All Party Parliamentary Group on Sickle Cell Disease and Thalassaemia starts work

David Burrowes MP, Secretary of the APPG, is UKTS’s local constituency MP. David has demonstrated his support of the Society and thalassaemia patients in Parliament following meetings with UKTS. David has also tabled a House of Commons adjournment debate on thalassaemia care with Parliamentary Under Secretary for Health Services Ann Keen of 4th February 2009.

The All Party Parliamentary Group (APPG) on Sickle Cell Disease and Thalassaemia held its first meeting in Westminster on 9th December 2008. This newly formed group of 20 MPs and peers was set up with the cooperation of UKTS and the Sickle Cell Society. The mission statement of the group is, “to reduce the health inequalities that are faced by sickle cell and thalassaemia patients in the UK by improving standards of care and by addressing other critical issues, as recommended by the key stakeholders. Members will achieve this aim by engaging with parliamentary colleagues, the government, health professionals and community and patient groups to raise awareness relating to the conditions and needs of patients.” UKTS was represented at this first meeting by Vice-President Dr Christos Sotirelis and Coordinator Elaine Miller.

Following the government’s recent move to make cancer patients exempt from prescription charges, the group agreed that thalassaemia and sickle cell must be included when the government’s review of prescription charges (led by Professor Ian Gilmore, President of the Royal College of Physicians) takes place in March 2009. Diane Abbott MP, Chair of the APPG, said; “It is shocking that people suffering from sickle cell disease and thalassaemia have to pay for prescriptions. Health professionals tell us that the average sickle cell patient needs up to six prescriptions a month, with thalassaemia patients needing up to eight prescriptions per month. With annual costs of up to £686, this could mean some patients are unable to purchase the treatments that are essential to keep symptoms under control. It is unfair that these charges put further pressure on people who are already living with a debilitating disease.” This view was echoed by UKTS Vice-President Chris Sotirelis who stated; “Until recently, thalassaemia patients did not survive past childhood. While medicine has advanced to ensure that thalassaemia patients live well into adulthood, the charges for prescriptions are outdated. Patients with thalassaemia face many challenges, but paying for their prescriptions should not be one of them.”

Below is a list of all the MPs and peers who are currently members of the APPG. Is your MP among them? If not, why not write to your MP and ask him/her to join the group – the more awareness we can generate among members of Parliament the better. Alphabetical order –
• Diane Abbott (Chair), Lab, Hackney North & Stoke Newington
• David Amess, Con, Southend West
• Celia Barlow, Lab, Hove
• Tim Boswell (Treasurer), Con, Daventry
• Lyn Brown, Lab, West Ham
• David Burrowes (Secretary), Con, Enfield Southgate
• Dawn Butler, Lab, Brent South
• Lynne Featherstone, Lib Dem, Hornsey & Wood Green
• Baroness Flather, Crossbench
• Kelvin Hopkins, Lab, Luton North
• Baroness Howells of St David’s, Labour
• Sadiq Khan, Lab, Tooting
• Norman Lamb, Lib Dem, North Norfolk
• Fiona MacTaggart (Secretary), Lab, Slough
• Khaid Mahmood, Lab, Birmingham Perry Barr
• Andrew Rosindell (Vice-Chair), Con, Romford
• Lee Scott, Con, Ilford North
• Lord Smith of Clifton, Lib Dem
• Sarah Teather (Vice-Chair), Lib Dem, Brent East
• Emily Thornberry, Lab, Islington South & Finsbury

Remember – your MP gets paid to work for you! If you have any issues about services in your area, why not write to your MP and get his/her support? Want to know how to contact your MP or get help in writing a letter? Contact Elaine Miller at the UKTS office 020 8882 0011 or elaine@ukts.org.

Political Intelligence is paid by Novartis Pharmaceuticals UK Ltd to run the group’s secretariat.
Dear Members,

Welcome to the first newsletter of 2009.

Just before Christmas, a good friend of mine became a member of a very exclusive club. While this club doesn’t provide roadside assistance or frequent flyer miles it does prove that against all odds and with a bit of luck anything can be achieved.

