



...continuing the fight against thalassaemia

PRESCRIPTION CHARGES CAMPAIGN GATHERS MOMENTUM

As a member of the Prescription Charges Coalition, the UK Thalassaemia Society is delighted that the campaign to ensure everyone with long-term conditions is exempt from prescription charges is gaining real momentum.

Nearly 4,000 people have written to their MPs on the basis of the evidence of our two *Paying the Price* reports and over 15,000 people have signed our online petition. Thank you to all those who have supported the campaign through any of these actions so far. Please do add your voice to our e-petition and share at this link:

www.bhf.org.uk/prescriptions

We were delighted that there was extensive media coverage of our campaign messages in national and regional media, including the Express, Daily Mail and Mail Online, the Mirror, Sun, Metro, BBC Breakfast, Radio 4's Inside Health and You and Yours, LBC and the Plymouth Herald.

However, on 11th March, the Government announced a 20p increase in prescription charges to £8.05 per item, to take effect from 1st April 2014, and a further increase to £8.25 per item from next April 2015. The Prescription Charges Coalition issued a statement in response:

"Millions of people with long-term conditions will be bitterly disappointed by the Government's short-sighted decision to put up the cost of their essential medicines by 40p over the next two years. Already, over one third of people in work with a long-

term condition find it hard to pay for their prescriptions and are rationing or stopping taking their medicines, compromising their health. These unfair, outdated and inequitable charges are forcing more people with long term health conditions into medicine poverty and we continue to call for the government to follow the strong example set by the other UK countries and abolish prescription charges for people with long term chronic health conditions"

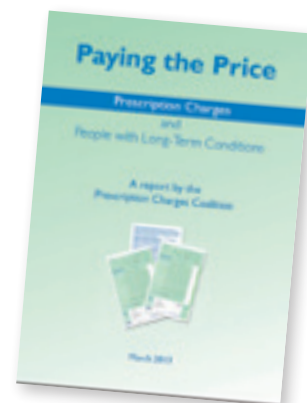
We launched our Prescription Charges and Employment Report to coincide with the announcement. Based on a survey of more than 5,000 people with long-term conditions, this finds that nearly four in 10 say that the cost is preventing them from taking their medication as prescribed. Of these, three quarters reported that this has affected their ability to work.

Jackie Glatter, Coordinator of the Prescription Charges Coalition, says: "I am delighted with the way that this campaign is gathering momentum. More than 30 organisations are now members and together we are a powerful force for change. It is clear from our research and the social media response we get at every stage that this is an issue which urgently needs addressing. I would encourage everybody to add their voice to our e-petition and share the link so we can make sure this happens".

Help with health costs

There is some help available with prescription

and wider health costs through the Prescription Prepayment Certificate and NHS Low Income Scheme. There are also exemptions from charges for some medical conditions. We have worked hard to raise awareness of these, including working with the Department of Health to improve the design of the information materials and see these redistributed to all pharmacies and GP surgeries and would encourage anybody who requires a large number of prescriptions to look into the options further. However, our research shows these measures are limited and inadequate. We will therefore continue to look for ways to increase public and political support for change to the unfair system of prescription charges for people with long-term conditions in England.



How you can support the campaign

Your help in promoting the campaign through your group newsletters, letters to the local newspaper and emails or letters to your local MP, will be invaluable in continuing to grow this campaign to a point where change must happen. Please visit www.prescriptionchargescoalition.org.uk for more information.

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A word from our President



Dear Friends

A lot has happened since the last time I wrote to you. On February 25th we held our Annual General Meeting at the Society's offices in North London; and it is my pleasure to introduce four new members of the UK Thalassaemia Society management Committee – Tina Bhagirath, Chris Fassis, Anand Singh Ghattaura and Raj Klair. All four of them are thalassaemia major patients, so they have in-depth knowledge of the issues we all face in our daily lives and in our treatment. We are already benefiting from their new ideas and enthusiasm – and we are trying very hard not to overload them with work! I think they would agree that there is far more to running the Society than it would appear from the outside – a glance at the "recent events and meetings" (page

13) shows how much goes on behind the scenes as we work to raise the profile and awareness of thalassaemia at every level; from Parliament downwards. Don't forget that if there are any local issues which affect you we would love to hear from you – we can't work miracles but we will always listen and help where we can!

As you will see from our front page article, we the members of the Prescription Charges Coalition are working very hard to get all the political parties to see reason and abolish prescription charges altogether for people who are living with incurable, long term conditions such as thalassaemia. This is a prime example of how we, as a very small charity, can work more effectively by joining forces with other organisations. In a similar way, we need the support and help of all our members - have you contacted your MP yet about prescription charges? Have you signed the e-petition (see front page)? If not, add your voice to the campaign and help us to make this change; so the children in our "thalassaemia family" do not have the additional burden of prescription charges once they reach the age of 18.

