UKTS Closes 30th Anniversary Year in Style

The final event of 2006, our 30-year anniversary, was our annual dinner dance on 25th November, held for the third year running at The Brewery in Chiswell Street, London EC1. The dinner dance is always a huge undertaking; and in this extra-special year we were determined to pull out all the stops to ensure that the occasion was truly memorable. Carrying on with the 30-year tradition, we had a “pearl” colour scheme for the evening and the room looked truly glamorous once it had been decorated – again thanks to the contributions of our friends Koulla Horatta of The Wedding Lounge (www.theweddinglounge.com – chair covers) and Helen Savva of Burgéon Floral Design (helen@burgeon.co.uk – flowers). A champagne reception greeted the guests before dinner, after which our President Mike Michael welcomed everyone; including our distinguished guests Prof Bernadette Modell (who was so instrumental in the founding of the Society) our Patron Peter Polycarpou and from overseas Mr Mian Atiq-ur-Rehman, President of the Welfare Hand Organisation which does so much to help children with thalassaemia in Pakistan.

After dinner the evening really started to warm up with the music of the band Spartacus, assisted by singer Maria Triantafillou. Needless to say, we also wanted to take the opportunity to raise some much-needed cash; and our volunteers were busily selling raffle tickets. Some of our readers will have taken part in our postal raffle and we thank all of you who bought tickets and congratulate the winners (please see page 3 for a list of the prizes and winning numbers). We also held an auction and here our Patron Peter Polycarpou came into his own as auctioneer, keeping the crowd laughing as he raised a fantastic £2,900. The biggest selling item was 2 concert tickets generously contributed by another Patron, George Michael, which raised £1,000.

By this time the dance floor was packed and the bar staff were at full stretch; but we had another great surprise in store – singer Antony Costa (of chart-topping band Blue) arrived fresh from his stage appearance in Blood Brothers at the Phoenix Theatre; and proceeded to bring the house down by performing one classic song after another. What remained of the evening flew by; and at one a.m. we could hardly believe that the event was over for another year. We have since had very positive feedback with many saying it was the best dinner dance they could remember. Thanks to all our wonderful friends who contributed goods or services or donated prizes – and a special big thank you to our members Maria Couppas, Koulla Kanias and Mary Zembylas for their help. Last but not least thank you to

Continues on page 3 ➡
A word from our President

Mike with wife Aggie at the dinner dance.

For a change (and to give Mike a rest!) we decided to print the speech which he gave at the dinner dance!

Good Evening Ladies and Gentleman, Honored Guests, welcome to the UKTS 30th anniversary dinner and dance.

Throughout history the Greeks have given the world many things, amongst them, democracy, the Olympics, the Mini and probably thalassaemia. In fact the oldest thalassaemic skeleton in Cyprus was of a child who lived about 6300 BC in Paphos. Since then the gene has traveled through history and around the world and in some case sitting silently as a carrier in people like Pete Sampras and Zinedine Zidane. Today, globally, there are approx 80 million carriers and 60 – 70,000 births per year.

In 1976 a young doctor persuaded a group of parents to form a society that would help their loved ones suffering from thalassaemia. This newly formed society faced several major challenges, the biggest of which was education and ignorance. This society like a thalassaemic child has grown. It has survived its troubled early teenage years and grown into a mature organization that represents the needs of patients suffering from thalassaemia.

The reasons our society was started 30 years ago and still hold true today and everything that has been achieved is due to the hard work of dedicated people that have given and, I hope, continue to give their time and expertise freely. Our society and a dedicated band of doctors, nurses and support staff have helped many a thalassaemic from where they were to where they are now, be it from:

- The Syringe Driver (pump).
- An oral chelator
- Furnishing of thalassaemia units
- Research – In growth, reproduction, screening and treatment
- Constant education within the communities

In 30 short years thalassaemics and the families of thalassaemics have come from:

- Hopelessness and despair
- Of no life or future

To a present where they have:

- The availability of 3 different chelators (to the envy of both the first and third world)
- a holistic treatment approach
- The ability to be the same as their non thal brothers and sisters. This year another barrier was torn down. This year we had a thalassaemic run the London marathon
- And for the first time quality as well as quantity of life.

The past has seen us contribute to the development of:

- The Syringe Driver (pump).
- An oral chelator
- Furnishing of thalassaemia units
- Research – In growth, reproduction, screening and treatment
- Constant education within the communities

The relief of persons suffering from thalassaemia.

The promotion and co-ordination of research in connection with thalassaemia.

