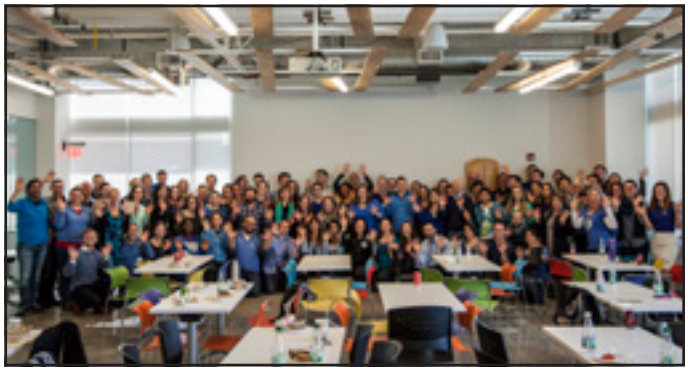
UNITED KINGDOM
Thalassaemia SOCIETY
matters
MAY 2015 ISSUE NUMBER 125
...continuing the fight against thalassaemia

New gene therapy studies show promising results in thalassaemia



The Bluebird Bio team in Cambridge, Massachusetts celebrating Rare Disease Day (28.2.15)

One of the most exciting presentations we heard at the TIF Pan-European Conference in Athens in November 2014 was from a company called Bluebird Bio, a biotechnology company committed to developing gene therapies for several severe conditions, including beta thalassemia. Bluebird Bio's gene therapy aims to treat beta thalassemia major and severe sickle cell disease by taking the patient's own blood cell producing stem cells; and inserting a fully functional human beta globin gene into them. These modified cells are then transferred back into the patient through infusion, a technique known as autologous stem cell transplantation.

In December 2014 at the Annual Meeting of the American Society of Hematology (ASH) in San Francisco, Bluebird Bio presented data from eight patients who had been treated with gene therapy developed by the company. In the first four subjects, each of whom had at least three months of follow up, treatment with Bluebird Bio's gene therapy had resulted in sufficient haemoglobin production to reduce or eliminate the need for transfusions in patients with beta thalassemia major.

These eight patients included the first five subjects treated in Bluebird Bio's ongoing Northstar Study (HGB-204); who all have thalassaemia major. The first two patients are producing steadily increasing amounts of haemoglobin and have now been transfusion free for several months. Three other patients have also been treated but it is too early to draw any conclusions on the success or otherwise of the therapy.

The remaining three patients were subjects of a separate study (HGB -205); and included two patients with thalassaemia major and one patient with severe sickle cell disease. Both the thalassaemia patients rapidly started to produce near-normal levels of haemoglobin after the therapy; and at the time of writing they remain transfusion free at 12 months and 9 months post-transplant, respectively. It is at present too soon to determine whether the sickle cell patient's transplant can be considered a success.

In both studies, the gene therapy has been well tolerated by the patients. One of the advantages of an autologous transplant is of course that the patient's own cells are being reintroduced to the body – there is no donor, so no risk of rejection or graft versus host disease. However it must be noted that before being transplanted, the patient still needs to undergo therapy to completely suppress their existing bone marrow cells (myeloablation); and this means that infection must be avoided at all costs. The myeloablation medicines also cause fertility to be compromised; so Bluebird Bio offers cryopreservation (freezing) of eggs or sperm to all patients before treatment.

We know that our readers will be as interested as we are in these exciting developments from Bluebird Bio. The early results are very promising, and we are cautiously optimistic as we await more long term safety information.

To learn more about the Northstar Study, please visit www.northstarstudy.com. For more information about the company, please visit www.bluebirdbio.com , where you can also sign up to receive Bluebird Bio updates.

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A word from our President

Dear Friends

As usual a lot has been going on at UKTS since our last issue of Thalassaemia Matters. We had hoped to release issue 125 earlier in the year and it is only sheer pressure of work which has prevented us from doing so. UKTS continues to be involved in many front-line organisations, working for improvements in healthcare for thalassaemia patients and others living with long term rare conditions – as demonstrated by a glance at "Recent events and meetings" on page 18! As we approach the summer months, we will be getting even busier; as we are working most weekends to raise awareness of thalassaemia at melas, fetes and festivals all over the UK. Our office will be sending regular updates; and if there is an event in your locality which presents an awareness opportunity, by all means let us know on office@ukts.org.

