassaemia? If so, are you giving blood to support the thalassaemia community – if not, why not? PLEASE NOTE that if you are a thalassaemia carrier, this does NOT prevent you from becoming a blood donor provided that you meet all the health and lifestyle criteria. Contact NHSBT today to find out whether you could be eligible to give blood and SUPPORT OUR COMMUNITY. Register now by visiting https://my.blood.co.uk/Account/Register or telephone 0300 123 23 23

Nepal Thalassemia Society Appeal Update

By NTS co-founder Wendy Pinker

Durga Pathak (in black cap) and men from our team delivering life-saving supplies to remote, totally devastated villages where many of our families live.

Thalassaemia families and friends pulling together to share what food could be salvaged.

Even the children help to distribute blankets, bedding and vital supplies that our donations have enabled.

Shortly after the earthquake on 25th April 2015 which devastated much of Nepal, myself and Elaine Miller of the UK Thalassaemia Society launched an emergency appeal for help for the families affected by thalassaemia. Many had lost their homes and all their possessions in the disaster and were sleeping in tents in or rough shelters with animals; and everyone was desperately short of food. I have been in as much communication as possible with our clinic President Durga Pathak in Kathmandu; and we now have information that a large number of our families have been affected including 6 families who have lost everything … their homes, their belongings and their livestock which is also their livelihood.

The response to our appeal has been staggering with almost **£20,000.00** being donated to date, much of which has come from members of the UK Thalassaemia Society. There have been fund raising events planned by both people I know and many who I have never met. It's truly humbling. Twenty thousand pounds probably would not go very far in the UK, but in Nepal it has enabled us to achieve a great deal - many of the Nepali children affected by thalassaemia would undoubtedly have gone hungry were it not for the generosity of our friends in the UK.

The events of the last few months have touched hearts all over the world and there are no words to express my sincere gratitude and thanks to all those who have helped and continue to help us in our mission to support our devastated families. Please accept my apologies for not writing personally to everyone… it has been a struggle to keep up with so much kindness and so much generosity. I am deeply grateful to all.

The help that you have given us will go a long way to getting many families back on their feet. It means everything to them to know that members of our international "thalassaemia family" care and were willing to help them in their hour of need.

Thank you so much for your donations and your support from all of us at the Nepal Thalassaemia Society.

With love, Wendy Pinker

EVERY SINGLE PENNY that is raised is sent directly to the Nepal Thalassaemia Society in Nepal… Not one penny will be used for administration or any other costs.

Thank you
Wendy Pinker
07836 572062
Email Wendy: pinkyland_2000@yahoo.co.uk
www.nepalts.org.uk
www.nts.org.np

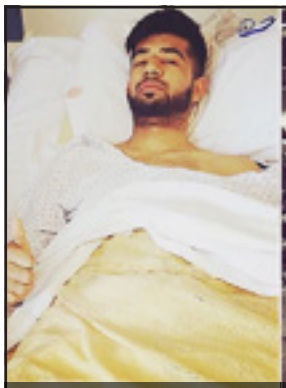
To make a donation please see the details below :

Bank Account
Nepal Thalassaemia Society
Account HSBC 71463209
Sort Code 40 47 34

Cheques
Payable to: Nepal Thalassaemia Society
Send to:
Wendy Pinker
13 Phoenix Way
Portishead
Bristol BS20 7FG

The Sky's the Limit

By Nabeel Javed



Nabeel felt down at the time of his surgery in 2014

...so he joined a gym...

...with transformative results!

"The sky's the limit". This is not just a saying - it is a fact. I personally believe nothing is impossible and if you want to achieve something all you need to do is work towards it. My name is Nabeel Javed and I can "hands on heart" say I feel like the happiest 19-year-old around. I'm a trainee construction manager for a reputable construction company and I'm also at university once a week studying construction management. I have a fantastic mom and dad along with an older sister all of whom I love to bits. I was diagnosed with thalassemia major at a very young age and it's been a part of me for nineteen years. I have never seen it as a burden - instead it was always a day off school for my blood transfusion and an excuse to occasionally not do P.E. when it was hockey (I hated hockey). Joking aside, thalassemia is a part of me and I have always treated my condition with respect; as I believe that whatever you give you always get. By this I mean I would attend my appointments and take my chelation medicine, resulting in having a good iron level and a controlled medical condition. I wouldn't change a thing about myself because I believe I am who I am for a reason. Thalassemia is just another obstacle that I've tackled along with many others - the next is most likely going to be marriage but I'm hoping that isn't for another 10 years haha!