To educate people on the problems of thalassaemia.

To offer counselling to sufferers and carriers.

To bring together patients, their families and well-wishers to exchange ideas and information.

To raise by any legal means the funds required for the above activities.

Good evening.

I close with a hope. I hope that in 30 years from now clinicians will be able to say "take two of these before bed and call me in the morning if you still feel thalassaemic".

Thank you.

Mike Michael
President, UK Thalassaemia Society
everyone who bought tickets for the dance or took part in the raffle.

**Winning Raffle Numbers**

**1st Prize**

A week’s holiday for 2 people (inc flights) at the exclusive, 5 star Intercontinental Aphrodite Hills Resort Hotel, Paphos, Cyprus (donated by Olympic Holidays)

**2nd Prize**

7 nights (accommodation only) for 2 at the Kapetanios Bay Hotel, Protaras, Cyprus (donated by Broadway Travel)

**3rd Prize**

1 business class return ticket from London Gatwick to any destination on their European network (donated by Malev Hungarian Airlines)

**4th Prize**

1 return flight to Athens (donated by Olympic Airlines)

**5th Prize**

1 return flight to Cyprus (donated by Cyprus Airways)

**6th Prize**

A Harrods hamper (donated by the Alayed Charitable Foundation)

**7th Prize**

A weekend for 2 in Norfolk (donated by the Russet House Hotel)

**8th Prize**

£100 gift vouchers (donated by Marks & Spencer Marble Arch)
UKTS Patron George Michael thanks NHS nurses

The end of 2006 saw our Patron, George Michael, finish off his best-selling “greatest hits” tour with a special free concert for NHS nurses at the Roundhouse Theatre in Camden on 20th December. George performed a selection of hit songs from his 25-year career to a specially invited audience of 2000 nurses. George, who lost his mother to cancer in 1996, staged the concert as a special “thank you” for the work done by nurses. “The nurses that helped my family at that time were incredible people and I realised just how undervalued these amazing people are,” wrote George on his website.

Some comments from nurses who attended –

“I had the time of my life. It was such a vibrant atmosphere. I thank George Michael for making us feel appreciated. We were all so touched by the comments he made. I am glad the work we do has not gone unnoticed.”
Rajani Kendrick, London

“A fantastic performance and atmosphere. So generous of George Michael. We really appreciated his actions, comments and generosity.”
Kate Laycock, Shrewsbury

Robonurse ????

In January 2007 I was (as usual) looking through the health section of Google news when I came across an item which brought a wry smile to my face. Apparently the EU are funding – to the tune of £2.5 million - a project which could have “robot nurses” on the wards to clean, tidy and even look after patients “within 3 years”! The project, called IWARD and being led by scientists at the Fraunhofer Institute in Germany, aims to produce robots which will help to keep wards clean and perform tasks like checking temperatures, blood pressures and handing out medicines.

Oh really? Any of our readers similar in age to me may remember a TV programme called Tomorrows World. I distinctly remember the presenters of this programme telling us with blithe assurance that by the 21st century we would no longer have to waste time on housework because robots would be doing it all for us. Needless to say no such thing has materialised and I’m very bitter about it. In fact every time I get out my ironing board I feel a sense of crushing disillusionment thanks to the lost hopes raised so long ago by Maggie Philbin et al. This being the case, I don’t think I’ll get too excited just yet about the prospect of having my blood pressure taken by Arnold Schwarzenegger in a frilly white cap. Call me crazy, but until robots are sorting my laundry I won’t believe they can sort out the staffing problems of the NHS.

Elaine Miller
UKTS Works with Screening Programme to Develop Public Outreach

UKTS is working closely with the NHS Sickle Cell and Thalassaemia Screening Programme to develop a public outreach programme.

The programme has two key goals. The first is to reach out to at risk communities to raise awareness of the conditions; the care available; the screening process and the choices within it; and some of the wider ethical and cultural issues.

The second aim is to explore different models of outreach to see what works most effectively so that good practice can be rolled out across the country.

Before embarking on the project, the Screening Programme commissioned research to identify health promotion agencies which already had strong networks within relevant communities. Liz Aram, Communications Consultant for the Programme comments, “It is vital that sensitive messages such as ours are delivered by people who are respected and trusted by local communities. Then the interventions are based on a grass roots understanding of what people need, and can be delivered in the right languages, in the right places and at the right level of detail.”

The research identified three agencies to deliver projects in Tower Hamlets, Manchester and Southwark. These will be run as pilots throughout 2007. It is hoped that the learning from these areas will inform other work around the country.

