



## UKTS GOES ALL OUT FOR AWARENESS IN 2014



The UKTS team with traditional dancers at Slough Mela 3.8.14.

As anyone from the world of thalassaemia knows only too well, the general public are not very well informed about thalassaemia – mention the word and you tend to get a blank look and the question “Thala-what??” We need to address this lack of knowledge; so that we can effectively lobby for better services and our fair share of resources from the NHS – after all, who cares about something they have never heard of?

Just as importantly, we know that there are many thousands of thalassaemia carriers out there in the world who are completely unaware that they may be at risk of having affected children. With this in mind, the Trustees of the Society have made a policy decision to step up the awareness work by attending more, larger events and speaking to more people than

ever before. We are, of course, a very small team but we have worked incredibly hard all Summer and have had a presence at some of the largest melas and festivals in the country. UKTS has taken awareness stalls at the following events:

Vaisakhi Festival, Slough	27th April
Middlesbrough Mela	7th & 8th June
Bradford Festival	13th, 14th & 15th June
Manchester Mega Mela	21st & 22nd June
Cyprus Wine Festival, Alexandra Palace	28th & 29th June
Sandwell & Birmingham Mela	5th & 6th July
Slough Mela, Upton Park, Slough	3rd August
Birmingham Eid Mela, Cannon Hill Park, Birmingham	17th August
Leicester Belgrave Mela, Leicester City Centre	25th August
London Mela, Gunnersbury Park, Ealing	31st August
Awareness drive, Sant Isher Salana Barsi Samagam, Ruislip	6th September
Manchester Diwali Mela	11th October
Awareness drive, Sikh Gurdwara, Wimbledon	18th October

Even people who have heard of thalassaemia often have very outdated information and do not realise that thalassaemia in the UK today is a manageable condition – fortunately we

can show them living examples of this. Many people assume that anyone who has thalassaemia must be an invalid; and often the surprise is evident in their faces as they realise that the person they are actually speaking to has thalassaemia and is an absolutely normal person!

It would be remiss of us not to mention the wonderful volunteers who have attended events with us and in some cases helped us to set them up. UKTS thanks the British Sikh Doctors’ Association (BSDO) for working in partnership with us to help raise awareness of thalassaemia within the Sikh community. Special thanks also to our member Gagandeep Singh Khattar and his wife Neha for their outstanding contribution to our awareness work.

We have distributed thousands of leaflets, booklets and films and spoken to many hundreds of people at these events. We are planning to attend more events during the Winter as they come up and will keep you posted. Next year we are aiming to reach even more events in England and we will be extending our awareness work into Wales and Scotland by attending melas in Cardiff, Glasgow and Edinburgh.

**Is there a Summer mela or a Winter event in YOUR area which UKTS could attend to raise awareness of thalassaemia? If so, please contact our office.**

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# A word from our President



Dear Friends

Finally the long, hot summer of 2014 is over – and what a summer it has been! Far from relaxing over the “holiday months” the UKTS team has been working harder than ever – this year we have focussed on awareness and ensuring that more and more members of the general public know what thalassaemia is – and whether their family could be at risk. From the front page story and some of the other articles in this issue, you will see that there has hardly been a weekend over the summer when UKTS has not been at an event!

We have also revived our Roadshow project (see page 6); so far this year we

have held 2 events in West Yorkshire and Birmingham and we have an East Midlands Roadshow coming up in November (see “Save the date” on page 3). As stated in the article, the UKTS team is ready and willing to engage with families affected by thalassaemia everywhere - have you ever looked at the Roadshow articles and wished UKTS would hold a meeting in your area? Ever thought we would never come to your area because there are not enough patients? Just try us – if you contact our office we will undertake to help you; we have no problem with visiting small groups or even individuals if you think there is anything we can do to help.

With the New Year of 2015 not too far away, one important advance I should mention is that annual members can now ensure that their membership of the Society will not lapse by becoming a standing order donor (see article on page 5). Who amongst us cannot afford £2 per month? It is a trivial sum to the individual; but it would be a huge support to UKTS if hundreds of people were to support us in this way! If you have not already done so, please fill in the form on page 15 – and urge your friends and family to do the same. If you would like us to send you a form (or forms!) and a reply paid envelope – just contact our office, we will be only too happy to do so!