This summer we will be going all out to raise awareness of thalassaemia with the general public; by taking stalls at some of the most high-profile melas and festivals (see page 3 opposite). If anyone would like to volunteer to come along to the stall and help at any of

the festivals, please contact Elaine our National Coordinator at elaine@ukts.org

As always, please send us your news, photographs and stories if you would like them to be included in Thalassaemia Matters. Have a great summer, enjoy your holidays and come home safely.

Best wishes until the next issue,

Gabriel Theophanous
President, UK Thalassaemia Society

STOP PRESS – Results from around half of clinical trials have never been published. Information on what was done and what was found in these trials could be lost forever to doctors and researchers, leading to bad treatment decisions, missed opportunities for good medicine, and trials being repeated. The contributions of the hundreds of thousands of patients who took part in those trials remain unused and unusable. Watch the new AllTrials campaign video at <http://www.alltrials.net/2014/new-alltrials-video-make-clinical-trials-count/>

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



The Thalassaemia International Federation (TIF), in collaboration with the Greek Thalassaemia Federation, is proud to announce the organisation of the 4th Pan-European Conference on Haemoglobinopathies & Rare Anaemias.

Date: 07 – 09 November 2014

Venue: Titania Hotel, Athens (<http://www.titania.gr/>)

You can find further information at
<http://www.thalassaemia.org.cy/educational-programme/events/4th-PanEuropean-Conference.shtml>

Summer Mela Festivals

This summer UKTS is pulling out all the stops to raise awareness of thalassaemia! We will be taking part in the following festivals and would be thrilled if some of our members pop by and visit us on the stall. Hope to see you this summer!

Middlesbrough Mela

7th & 8th June 2014
 Centre Square, Town Centre
 Middlesbrough TS1 2DA

Bradford Festival

13th, 14th & 15th June 2014
 Bank Street, Darley Street, Kirkgate, Tyrrell Street
 Bradford BD1 3HL

Manchester Mega Mela

21st & 22nd June 2014
 Platt Fields Park, Fallowfield, Manchester M14 6LA

Sandwell & Birmingham Mela

5th & 6th July 2014
 Victoria Park, Smethwick
 B66 3NT

Slough Mela

3rd August 2014
 Upton Park, Upton Court Road
 Slough SL3 7LU

Leicester Belgrave Mela

25th August 2014
 Leicester City Centre

Meet the Committee

The UK Thalassaemia Society held its AGM on the 25th February 2014. We were delighted to welcome four new Trustees to the UKTS Management Committee – Tina Bhagirath, Chris Fassis, Anand Singh Ghattaura and Raj Klair. It is always refreshing for any organisation to have new people with new ideas and perspectives; and we look forward to a very productive year!

The Trustees of the Society are (in alphabetical order):

Tina Bhagirath



As a career driven British Asian thalassaemic, I know the challenges which face us as a community and the stigmatisation of having a disorder. I've had treatment at a handful of hospitals across

London before settling at the Whittington. I know the struggles faced by thalassaemics in the UK as we try and balance work, home, chelation while trying to establish regular treatment of a certain standard in order to have a good quality of life. I have been involved in awareness and fundraising work with the UKTS since 2007, and I am hoping as a member of the committee, to have the opportunity to have a greater part the important work we have ahead."

George Constantinou (Secretary)



George is a beta thalassaemia major patient. He is a founder member of the UKTS, having served on the Management Committee from 1976-1985 and again from 1999 to the present

day. George has been a tireless campaigner on behalf of thalassaemia all his adult life and has conceived and been involved with many UKTS projects including conferences and awareness projects. He was involved in producing the revised version of the UK National Standards for thalassaemia treatment (published October 2008) and with the finance committee of the Society. George is a hotel manager by profession; is married and has a daughter. He has served as Secretary of the Society in 2013.

Chris Fassis (Assistant Secretary)



Hi my name is Chris Fassis and I'm returning to the UK Thalassaemia Society for a number of reasons. Firstly because I know that I can be of great help furthering the position of the UKTS when it

comes to promoting its international profile and

presence; gained through my grasp of media and public relations knowledge. I say this as a person who has been instrumental in successfully helping to run the Red Cell Patients Group at the UCLH for a number of years now. (Chris is a beta thalassaemia major patient.)

Pany Garibaldinos (Assistant Treasurer)



Pany is a 56 year old beta thalassaemia major patient. He was a founder member of UKTS in 1976 and served on the Management Committee for many terms in the early years of the Society.

He returned in 2010 to add his experience to the Management Committee. As one of the older patients, who has experienced the progression of thalassaemia treatment from the bare minimum of blood transfusions to the sophisticated treatment régimes of the present day, Pany feels that his experiences will enable him to make a valuable contribution to the work of the Society. Pany is married with a son; and he is a driving test examiner by profession. He has served as Assistant Treasurer during 2013.

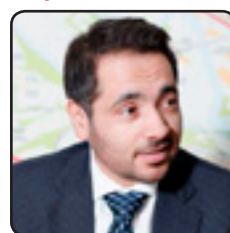
Anand Singh Ghattaura (Vice President)



Having lived with thalassaemia major for the past 30 years, I know what it is like to have this condition, particularly through school, university, building a career and being treated at a local hospital with

limited thalassaemic expertise. Many people have helped me along the way and this has spurred me to help others and to make a difference. As a life member, I have seen the great work the charity has done. I am an active member of the Sikh community in Berkshire and I work in marketing for a large global City law firm.