In Tower Hamlets, the Programme will work with Social Action for Health (SAfH) to target the Bengali community. The project will use an existing network of “health guides” who talk to a variety of local groups about a range of health issues. The guides will be trained to talk about thalassaemia, to offer information, encourage discussion and debate and obtain feedback from local people about their knowledge, views and needs. A similar project in Manchester will work with outreach workers employed by the Black Health Agency to reach out to the Pakistani community.

In Southwark, the Programme intends to work with Wo-manbeing Concern to target the black African community. The project will develop a drama on DVD and this will be disseminated via a network of specialist health promotion agencies.

UKTS will play an important role in the project in areas such as developing the training and information resources for the agencies, sourcing patients who can speak about their experiences of thalassaemia and screening and offering advice and networking. Members of UKTS who would be interested to support the project and/or to contribute personal accounts of living with thalassaemia or screening choices should contact Elaine Miller at the UKTS office.

The First Independent Cypriot Film Festival

The first Independent Cypriot Film Festival was held at the Phoenix Cinema, North London, on 11th December 2006. Among the organisers was UKTS Patron Peter Polycarpou, who said; “This wonderful event brought both sides of the Turkish and Greek Cypriot community together through moving image and the arts.” Among the films screened were Peter’s own production “Mad George” and “Rifts” by acclaimed young director Vicki Psarias. After the films there was a reading from the book “The Cypriot” by novelist Andreas Koumi. A raffle was held in aid of charity from which a donation of £110 was made to UKTS. Committee member Katerina Read and Coordinator Elaine Miller attended the event on behalf of UKTS.
North of England Bone Marrow & Thalassaemia Association
Ninth Annual Conference

Summary
The conference began with welcomes from both the Chairperson and Vice-Chair, Dr. Kate Ryan and Zanib Rasul respectively. The programme of speakers addressed a mixed audience of Thalassaemic patients, their families and some care professionals. As such, the new information offered was extremely useful in bettering their treatment handling and understanding.

In previous years we have hosted workshops to discuss different areas, which have been very successful, but this year the format followed that of talks from our guest speakers in the morning, followed by opportunities to ask questions, as well as a panel made up of speakers and some experienced patients, after lunch. Dr. Malcolm Walker, Consultant Cardiologist at University College Hospital, London, kicked off the lecture section of the programme, with a thorough but accessible talk about the effects of Thalassaemia and its treatment on the heart. He outlined the clinical examinations and tests carried out on Thalassaemia patients suspected of heart problems, as well as stressing the absolute importance of early treatment, with the support of case studies. Dr. Walker added a new dimension to the programme, as the conferences usually concentrate on Bone Marrow Transplant, Iron Chelation and Blood administration. He was ardent in his warnings that heart problems caught early on can be eliminated, and that great care should be taken in treating Thalassaemia patients, with consideration of their treatment.

Following the overall theme of living with Thalassaemia, Nazi Arfin, Diabetes specialist from the Manchester Diabetes Centre, delivered a presentation on the dangers of Diabetes, and the importance of a balanced diet, to complement a healthy lifestyle.

Yameen Rasul presented feedback from the Patients’ Point of View Forum held at Center Parcs in July 2006, where there was much discussion on the then unlicensed drug, Exjade. With one of NEBATA’s aims in mind, of ensuring free access to information on Thalassaemia and its treatment, the forum presented patients’ own experiences of the main iron Chelation drugs, Exjade and Deferiprone, giving real life experiences to answer concerns regarding the treatments. The informal setting of the forum allowed participants to discuss new issues comfortably, which can now be addressed through NEBATA’s work.

We very much enjoyed a brief talk from new father and Thalassaemia patient himself, Tanver Khan, who spoke of his triumph in reducing his iron levels enough to be able to start a family, with the help of IVF treatment. His story was one of encouragement for any Thalassaemic patient.

The presentation section was concluded by Dr. Farrukh Shah, Consultant Haematologist at Whittington Hospital, London, followed giving an update on iron Chelation therapy, with special emphasis on the newly-licensed Exjade. The views of an impartial physician allowed patients and their families to make informed opinions on the treatment available, and whether they might like to try this new drug, as well as understanding on a deeper level, the effects of the drug, from a medical side. Although we appreciate the input from drug companies that kindly support us in our work, we strongly believe that information on treatment should be given freely to patients. She mentioned leading analyses on the subject of iron Chelation, including that of Dudley Pennell. It is with the bank of knowledge and experience that NEBATA has, from patients, families and care professionals that we try to provide the best care and information for Thalassaemia sufferers.