Finally, I want to mention that we are getting ready to represent the Society at the 4th Thalassaemia International

Federation Pan-European conference in Athens in November 2014. Some of you reading this newsletter will be UKTS patient members who are looking forward to attending this conference, aided by a financial grant from the Society. We look forward to seeing you all in Athens; and we will bring back news and updates from the conference for those who are not attending. Watch this space!

Best wishes until the next issue.

**Gabriel Theophanous**  
President, UK Thalassaemia Society

## New Year Challenge:



Join Thalassaemia UK on FACEBOOK



Follow @UKThal on Twitter

### 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*

**Anand Singh Ghattaura**

*Secretary*

**George Constantinou**

*Assistant Secretary*

**Chris Fassis**

*Treasurer*

**Romaine Maharaj**

*Assistant Treasurer*

**Pany Garibaldinos**

*Committee Members*

**Tina Bhagirath**

**Raj Klair**

# SAVE THE DATES

## UK Thalassaemia Society East Midlands Roadshow

**Saturday 29th November 2014**

King Power Stadium, Filbert Way, Leicester LE2 7FL  
Thalassaemia patients and family members welcome –  
please contact Elaine on 07958 084 892 / elaine@ukts.  
org if you would like to attend.

## UK Thalassaemia Society Dinner & Dance

**Saturday 6th December 2014**

The UK Thalassaemia Society annual dinner dance will  
be held on Saturday 6th December 2014 at the Regency  
Banqueting Suites, 113 Bruce Grove, London N17 6UR  
(free parking)



**Tickets £50 (drinks included)**  
Dancing to the music of DJ Paul  
"Funksy" Savvides, famous club/  
party DJ and radio presenter from  
London Greek Radio

**TICKETS AVAILABLE NOW**

– please contact Katerina in the London office  
0208 882 0011 / katerina@ukts.org

## 2015 UKTS Annual Sponsored Walk

**Sunday 31st May 2015**

The 2015 UK Thalassaemia Society annual  
sponsored walk will be held at Alexandra  
Palace, North London  
All are welcome – further information to  
follow.

# Our Awareness Summer



UKTS stand at Manchester Mela



UKTS stand at Bradford Festival 13-15.6.14



Spongebob visits UKTS at Birmingham Eid Mela 17.8.14



London Mela Ealing 31.8.14



UKTS thanks Sandeep Phull of Practical Car & Van Rental for donating his services for the London Mela. [www.practical.co.uk](http://www.practical.co.uk)



With BSDO Sant Isher Singh Ji Samangam, Ruislip 6.9.14



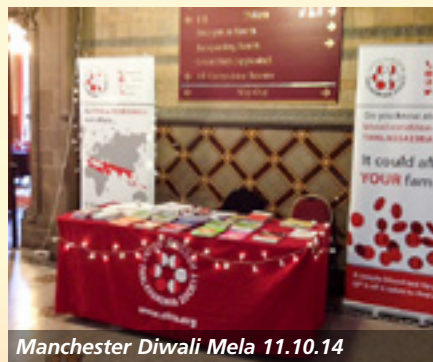
Leicester Belgrave Mela 25.8.14



Our VP Anand at Sandwell Mela 5-6.7.14



With BSDO at Sikh Gurdwara Wimbledon 18.10.14



Manchester Diwali Mela 11.10.14



Asst Coordinator Katie braves the weather, Middlesbrough Mela 7-8.6.14

# Annual Members

## – New standing order membership takes the hassle out of renewal!

As all our annual members will know, all UKTS memberships come up for renewal in January; so at that time of year we send you a reminder (usually together with a newsletter) asking you to either send in a cheque for £10 or telephone our office to pay by credit/debit card. You will also be aware that, for some years now, we have included a standing order donation form in our newsletter (see page 15) for those people who have kindly chosen to regularly support the Society.

The Trustees of the Society have decided to confer membership on all standing order donors while their standing order remains in place. This means that, if you have a standing order set up, your membership of the Society will not lapse

– no more remembering to write out a cheque or phoning the Society every year – you simply fill in one form and your membership continues from one year to the next without you having to take any action whatsoever. For patients, membership of the Society brings the additional benefit of eligibility for UKTS grants to attend international conferences - some of our patient readers will be benefiting from a UKTS grant to attend the TIF conference in Athens in November 2014 and some will have received grants for past TIF conferences. So by starting a standing order, when the next TIF conference comes up you will have the security of knowing that your membership is in place and you will be able to claim any

grant decided upon by the UKTS Trustees.