Raj Klair



As a 38 year old beta thalassaemia major patient, I understand what it's like to live with the condition and undergo treatment. I want to give something back to society and I believe this is the best way. As

an entrepreneur - organisation, communication and networking are key skills one should possess. I believe I can use these qualities to make a difference.

Romaine Maharaj (Treasurer)



Romaine's daughter Roanna is a beta thalassaemia major patient. Prior to moving to the United Kingdom in 2004, she served as the President of the Society of Severe and Inherited Blood Disorders,

Trinidad and Tobago, one of the founding members of TIF.

Romaine was also the Head of a mortgage division for one of the major banks in the Caribbean, her financial background spanning a period of twenty three years. Currently she is working as the Student Officer at the Trinidad and Tobago High Commission, London. Romaine joined the Board of Trustees officially in 2010 and served as the Treasurer in 2013

Gabriel Theophanous (President)



Gabriel is a 36 year old beta thalassaemia major patient. He works in accounts and is currently studying towards an ACCA qualification. In 2006 he became the first thalassaemia major patient in the world to

complete a marathon race, a remarkable achievement. In 2013 he repeated this feat when he again completed the London marathon, raising funds for the Society and raising the morale of thalassaemia patients everywhere. He has served as President of the Society for the past 2 terms.

Royal College of Obstetricians and Gynaecologists release: New guideline for managing thalassaemia in pregnancy announced at the RCOG World Congress in India

New advice for clinicians on the management of women with thalassaemia in pregnancy, a condition that affects more than 70,000 babies worldwide each year, was published on 28 March 2014 by the Royal College of Obstetricians and Gynaecologists (RCOG) at the annual RCOG World Congress in Hyderabad, India.

Thalassaemia is a common inherited blood disorder caused by an abnormality with how the body produces haemoglobin, which affects the function of red blood cells in the body leading to a red blood cell deficiency, or anaemia.

While globally there are around 100 million individuals who are carriers, it is most common among communities with Mediterranean and Asian origins. There are an estimated 1,000 individuals affected by thalassaemia in the UK, with the Indian, Pakistani and Bangladeshi communities accounting for 79% of all thalassaemia births.

This first edition guideline looks at how to best manage pregnant women with beta thalassaemia major, the more severe form of the condition which requires regular blood transfusions each year, and the milder form beta thalassaemia intermedia.

Thalassaemia can be the cause of many health problems due to the increasing overload of iron in the body, including complications for the major organs, bones and hormones, which are associated with possible heart failure, osteoporosis and delayed or incomplete puberty.

These complications are also associated with an increased risk to both mother and baby during pregnancy, with a higher risk of maternal cardiomyopathy and diabetes as well as foetal growth restriction. Most women with thalassaemia will also require ovulation induction therapy to achieve pregnancy.

The new guidelines stress the importance

of a multi-disciplinary healthcare team, emphasising that women with thalassaemia should be assessed by a cardiologist or haematologist prior to and throughout their pregnancy to ensure maintenance of haemoglobin and to plan the pregnancy accordingly.

The guideline stresses that iron chelation therapy is complex and should be tailored for treatment of the condition during pregnancy, it is also recommended that blood transfusions should continue on a regular basis for women with beta thalassaemia major. For women with beta thalassaemia intermedia transfusions should be considered if there are signs of worsening anaemia or foetal growth restriction.

Furthermore, monthly check-ups throughout the pregnancy, and fortnightly in the final trimester, are suggested to all women with thalassaemia. Although there is no specific evidence regarding the timing or mode of delivery, the guidelines recommend continuous foetal monitoring as women with thalassaemia are considered to be at an increased risk of operative delivery.

Philip Owen, Chair of the RCOG Guidelines Committee, said:

“These new guidelines aim to provide a comprehensive set of recommendations for the best support and treatment of women with thalassaemia before and throughout pregnancy.

“Thalassaemia is a common inherited blood condition, for which partner screening and genetic counselling should be recommended as beneficial to all women who are pregnant or want to start a family.

“Pregnancies affected by thalassaemia need to be treated as high-risk and should involve a multi-disciplinary team with obstetric and haematology specialists to manage it properly. Currently, there is no established

evidence based guidance for treating this condition in pregnancy and we hope this new guideline will be a valuable resource for healthcare professionals.”

Gabriel Theophanous, President of the UK Thalassaemia Society, said:

“The UK Thalassaemia Society is delighted to see the introduction of guidelines for the management of pregnancy in women who have thalassaemia. The guidelines will be a wonderful resource to clinicians throughout the UK and will be of particular value in areas of low prevalence where there is limited experience in this field.

“Parenthood is an important part of life and with modern treatment it is something that many people with thalassaemia can look forward to. Our grateful thanks to the RCOG and all those who have contributed to these guidelines.”