With each year that passes the 40 year old thalassaemic club opens its doors to new members. In fact some of the original club members have become so frustrated that they can’t find a seat in the club room that they’ve opened up a new area and started the 50 year old thalassaemic club. At this moment in time the three founding members of the over 50’s club have got the fireplace to themselves, however I say this to Mr. C, Mr. C and Mr. G enjoy it while it lasts, very soon there will be some more members and if you want peace and quiet you’re going to have to start the over 60’s club.

Normally people hate growing old. We shouldn’t, we should celebrate this fact, especially a thalassaemic born between the late 1950’s and early 70’s. These are first generation thalassaemias and parents, a generation that had to deal with no chelation, poor treatment, lack of knowledge, language barriers and the spectre that their child or children wouldn’t live past their teens. To them the future seemed hopeless.

So what happened, how against all the odds did we get into our 40’s and 50’s? Well I think three things tipped the odds in our favour; knowledge, chelation and sheer stubbornness.

We have seen the effects of new knowledge and better chelation options in ourselves and in the generations that came after us. But what has stubbornness provided? For first and second generation thalassaemias stubbornness taught us how to ignore the “you can’t do that” quote from well meaning family and friends and it gave us the drive to be normal to gain normality. For our parents and carers it taught them how not to give in, it gave them the skills needed to face a young child with a loaded butterfly needle.

I, like many thalassaemias of my generation, created a 30 year plan working on the fact that I was going to prove the doctors wrong and get way past my teens. My plan included; education, job, travel, love, marriage, home and kids; maybe not in that particular order but still I like many of my generation have achieved all this and much more.

Looking back I can see that we have all achieved the one thing that was the real driver and that is normality. I and we are exactly the same and can achieve the same as and more than non-thalassaemias if we want to.

At the Singapore conference in one of the question and answer sessions a young 16 year old well chelated thal made a comment. She said that she had no issues with her thalassaemia or her treatment but she was worried that she didn’t know how long she would live.

The thing is nobody on the planet knows how long they will live but if you look at the members of the over 50’s club they are aiming for a pension so if we can do that then the current generation have no limits.

And finally to the Mr. C’s and Mr. G – you had better make some room because we are eyeing up the space in front of the fireplace!

Until the next issue.

Mike Michael
President
UK Thalassaemia Society

A word from our President

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

Mike Michael
President

Dr Christos Sotirelis
Vice-President

Menuccia Tassone
Secretary

George Constantinou
Treasurer

Philip Agathangelou
Assistant Treasurer

Costas Kountourou
Committee

Bharat Nathwani
Committee
The NHS Sickle Cell & Thalassaemia Screening Programme organised this conference; which was titled “Can we develop a preconception service in England?” The event took place at the Devonport House Hotel, Greenwich, London and was attended by health professionals from all parts of the UK, as well as patient and parent representatives. Dr Allison Streetly, the Director of the NHS Sickle Cell and Thalassaemia Screening Programme, stated in her welcome to the delegates; “We believe that public education is fundamental to enabling informed choice. Ideally, since a test for carrier status can be offered at any time, it is better if people are offered information and testing before they embark on pregnancy so they can reflect on the choices available to them without the pressure of a developing pregnancy.”

The first day of the meeting drew on the experiences of four successful preconception screening programmes which have taken place overseas. Two of these programmes take place in schools, where 16 year olds are offered testing. These presentations were given by;

- Dr Martin Delatycki, Murdoch Children’s Research Institute, Australia – Tay-Sachs disease, cystic fibrosis, Fanconi’s anaemia
- Prof Graham Serjeant, Sickle Cell Trust, Jamaica – sickle cell disease, beta thalassaemia, HbC

The other two programmes concentrate on testing of couples before marriage; and the presentations were given by;

- Dr Shaikha al Arrayed, Head of Genetic Department, Ministry of Health, Bahrain – haemoglobinopathies
- Dr Paul Telfer (on behalf of Dr Androulla Eleftheriou, Executive Director, Thalassaemia International Federation, Cyprus – thalassaemia

All four presentations were extremely interesting and provided a great deal of food for thought, not least on the ethical issues raised by the idea of introducing anything similar in England.