In all seriousness, the main reason I wanted to write this article is to motivate thal patients towards achieving a healthier lifestyle and to get to the gym! Just over 12 months ago I was skin and bones, underweight, weak and I had never really entered a gym. I had always seen guys with huge muscles walk around and thought to myself that I could never be like that as I have a medical condition. For some reason I always thought thalassaemia patients are unable to build muscle and their strength is restricted. A lot of my friends would go to the gym quite regularly and were very muscular. For my part I was always fascinated by the gymnasium but never thought I could participate in it. I would make excuses to myself such as "I get too tired, I don't have enough blood, I have an illness, I can't go to the gym". Little did I know that this was all in my head and not one of these points was true.

Unfortunately due to my spleen becoming enlarged and my haemoglobin dropping extremely low I had my spleen removed. After the operation I became very weak and lost a lot of weight. I looked in the mirror and told myself I can't allow myself to be like this and I need to do something about it. I decided I have had enough of making excuses about attending a gym and that if anyone can do it then why can't I. So I did it! I motivated myself and joined up to my local gym… twelve months later I can honestly say I have never looked back.

From 10 stone I now weigh 12 stone due to intense muscle gains, and I have gone from only being able to lift really embarrassing light weights to being the one in the gym who lifts the biggest weights. I realised that the restrictions were all in my head and thalassemia did not physically restrict me from exercising. I now feel healthy and strong and I can't get enough of the gym - I attend the gym five days a week without fail. I have gone from the kid who thought building muscle was never possible to being the guy who gets approached for advice from normal (non-thal!) people wanting to build muscle. I never thought this was possible until I proved for myself that the quotation "the sky's the limit" is a fact. Most of the things that restrict us are the fears in our own heads which stop us from even trying new things. The "old" Nabeel of 18 months ago would not even recognise the person writing these words today – if I had gone on listening to the fears and hesitations in my own head I might never have entered the gym for the first time. Honestly I have learnt nothing is impossible, so if you're a thal patient wanting to do something but you feel restricted because of your medical condition then WAKE UP! Honestly take action now and you will never look back!

For any readers who want advice on gym, nutrition, workouts or general advice please don't hesitate to contact me on nabeel_javed@hotmail.co.uk !

My life with thalassaemia

By Feral Hassan

My name is Feral Hassan, and I have thalassaemia.

Said in this way it conjures up a room full of people sitting in a circle, declaring their alcoholism to the world. But of course, aside from the inflection in both statements, the two are completely different. Although there may have been a time in the lives of some of us when the emotion and trepidation in delivering the former statement may have been similar to those that have had to admit to the latter! I'm not sure that this is so anymore. Kids seem to have so much more confidence nowadays. But I'm one of the old school - fifty-six next birthday.

My five and a half decade long flirtation with thalassaemia, if I may call it that, began when I was circumcised at six months old. It was then that I was first diagnosed, and I began receiving blood transfusions when I was a year old. At the time my parents were told that my life expectancy was somewhere around twenty years of age. And at the time, with the treatment as basic as it was back in the sixties (there was no iron chelation in those days), that was probably a fair estimate. Thankfully things have since moved on. And thanks to the extra three and a half decades I have so far been afforded, so have I.

Growing up with thalassaemia, in the East End of London back in the 60s and 70s, I felt alone and isolated. There was no-one else with thalassaemia living anywhere near me. I was born in Hackney, where, had we have stayed, there would have been others (there were large Turkish and Greek communities). However, when I was three years of age my family decided to move further east to Forest Gate, an area which at that time still held on to some remnants of the reason it had been so named. It was a great area to grow up in, and I shall always remember my days there with great affection. But, there was no-one else with thalassaemia nearby. So, I had to travel back to Hackney, and the Queen Elizabeth Hospital for Children, for my treatment.

The hospital was closed a few years ago, and knocked down more recently to have luxury apartments built in its place - the way of all things, it seems. That hospital has always held a place close to my heart, and this is why, when I finally decided to follow my ambition to write, I had to include it in one of my plots, albeit in the second book.

My very first memory is of being at the Queen Elizabeth Hospital: I am in a cot, having received my transfusion, and waiting for my parents to come and collect me. I am standing up and holding onto the sidebars, looking longingly towards the doors at the very other end of the ward. When they finally walk in, and I see them, I burst into tears. Quite an ignominious memory to have really, considering I was fifteen at the time!!! No, but seriously, I must have been around two or three. And since then, whatever I have done and wherever I have been, some of my dearest memories are of times spent in hospital, be it the QEHFC, or the University College Hospital where I later moved to, aged around eighteen.