For press enquiries in India, please contact Caitlin Walsh on + 91 9958482214 or email cwalsh@rcog.org.uk

For press enquiries in the UK, please contact Naomi Courtenay-Luck on + 44 07986 183 167 or email ncourtenay-luck@rcog.org.uk

Notes

View the full guideline on Management of Thalassaemia in Pregnancy

<http://www.rcog.org.uk/womens-health/clinical-guidance/thalassaemia-pregnancy-management-beta-green-top-guideline-no66>

For more information on thalassaemia and treatment or support options, please see NHS Choices or visit the UK Thalassaemia Society website.

The RCOG Guidelines App is now available on android, with an updated design and interface for iOS7. Download the RCOG Guidelines app for Android or the RCOG Guidelines app for iOS.

Thalassaemia and Pancreatic Enzymes

Emily White, BSc. Registered Dietitian
Specialist Liver Dietitian, Royal Free Hospital, London



Emily White

The pancreas is a long flat gland that sits below the stomach. It releases insulin to bring down blood sugars, glucagons to stimulate the liver to produce sugars for energy and also importantly, digestive enzymes. There are many reasons that the pancreas' function can become impaired and for those with thalassaemia it can be iron overloading from multiple blood transfusions used to treat the condition.

Whatever the cause of pancreatic damage it can have various effects on health. Around 90% of the pancreas produces enzymes that help us to digest carbohydrates, proteins and fat in our diet. One of the signs of pancreatic enzyme insufficiency is pale or yellow coloured, smelly and oily stools which are often loose and frequent. When stools are like this

it indicates that fat is not being broken down and absorbed by the body and this is called steatorrhea. The implications of this are malnutrition and difficulty in gaining weight due to malabsorption. If the pancreas is not producing these enzymes then it is likely that people are at risk of being deficient in the fat soluble vitamins A, D, E and K. It is well known that vitamin D can be made in the body from sunlight, so getting out in the sun is useful. However, in our climate here in the UK we can only synthesise vitamin D from the sun from around April to October. During the other months the sun is too far away to give us the vitamin D that we need. Severe long term deficiencies of these vitamins can cause conditions such as night blindness and osteoporosis. Blood tests can identify vitamin deficiencies and supplements can be taken to top them up. Malabsorption is not obvious, and in fact signs are often not detected until around 90% of the pancreas is not working properly. A test can be performed on a stool sample called a faecal elastase test to check for pancreatic enzyme insufficiency.

If I suspect a pancreatic enzyme insufficiency I do not recommend restricting fat but instead look to trial some pancreatic enzymes that come in capsules and are taken with food. There are a few brands of the pancreatic enzymes and generally speaking foods containing fats and larger meals need a greater dose, and if a large meal is being eaten then splitting the dose helps to cover the whole meal. The dose can vary between people and depends on how well the enzymes are tolerated. The capsules have to be

swallowed whole so that they have the best chance of making it through the stomach without being destroyed by the stomach acid, and are then able to do their job in the duodenum, just past the stomach. If the symptoms are caused by enzyme deficiencies, then soon stools will become more formed, less frequent, more 'normal' in colour, result in a reduction of wind and pain on eating, and finally people can start to put on weight.

It is known that iron overloading can cause diabetes but research into the effects on other functions of the pancreas is less clear, but certainly having transfusion therapy over a long time can affect the pancreas, so having an awareness of this might just help if those awkward questions do not get asked in clinic.

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UKTS Profile

Professor Elizabeth Anionwu

Questions by Elaine Miller, National Coordinator, UK Thalassaemia Society



Professor Elizabeth Anionwu

Everyone in the field of red cell haematology will be familiar with the name of Professor Elizabeth Anionwu (or to give her full title: Professor Elizabeth Nneka Anionwu, CBE, FRCN, RN, PhD, Emeritus Professor of Nursing, University of West London). In 1979 Elizabeth was appointed as the very first specialist nurse counsellor for thalassaemia and sickle cell disease in the UK, at Willesden Hospital in Brent. Since then her career has made spectacular progress. The Brent Centre became the model for other centres throughout the UK; and Elizabeth herself eventually entered the academic world becoming a senior lecturer in community genetics. This eventually led her to set up the Mary

Seacole Centre for Nursing Practice at Thames Valley University, now the University of West London. (N.B. For those readers who have not heard of Mary Seacole, read the full article – she has a fascinating history similar to that of the much better known Florence Nightingale!)

Elizabeth is now retired but retains her role as Emeritus Professor of Nursing at the University of West London. She was awarded the CBE in 2001 for services to nursing; and in 2004 she was created a Fellow of the Royal College of Nursing (FRCN) for the development of nurse-led sickle cell and thalassaemia counselling and education and leadership in transcultural nursing. Despite her formidable intellect, Elizabeth remains very much a nurse at heart – everyone who meets her is immediately struck by her warmth, humanity and the kind of empathy which only comes from a lifetime spent in caring for others. The UK Thalassaemia Society is very grateful to Elizabeth for her many years of hard work in raising the profile of thalassaemia and sickle cell disorders; and now for sharing her story with our readers.