The day was rounded up with a panel made up of Tanver Khan, Dr. Kate Ryan, Dr. Andrew Will, and Dr. Farrukh Shah. Chaired by Yameen Rasul, the audience were invited to write down questions to be put to the panel. There was a range of topics covered, and without the pressure of standing up and speaking in front of a large audience, participants felt free to ask about anything.

Overall, we are very pleased to report that this year’s conference was a success, and from the evaluation forms filled in by delegates, there was a high level of satisfaction with the topics covered and the format that the day took.
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Gene Therapy for Thalassaemia: An Update

Dr Michael Antoniou,
Nuclear Biology Group, Department of Medical and Molecular Genetics,
King’s College London School of Medicine, Guy’s Hospital, London.

As some of you may recall, at the 2005 UKTS AGM I gave a presentation detailing advances towards a gene therapy cure of thalassaemia. I described how the invention of a new “lentivirus” gene delivery vector system had at long last provided the means by which a -globin gene unit capable of functioning sufficiently well to be of consistent therapeutic value, could in principal be efficiently delivered to bone marrow stem cells of a person with thalassaemia, with potential life-long cure. This is all very exciting stuff given many years of frustration in knowing what we needed to deliver in terms of -globin therapy gene unit but not having the technology to do so!

The European Society for Gene and Cell Therapy (http://www.esgt.org) held its annual meeting last year in Athens, Greece (9-12th November, 2006). Given the obvious local interest, it was not surprising that the conference organisers devoted a session entirely to gene therapy for thalassaemia. By way of updating you all on progress made since the presentation I gave at the AGM a couple of years ago, I now summarise the main points raised by the speakers at this session.

There were four main speakers, representing all the key groups involved in thalassaemia gene therapy research; Prof Michel Sadelain (Memorial Sloan-Kettering Cancer Center, New York, USA), Prof Puman Malik (Childrens Hospital Los Angeles, Los Angeles, California, USA), Prof Philippe Leboulch (Genetix Pharmaceuticals, Cambridge, Massachusetts, USA) and Prof Giuliana Ferrari [Telethon Institute for Gene Therapy (TIGET), Milan, Italy]. The session was chaired by Prof George Stamatoyannopoulos (University of Washington, Seattle, USA). All speakers presented their work involving the use of their version of a lentivirus gene delivery vector containing a -globin therapy gene unit. The design of the -globin therapy gene unit was similar in all cases with elements of the locus control region (LCR) master regulator linked to a mini- -globin gene. However, I will restrict my comments to those that had something significantly new to say!

Fittingly, the first to speak was Prof Sadelain who pioneered the development of globin gene therapy lentivirus vectors. He did not have any new data to present with respect to further developments of this system for thalassaemia but did show recent advances of great relevance to gene therapy for sickle cell disease. Prof Sadelain has developed an ingenious approach where the globin gene therapy lentivirus vector also possesses the ability to destroy the product of the sickle cell mutant b-globin gene (by a process known as RNAi), giving a more efficacious therapeutic effect as witnessed in animal models of this disease. Prof Sadelain also focused on speculating as to what might be the best and safest (least invasive or debilitating) approach to administering the gene therapy. Just to remind you, it is generally agreed that at present the only option we have to delivering the gene therapy is via what is known as an “ex vivo” approach. This is where bone marrow stem cells are removed from the patient, grown in the laboratory and genetically corrected with the globin-lentivirus gene therapy vector and then injected back into the patient where they originally came from. The corrected stem cells find their way back to the bone marrow where they re-establish themselves and now start producing normal rather than thalassaemic red blood cells. Bearing this ex vivo procedure in mind, Prof Sadelain posed questions as to whether it would be best to either obtain blood stem cells straight from bone marrow or first mobilising them into the circulation by administering a certain cell growth factor (known as “GM-CSF”) and...
then harvesting them from the blood. He also discussed the important question regarding what is known as “conditioning” of the person being treated. This is similar to what happens in a bone marrow transplant situation. In order to prepare the patient to receive the bone marrow graft from the donor, they must first have their own diseased bone marrow destroyed by chemotherapy. Then the normal bone marrow from the donor will establish itself in the vacated space without any competition. Similarly, it is generally accepted that in a thalassaemia gene therapy context, once sufficient bone marrow cells have been removed for correction by the ex vivo procedure, the remaining diseased bone marrow in the patient needs to be destroyed. The question is, how much needs to be destroyed? Should it be completely destroyed with high dose chemotherapy (as in a donor bone marrow transplant) with all the toxicity risks that this entails? Or, should it be only partially destroyed with a safer lower dose of chemotherapy with the risk that this may not destroy enough of the remaining large quantities of diseased bone marrow, which may then out-compete the corrected bone marrow stem cells once they are returned to the patient leading to a treatment failure? I do not believe there are definitive answers to these important clinical questions at present, as we don’t have sufficient information to provide them. But these were definitely very important issues to raise for consideration. During discussions Prof Sadelain did say that based on the very encouraging results he has obtained in animal models, he had submitted an application to conduct a gene therapy clinical trial for thalassaemia to the authorities in the USA about 2 years ago but that he was still negotiating with them! Clearly, the US authorities are taking, quite justifiably, a very cautionary approach. The ex vivo gene therapy protocol in combination with chemotherapy conditioning is going to be quite a stressful and demanding procedure to go through. Given these significant safety concerns, one needs to be sure that the treatment will work before committing the patient to such a trial.