One very important project that we have begun in 2015 is the updating of our publication Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK. This will be the third edition of the book, the first two editions having been released in 2005 and 2008. A writing group of eminent clinicians (led by Dr Anne Yardumian, Chair of the UK Forum on Haemoglobin Disorders) are working on revising all sections of the book. We hope to launch the finished product in early 2016; and – as has been the case with the first two editions – the book will be available free of charge from the UKTS office to health care professionals, patients and carers.

I am sure that all of you will have been fascinated on reading the front page of this issue, as were I and the other UKTS members who first heard about Bluebird Bio's research at the TIF Athens conference last November. Could it be that a cure for thalassaemia will be widely available within our lifetimes? It is, of course, too early to be sure – but with every small step along the road of research we are surely getting closer. That elusive cure is just over the horizon, just out of our reach. We may not be quite there yet, but I am full of hope for the young thalassaemics of today.

Finally friends, I cannot leave you without mentioning the plight of our friends from the Nepal Thalassaemia Society. As the article on page 11 makes clear, the situation in Nepal is heartbreaking, and the children affected by thalassaemia, who are already very vulnerable, are at great risk from the dreadful living conditions and shortage of essential supplies. Please read the appeal and if you can, spare a few pounds for these members of our "thalassaemia family" who are in desperate need. Our most grateful and humble thanks to everyone who has already donated – we will keep you posted with news of the relief efforts and how your donations are being put to good use.

Sending you all good wishes, until the next issue.

Gabriel Theophanous
President, UK Thalassaemia Society

Our Mission Statement

To be the definitive source of information, education and research for those affected by, or working with thalassaemia.

The UKTS Management Committee

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

Announcing the

UK Thalassaemia Society's Annual General Meeting 2015

2.30pm, Sunday 14th June 2015
UK Thalassaemia Society
19 The Broadway, Southgate, London N14 6PH*

Presentation by Dr Ploutarchos Tzoulis,
Consultant Physician in Endocrine and Diabetes from the award winning team at Whittington Health

"Thalassaemia and Diabetes"

All UKTS members are welcome
Please contact the Society on office@ukts.org or 0208 882 0011 to register your attendance

See enclosed letter regarding nominations to the UKTS Management Committee.

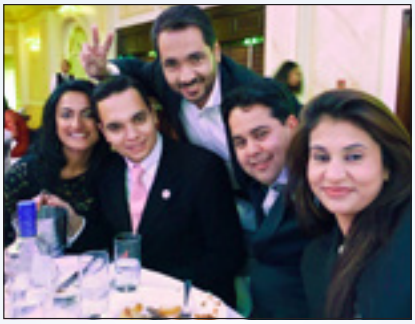
N.B. For all members living more than 20 miles from the UKTS office address above, the Trustees of the Society are offering a discretionary grant of £30.00 per member to assist with travel costs. This amount is a non-negotiable flat fee payment. **All claimants must notify the UKTS office of their attendance by 1st June 2015.** Only those with life and currently paid-up annual membership will be eligible to claim. Payment will be made on attendance at the AGM.

* ***Depending on the numbers who register to attend, we may move the event to a larger venue. Any such change will be communicated well in advance.***

UK Thalassaemia Society Annual Dinner Dance

Regency Banqueting Suite, London N17 6th December 2014

By Tina Bhagirath



L-R – Nishel and Gabriel Theophanous, Raj Klair, Gagandeep and Neha Khattar

Our members showing their paces on the dance floor

The dinner and dance was a lovely event. I was really happy that everyone was enjoying the night. The dance floor was on fire with all the mesh mash of traditional and modern Greek and Punjabi music. It's was absolutely wonderful to see both cultures getting involved in each other's traditional dances.

The raffle went really well, we had some great prizes this year. And a massive thank you to all those that helped me out in the night with my 'wholesale approach' of "Hi, how many books can I give you?" We raised £1,846 on the evening.

We had our long standing supporters, one of which said "I bring my children every year so they will know how important this event is and will continue to attend once we cannot." I'm also pleased that we had some new faces.

Elena P (member): "This was my first time attending the UKTS dinner and dance. I was excited to be going and enjoyed dressing up for the occasion. My friends and I really had a ball. Dinner was fantastic and the music did not stop me from dancing. It was great for the money to be going to such a great cause. Will be recommending it to others and can't wait for the next one!"

I would like to thank everyone who bought a raffle ticket, attended the dinner and dance and a special thanks to Katie Loizi-Read (in the UKTS London office) Koula Kanias (ticket sales) and Amit Ghelani (photography) who helped make this event a success.