The second day concentrated on examining settings where it might be possible to offer a preconception service; and ways of reaching out to young people to raise awareness of the need for thalassaemia/sickle cell screening. The following presentations were given;

- Dr Anjana Oswald, Faculty of Sexual & Reproductive Healthcare – sexual health & family planning
- Dr Jane Logan GP, Mawbey Brough Health Centre – primary care
- Heidi Wright, Head of Practice & Quality Improvement Director, Royal Pharmaceutical Society – pharmacies
- Elizabeth Bayliss, Social Action for Health – community setting using peer approaches
- Nell Banfield, Qualifications & Curriculum Authority & Bola Ojo, Consultant in adult & community learning – possible approaches to working with schools

There were also discussion workshops and ideas sessions in which all the delegates took part. It was obvious from the animated discussions and exchange of ideas that everyone present felt extremely enthusiastic and inspired by what they had heard on both days. The strong, unanimous feeling pervading the event was that preconception screening has to be the way forward. There are without doubt numerous practical and ethical problems to be overcome before we get there; but with such unity and strength of feeling among both health professionals and those affected by the conditions, we must surely prevail – and the introduction of preconception screening will see the realisation of one of the long-term goals of the UK Thalassaemia Society.

Elaine Miller
“She doesn’t want to have heart complications in the future”.

Regular monitoring of liver iron concentration (LIC) enables clinicians to make better informed decisions on the management of chelation therapy and will decrease the risk of cardiac iron loading occurring.

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The Adolescent Thalassaemia Patients

By Dr. Michael Angastiniotis
Medical Adviser to the Thalassaemia International Federation

Thalassaemia is a chronic disorder which the patient lives through from birth to old age. Why then do we single out adolescence which is a relatively short period of the life cycle? Clearly this period of growth, biological changes, psychological development, maturation and social adjustments, presents challenges which may affect both the course of a chronic condition such as thalassaemia and its psychosocial consequences.

Adolescence

Many define adolescence as the period from 8 – 21 years. This is too broad an age range if we are interested in examining responses to chronic disease, complicated treatment and the adaptation to all this as well as having to go through the adjustments that all must go through, with or without thalassaemia. Dividing the period to early, mid and late adolescence would give more meaningful results especially in researching the psychosocial consequences of thalassaemia. The meaning of illness, the reasons for changing treatment, the significance of complications, are viewed differently as the patients develop through this period of their lives. This must be kept in mind when evaluating published research which often ignores the maturation process.

Adolescence is a period of change during which the bodily changes are accompanied by psychological changes which are mainly related to the need to become independent. Being a teenager is a time to assert one’s autonomy, controlling one’s life and challenging authority. The bid for autonomy is precisely what worries parents and caretakers alike. The most effective way to assert independence is by saying no, by being negative. This may lead to negative behaviour or behaviour which the parents may perceive as dangerous and sometimes it is. This is common to all adolescents and thalassaemia patients are no exception. What really scares both families and doctors is the possibility that the obedient child, who took his/her injections and other medications regularly under parental supervision, may now refuse it in order to assert independence.

Adolescence in Thalassaemia

It must be remembered that thalassaemia, over and above the stresses of adolescence may bring with it additional factors which can cause stress. These factors are related to the condition itself and will affect the adolescents with thalassaemia to varying degrees – they include altered appearance, poor growth, delayed puberty, uncertainties about the future, guilt feeling about being a burden but more importantly in this age group, a sense of being different from peers, without forgetting the demanding treatment, family stresses and negative feelings possibly caused by health services and society in general. Society often has an undercurrent of poor acceptance when it comes to relationships, education, career and marriage of patients with thalassaemia.

Having all these possibilities in mind, thalassaemia drew the attention of psychologists and psychiatrists in the last 30 years (the first publication was in 1971). In their studies these professionals sought to find out whether thalassaemia patients did have psychological disturbances and certainly found them.