Prof Giuliana Ferrari described work using a globin-lentivirus gene delivery vector designed and built in my own laboratory and was the newest set of research data presented. The design of this globin-lentivirus vector was based in part upon work funded in my group by UKTS some years ago. The testing of the vector has been done in Prof Ferrari’s laboratory with support from the Italian Telethon organisation. The main difference between our lentivirus vector and those of others is that it possesses a more compact version of the locus control region master gene regulator as well as mini-α-globin therapy gene. Prof Ferrari presented data that clearly shows that despite its simpler design and smaller size, our version of the globin lentivirus therapy vector can cure thalassaemia in mouse models of this disease as efficiently as the larger versions of globin lentivirus vectors developed by all other groups. In addition, Prof Ferrari’s

Continues on page 10 ➡
data in the mouse model of thalassaemia suggest that the bone marrow parent cells that ultimately give rise to red blood cells and which have been corrected by this gene therapy, have a survival advantage over those that failed to take up the therapy gene. This is encouraging in that it suggests the possibility that correcting relatively few bone marrow stem cells of thalassaemic patients may be sufficient to achieve a therapeutic effect at least in thalassaemia intermedia. In addition, Prof Ferrari’s group in collaboration with Prof Guido Lucarelli (Rome, Italy) has obtained large numbers of bone marrow stem cell samples from patients with various types of -thalassaemia (both major and intermedia). Prof Ferrari’s group has shown under laboratory conditions that treatment of these human bone marrow stem cell samples with our compact globin lentivirus vector can completely and reproducibly correct their -thalassaemia defect. This is the most extensive study of its type and again bodes well for future use in gene therapy in patients. Furthermore, the overall smaller size of our globin lentivirus vector gives it two additional advantages over larger versions, (i) it makes it a lot easier to manufacture, a not insignificant consideration when you are thinking of scaling up production for clinical trials and (ii), it leaves more “space” in the vector to incorporate additional genetic units that may increase its efficiency still further.

The person that we were all waiting to hear was the final speaker, Prof Philippe Leboulch. Unlike the cautionary approach taken by the authorities in the USA, the government in France took a different view and approved an application by Prof Leboulch to carry out a gene therapy clinical trial with -thalassaemia and sickle cell disease patients at a hospital in Paris. So as you can imagine we were all eager to hear how the trials were being conducted and how things were progressing. The trials started last year and will involve treating 5 -thalassaemia and 5 sickle cell disease patients within the age range of 5-35 years. The treatment being administered is, as expected, a standard ex vivo procedure as I’ve described, where bone marrow stem cells are isolated from the patients and genetically modified with his version of the globin lentivirus gene delivery vector. However, patients also receive a full chemotherapy-conditioning programme with Busulfex to destroy their diseased bone marrow (very similar to those receiving a bone marrow transplant), before their genetically corrected stem cells are returned to them. In addition, again similarly to what happens in a bone marrow transplant from a donor, some of the bone marrow harvested from the patient is stored without further treatment so that it can be returned to the patient in case the gene therapy treated transplant fails and complications arise. Prof Leboulch reported that up to the time of the conference two people with -thalassaemia had been treated, one in May and the other in September 2006. It is clearly early days in this trial and Prof Leboulch gave no information as to whether there were any signs if the gene therapy was working or not. However, in the first patient treated the number of copies of the globin lentivirus therapy vector delivered to each cell was apparently 3, which is rather high. The reason why this is a concern is that the globin lentivirus therapy vector randomly splices itself into the DNA of the bone marrow cells, which raises the possibility that this insertion may disrupt normal gene function with negative side effects such as cell death at one extreme and cancer at the other. Obviously the more copies of the globin lentivirus therapy vector you insert into the cells the more chances there are of host gene function being disturbed and things going wrong. So there is a safety issue connected with having so many copies of the therapy vector in the bone marrow cells of this patient.