Update from the AllTrials campaign

AllTrials calls for all past and present clinical trials to be registered and their full methods and summary results reported. UKTS is one of 556 organisations which support AllTrials.

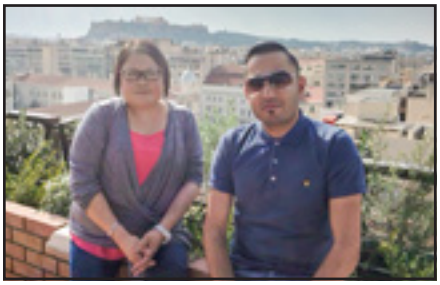
For the first time ever, the World Health Organisation (WHO) has taken a position on clinical trial results reporting, and it's a very strong position! The WHO now says that researchers have a clear ethical duty to publicly report the results of all clinical trials. Significantly, the WHO has stressed the need to make results from previously hidden trials available. Ben Goldacre (a British physician, academic, science writer and AllTrials campaigner) said, "This is a very positive, clear statement from WHO, and it is very welcome." Ilaria Passarani from the European Consumer Organisation BEUC called it "a landmark move for consumers." It is the position you, we and hundreds of people and organisations wrote to the WHO last autumn urging them to adopt. Well done!

You can read more about the WHO's statement and responses to it on the AllTrials website

http://www.alltrials.net/

TIF Pan-European Conference – Athens, November 2014

By May Kong



May (L) with fellow UKTS member Jatinder Karir. Note the view of the Acropolis from the hotel's roof garden

In November 2014 the UK Thalassaemia Society gave travel grants to all patient members who wished to attend the Thalassaemia International Federation Conference in Athens, Greece. Thank you to May Kong of Edinburgh for sharing her experience of her first thalassaemia conference.

My name is May Kong, I am 41 years old and a thalassaemia major patient. I was born in Preston UK, but my family moved up to Edinburgh when I was 6months old. We now live just outside of Edinburgh and if you can believe it, I had never met another thalassaemia patient in my life – until the 6th November 2014, when I attended my first conference at the TIF Pan-European Conference on Haemoglobinopathies in Athens. If any thalassaemia patient or parents that have never attended one of these conferences are reading this, I would highly recommend it. I didn't have any expectations as I had never heard from any other patients about these conferences - however I LOVED every single thing about it. I gained knowledge about new research in thalassaemia and in the best ways of looking after oneself. The highlight for me though was meeting my now new found extended family! Through chats and laughter over those few days I discovered that even though we all have one thing in common – thalassaemia - it has never ruled us. After this overall experience I now look forward to the next conference. Also, most importantly I now know I have made some great and amazing friends for life. There are so many people to thank for making me feel so welcome and looking after me at my first ever conference, however one person I can't thank enough is Elaine Miller of UKTS, thanks for your kindness. If I had not met Elaine at the Scottish Managed Clinical Network meeting in Edinburgh (in May 2014) I would never have heard about the conference and would to this day have never met another thal patient!

Prescription charge increase will hit patients say charities

The Prescription Charges Coalition (PCC), a group of 40 charities representing millions of people with long-term health conditions, today condemned the latest rise in prescription charges in England from £8.05 to £8.20 from 1st April 2015.

Prescription charges have risen for 35 out of the past 36 years. Research by the PCC consistently shows that 1 in 3 people with long-term conditions such as asthma or Crohn's and colitis in England do not collect medicine because of cost. Three quarters of those say their ability to work has been affected as a result.

Jackie Glatter from the Prescription Charges Coalition said: "This further increase in the prescription charge is likely to worsen the significant impact charges already have on people with long term conditions.

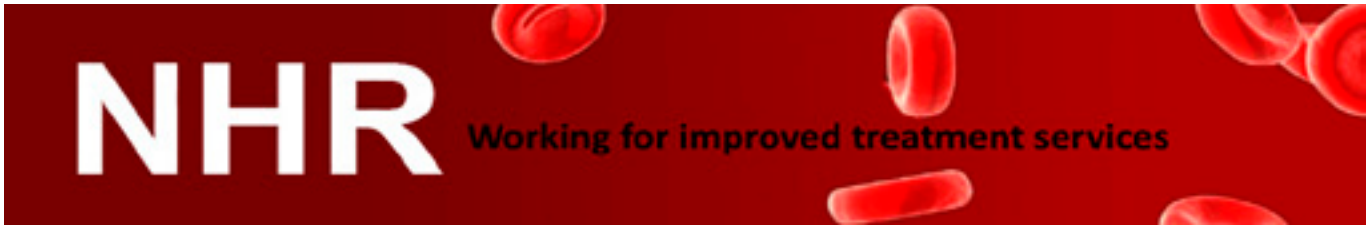
"There is a strong evidence base which demonstrates that prescription charges act as a barrier to people with long term conditions getting the medicines they need."