The minimum donation is just £2 per month – less than a cup of coffee – and in addition to knowing that your membership will renew automatically you have the satisfaction of knowing that your support is helping us to keep the Society running. We all know how costs have increased over the last few years; so every £1 we receive in donations is a help.

**WANT TO SIGN UP? YOU WILL FIND THE FORM ON PAGE 15**

**IF YOU WISH TO RECEIVE A PRINTED FORM AND A REPLY PAID ENVELOPE, OR YOU WOULD LIKE MORE INFORMATION, PLEASE CALL OR EMAIL ELAINE MILLER 07958 084 892 [elaine@ukts.org](mailto:elaine@ukts.org)**

## Prestigious award for Whittington Joint Diabetes / Thalassaemia Clinic

The diabetes team at the Whittington Hospital, North London, were awarded a special commendation for their joint

diabetes/thalassaemia clinic in the category of Diabetes Team of the Year at the BMJ awards ceremony in May 2014. Only

services dealing with a rare but significant patient population with complex and usually unmet requirements. The team had an excellent dynamic and obviously included their patients in every step of the process. The judges would like to commend this excellent team on their work, which has huge relevance, particularly when considering unmet global healthcare needs."



L-R Dr Farrukh Shah Consultant Haematologist, Varsha Rajashekar Diabetes Dietitian, Dr Ploutarcho Tzoulis Speciality Trainee, Romilla Jones Diabetes Nurse Specialist, Dr Maria Barnard Consultant Diabetologist, Emma Prescott Thalassaemia Nurse Specialist.

5 teams from 450 entries were awarded special commendations; so this is a marvellous achievement and it is to the great credit of all the team members that the BMJ singled them out for this honour. The BMJ said:

"This was an innovative interdisciplinary approach to providing specialist

We at UKTS are thrilled that the diabetes/thalassaemia clinic has received this recognition; and we sincerely congratulate all the members of the team.

*The following team members are also part of the UKTS Scientific Advisory Panel:*  
Dr Maria Barnard (Diabetes)  
Dr Farrukh Shah (Pathophysiology)  
Emma Prescott (Nursing)

# Return of the Roadshow

## – UKTS starts new round of local meetings

As many of our members will be aware, the UK Thalassaemia Society has been running a “Roadshow” project for some years. The Roadshows are local meetings for families affected by thalassaemia. They are smaller and more informal than a conference; ideally the Roadshow is a forum for discussion and where thalassaemia patients and family members can speak directly to UKTS Trustees and staff about what is important to them. We usually invite some local health care professionals to join us for the day; but the focus is very much on the families. Lunch and refreshments are provided.

**Would you like us to hold a Roadshow in YOUR area? It doesn't matter how small your patient group is – please contact Elaine Miller on 07958 084 892 [elaine@ukts.org](mailto:elaine@ukts.org)**



*Prof Bernadette Modell*

**West Yorkshire Roadshow** So far in 2014 we have held 2 Roadshows. The first was on Saturday the 31st May 2014 at the Carlisle Business Centre in Bradford. All patients (and their family members) from the Leeds/Bradford/West Yorkshire area were invited. UKTS personnel who attended were; Anand Singh Ghattaura (Vice-President), Romaine Maharaj (Treasurer) and Elaine Miller (National Coordinator).

We heard some very interesting presentations from Dr Sally Pollard (Consultant Paediatrician, Bradford Royal Infirmary) on Optimising Care in Thalassaemia and Dr Sangeeta Chattoo

(Research Fellow, University of York) on Social Implications of Carrier Diagnosis. Anand spoke about his personal experience of managing a busy life and thalassaemia treatment; and Elaine spoke about claiming DLA for children. We were also joined by PhD student in health psychology (and thalassaemia patient) Roanna Maharaj, who led a workshop in the afternoon session on transition from paediatric to adult care; and all the implications of patients leaving childhood behind and taking up responsibility for their own lives and treatment – what does it mean for parents as well as children? Many of our guests had interesting contributions to this discussion.