In addition, the first patient also developed complications 27 days after treatment, which necessitated some of their untreated back-up bone marrow to be given to them; they recovered soon after this. Prof Leboulch’s presentation resulted in a great deal of lively discussion! Some of audience were particularly concerned about the fact that full chemotherapy conditioning had been administered to the patients as part of the trial protocol. The rigours and risks of full chemotherapy conditioning is justified in a bone marrow transplant from a donor situation because we are now very good at this procedure and have a greater than 90% success rate, particularly with young patients (17 years old or younger) who are in a good state of health (well transfused and chelated). I believe that the misgivings of some of the scientists present at the meeting about the full chemotherapy conditioning component of the trial stems from the fact that the data to date from both animal model studies and bone marrow gene therapy trials for other diseases suggest that it is unlikely that the gene therapy technology as it stands will be as effective as a regular bone marrow transplant from a donor.

So, although on the one hand it is exciting that a clinical trial for thalassaemia had finally begun, on the other hand there were many at the meeting who thought that it is premature. My personal view, and I know some in the field will disagree with me on this, is that the currently available lentivirus gene delivery vector systems are still not quite good enough and that there are still too many other unanswered important biological questions to press ahead with thalassaemia/sickle cells disease gene therapy trials at present. Firstly, we still need to get our globin lentivirus gene delivery vectors working more effectively and with a higher safety profile. Secondly, we need to be sure that we are efficiently delivering our globin lentivirus therapy vector to the true bone marrow stem cells, which can provide the effective and life-long cure that we are after. After all it is always important to remember that thalassaemia (and sickle cell disease) are not fatal conditions. Thalassaemia can be treated successfully with transfusions, which with the recent availability of oral iron chelators should make it a much more tolerable procedure. In addition, if you are fortunate enough to have a matched donor, thalassaemia and sickle cell disease can be cured with a bone marrow transplant. Given these well-established alternatives I believe we need to be much more sure that a very demanding gene therapy procedure is going to work for thalassaemia and sickle cell disease than, for example, blood diseases (e.g. immune deficiency disorders) for which alternative treatments are simply far from ideal or not available and which result in a poor quality of life and death at an early age. I would be interested to hear your views!
Japan – a combination of old and new, streets are spotlessly clean, the people courteous, that’s why I always pick Japan for my holidays, especially Hokkaido. This is my second trip to Hokkaido. The first time I visited was in winter, the snow was thick on the ground; all I could see was a world of silvery white. This time I picked autumn to visit, and can see the city streets in its originality, leaves in shades of red, yellow and green, it’s like a natural symphony.

There are 2 things I found quite intriguing:

Most hotel guests will wear the bathrobe provided by the hot springs hotel to dine at the hotel’s restaurant, giving a very homely atmosphere. However, the overlapping directions of the bathrobe must be correct, as the opposing direction is being identified as dressed on dead bodies, which will shock and scare the others.

Perishables in Japan are mostly marked by using the founding year for Japan instead of the usual AD. Some places of interest will have blackboards that inform visitors of the place name and Japanese date that day, which makes it very helpful for tourists like me who simply love shopping.

Due to the geographical location of Taiwan, snow only falls on high mountains. During snow season, one need to travel long distances, sit through hours of traffic jams, thus able to behold the beauty of snow scenes. Snow in Taiwan is far-away and expensive. I love snow, though I will need to wear layers of thick fleece, a beanie and gloves – looking like a polar bear; but I love to tell my dear friends: watch out for the polar bear!

Travelling has become a very important aspect of my life style. I look forward to my next trip, which I believe will be quite soon.

Hokkaido is the second largest, northernmost and least developed of Japan’s four main islands.

Hokkaido’s weather is harsh in winter with lots of snowfall, below zero temperatures and frozen seas, while in summer, it does not get as hot and humid as in the other parts of the country.

With its unspoiled nature, Hokkaido attracts many outdoor lovers, including skiers and snowboarders in the colder seasons and hikers, cyclists and campers from June to September.