Tracy Keown, from Surrey, whose 21 year old son had a stroke due to not being able to afford the warfarin he needed since having an aortic valve replacement, said "No parent should see their child nearly lose their life because a life-saving medication costs money, while nit lotion can be obtained for free."

Jackie Glatter added: "This is likely to cost the NHS more in the long-run as it leads to poor health, increased admissions to hospital and lower productivity as people have to take time off work.

"People with long-term conditions deserve better. The current system of exemptions for prescription charges has not changed since 1968 and is outdated, arbitrary and unfair. The Prescription Charges Coalition is calling for everyone with a long-term condition to be exempt from charges so that they can manage their condition effectively and get on with their lives."

For more information about the Prescription Charges Coalition, visit www.prescriptionchargescoalition.org.uk



The National Haemoglobinopathy Registry – are you registered?

We have probably all read stories in the press about our personal information being sold or used for marketing and this is indeed very worrying. None of us likes to think of unauthorised persons having access to our personal details – it brings up an uncomfortable feeling of being watched by "Big Brother"! However, there are instances where (with appropriate safeguards) data collection can be incredibly useful; and healthcare planning is one of these cases. Healthcare planners need to know exactly how many patients are registered with each hospital and what treatment they are being given so that over the long term, this information will enable us to track which treatments are most effective. Adverse events such as life-threatening complications and emergency admissions are also reported and these can help to highlight specific problems and improve outcomes as doctors can see patterns emerging from the data.

Ask your doctor if you are registered

The UK Thalassaemia Society strongly endorses the NHR and recommends that all patients speak to their doctor to make sure that they are registered.

What is the National Haemoglobinopathy Registry?

The National Haemoglobinopathy Registry (NHR) is a database of patients with red cell disorders (mainly sickle cell disease and thalassaemia major) living in the UK. This database collects information which is required by the Department of Health from the hospitals which treat patients with red cell disorders. The central aim of the registry is to improve treatment services - without the right information, hospitals will not be able to obtain and direct the money required to do this. The NHR provides invaluable information with which to negotiate for improvements in the red cell haematology service that will in turn lead to improvements in patient care. The data is also essential for healthcare planning, identifying patient numbers and research into improved treatment methods. For anyone worried about their information being held in a database, it is important to remember that any data used for these purposes is presented as anonymous group reports and cannot be traced back to individual patients.

What sort of information is collected?

The NHR collects information on diagnosis, date of birth, GP code, NHS number, name, the use of blood transfusion, therapy types, and the risk factors for some of the disease complications such as use of iron chelation therapy. The database also collects information on causes of death. A complete list of information types collected can be viewed on the NHR website.

Why is it important to collect this information?

In the future, with changes in the nature and organisation of medical services and advances in treatment, we will need to keep more detailed information on basic treatment of red blood cell disorders, treatment outcome and the natural history of sickle cell disease and thalassaemia. This will help advance the understanding and treatment of these conditions and in turn improve the standard of care. This information is vital when negotiating for adequate resources for your treatment and care.

How safe is the NHR? How can I be sure that unauthorised people will not have access to my information?

Absolute patient confidentiality is extremely important. This is a "named database" in which we store data on named individuals identified also by their NHS Number.
The data is stored in a secure office in Manchester Royal Infirmary in accordance with security standards laid down by the Data Protection Act (DPA) of 1998. The NHR is inspected regularly to confirm that it continues to comply with legislation such as the DPA. All data is held within the NHS, incorporating a number of security features to ensure security of the data. This is far more secure than a paper system or the post. The combination of passwords, encryption and other security provide a much higher level of security than e-mail, internet shopping or even internet banking. Information with the patient's name or NHS number is only shared with the patient's own hospital. Hospitals can only access data on their own patients. No outside agency or organisation can access the NHR and the NHR cannot be used to identify a patient's address. Reports from the database always show anonymous data that cannot be traced back to individual patients.
You can download the NHR patient leaflet yourself by following the link below:
http://www.nhr.nhs.uk/docs/patientinfoleaflet/PIL.pdf

The Heavy Iron Load of the Heart

Dr Amna Abdel-Gadir and Dr J Malcolm Walker

The only way the human body can regulate iron levels is by limiting the amount absorbed from the gastrointestinal tract. Patients with haemoglobin disorders such as βthalassaemia major require blood transfusions to survive, but iron overload develops without appropriate chelation. Iron is not equally distributed in the body, and deposits preferentially in the liver, brain, and the heart. This deposition leads to organ damage and loss of function.