They described negative feelings such as low self esteem, poor self image, conduct disorders, bad moods, temper, dependency, fears and anxiety. These conclusions were common in the literature until around 1990 and still appear in studies coming from developing countries. Could the quality of care have something to do with these consequences?

In 1995 Professor C. Vullo of Ferrara, and his team published a study which came to another conclusion: “Thalassaemic adolescence scored better than healthy peers in tests of social adjustment” and again in another study “children and adolescents with chronic disorders do not differ as much as assumed from healthy controls”. Why such a different conclusions? Probably because the earlier studies were designed to detect pathology and negative responses and certainly found them. They did not however attempt to detect the coping mechanisms, the possibility that patients balanced out the stress factors with strategies and behaviours aimed at adapting to their condition, and aiming for a better quality of life.

The psychosocial balance

In all our lives, events and situations causing stress are with us almost daily. Yet we all balance these by learning how to cope, each person adopts ways of coping which suit the situation and our personality. Such mechanisms include forgetting the problem and focusing on something else to reduce the impact, or even passively accepting the situation. More useful however is playing an active role in solving our problems and seeking support from family, friends and caregivers (including the thalassaemia associations in this case). Spiritual support according to our religious beliefs has been shown to be a very positive help in coping. Support from trusted caregivers – doctors, nurses,
and psychologists is central in the case of thalassaemia.

It must be pointed out that some ways of coping can have the opposite results. One example is becoming aggressive and blaming others for our plight. This is quite common and serves only to produce more negative feelings. Withdrawing into our selves and becoming “engulfed” in our problems is another counterproductive way of coping – in fact this is not coping at all.

**Assessing the balance**
When faced with individual patients, various factors must be considered:

- The clinical condition – a patient with complications and in poor physical conditions may not be coping psychologically as well as one in a good state of health.
- The patient’s social environment such as the immediate family, may be coping, or they may be trapped in guilt feelings, denial, over protection and social isolation.
- The person providing the information must be considered. Is it the patient, a parent, a teacher? Each has a different perspective and it is known that perceptions of adolescent behavior and adjustment vary depending on the observer. Studies have shown for example, that there are different opinions about the illness between parents and adolescents with chronic disorders.
- Also it must be remembered that communicating with adolescents about their problems is often difficult and unskilled professionals are frequently unable to elicit reliable information.
- The development stage of the adolescent must be remembered. A 10 year old and an 18 year old do not the respond in the same way.
- The health professional doing the assessment must take time and listen!

**How can services help?**
The first requirement is for the healthcare team to recognize problems in coping and adjustment early and to deal with them. This is because adolescents are more flexible in changing their ways of coping than adults, so that help at this age will prevent entrenchment of maladaptive coping.

To recognize problems early, the service should be orientated to comprehensive care – treating, in other words, the whole person and the family, catering for physical health, emotional health and not ignoring educational, financial and other needs. In practice this means a service in which:

- Staff are willing to spend time and listen.
- There is respect for privacy and confidentiality.
- Adolescent concerns such as sexuality, contraception, puberty, diet, risky behaviour, school problems etc. find a willing ear, even if sometimes not clearly expressed by the teenager.
- Clinic appointments must cater for patients’ school and work commitments.

Such adolescent friendly services were described many years ago for thalassaemia (Mazera 1990). However, few thalassaemia clinics are adapted to cater for these needs even today. More recently standards for services catering for chronic disorders have been set both by the European Union (The Task Force Criteria for Chronic Care) and a US based group who developed the so called chronic care model (the Wagner or CCM model (Wagner 2001)). These standards and models emphasize patient involvement, self management strategies, links with the community and involvement of the community in patient support, and good clinic organization with decision support for the health providers.

We tried to ascertain the extent to which extent chronic care services in Cyprus (not just for thalassaemia), live up to the expectation of the chronic care model and to what extent the doctors in-charge feel that they get support from the health authorities to provide comprehensive care. Only two services, out of fifteen questioned, indicated that they receive high overall support. Nine of the fifteen indicated low support.