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 Birmingham and grew up in the Midlands and Cheshire before coming to London in the 60s to train as a nurse. My heritage is Irish and Nigerian.

How did you choose a career in nursing – and later on, how did you come to enter the field of haemoglobinopathies?

As a child I was severely affected by eczema and was so impressed by the care of one particular nurse that I decided that would be my chosen career.

After completing my nursing studies I did part of a midwifery course in Edinburgh, then spent 9 months in Paris living with a family of doctors and teaching English to their two young children. I then returned to England to do my health visiting and it was whilst working in the early 1970s as a health visitor in Brent that I first encountered children with beta thalassaemia major and sickle cell disorders. I never realised at this time that in 1979 I would become the first specialist nurse counsellor for these conditions in Britain, working with Dr Milica Brozovic, consultant haematologist at Central Middlesex hospital. Looking back though, it was my lack of knowledge and poor services for sickle cell and thalassaemia that motivated me to learn more and get involved both within the NHS and the voluntary organisations. I needed to travel to the USA to obtain information about the health promotion side of care and that's where I first encountered specialist SCD & Thalassaemia nurses. That gave me the idea about becoming one in the UK.

As the first haemoglobinopathy nurse in 1979, things must have been very different for thalassaemia and sickle patients when you first started working with them. Could

you please tell which advancements over the years have given you the most satisfaction – and what further treatment advances would you like to see happen in the foreseeable future?

The advances that strike me are firstly the improved awareness of the conditions amongst many more health professionals and the public, although it is not at quite at the level I would like. Professor Bernadette Modell was very influential in bringing thalassaemia to the attention of the media. I can still remember, in 1978 I think, watching probably one of the first TV programmes about beta thalassaemia major. It was called 'Sea in the Blood' and was an extremely emotional film about the impact of the illness on families in Cyprus and Britain – it made me cry. The media coverage of sickle cell conditions came a few years later and I remember being involved in the early 1980s in a BBC Horizon TV programme.

The improvement in chelation therapies and widespread screening programmes are other significant advances. There is still a great deal of research and progress required to improve the quality of life for affected individuals that needs to embrace their health, psychological and social status. In addition, there are disturbing inequalities in care as highlighted by the UKTS and the Sickle Cell Society as well as peer reviews of child and adult services. Of course, like everybody else, I want to see a safe method of curing the conditions.

Is there any particular person who has been an inspiration to you in your career and if so, why that person?

Dr Milica Brozovic for opening the door for me to specialise in haemoglobinopathies and educating me so well about the conditions and for the way she provided expert and compassionate care.

You are a prominent figure in the world of screening; having been a member of the Steering Committee of the NHS SCTSP from the outset. How do you think the screening programme has changed the picture of the haemoglobinopathies in England?

I would like to take this opportunity to

thank Dr Allison Streetly, former Director of the NHS Sickle Cell & Thalassaemia Screening Programme and Archbishop John Sentamu, recently retired Chairman of the Committee. Their energy and commitment over the years has been incredible and has enormously helped to develop the services we see today.

I have your book "The Politics of Sickle Cell and Thalassaemia" which you co-authored with Prof Karl Atkin. Could you please tell us what inspired you to write the book? Are you the author of any other publications?

Karl and I wanted to bring together a readable publication covering the scientific, medical, nursing, and social aspects of the conditions. In addition we wished to chronicle the politics behind how they had shifted from being marginalised issues to being placed much higher on the NHS agenda. I have written quite a few articles, mainly for the nursing press. The publication I am most proud of was a booklet I wrote in 1983 with June Hall called 'A handbook on sickle cell disease: A guide for families'. It was the first such guide specifically designed for parents and was published by the Sickle Cell Society.

You are now retired, although an Emeritus Professor at the University of West London and continuing with many of your other roles, e.g. the Steering Committee – could you please let us know which roles you have chosen to continue with even in your retirement?

I am very honoured to be a member of the Scientific Advisory Panel to the UKTS as well as a Patron of the Sickle Cell Society.

Could you please say a little about the Mary Seacole Memorial Statue Appeal (I believe you are Vice-Chair), how much more money is required and the link for donations?

Delighted to! Mary Seacole (1805-1881) was a Jamaican-Scottish nurse who travelled to London to offer her services to nurse wounded soldiers in the Crimean War but was turned down. Not giving up, she funded her own passage out to the battlefields and became a Victorian celebrity for her compassionate care

to the sick and dying. Unfortunately her achievements were forgotten after her death but now the Mary Seacole Memorial Statue Appeal (<http://www.maryseacoleappeal.org.uk/>) is on track to erect, next year, the first ever statue of her in the world and the first to be named after a Black woman in the UK. It will be sited in the gardens of St Thomas' hospital, overlooking the River Thames and the Houses of Parliament. We have raised over £345,000 and now require a further £90,000 to reach our target. Donations can be made online via: <http://www.justgiving.com/maryseacolememorial/donate>

What hobbies and pastimes have you been able to take up since your retirement in 2007 (if any)? I know you are a proud grandmother!