What does iron do to the heart?

The uptake of iron in the heart is much slower than in the liver, and therefore iron loading occurs much later in comparison to liver loading. Iron deposition in the heart usually begins at an accumulation of 20g, and appears to follow a characteristic pattern. Initially it is deposited in the muscles of the main pumping chambers of the heart (ventricular myocardium), and then in the atrial myocardium and electrical (conducting) system. These changes can result in a reduced cardiac function, which may lead to heart failure. Arrhythmias can also complicate severe iron loading of the heart and precipitate acute decompensated heart failure. Early treatment with intensive chelation therapy (intravenous therapy 24 hours a day, 7 days per week) is life saving in these now rare circumstances. In the older βthalassaemia major patients, even in the absence of current iron overload and with otherwise good heart function, arrhythmias may occur in up to 40% of the over 40-year age group. Atrial fibrillation (AF) is the commonest arrhythmia in this group and needs to be clinically assessed as it may pose a risk for complications, including stroke.

Measuring iron in the heart

Dr Lisa Anderson developed in 2000 a non-invasive method to measure heart iron using the MRI T2* parameter, in a joint British Heart Foundation funded project supervised by Professor Dudley Pennell and Dr Malcolm Walker. Since the widespread adoption of tissue iron measurement with the MRI T2*, used to guide and monitor the effectiveness of therapy, there has been a greater than 70% fall in cardiovascular mortality in β-thalassaemia major.

It is important to measure cardiac iron directly as it does not always correlate with liver iron or blood ferritin levels. A value of 20ms and above is considered to be normal. Values less than 20ms indicate the presence of iron in the myocardium, where <20-14ms indicates mild, <14-10 indicates moderate, and less than 10ms quantifies severe iron loading.

In countries where MRI is not available, echocardiography is used to monitor the heart function and trends in ferritin levels are carefully assessed.

T1 mapping for iron overload – the theory

T1 mapping is a method in development that may compliment T2* in confirming the presence of iron in the heart when the diagnosis may not be clear. T1, like T2*, is an MRI measurement altered by the presence of iron. In a short, single breath-hold a colour image is instantly visible providing an immediate value (figure 1). This removes the need for complex analysis after the scan has been acquired. T1 mapping may be particularly useful in patients who are not able to breath-hold for long periods of time such as children and pregnant women, and also in countries where T2* is costly and time-consuming.

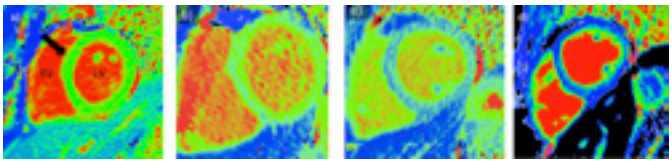


Figure 1. T1 mapping images demonstrating different severities of iron loading. Picture a) is from a healthy volunteer without iron loading, b) mild iron; c) moderate iron; d) severe iron loading. Note how the myocardium (black arrow) changes in colour from green to blue with the severity of iron.
(RV: right ventricle; LV: left ventricle)

The future

Together with Dr Malcolm Walker, Professor John Porter and Professor James Moon at University College London we have started to look at the relationship between T1 mapping and T2*, and have found a close correlation between the two measurements. This is particularly seen when the value of T2* starts to become abnormal. Based on these initial findings we aim to investigate the use of T1 mapping further by recruiting patients with thalassaemia, including children and pregnant women. We want to reproduce the findings we have already found on a larger scale.

We hope that with the help of the thalassaemia community we will be able to bring T1 mapping into clinical practice to benefit patients all over the world.

For further information please see drmalcolmwalker.com or drmalcolmwalker.co.uk.