Bringing these results to the attention of the authorities will provide information on how to improve the services.

The patients were also asked to assess the support they were getting from services and again the weak points were identified.

One such weakness is that patients are not given choices about treatment and so are not involved in treatment decisions.

Patient involvement and participation in medical decision making, in other words self-management, helps the patients’ independence and improves adherence to treatment, coping and quality of life. There is need to enhance clinicians’ skills in promoting the patient to a partner in decision taking rather than a passive receiver of prescriptions.

Other studies have shown that adolescents value doctors who pay attention and take their concerns seriously (Britto 2004).

Adolescence is also a time to consider the educational needs and so liaison of clinic and school will be useful.

Finally it is a time to start preparing the transition from paediatric to adult care which in some cases may be difficult.

The main conclusion is that adolescents with thalassaemia expect support from their health care providers and their families to grow independent and take an active part in their own care.

They will be helped by those who listen, pay attention to their opinions and respond to them. Success in coping at this age will be a firm base for successful coping later in life.

**Further reading**
The International Thalassaemia Conference 2008 was held on 8-11 October at Suntec City, Singapore. Here we see (from 2nd left, back row) UKTS members Brandon Michael, Mike Michael, Costas Kountourou and Andy Charalambous. Third from left (front row) is our great friend Maria Kastoras, Coordinator of our sister Society in Australia, the Thalassaemia Society of Victoria. We have been thinking of all our friends in Victoria during the recent tragic events which have taken place there.
We, Ajay and Meenakshi were blessed with a baby boy, Avi, on 20th September 2008. He weighed 5.6lbs and was born after 37 weeks by Caesarian section at 02.40 am in the Whittington Hospital, where Meenakshi goes for her thalassaemia treatment. I was sitting by Meenakshi in the operating theatre supporting her. It was a great feeling when the doctors put my baby in my arms. Meenakshi was overjoyed to see him. She was discharged on the 4th day. We has sleepless nights for 2-3 weeks, but Avi is a cool baby. We always cuddle and play with him. We are thankful to the UK Thalassaemia Society and the team at the Whittington Hospital for their kind support.

Ajay Kumar

My name is Sabrena and I go to preschool, My best friend is Dillon who is really cool, I watch Big Cook Little Cook on TV, Playing with Play-Doh is lots of fun for me. I just love grapes to eat, And sometimes chocolate for a treat. Black is a colour I like a lot, My teddy is the best present I ever got. My favourite person is Dinah, who is a gem, So this, my first poem, is just for them!

by Sabrena Afridi, age 5

My name is Ahmad Tarin, and I am currently doing my MSc in Accounting and Finance at the University of Birmingham. I completed my undergraduate degree in Accounting and Finance in July 08 from the same university (see photo). I was diagnosed with Thalassaemia Major when I was around 5 months old. I have two younger brothers who are carriers for Thalassaemia Major. My family moved to the UK in 1995 from Pakistan when I was 8 years of age. I have been looked after extremely well by my doctors. I have my blood transfusions every fortnight and take a combination of Desferrioxamine and Deferiprone.

Congratulations to Meenakshi and Ajay on the birth of their son Avi

Congratulations to Ahmad on his Graduation

Thank you to Alex and Marilyn

My Poem

Sabrena has beta thalassaemia. She is under the care of Dr Georgina Hall at the John Radcliffe Hospital, Oxford.
Dinner & Dance 2008
By Photoulla Wilson

The annual dinner and dance was held at the Penridge Suite, North London on 22nd November 2008 organised by Maria Gavriel and Photoulla Wilson.

The aim for the evening was for all our guests to have a wonderful time, continuing the support of the UK Thalassaemia Society and to raise as much money as possible. Our guests were very complimentary of the evening’s entertainment and generous with their donations, proving the dance to have been a success.