Walking in my fantastic local park, reading for pleasure (especially on my new Kindle!), watching much more TV (particularly comedy and detective programmes) and having lunch with friends. Yes, I have a sweet 6 year old grand-daughter who gives me so much pleasure.

What is your favourite holiday destination?

France.

Your favourite food?

At the moment, curried okra and lentils and honeydew melons.

Your idea of a perfect day?

A lie-in, looking out of the window and seeing the sun shining, listening to Classic FM, having a telephone chat with my daughter, 6 year old grand-daughter and a good gossip with friends. Going for a walk, doing a bit of cooking, learning something new and/or funny via the social media, watching some TV. If I'm on the tube reading my Kindle, or on the train watching programmes I've downloaded onto my iPad.

Is there anything else at all that you would like to share with us?

My daughter Azuka is an actress and plays the feisty receptionist Louise in BBC TV Casualty – I am such a proud mother!!

Double Baby Congratulations to Rita and Andrew

By Rita Rodricks



Ellie (L) and Dylan

Andrew and Rita Rodricks are proud to

announce the birth of our twins, Dylan & Ellie, born on the 19th June 2013 at North Middlesex Hospital. I am 44 years old, with thalassaemia major; and we had been trying for 7 years to have a baby. It was hard continuing with IVF (both emotionally and financially) with the repeated knock backs, but we kept on with it and now we are blessed with two beautiful children. I would just like to say don't give up just because you have thalassaemia. It didn't beat us! I was so shocked when told we were having twins. I had a good pregnancy until the eighth month when I started having difficulties; and my babies were born at 34 weeks. As they were premature the twins remained in hospital for 2 weeks, until their weights reached the correct

levels. Other than that, they are perfectly healthy babies!

We know that all our readers will be thrilled for the proud parents. Rita is under the care of Consultant Haematologist Dr Anne Yardumian at the North Middlesex Hospital. Our grateful thanks to Dr Yardumian, Consultant Obstetrician Miss Frances Evans, Transfusion Practitioner Karen Madgwick and Clinical Nurse Specialist Francis Mate-Kole – says Rita “I had wonderful support from my doctors; they were absolutely brilliant – and Karen was there for me morning, noon and night. My nurse Francis even came in on his day off to cannulate me while I was on the labour ward! I thank them all from the bottom of my heart.”

Thank you to St Michael's School, Oxford



Many thanks to the staff and pupils of St Michael's Church of England School Oxford, for raising £110.95 in aid of the UK Thalassaemia Society. Young thalassaemia patient Sabrena Afridi (11), who attends St Michael's, played a violin solo and sang at the local church in order to raise funds for UKTS. Sabrena is under the care of Dr Georgina Hall at the John Radcliffe Hospital, Oxford. Sabrena is seen here at Iffley lock, Oxford.

Engagement Congratulations to Komal and Shaharyar



Congratulations to thalassaemia patient Komal Soomro, whose engagement took place on 3rd March 2014 in Pakistan. Komal, who lives with her family in Dublin, Republic of Ireland, hopes to be married to her fiancé Shaharyar in June 2014.

Komal is under the care of Dr Corinna McMahon, Our Lady's Hospital for Sick Children, Dublin

UKTS injects thalassaemia awareness into the Slough Sikh community

By Anand Singh Ghattaura



The Worshipful Mayor of Slough, Councillor Balvinder Singh Bains (centre) with stall volunteers at the festival



UKTS Vice-President Anand Singh Ghattaura (L) and UKTS Committee Member Tina Bhagirath (R) with a distinguished visitor

On Sunday 27 April 2014, the Slough Sikh community came together for the festival of Vaisakhi, which celebrates the founding of the Sikh community known as the Khalsa. Over 2,000 people from across Berkshire, Buckinghamshire and West London attended the Nagar Kirtan, which saw the Sikh Holy Scriptures carried from Gurdwara Siri Guru Singh Sabha to Ramgarhia Sikh Gurdwara in Slough.

Ramgarhia Sikh Gurdwara invited the UKTS to set-up an awareness stall to highlight thalassaemia and how it affects the Sikh community. The stall was a great success with both the younger and the older generation, with many questions being asked on how you can test for thalassaemia, what is the difference between carrier and major and how does thalassaemia affect marriage and having children in the future.

Friends and families distributed information leaflets on thalassaemia in both English and Panjabi and donations were made to the UKTS.

The Worshipful the Mayor of Slough Councillor Balvinder Singh Bains also took an interest in finding out about thalassaemia and asked how people in the UK are affected by it.

On behalf of the UKTS, I would like to thank Inderjeet Singh Ghattaura, the General Secretary of Ramgarhia Sikh Gurdwara for arranging our presence at the Gurdwara, Tina Bhagirath and most importantly all the friends and family which helped tirelessly on the day in order to make it a great success.

The UKTS is hoping to do many more awareness events within the Asian community.



The UKTS stall ready for action!

UKTS thanks blood donors



Thalassaemia patient Vasos Melides (R) presents a Diamond Award (for having made more than 100 donations); to blood donor Mr Philip Mansfield.