Last but not least, we were joined in the afternoon by a very special guest – Professor Bernadette Modell. This amazing lady, the pioneer of thalassaemia treatment in the UK (and a founder of the UK Thalassaemia Society), held outreach clinics in Bradford many years ago and knew some of the patients, now in their forties, as little children. The families were thrilled to see her and of course, being Prof Modell, she remembered every single person – AND their parents! A huge thank you to Prof Modell for giving up her Saturday and making the long journey from London to Bradford; and to everyone else who attended the Roadshow.

**Birmingham Young Patients' Roadshow** was our second of the year, held on the

16th August at the Midland Arts Centre in Cannon Hill Park, Birmingham. UKTS personnel who attended were; Gabriel Theophanous (President), Anand Singh Ghattaura (Vice President) and Elaine Miller (National Coordinator). We were also joined by Roanna Maharaj, who was continuing her research into the issues faced by parents and youngsters during transition. Dr Christine Wright (Consultant Haematologist, Birmingham City Hospital) joined us for most of the day; and we had a very pleasant, informal discussion covering many aspects of managing thalassaemia and coping with work, education and relationships.

Patients and family members from the Birmingham area, Coventry and Leicester attended the Roadshow; and we are especially grateful to Giuseppe Cetera from Rugby for bringing his delightful children along – when a giant spider ran into the middle of our circle we all stood up and screamed like idiots; Giuseppe's young son Louis calmly picked up the spider and put it out of the window saying matter-of-factly “I have a tarantula at home.” We all felt pretty pathetic I can tell you (in our defence, that spider was HUGE!).

UKTS is indebted to Barbara Bailey, the Nurse Specialist for adolescents with haemoglobin disorders in the Birmingham area, for her help in setting up and organising this event.



*Midland Arts Centre, Birmingham*

# Bone Disease in Thalassaemia

**Dr Judith Bubbear, Consultant Rheumatologist,  
Barts Health NHS Trust**



## **Bone disease in thalassaemia**

Osteoporosis is a disease that is commonly associated with women who have gone through the menopause. Although this is the largest group of patients that we see in the osteoporosis/metabolic bone clinics there are other rarer conditions that are associated with osteoporosis. Osteoporosis literally means “porous bones” and is a thinning of the bone structure that makes the individual more prone to fractures (broken bones). Fractures can occur with less trauma and these are called fragility fractures. Osteopenia is a term used when the bones are less dense than a young adult’s bones, but haven’t quite reached the level of osteoporosis. It is estimated that up to 50-80% of people with thalassaemia have osteopenia or osteoporosis.

The consequences of this reduction in bone density for patients are bony pain and fragility fractures. Fractures are estimated to occur in 70-80% of people with thalassaemia, although 1 in 5 patients will have no bony symptoms. The pathology that underlies this bone disease is complex; with many possible factors influencing the bone including

delayed sexual maturity, dysfunction of the parathyroid and thyroid glands, growth hormone deficiencies and direct toxicity of iron on bone cells. Bone is a dynamic tissue that is very metabolically active and is constantly undergoing break down and build up. We know from measuring proteins in the blood of patients with thalassaemia that there is a higher rate of bone loss (resorption) than bone formation and therefore the overall balance is that the bone density will be reduced and the bones more liable to fracture.

## **Treating low bone density**

### **Lifestyle measures**

There are things in our lifestyle that can influence our bones and anyone with bone disease should be trying to do what they can to optimise their bone health. Smoking is linked to lower bone density and fractures. Giving up smoking therefore, as well as having many other benefits in terms of reducing the risk of cancer, heart disease and strokes, can improve the health of your bones. Physical activity is also important to our bones. The stimulation of weight-bearing exercise improves bone density and bone strength. Exercise such as a walking, jogging or exercise classes with some impact e.g. aerobics stimulate the bone to maintain its density. Very high impact exercise is best avoided by patients with osteoporosis due to the risk of fracture, but walking is suitable for all.

### **Sex hormones**

People with thalassaemia can have low levels of the sex hormones, which are also essential hormones for our bone health. If there are low levels of the sex hormones

then treatment with testosterone replacement therapy or using the oral contraceptive pill or HRT in women may be appropriate. However these treatments aren’t suitable in all patients and need to be discussed with your haematologist.