I think that it says something about us as people living with thalassaemia, that we can look back with fondness at times we've spent in hospitals. For it is there that I forged some of the most rewarding relationships during my life, with people that understood exactly how I was feeling, because they were feeling exactly the same. They were going through the same things as me. And the fondness in which I hold these memories is multiplied by the fact that they are all that remain with me, not only of the places, many of which still stand, but, more importantly, of those friends that have unfortunately fallen along the way.

One of my fondest memories is of evenings we spent, sitting in corridors outside wards at the UCH, visiting whichever person it was that may have been in for their treatment at the time. This became a regular occurrence, sometimes every night. There may have been up to twenty or thirty people, both thallies and non-thallies, at times – just sitting chatting, joking, generally having a laugh. Sometimes we were there well into the night, prior to going clubbing in the West End, or just out for a meal. The UCH staff were brilliant, and quite obviously very tolerant of us. We would be told to be quiet on occasions if things became a little rowdy, but we were never asked to leave. We had a great relationship with them.

My education was pretty standard. Of course I had to take regular time off to have my blood transfusions (and whatever operations, or procedures that were recommended), and I remember being called out of class or even assembly sometimes, to go to the office and be injected with my daily dose of Desferal by the district nurse. So, having wafted through school and college, I left full time education and went to work in shipping and forwarding, where I remained for the next thirty years (except for two periods of respite: a year in Cyprus being one, and a few months working at the former offices of the UKTS in Nightingale Lane, Hornsey, being the other).

All through this period I harboured a longing to write, and I did (small bits

Continues on page 12 ➡

'n' pieces, here and there). But what I really wanted was to write a book. I have always been a voracious reader of books, so I considered writing one to be the next natural step for me. And I finally did. It's nothing to do with thalassaemia, but I like to think that having thalassaemia has helped shape me into the person that can be seen in between the lines of the book. It is called The Room of Concentric Circles and is available in paperback, through Amazon and CreateSpace (or ordered from local bookshops), and as an e-book through Amazon Kindle. It is the first in a series of the adventures of a rookie private investigator. I have also written the second book and am in the process of finalising it before it too is released. And my wife, Andrea, and I are now collaborating on a series of children's adventure stories which I am writing, and she will then illustrate.

I now lead a relatively quiet life in Norfolk with my wife, Andrea. We moved here around ten years ago, and when we did we agreed to foster children. Soon after our decision two brothers, one ten years old at the time and the other six, landed on our doorstep. That was eight years ago, and I'm sure I don't have to tell you that life wasn't always as quiet as it has now (mostly) settled down to be!

I have lived all my life with thalassaemia, and have now reached the point that I don't actually see it anymore. Yes, it still has its restrictions, but gradually, as you get older, you train yourself to live within those restrictions so that they are no longer quite so restrictive. In many ways I feel I have been blessed by thalassaemia. For me it is normality. I was born with it. I have never known a life without it. I feel that I can adapt to things much easier than I imagine a healthy person would if struck down by something later on in life. It has been the one major factor in my life that has helped me remain grounded in everything that I do, or have ever done. From a very early age I felt humbled, and saw also that it had a humbling effect on those around me that knew I had it. I don't mean this in a negative way - quite the opposite in fact. When I was young I felt special, and yes, privileged in a way. I had accepted long ago that in life there are people that, through no fault of their own, do not conform to the norm. I was the only one of the family and friends in my everyday life that had thalassaemia, so in a way I felt something of a martyr. I had it, so no-one else had to. And in return I was repaid by people's kindness, which I received in bundles. However, by the time you get to my age you stop looking at things the same way. You no longer see things as you once did.

As for anything else, whatever comes along now will be an added bonus. There are few places left, if any, that it is my ambition to visit before I go the way of all things living. And there is certainly no activity that I simply must complete in order to fulfil my life. My life is already fulfilled by the people I have already met, the places I have already been, and the things I have already done. I have my wife and family and I have achieved my ambition of becoming a writer – not bad for someone who was not expected to live beyond the age of twenty! I have done it all, I need nothing further.