On 17th January 2014 the NHS Blood & Transplant Service held (NHSBT) a celebration lunch at the Bentley Hotel Lincoln, to honour local people who have been regular blood donors. NHSBT kindly asked UKTS National Coordinator Elaine Miller to attend and give a presentation to the guests, so that they could learn about thalassaemia and how much we in the thalassaemia community owe to blood donors. It was a wonderful opportunity for us to thank the people who literally keep us, our friends and family members alive by their generosity. We were also fortunate enough to have local thalassaemia patient Vasos Melides with us; and Vasos spoke movingly about his life growing up with thalassaemia, his success in education and career; and of his gratitude to blood

donors who made this possible.

The presentations were very well received as most of the guests had never heard of thalassaemia; and many remarked on how they had always thought of blood transfusions being used in cases of accidents and surgical emergencies – they did not realise that there is a small group of patients for whom blood transfusions are an essential way of life.

After the presentations there was a ceremony in which Vasos presented awards to the most prolific blood donors in the East Midlands region. It was an honour to be represented at this NHSBT event and we hope to be invited to similar events in the future.

Presentation at St Andrews the Apostle Greek Orthodox School



UKTS Assistant Coordinator Katerina Loizi (far right) gave an awareness presentation at St Andrews the Apostle Greek Orthodox School on 27th March 2014.

On the left is Headmaster Mr Ahearn with science teachers and students.

Turkish station Genc TV helps to raise thalassaemia awareness



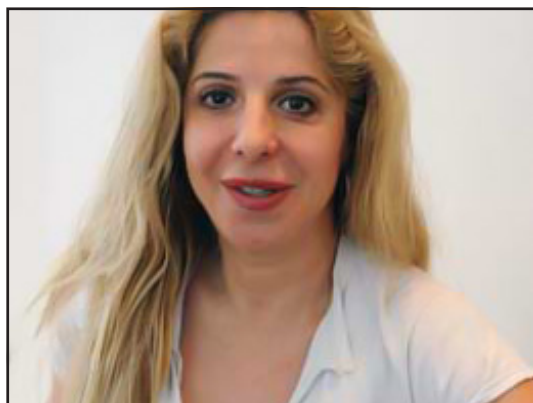
L-R Tanya Yucel, presenter Songur Cambal and Dr Izbel Yusuf

Former UKTS Trustee (and thalassaemia patient) Tanya Yucel organised and took part in a live TV show on Genc TV, a Turkish station which is based in Palmers Green, North London. The programme aired on the 29th April 2014; and was available to satellite TV

viewers in the UK and also to viewers in Northern Cyprus.

Tanya was assisted by Dr Izbel Yusuf, a fluent Turkish language speaker who has a sister who suffers from thalassaemia. The programme covered thalassaemia and its treatment, screening and testing for carriers, the importance of blood donations and how to donate money to UKTS. There was also a live phone-in so that members of the public could ask questions and make comments.

Many thanks to Tanya, Dr Yusuf and to Genc TV for their fantastic support in raising awareness in the Turkish community.



Antonia Kurdash

UKTS thanks our Virgin London Marathon runners

The 2014 Virgin London Marathon was held on Sunday 13th April. We had 2 brave runners on behalf of the UK Thalassaemia Society – Antonia Kurdash and Rencis Baletti. Both ladies finished the race and raised some very welcome funds for the Society. Our grateful thanks to both runners and of course to all their friends and family members who sponsored them.

Antonia Kurdash was inspired to run by her friend and neighbour Androulla Andreou-Panayis, who has thalassaemia, and she rightly feels that raising awareness is just as important as raising money. “Androulla is my inspiration for everything,” she said. “People have donated because I’m running the marathon, not because it’s to raise money for UKTS. It’s very sad that they don’t know what the illness is.”



Rencis and her Mum Fugen Baletti

Rencis Baletti has thalassaemia in her family, so she is well aware of the condition; and she is currently helping UKTS with a project to design new awareness posters. Says Rencis; “Thalassaemia has directly affected members of my immediate family; I am a thalassaemia carrier and so is my Mum. I always wanted to help out the Charity and what better way to go about it than by running the Marathon! Despite training nothing can prepare you for it, it was an exhausting, emotional yet an exhilarating experience. It’s safe to say I will never run a full one again, but the support was amazing and I loved every second of it.”



Sobia with Mr Mohammed Abbasi, Sheriff of Oxford

Awareness at Brooke’s University Oxford

A fund raising reception was held in Brooke’s Restaurant, Brooke’s University Oxford on Monday 28th April 2014. The event was organised by Mrs Sobia Afridi, whose daughter Sabrena has beta thalassaemia major. Since Sabrena was a baby, Sobia and her husband Amjad have both been wonderful advocates for thalassaemia, having formerly spoken on the local radio and been interviewed by the BBC to raise awareness of the condition.