## **Bisphosphonate drugs**

The bisphosphonates are a group of drugs that reduce bone resorption (breakdown). They have been extensively used in treating post-menopausal women with osteoporosis and are also used in treating some forms of cancer that affect the bones. It is difficult to do large studies of treatment in rare diseases, but studies lasting 1 or 2 years have shown these drugs to reduce the resorption of bone, improve the density of the bones and reduce back pain. Some of these drugs are oral and taken weekly e.g. alendronate. Others are intravenous (given via the veins) and are given less often: monthly, 3 or 6 monthly e.g. pamidronate or zoledronate.

## **Complications of long-term bisphosphonate use**

Bisphosphonates have been used in osteoporosis for around 20 years. More recently there have been reports of potential side-effects of long-term use. The first of these is a condition called osteonecrosis of the jaw (ONJ). This is a condition that affects the inside of the mouth. A hole appears in the gum and the underlying bone is exposed. It doesn’t heal for weeks and can take months to improve. ONJ does occur in patients who haven’t taken any bisphosphonate, but the rate appears to be higher if you have received treatment with a bisphosphonate. The mechanism behind this isn’t well

understood. The risk of ONJ in post-menopausal osteoporosis is estimated at around 1:10,000. The rate in thalassaemia patients treated with bisphosphonates is not known.

The second reported rare side-effect is unusual fractures of the thigh bone (atypical femoral fractures – AFF). When a patient with osteoporosis breaks their hip it is usually across the neck of the femur (thigh bone), however we now have reported cases of fractures lower down the femur that occur on minimal trauma. There have been cases of these fractures in patients with thalassaemia treated with bisphosphonates. These fractures can be difficult to heal and cause significant. Again these are rare fractures, but cause

significant problems for affected patients.

Both the American and UK guidelines for treating osteoporosis in thalassaemia patients advise using bisphosphonates in some patients, particularly those who have fractured. However long-term use may not be suitable. The bisphosphonates are long-acting drugs that stay in the bones working for years after they are given. This has led to the concept of a “drug holiday” i.e. a break in treatment, usually for a couple of years, to try to reduce the incidence of these rare side-effects. Evidence in post-menopausal women suggests that a 2 year break in treatment does not lead to thinner bones or more fractures. Doctors therefore may suggest a break in bisphosphonate treatment in

patients with thalassaemia, but this is determined on a case by case basis.

**Conclusion**

Osteoporosis is a common problem in patients with thalassaemia with consequences of bony pain and broken bones. There are treatments, such as bisphosphonates that have evidence for being used in osteoporosis in thalassaemia. There are rare side-effects of these drugs and we may be able to reduce these by having breaks in treatment – “drug holidays”. This is an area that would benefit from further research and ongoing collaboration between different specialities.

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# Using Biological Materials in Research

By Dr Christos Sotirelis



*Dr Christos Sotirelis*

In light of recent developments in technologies such as whole genome sequencing and the increasing practice of exchanging samples and data between centres and across borders, the Council of Europe’s Committee on Bioethics is

updating its 2006 Recommendation on ‘the use of biological materials of human origins in research’. In March, the Council issued a consultation document and asked for views on the proposed amendments. The Recommendation aims to protect the rights and privacy of individuals who give biological samples (like blood or skin) for research and gives guidance to researchers on storing and using the samples.

The UKTS through our member Dr. Chris Sotirelis is a member of the Rare Disease Patient and Ethics Council which co-ordinated a collaborative response including: the RD Connect, Neuromics and Eurenomics projects; the Patient Advisory Council for those projects; the Interdisciplinary Scientific Committee of the International Rare Disease Research Consortium (IRDiRC); and Eurobiobank.

The response emphasised the

importance of balancing individual citizens’ right to privacy and their right to receive medical treatment and benefit from prevention of disorders through the advancement of research. We emphasised the scarcity of biological materials within rare disease research and therefore the importance of being able to re-use samples for more than one research project, including making samples available across different countries and different disease groups.