Wedding congratulations to Komal and Shaharyar

Congratulations to Komal Soomro of Dublin, Republic of Ireland, who was married in Dublin on 11th July 2015 to her husband Shaharyar Hussain. Says Komal "We got engaged in March 2013 and had a long engagement - Shaharyar is from Pakistan and we had to wait for his visa before we could get married. I would like to tell all my thal major friends that thalassaemia is no barrier to having a normal life!"

Mount Snowdon climb

Well done to Yusuf and Mohammed – raising funds AND awareness for UKTS

Mohammed (L) and Yusuf on their way to the summit

Raising funds and raising awareness for thalassaemia are both difficult things to do and it is not too often that both are achieved simultaneously! When friends Yusuf Ahmet and Mohammed Sheikh learned about thalassaemia and the low level of awareness of the condition, they made a spontaneous decision to do something to draw attention to it – by climbing Mount Snowdon on 28th November 2015!

Says Yusuf:

Neither of us are directly affected by thalassaemia, so people were wondering why we were raising money for the Society. I guess we were just really shocked to learn that so many people were unaware of what it actually is and the lack of knowledge out there. We felt that we wanted to do something spontaneous and drastic in order to raise awareness amongst our circles of friends. I've never climbed a mountain before and with no training or preparation we managed to take on the angry Welsh weather and climb to the summit of the mountain in just under 2 hours and 15 minutes! It was an amazing experience and in the end we managed to raise over £200 in the space of just 24 hours. We felt happy with that, given that we weren't even thinking about raising money to begin with and just wanted to raise awareness. A few of our friends have even subsequently scheduled blood test appointments with their local GP's as a result of our crazy adventure. We both hope to continue to work with the UK Thalassaemia Society and look forward to the next fundraising event!

Huge respect and thanks to Yusuf and Mohammed for their effort and we are delighted to have their support and to learn that some of their friends have now been tested. Their Justgiving page is still open if anyone wishes to make a donation - great work guys!

https://www.justgiving.com/Yusuf-Ahmet

UKTS thanks Commercial Temperance Masonic Lodge

UKTS thanks Commercial Temperance Masonic Lodge for adopting the Society as its chosen charity for 2015 and 2016. We are very grateful for the continuing support of the Lodge and the generosity of its members; it means a great deal to us to have been chosen and we will put the donation to good use.

Mr Simon Burt of the Lodge presents his fellow Lodge Member UKTS Assistant Secretary Anand Ghattaura with a donation of £326.

Harrow Health awareness day

Thanks to UKTS member Mrs Sonoo Malkani for her work in promoting awareness of thalassaemia at a health awareness day at Harrow Civic Centre on 4th October 2015.

L-R: Mrs Sonoo Malkani, London Assembly Member Councillor Navin Shah, the Mayor of Harrow Councillor Krishna Suresh and the Mayoress Councillor Mrs Sasi Suresh.

UKTS thanks the Bank of Cyprus UK

The Bank of Cyprus UK has a policy of making a charitable donation in lieu of sending festive greetings cards at this time of year. Once again UKTS is the grateful recipient of their very generous donation of £3,000. Our thanks to all at the Bank of Cyprus UK for their continued support of our work.

Bank of Cyprus UK Credit Delivery Officer Electra Costi (R) presents the cheque to UKTS Office Administrator Katerina Loizi-Read on 19th October 2015.

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*, Anand Singh Ghattaura *Asst. Secretary*, Tina Bhagirath *Asst. Treasurer*, Elaine Miller *National Coordinator*, Katerina Loizi-Read *Office Administrator*, Dr Christos Sotirelis *Trustee Advisor*, Jatinder Karir *co-opted committee member*, Saloni Thakrar & Sonoo Malkani *parent members*, May Kong *patient member*

Acronyms

APPG – All Party Parliamentary Group for Sickle Cell & Thalassaemia
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
SHCA – Specialised Health Care Alliance
TIF – Thalassaemia International Federation
UKFHD – UK Forum on Haemoglobin Disorders