After starting the evening with a champagne reception, stuffing our guests with a 7 course meal accompanied by all they could drink, our supporters and band for the evening, Millennium, kept us on the dance floor all night. Mrs. Nitsa Psaromitis, who has supported the charity for 32 years, started the ball of donations rolling by very generously giving £1000 for the opening song. This was dedicated to her daughter, in memory of her late...
The Charity Event @ N20 Upstairs on the 15th November 2008 was a great success! Many people made the effort to support the UK Thalassaemia Society, with a turnout of over 150 people and in return they were rewarded with a fantastic evening.

The night was organised by Athena Klitou with help from her sponsors: (alphabetical order) Anastasia Flowers, Arch Printing, Arsenal FC, Bar N20, Bubble Designs, Burgéon Flowers, Catwalk, Chelsea FC, Diamonte Décor, DJ BFG, DJ Smerts, DJ Stylz, DJ Toppa, Elysium, Fairybox, Kyri and Michael (Greek dancers), Lizzy’s Beauty Salon, Manchester United FC, Nafoura Events and Entertainment, Olympic Holidays, Parikiaki Newspaper, Studio Hair and Beauty, The Tanning Shop, Triangle Gym (Palmers Green), Selene, South West Studios, Sunburst, Tottenham Hotspur FC, Valorous Distributions and Zinos Jewellery.

The raffles and auction went well and all together they managed to raise £3,000 after expenses were covered. More pictures of the night are available to be seen through facebook - Contact Athena Klitou.

Athena would like to thank everyone as individuals for the time and effort that they dedicated to the evening. To all those companies which offered their services for free or at a reduced rate and for all the finer details that people don’t always see.

Well done to Tina Michael who bagged the 1st prize of our raffle, a holiday (kindly donated by Olympic Holidays. Second and third prizes were won by George Michael & Kika Costa, kindly donated by Broadway Travel and A&P Polishers. Forth and fifth prizes were scooped up by Mrs. Lizou and Maria & Harry Skaliotis, kindly donated by Arcadia Topshop Brent Cross and Brian’s DIY. Thank you to all the companies which donated prizes for the raffle.

Lastly, but, by no means least, on behalf of the UK Thalassaemia Society, Maria and Photoulla would like to thank everyone as individuals for the time and effort that they dedicated to the evening. To all those companies which offered their services for free or at a reduced rate and for all the finer details that people don’t always see. Thank you to the St. Paul’s Press for the free printing of our tickets, the Penridge Suite (the food and drink was very enjoyable!), Millennium for singing and playing great music all night, to Burgéon for their always impressive flower arrangements (sponsored by Mr. Alpesh Patel and Premier Mobile), Aroma for their delicious cakes and to Eternity Stylings, who gave the hall the finishing touch with their chair covers Thank you.
The UKTS West Country & Wales Roadshow took place at the OSCAR Bristol Centre, Stapleton Road, Bristol, on Saturday 15th November 2008. I should say at the outset that we are greatly indebted to Anndeloris Chacon, the OSCAR Centre Manager, and her staff for their hard work in helping us to organise the day and letting us use their premises. Bristol may not have the largest population of thal patients but they certainly have a dedicated champion in Anndeloris and we could not have run this event without her help.

Although compared to the rest of the UK, the West Country and Wales do not have too many thalassaemia patients; we thought - all the more reason to go down there and show that we are prepared to travel to any part of the UK to visit our “thalassaemia family”. We invited all the patients on our database who live in Wales or the West Country. Seventeen people attended, which included both thalassaemia patients and members of their families; mostly from the Bristol area but some people travelled from Wales for the occasion. The UKTS party consisted of; Andy Charalambous, Elaine Miller, Chris Sotirelis, Menuccia Tassone and Gabriel Theophanous.