Over fifty guests and ten children attended the event, which had the dual purpose of raising awareness of thalassaemia and funds for the Society. UKTS National Coordinator Elaine Miller gave a presentation about thalassaemia and the fact that a carrier test can be requested before starting a family. Many distinguished guests were present, including Mr Graham Upton the former Vice Chancellor of Brooke’s University; and Mr Mohammed Abbasi, the Sheriff of Oxford. Said Sobia “Everybody went away from this event knowing what thalassaemia is; and we raised over £1,500 for the Society. I would like to thank UK Marketing at Brooke’s for all their support. Watch this space as I am already thinking of the next event!”



Sabrena (in red) with children at the event

Recent Events & Meetings

Those who attended meeting on behalf of the UK Thalassaemia Society are: Anand Singh Ghattaura *Vice-President*, George Constantinou *Secretary*, Tina Bhagirath *Committee Member*, Elaine Miller *National Coordinator*, Katerina Loizi-Read *Office Administrator*, Roanna Maharaj *patient member*, Vasos Melides *patient member*, Tanya Yucel *patient member*

Acronyms

- APPG – All Party Parliamentary Group for Sickle Cell & Thalassaemia
 HCC – Hepatitis C Coalition
 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*
- 13 January 2014 – awareness presentation, Bradford College *Elaine Miller*
- 14 January 2014 – awareness presentation, Bradford College *Elaine Miller*
- 16 January 2014 – awareness presentation, Bradford College *Elaine Miller*
- 17 January 2014 – awareness presentation, NHSBT blood donor reception Bentley Hotel, Lincoln *Elaine Miller, Vasos Melides*
- 21 January 2014 – APPG meeting, London *George Constantinou, Roanna Maharaj*
- 21 January 2014 – members' meeting at UKTS offices, London – presentations by: Prof Marc Turner, Scottish National Blood & Transplant Service; Dr Michael Antoniou, King's



College London

- 22 January 2014 – RDUK meeting, London *George Constantinou*
- 28 January 2014 – HCC meeting, London *George Constantinou*
- 5 February 2014 – NHSBT stakeholder telesurvey *Elaine Miller*
- 16 February 2014 – awareness presentation, St Andrew's Greek Orthodox Cathedral Hall *Elaine Miller*
- 19 February 2014 – NHS SCTSP steering committee meeting, Bishopthorpe Palace, York *Elaine Miller*
- 25 February 2014 – UKTS AGM, UKTS offices, London
- 26 February 2014 – RDUK reception, Westminster, London *George Constantinou*
- 10 March 2014 – UKFHD peer review steering committee meeting, St Thomas's Hospital, London *Elaine Miller*
- 19 March 2014 – awareness presentation, Norton College, Sheffield *Elaine Miller*
- 27 March 2014 – awareness presentation, St Andrew the Apostle Greek Orthodox School, London *Katerina Loizi-Read*
- 31 March 2014 – APPG meeting, London *Anand Singh Ghattaura, George Constantinou, Roanna Maharaj*
- 1 April 2014 – awareness radio programme, London Greek Radio *Katerina Loizi-Read*
- 2 April 2014 – SHCA meeting, Westminster, London *George Constantinou*
- 9-13 April 2014 – International Liver Congress, ExCel Centre, London *George Constantinou, Katerina Loizi-Read*
- 27 April 2014 – Vaisakhi Nagar Kirtan Sikh Festival, Slough *Anand Singh Ghattaura, Tina Bhagirath*
- 28 April 2014 – awareness presentation, Brooke's University, Oxford *Elaine Miller*
- 29 April 2014 – RDMCC workshop, London *Elaine Miller, Roanna Maharaj*
- 29 April 2014 – awareness television programme, Genc TV, London *Tanya Yucel*

Obituary

Maria Kastoras

24.1.1969 – 25.12.2013



On December 25th 2013, Thalassaemia Australia lost a dear friend, work colleague and community educator Maria Kastoras.

Maria was an integral part of Thalassaemia Australia for over 30 years, where she initially assisted family members with fundraising and later becoming both the President of the organisation and then a staff member as well!

In her time with us, Maria cherished her role as community educator and spoke to thousands of students, community groups and corporate organisations about thalassaemia. Maria gave freely of her own personal story to encourage others to become more aware of genetic blood conditions,

and advocate on behalf of our members for better care and treatment.

On an international level, Maria presented at a number of the TIF Conferences, was an active member of the TIF Board and was always willing to share her experiences and the work of Australian thalassaemia community to help others. Some of her greatest work however was carried out in quiet conversations with young patients from around the world, encouraging them to embrace their condition, become informed and look forward to a brighter future.

During the international conferences Maria met and made many 'friends for life', they

laughed together, cried together and shared experiences that will never be forgotten and neither will her smile or her laughter. Maria always affectionately referred to you as her 'other family'.

On behalf of Thalassaemia Australia Committee of Management and Staff we would like to thank you for embracing Maria into your lives, and thank you for the support that Maria's family and friends has received over the recent weeks. Please know that we have passed on your heartfelt condolences to Maria's son Theodore and parents Mr & Mrs Marinakis – to know Maria was to love her, and she will be forever in our hearts.



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:

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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 _____