The Council of Europe is a human rights organisation which works directly with the European Parliament. The response can be found here <http://rd-connect.eu/rdcon/files/Joint-response-to-CoE-working-document.pdf> and the original consultation document here <http://rd-connect.eu/rdcon/files/CoE-working-document-on-research-on-biological-materials-of-human-origin.pdf>



# UKTS Profile



## Dr Anne Yardumian

Questions by Elaine Miller, National Coordinator, UK Thalassaemia Society

*Dr Anne Yardumian is a Consultant Haematologist at the North Middlesex University*

*Hospital and is Chair of the UK Forum on Haemoglobin Disorders. Dr Yardumian is also the Editor-in Chief of the Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK. She lives in Cambridgeshire with her husband; their three daughters no longer live at home, but instead they look after a lop-eared rabbit belonging to their middle daughter!*

**Can you tell us a little bit about your background – where you were born, your education, whatever you wish to share?**

I was born in Liverpool, the second daughter of doctor parents. My mother was a Glaswegian, the first in her family to go to University who would – in later times – have been a career doctor [she would like to have been an obstetrician] but at that time when she married felt she had to give priority to her family, and she did some general practice and family planning after that. My father was a GP – as had been his father [an Armenian refugee who fled to the UK in childhood: hence the name!] and I have never known a person who loved his job more – or who was better at it.

**At what age did you decide that you wanted to make a career in medicine?**

**Did you choose medicine for any particular reason?**

I really loved science at school, unashamedly – I wish more people, girls in particular, would be comfortable with that! Actually, I wanted

to do biology or even botany at University; but was easily persuaded that medicine might have a more useful endpoint. I am so very glad I was gently pushed that way. Although I still love a rhizome... my patients are infinitely more rewarding! I think I am the second happiest person I know in my job, after my father.

**Given that there are so many medical specialities, what attracted you to red cell haematology?**

Isn't it curious, how one finds oneself completely committed to a particular field, given how many avenues there might have been? I think it is often down to inspirational people one meets along the way, in training. Dr Milica Brozovic, whom some readers might remember, was the senior haematologist at Central Middlesex Hospital when I arrived there as a quite junior trainee; her commitment to improving care for people with sickle cell disease was legendary, and with Elizabeth Anionwu [now Professor] she had set up the Brent community centre. I was caught by their ambitious and far sighted vision, and so in more senior trainee jobs I sought out other red cell haematology posts, spending time then at Whittington Hospital with Dr Beatrix Wonke and – all along the years – Professor Bernadette Modell. Talk about inspirational! Who wouldn't have wanted to follow in such footsteps? And then, as soon as I started working in the field, there were the patients, and families, who – if one hadn't already been hooked – did the job good and proper. No looking back after that.

**In your career, what have been the most significant medical advancements in the treatment of thalassaemia?**

Going back a long way – some may not remember! – having white cells filtered from

the blood at source to save having tiresome in-line filters with every unit of red cells, probably helped a bit.. but overshadowing all would, I think, be the availability of a range of iron chelators. When I started as a consultant, it was basically desferrioxamine (Desferal), with 'L1' [deferiprone / Ferriprox] in development. Desferrioxamine – an amazing, life-saving drug – is, of course, very hard to use and in some other regards isn't the optimal drug either. Sadly I still remember people who died from iron overload who had no alternative treatment. Now – with deferiprone and deferasirox generally available – we are in a much better place, where we can decide, with patients, what would be best for them in terms of managing iron in the different organs, and what suits them individually. And – talking about iron in different organs, the ability to visualise how much iron there is in the heart, liver, endocrine glands and elsewhere, with magnetic resonance techniques, has itself been a very important advance. And finally, I think that the continued alliance between patients, families, and health care professionals – exemplified in the UK Thalassaemia Society better than in any other partnership I know – has enabled us jointly to set standards we can all buy into, make arrangements to ensure that standards are being met, and continually strive towards high quality care for patients, wherever they live in the UK. Of course we now have a system to peer review all the main treatment centres, and this provides a continuing process of monitoring how well different centres are at providing services that match good quality requirements. I think those of us across the professional / voluntary sector who were engaged in setting up this assurance check are entitled to feel slightly proud!

# Wedding congratulations to...



## Alex and Jeff

Thalassaemia patient Alexandra Hau is delighted to share the news that she was married to her fiancé Jeff Watson on the 8th May 2014. The wedding took place at Braxted Park, Witham, Essex; and the happy couple then jetted off for a honeymoon in Mexico. They are currently enjoying renovating their house near Southend. Thank you to Alex and Jeff for sharing this beautiful wedding picture with our readers.

*Alex is under the care of Dr Ian Grant at Queen's Hospital, Romford.*

## Maria and Robert

Wedding congratulations to thalassaemia patient Maria Fletcher (née Gavriel) on her marriage to her fiancé Robert. The wedding took place on 26th July 2014 in Paphos, Cyprus, with just family members present. Long-standing readers may remember that Maria is a former Trustee of the UK Thalassaemia Society. May we wish every possible happiness to the new Mr and Mrs Robert Fletcher.