As usual with our Roadshows, the day was friendly and informal. We started off with a few presentations – Chris Sotirelis, our Vice-President, spoke on the subjects of “being an empowered patient” and “Exjade – frequently asked questions and answers”. Coordinator Elaine Miller gave a presentation on fertility titled “patients can be parents” (using slides by kind permission of Sister Emma Prescott, Thalassaemia Nurse Specialist, Whittington Hospital, London). Andy Charalambous gave his both moving and funny personal experience “journey of a reluctant chelator”; which was followed by an absolutely fascinating account from Wendy Pinker about her work with the thalassaemia children of Nepal. (Some of you may remember reading in earlier issues of TM about Wendy’s work – a native of Bristol, she is currently in the UK awaiting the birth of her first child.) Last but not least, Gabriel Theophanous gave an account of how he trained for and ran the London Marathon in 2006.

After the presentations we had a delicious lunch; and spent the afternoon networking and discussing various issues – thalassaemia and otherwise – most of our guests being young men, football featured prominently! It was great to meet people new to us at the Society and there was a lot of laughter and fellow feeling in the room, always good to be part of. We left feeling that we had made some new friends and we hope that they felt the same.

Many thanks to all who attended, Anndeloris, the staff at the Cardiff Centre who arranged for their patients to attend; and finally our stalwart driver Chris Demetriou, now a veteran of our Roadshows, for his good humour in putting up with us screaming like banshees with laughter in the back of the van (always a risk when Andy and Gabriel are around!).

Don’t forget – wherever you live, if you have a patient group – or if you are just a small, informal group of friends who have thalassaemia/are parents who have children with thalassaemia – if you would like us to arrange a visit to your area, just give us a call on our office number!

Elaine Miller
My Godmother

Androulla Nicolaou, supporter of the UK Thalassaemia Society, sadly passed away on 17th November 2008, age 62. She was a great mother, grandmother, godmother, auntie, sister and wife and those of us who knew her felt lucky to have been part of her life.

She had a knack of making those around her feel very special and loved and her happiest times were those spent with her family and friends.

I can not explain the massive loss that my family and I feel now that she's gone, she was always there for me and I can honestly say that I could not have wished for a better godmother. The memory of the wonderful person she was will forever stay within my heart and never forgotten. Her funeral raised £460 & €100 for the UK Thalassaemia Society.

Thank you to Martin Jarvis and David Ricketts (North Middlesex Hospital)

In November 2008, UKTS was fortunate enough to receive donations from two key members of staff at the North Middlesex Hospital. Mr Martin Jarvis (Head of Molecular Diagnostics) and Mr David Ricketts (Laboratory Manager, Biochemistry) were both presented with Innovation and Creativity Awards. They were kind enough to pass their respective prizes of £100.00 on to UKTS.

Largely thanks to Martin’s work, the North Middlesex Hospital has developed a molecular service that is very unusual in a non-teaching hospital. Martin is a nationally recognised expert in the detection of haemoglobinopathies. His work has resulted in the detection of two previously unknown mutations that have been named by the laboratory. He donated his prize to UKTS as a gesture of thanks; as the Society originally donated the Hybaid Thermocycler Instrument to his lab; which proved to be a vital piece of equipment and significantly increased the molecular capabilities of the lab.
Notice to Parents and Teachers

At UKTS we are well aware that many parents of thalassaemic children experience difficulty in explaining the condition to their child’s teachers or carers. We have therefore designed a new leaflet which gives all the necessary information in an easily accessible format so that parents can give these to the teachers at their child’s school. The leaflets are available to parents FREE of charge from the UKTS office – call us now on 020 8882 0011.

UKTS is grateful to the following for their assistance with this project:

- Isabel Adams, Thalassaemia Nurse Specialist, Birmingham Children’s Hospital (BCH)
- Munira Bharwani, parent
- Jane Carrington-Porter, teacher, of James Brindley School based at BCH
- Susan Crawford, Specialist Nurse Haemoglobinopathy, Birmingham Sickle Cell/Thalassaemia Services
- Dr Philip J Darbyshire, Consultant Paediatric Haematologist, BCH
- Pamela Hayes, School Nurse, Swanshurst School, Birmingham
- Nazam Rehman, parent

Thanks to Pat

At the end of 2008 UKTS said a reluctant goodbye to Pat Hayward, our part-time Assistant Coordinator who retired on 24.12.08. Pat had been with the Society since May 2004. All of us at UKTS thank Pat for her services to the Society and wish Pat and her husband Richard a very happy retirement.