This travel article was written by Shannon Lee YaLi, a patient from Taiwan. Born in 1973, she currently works as a civil servant in charge of managing a government department’s website.
Vava Tsioupra – meet the newest member of our team

I am the son of Greek Cypriot immigrants, both from Komi Kebir, which is now in the occupied North of the island. I was born and brought up in Finsbury Park in a working class family. From an early age I was interested in audio engineering and electronics, having helped a friend of the family setting up equipment for shows in London. This eventually led me to a degree in electronics, after which I worked as an audio engineer in both studios and live sound. I had the chance to ‘play’ with the best audio equipment in the world and work for many talented, well known artists. This was a great deal of fun, but I knew that it was not an easy life for older engineers, with late nights and awkward working hours. I was lucky enough to be able to begin working on the management side of the organisation I was at and after a short period I decided to try looking at furthering my career in this area. I eventually went ‘back to school’ and finished a part time MBA. It gave me immense satisfaction, as all the work was done whilst keeping a job going. During this time, I did exactly what the course tutor said not to do, change job, get married or move, somehow I managed all three!

Around this time, I met my wife Elena and we began our lives together. At the same time, I moved jobs, to begin working for my brother, with whom I eventually became partner. Elena and I now have two girls of 7 and 4. Apart from my brother Louis, I also have a sister, Katia, a great brother and sister in-law and lots of lovely nieces and nephews. My Mum is still with us, but Dad passed away a few years ago. The ‘old dear’ is my version of the godfathers ‘consiglieri’, she is the one who tells me ‘the way things are’, no holds barred! Elena, me and the kids regularly attend our local church and are practising Christians. I think practising is a really good word, but not the way it is meant, as I don’t think I will ever get it quite right!

I was pretty unaware of thalassaemia until working for my brother, when I first met the lovely (UKTS member) Maria Couppas. Maria and I worked together and became good mates. I slowly became aware of the harsh realities of living with thal. The nights at the hospital for transfusions, the ups and downs of living with a long term illness and the amazing willingness to get on with it, made me feel a bit pathetic about my own worries, if the truth be told.

I also had thal force its way into my own life. When our first child was born, the doctors told us she might have thal. The questions began, who carried it - on whose side, etc, etc. In our case, we were lucky enough to just have a scare, but this very personal ‘brush’ certainly left its mark.

My business now is to provide promotional products and business gifts to a very wide range of clients, from small local companies, to large blue chips. This was how I came into contact with the UKTS, when I began working with Costas Kountourou, on a number of projects. Our company, Ellenhel, supplied bags, folders, organisers, pens and lots of other products, over a period of time. It was always a pleasure to work with Cos, even though everything I did for the UKTS was last minute (some things never change!) . I really tried to make sure that the society got the best deal and service at all times. I think Cos realised that I always was happy to go that extra yard, so he thought he would take a mile! After getting me to sell tickets for the dinner and dance, he worked on me to get involved further and I decided to get involved on the committee. Wanting to get involved was not really a hard choice, after seeing the brilliant work the UKTS does, but how much help it needs. The hard bit was thinking about the time involved. In the end I ‘jumped’ and although there never seems to be an end, you can’t help but want to continue, mainly because of the good work being done, but also by seeing the dedication of the staff and committee members. It makes it really hard to think of walking away.

My main impressions of my first year, are incredulity at how such a small number of people can get so much done, but also at the amazing generosity of spirit and time coming from so many people of all different kinds, all willing to ‘do their bit’ small or large. From donations to cakes, to offers of help just lifting things and licking stamps. I have been fortunate to meet many wonderful people this year and I look forward to meeting even more next year. Sorry to end on a slightly lower note – BUT – I have also been amazed to see that there are still many people who do not get the care that they deserve and that is where the focus must always be. There are still lots of people who need help in so many ways. So we must continue working to fresh goals. If you think you can help even in a small way, get in touch and we will find you something to do!
Sheniz Osman and Chelsea FC – top of the fundraising league

Once again we say a heartfelt thank you to Sheniz Osman, who works in the Corporate Sales Dept of Chelsea FC. Sheniz, whose brother Remis has thalassaemia, asked the club to raise money for UKTS at one of their regular home match day charity raffles as they did last season. The raffle took place at Stamford Bridge on Saturday 13th December 2006 when Chelsea played Newcastle, and raised a magnificent £4,115! Sheniz and Remis visited our office on 16th January 2007 to present the cheque.