*Maria is under the care of Prof John Porter at University College of London Hospital, and Dr Claire Chapman at Leicester Royal Infirmary.*



# Baby congratulations

Many congratulations to Michael and Tricia Paraskeva of Bristol, on the birth of their first child, a daughter. Baby Minnie Androphina was born on 4th July 2014 at the Southmead Hospital, Bristol – the same hospital where proud Dad Michael was born, and where he still attends for his regular transfusions as a thalassaemia patient! Michael is under the care of Dr Priyanka Mehta at the Bristol Haematology Unit.



## Transfusion: A Patient Survival Guide

Remember Josephine Bila from issue 122 of TM? She is a thalassaemia patient from the USA who gave a presentation "Believe in Yourself" at the last TIF conference in Abu Dhabi. Jo has now written a book called "Transfusion: A Patient Survival Guide". You can check out the book by following this link:

<http://transfusionsurvivalguide.com/>



# Lady of the Lake – Lyndsey swims for UKTS



Huge thanks and congratulations from all at UKTS go to Lyndsey Reast of Denby, Derbyshire, who completed the Great North Swim in Lake Windermere on 14th June 2014 to raise money for the UK Thalassaemia Society. Anyone who has been to Lake Windermere will attest to the fact that it is absolutely enormous – AND absolutely freezing!

Says Lyndsey: "The swim itself starts and finishes at The Low Wood Hotel near Ambleside on Windermere. The setting and scenery are absolutely breathtaking, not that you can take much in when you're battling for space with 200 other participants in each swim. (Close to 10,000 swimmers take part during the weekend at half hour intervals.) Swimming in open water is amazing; but as scary as it is when I'm in the water, I absolutely love it!"

Lyndsey completed the 1 mile swim in 39 minutes, 52 seconds and raised an amazing £619 for the Society. She says: "As my husband has beta thalassaemia trait and has been having a few health issues this year which has had a knock on effect for his thalassaemia, this was something very close to our hearts at the moment."

*And may we say to Lyndsey and every one of the amazing people who raise funds for the Society, it touches our hearts to the core that you are prepared to go to such efforts to raise money for UKTS, a very small charity working for a little known condition, rather than the bigger, more well-known charities. We promise you that we will put every penny to good use!*

## UKTS thanks Embankment Golf Club, Wellingborough

The UK Thalassaemia Society sends most grateful thanks to all the members and especially the club Captain Mr George Khaw for choosing the Society as one of the charities to benefit from their fund raising efforts. We truly appreciate their wonderful donation of £1,025 which will be an immense help in our work. Thank you so much to everyone at the club for thinking of us



L-R Lady Captain Pauline Terry, Hon. Treasurer Andy Foster, Social Secretary Mick McGrady, Club Captain George Khaw

# Follow us on social media

By UKTS Committee member Tina Bhagirath



Social media is a powerful tool to help in getting the UKTS messages to a much wider audience. My intention is to utilise this method, with the help of Twitter, Facebook and a blog (coming early 2015) to capture those thalassaemia patients for whom we currently have no contact details; and keeping those we know up to date as things are happening.

We have seen a great increase in people following @UKThal on Twitter.

opportunity to sincerely thank him from all of us at the UKTS for his hard work in raising our profile and continuing to support us, he is a vital member of the social media team.

This summer I have become involved with (thalassaemia patient) Amit Ghelani's Facebook page 'Thalassaemia UK' which was the only established UK Facebook with a regular following; with UK and international patients/friends/family posting comments and

Thanks to our volunteer "social media guru", Perdeep Rullay, we are currently at 170 followers, which is a far cry from what it was when he agreed to take over our page. I would like to take this

news. Amit has kindly allowed me to use his established platform to post information and keep everyone updated with events work being done.

I would like to request that all those reading this newsletter, members and non-members alike, to join us on Facebook and Twitter now and help us get the message to as many people as possible, to help us to inform, educate and become more inclusive of our younger 'social media generation'! I will be honest – I personally didn't know what a tweet or retweet was and had absolutely no idea how to use Twitter; but if I can do it anyone can - it takes less than five minutes to join!