DONATIONS

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

- Mr Arafat Ali £15.00
- Assoc Guyanese Nurses & Allied Professionals £50.00
- Mrs R.V. Calcutt £20.00
- Mr George Constantinou £400.00
- Mr S. Gandhi £100.00
- Mrs Marilyn & Ms Alex Hau £176.50
- Mr Kayhan Izmen £311.50
- J.K.P. Consulting £30.00
- Mr Martin Jarvis £100.00
- Mrs A Katsouris & family £50.00
- Ms Athena Kliotou £2,530.77 (party night 15.11.08)
- Mrs Maria Kyriakkides £50.00
- Mrs E. Louca £150.00
- Mr Michael Michael £5.00
- Mr & Mrs K.S. Panesar £11.00
- Mr J.K. Pitrola (in memory of Mrs Manjulaben Hansrajbhai Solanki) £60.00
- Mr David Ricketts £100.00
- Mr & Mrs S Soni (The Gold Centre) £75.00
- Mrs Betty Why £10.00
- Mrs Photoulla Wilson (in memory of Mrs Androulla Nicolaou) £539.03
- Mrs Tanya Yucel (party night 20.9.08) £1,650.00

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The views expressed are not necessarily that of the Society.
Please Support The UK Thalassaemia Society by Making a Monthly Donation

STANDING ORDER FORM

To the Manager [Name of Your Bank]

Address

City Postcode

Please pay: Bank of Cyprus UK, PO Box 17484, 87 Chase Side, London N14 5WH

For the credit of: UK Thalassaemia Society, Registered Charity No: 275107
Sort Code 30-00-42 Account Number 00593812

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:

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

<table>
<thead>
<tr>
<th><strong>Title</strong> (Mr/Ms/Miss/Ms/Other):</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>First Name(s):</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Surname:</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Address:</strong></td>
<td></td>
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<tr>
<td><strong>Post Code:</strong></td>
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<tr>
<td><strong>Occupation:</strong></td>
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<tr>
<td><strong>Ethnic Origin:</strong> (Optional)</td>
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</tbody>
</table>

## Contact Details

<table>
<thead>
<tr>
<th><strong>Telephone:</strong></th>
<th><strong>Home:</strong></th>
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<tbody>
<tr>
<td><strong>Mobile:</strong></td>
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<td><strong>Fax:</strong></td>
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<tr>
<td><strong>Email:</strong></td>
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</table>

<table>
<thead>
<tr>
<th><strong>Are you a:</strong></th>
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<tbody>
<tr>
<td>☐ Patient</td>
<td>☐ Parent/Relative</td>
</tr>
<tr>
<td>☐ Healthcare Professional</td>
<td>☐ Association</td>
</tr>
<tr>
<td>☐ Other (Please state)</td>
<td></td>
</tr>
</tbody>
</table>

## Membership Required (please tick)

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

## Membership Required

<table>
<thead>
<tr>
<th><strong>Patient's Name(s):</strong></th>
<th></th>
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<tbody>
<tr>
<td><strong>Date of Birth:</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Sex:</strong> ☐ Male ☐ Female</td>
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</tr>
<tr>
<td><strong>Type of thalassaemia: (e.g. Major, Intermedia, Haemoglobin H etc)</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Hospital where-treated:</strong></td>
<td></td>
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<tr>
<td><strong>Address:</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Telephone:</strong></td>
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</tbody>
</table>

### Blood Transfused (please tick)

☐ Whole ☐ Washed ☐ Frozen ☐ Filtered

### Chelation (please tick)

☐ Desferal ☐ Deferiprone ☐ Desferal & Deferiprone

<table>
<thead>
<tr>
<th><strong>Transfusion Frequency:</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Units received at each transfusion:</strong></td>
<td></td>
</tr>
</tbody>
</table>

| **Blood Type:** |  |

## Office Use

**OFFICE USE:** Date Paid ___________ Receipt No ___________ Approval Date ___________