Here we see (L to R) Remis, Mike our President, Sheniz and Costas our Secretary. Our grateful thanks to Chelsea FC and the Osman family – and our sincere congratulations to Sheniz who is going to be married this summer.

In memory of Mrs Kyriadou Christodoulou

We were very grateful to receive a donation of £490.50 from Mrs Panayiota Karpasitis; collected in loving memory of her late mother Mrs Kyriadou Christodoulou, who sadly passed away on 24th November 2006. Mrs Christodoulou had requested that her friends and family should donate money to charity instead of sending flowers to her funeral. We thank them for their generosity at this very sad time.

UK Thalassaemia Society Annual General Meeting

Sunday 15th April 2007

We are pleased to announce to our members that this year’s AGM will take place at 3pm on **Sunday 15th April 2007**. The meeting will be held at:

**The Drawing Room, Avenue House**
**17 East End Road, London N3 3QE**
**Tel. 020 8346 7812**

All paid-up members of UKTS are eligible to attend the AGM and can vote in the business being transacted. The agenda will include the following:

- A report on the activities of the past year by the President
- A report on the audited accounts of the Society by the Treasurer
- Consideration of any applications for membership/nominations to the Management Committee that may have been rejected
- Election of the Management Committee of the Society
- Any other relevant business

PLUS A PRESENTATION ON THE NEW ORAL CHELATOR EXJADE BY PROFESSOR JOHN PORTER OF UNIVERSITY COLLEGE OF LONDON

At this time members are invited to make nominations to the Management Committee for the year commencing 15th April 2007. Inside this issue of TM you will find a letter giving full details of the nomination procedure and the appropriate form. **PLEASE NOTE THAT ALL NOMINATIONS MUST BE RECEIVED BY THE UKTS OFFICE BY 31ST MARCH 2007.**
A Tribute to Mr Tony Lee

A celebration of the life of Mr Tony Lee (26.10.44 – 15.8.06) was held on 24th November 2006, at Walthamstow Assembly Hall, London E17. A lifelong community worker, Mr Lee was honoured by a civic award in 2003 for his work promoting music and dance for the young people of Waltham Forest. Many of the youngsters who had benefited from his work performed at the event; where UKTS was represented by Ms Nina Demetriou. A collection was taken and a donation of over £215 was presented to the UK Thalassaemia Society in memory of Mr Lee, who was a thalassaemia carrier. We are very grateful to Mr Lee’s family and friends and especially to his widow Marlene Fielding.

Brave and beautiful Harleen jumps for UKTS

Many thanks to intrepid young UKTS supporter Harleen Hayer, who carried out a parachute jump in aid of the Society on 25th November 2006. She raised a total of £1,300, a magnificent effort! Says Harleen, pictured here, “It was an amazing experience, I would thoroughly recommend it!”

The UKTS Personal Organiser

• Are you a thalassaemia patient/parent of a thalassaemic child?
• Do you have the UKTS specially designed personal organiser for thalassaemia patients?
If not why not – all it takes is a call to our office.
This valuable aid to keeping your own patient – held medical record is FREE to patients and parents/carers of children with thalassaemia.

Call 0208 882 0011 to order your copy now!

Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK

How does your treatment compare?

This new publication is available from our office on request for healthcare professionals and thalassaemia patients living in the UK. Now available to download free from the UKTS website.

Contact our office on 020 8882 0011 or email office@ukts.org.
UKTS thanks the Bank of Cyprus

Instead of sending Christmas cards the Bank of Cyprus donated money to charity in January. Here we see UKTS Vice-President Chris Sotirelis being presented with a cheque for £600 by the Customer Service Manager of our local Southgate branch, Maria Sparsi. Many thanks to the Bank of Cyprus for their continuing and greatly valued support.

DONATIONS

Our most grateful thanks to all our donors for their generosity.

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UKTS Welcomes NEW-MEMBERS

**Annual**
- Ms Sarchia A Smithson

**Life**
- Ms Sheniz Osman

British Society for Haematology 47th Annual Scientific Meeting

30 April – 2 May 2007
BIC, Bournemouth

For further information please visit
www.b-s-h.org.uk

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The views expressed are not necessarily that of the Society.
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: _____________________________________________
Postal 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

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

Type of thalassaemia: (e.g. Major, Intermedia, Haemoglobin H etc) ____________________________
Hospital where-treated: ____________________________
Address: _____________________________________________
Telephone: ____________________________

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

OFFICE USE: Date Paid ____________________________ Receipt No ____________________________ Approval Date ____________________________