**New Year challenge:**

Join Thalassaemia UK on FACEBOOK

Follow @UKThal on Twitter

Thank you!



People of all generations...

## UKTS Sponsored Walk/Run

People of all generations took part in the sponsored walk – as seen in this picture of our members the Thakrar family from NW6.

The 2014 United Kingdom Thalassaemia Society sponsored walk/run took place on 4th May 2014, at Alexandra Palace, North London. 67 walkers/runners took part and we raised £1,314 to help with the work of the Society.

Thank you to all who took part and of course all who sponsored them!

# Recent Events & Meetings



Those who attended meeting on behalf of the UK Thalassaemia Society are: Gabriel Theophanous President, Anand Singh Ghattaura Vice-President, Chris Fassis Asst. Secretary, Romaine Maharaj Treasurer, Tina Bhagirath Committee Member, Raj Klair Committee Member, Elaine Miller National Coordinator, Katerina Loizi-Read Office Administrator, Roanna Maharaj patient member, Hattie Osman parent member, Gagandeep Khattar 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  
 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

- 16 December 2013 – UKFHD Committee meeting, British Society of Haematology London *Elaine Miller*

- 4 May 2014 – UKTS sponsored walk, Alexandra Palace UKTS team
- 8 May 2014 – SCTSP newborn outcomes committee meeting, London *Elaine Miller*
- 13 May 2014 – peer review committee meeting, Guy's Hospital London *Elaine Miller*
- 31 May 2014 – West Yorkshire Roadshow Carlisle Business Centre Bradford Anand Singh Ghattaura, Romaine Maharaj, *Elaine Miller, Roanna Maharaj*
- 31 May 2014 – TIF Board meeting, Kensington London Gabriel Theophanous
- 7-8 June 2014 – Middlesbrough Mela *Elaine Miller, Katerina Loizi-Read*
- 13-15 June 2014 – Bradford Festival *Elaine Miller*
- 16 June 2014 – Living with Sickle Cell or Beta Thalassaemia Trait workshop Friends House Euston Anand Singh Ghattaura, *Elaine Miller, Katerina Loizi-Read, Hattie Osman, Roanna Maharaj*
- 16 June 2014 – APPG meeting, Westminster Anand Singh Ghattaura
- 17 June 2014 – SHCA meeting, Westminster Roanna Maharaj
- 21-22 June 2014 – Manchester Mega Mela *Elaine Miller*

- 21 June 2014 – NEBATA conference Manchester Anand Singh Ghattaura, Raj Klair
- 28-29 June 2014 – Cyprus Wine Festival, Alexandra Palace *Chris Fassis, Katerina Loizi-Read*
- 5-6 July 2014 – Sandwell & Birmingham Mela, Anand Singh Ghattaura, Elaine Miller
- 10 July 2014 – PCC meeting, Royal Pharmaceutical Society, London *Elaine Miller*
- 16 July 2014 – SHCA meeting, House of Lords Roanna Maharaj
- 31 July 2014 – awareness day, St George's Conference Centre Leeds *Elaine Miller*
- 31 March 2014 – APPG meeting, London Anand Singh Ghattaura, George Constantinou, Roanna Maharaj
- 3 August 2014 – Slough Mela Anand Singh Ghattaura, Tina Bhagirath, Elaine Miller, Gagandeep Khattar
- 16 August 2014 – Birmingham Young Patients' Roadshow, MAC Centre Gabriel Theophanous, Anand Singh Ghattaura, Elaine Miller, Roanna Maharaj
- 17 August 2014 – Birmingham Eid Mela *Elaine Miller*
- 25 August 2014 – Leicester Belgrave Mela *Elaine Miller*
- 31 August 2014 – London Mela, Gunnersbury Park Ealing Anand Singh Ghattaura, Tina Bhagirath
- 6-7 September 2014 – (in association with the British Sikh Doctors Organisation) Sant Isher Salana Barsi Samagam, Ruislip Anand Singh Ghattaura
- 26 September 2014 – NHSBT Birmingham blood donor awards *Elaine Miller*
- 1 October 2014 – UKFHD Academic Conference London Anand Singh Ghattaura, Katerina Loizi-Read
- 11 October 2014 – Manchester Diwali Mela *Elaine Miller*



**Help us to help you by supporting YOUR Society  
– every £1 is precious!**

**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 \_\_\_\_\_