- 2 & 3 May 2015 – TIF Board meeting, London Gabriel Theophanous, *Tina Bhagirath*
- 6 & 7 May 2015 – peer review of haemoglobinopathy services, North East (James Cook University Hospital Middlesbrough & Newcastle Royal Infirmary) *Elaine Miller*
- 10 May 2015 – sponsored walk for International Thalassaemia Day, Alexandra Palace, North London
- 21 & 22 May 2015 – peer review of haemoglobinopathy services, Dublin Republic of Ireland *Dr Christos Sotirelis*
- 14 June 2015 – UK Thalassaemia Society AGM, UKTS office
- 14 June 2015 - awareness event, Harrow Vaisakhi Mela, *Anand Singh Ghattaura*
- 16 June 2015 - Access to drugs for ultra-rare diseases meeting, London *Dr Christos Sotirelis*
- 18 June 2015 – Generic policies workshop, London *Dr Christos Sotirelis*
- 25 June 2015 – NHSBT stakeholder event, London Tina Bhagirath, *Elaine Miller*
- 27 June 2015 – awareness presentation, Newham annual haemoglobinopathy conference, London *Gabriel Theophanous*
- 29 June 2015 – SCTSP Advisory Board working group, Skipton House London *Elaine Miller, Saloni Thakrar*
- 1 July 2015 – APPG Secretariat meeting, London *George Constantinou*
- 4 July 2015 – awareness event, Southampton Mela Anand Singh Ghattaura, Jatinder Karir
- 18 July 2015 – awareness presentation, Barking, Havering & Redbridge annual haemoglobinopathy conference, London *Elaine Miller*
- 25 & 26 July 2015 – awareness event, Manchester Mega Mela *Elaine Miller*
- 26 July 2015 – Greek Police Association event, London Katerina *Loizi-Read*
- 5 August 2015 – NSC meeting on carrier diagnosis, Skipton House London *Romaine Maharaj, Elaine Miller*
- 28 August 2015 – meeting with Scottish families affected by thalassaemia, Glasgow *Elaine Miller, May Kong*
- 29 & 30 August 2015 – awareness event, Edinburgh Mela *Elaine Miller, May Kong*
- 6 September 2015 - awareness event, London Mela *Anand Singh Ghattaura, Tina Bhagirath*
- 6 September 2015 - awareness event, Walsall Mega Mela *Elaine Miller*
- 12 September 2015 - awareness event, Leyland Health Mela *Elaine Miller*
- 14 September 2015 – UKFHD committee meeting, British Society for Haematology, London *Elaine Miller*
- 21 September 2015 – SCTSP newborn information governance & clinical advisory group meeting, Guy's Hospital *Elaine Miller*
- 24 September 2015 – peer review of haemoglobinopathy services, Alder Hey Hospital, Liverpool *Elaine Miller*
- 26 September 2015 – awareness presentation, Republic of Ireland haemoglobinopathy conference, Dublin *Elaine Miller*
- 29 September 2015 – peer review of haemoglobinopathy services, Royal Manchester Children's Hospital *Elaine Miller*
- 1 October 2015 – awareness presentation, NHSBT donor ambassador training event, Birmingham Elaine Miller
- 3 October 2015 - awareness event, Fylde Coast Health Mela *Elaine Miller*
- 4 October 2015 - awareness event, Health Awareness Day, Harrow Civic Centre *Sonoo Malkani*
- 7 October 2015 – SCTSP procurement meeting, Skipton House London *Elaine Miller*
- 9 October 2015 - SCTSP Advisory Board working group, Skipton House London *Elaine Miller, Saloni Thakrar*
- 13 & 14 October 2015 – peer review of haemoglobinopathy services, West Midlands (Wolverhampton Hospital & Birmingham Children's Hospital) *Elaine Miller*
- 17 October 2015 - awareness event, Manchester Dashehra Diwali Mela *Elaine Miller*
- 18 October 2015 – NEBATA annual conference *Katerina Loizi-Read*
- 22 October 2015 - peer review of haemoglobinopathy services, Croydon University Hospital *Elaine Miller*
- 4 November 2015 – SCTSP Advisory Group meeting, London *Elaine Miller, Saloni Thakrar*
- 5 November 2014 – peer review of haemoglobinopathy services, Imperial (St Mary's Hospital London) *Elaine Miller*
- 9 November 2015 – Leeds community services scoping meeting *Elaine Miller*
- 10 & 11 November 2015 – Genetic Alliance UK advanced therapies workshop, Cambridge *Katerina Loizi-Read*
- 12 November 2015 – awareness interview, ALL RM Radio Manchester *Elaine Miller*
- 19 November 2015 - peer review of haemoglobinopathy services, Oxford University Hospitals *Elaine Miller*
- 19 November 2015 – SITA award ceremony, Abu Dhabi *George Constantinou*
- 14 December 2015 – UKFHD committee meeting, London *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 _____

Designed and printed by Orion Design & Print Ltd. Tel: 020 8351 3222 Email: Sales@Orion.gb.com