Continues on page 8 ➡

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Alternatively please contact us at:
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67 Chenies Mews, London WC1E 6HX

Dr Amna Abdel-Gadir BSc, MBBS, MRCP

Dr J Malcolm Walker BSc MBChB MD FRCP

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Centre for PGD Guy's & St. Thomas' Hospital Update

October 2014

Preimplantation Genetic Diagnosis (PGD) started nearly 25 years ago and thousands of babies have been born worldwide since then. In our centre we have been offering PGD to couples at risk of having children with serious genetic disorders since 1997 and are now in our 17th year of service. Over that time there have been many changes to what is offered and a significant increase in the number of referrals and PGD treatment cycles.

This is our latest update and we hope you will find it helpful. Our contact details are provided below and we are always happy to help when we can.

What is Preimplantation Genetic Diagnosis (PGD)?

PGD uses IVF (in vitro fertilisation) to create embryos in the laboratory from the eggs and sperm of a cou ple who are at risk of having a child with a genetic condition. Each embryo is then tested for the particular genetic disorder. One (occasionally two) unaffected embryos are then transferred into the womb, in the hope that a pregnancy will occur.

Who can have PGD?

PGD is only offered in a few centres in the UK. Our PGD centre is able to offer PGD for many of the most common genetic conditions and for most chromosome rearrangements. In many cases we are also able to set up PGD tests for rare genetic conditions, on a case-by-case basis.

There are two steps to treatment. The first step is to create, biopsy and test embryos. The second stage is to transfer unaffected embryos to the uterus (also known as womb).

How do I get referred?

Please ask your genetic counsellor or consultant geneticist for more details. They can then refer you to our centre for an initial appointment. Before offering you an appointment we often have to discuss individual cases as a team, particularly if testing is requested for a condition for which we have not offered PGD before. We are usually able to offer you an appointment within 8 weeks of referral and sometimes sooner.

Is treatment available on the NHS?

If you live in England there is an NHS national funding policy. This means if you are eligible you may be able to have UP to 3 cycles of PGD. PGD funding is only be available if:

- You have no healthy children from your current relationship
- Female is under 40 years old at time of treatment
- Female's Body Mass Index is between 19.5 and 29

- Neither partner smokes
- A UK licence is agreed for PGD for the condition affecting your Family (we can apply for a licence if one does not exist already)
- There is no indication that PGD is unlikely to work for you.

Does it work?

There are many things that affect the chance of success. Our significant success rates reflect the largest number of cycles done in any centre in the UK.

The further through the steps of a cycle a couple gets, the better the chances of success.

Guys Success rates Sept 1997- Dec 2013;

Cycles started	Clinical pregnancy rate	Babies born
1741	31% per cycle started 40% per embryo transfer	Total: 555 406 singletons 134 twins (67 sets) 15 triplets (5 sets) *

Babies born September 1997- December 2014

Total number of PGD babies 582		
Singletons = 427	Twins = 140 (70 sets)	Triplets = 15 (5 sets) 3 sets resulted from the transfer of only 2 embryos

The above table gives the success rate of all our cycles. More recently success rates have improved and over time we expect this will change the above figures too. If you would like details of success rates in other UK centres you can find this information on the Human Fertilisation & Embryology Authority (HFEA) website: www.hfea.gov.uk

What does PGD involve?

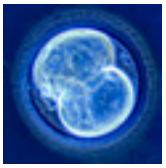
For some genetic conditions, prior laboratory work up is required to develop a genetic test that will be used on the embryos. This preliminary work can take anything from two to nine months depending on the technical requirements of the case.

Egg collection and fertilisation

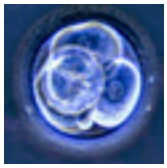
Even though most couples who have PGD are able to become pregnant naturally, they will need to undergo in vitro fertilisation (IVF) to produce embryos for testing. First, the ovaries of the female partner are stimulated to produce several eggs. This is achieved by using a combination of fertility drugs and once the eggs are mature they are collected under anaesthetic. The sperm are then used to fertilise the eggs in the laboratory.

Testing embryos

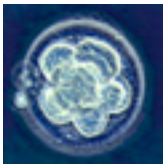
Eggs which are successfully fertilised become embryos. Five days later, once the embryo has grown to a ball of cells (known as a 'blastocyst') a small sample of cells is very carefully removed (this is called the embryo 'biopsy').



Day 1 early embryo



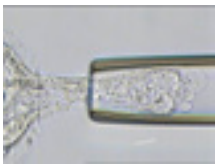
Day 2 embryo



Day 3 embryo

Day 5/6 blastocyst

Blastocyst held in position



Cells extruded through small hole made in the outer coating of the embryo

Cells removed and sent for testing

After the biopsy the embryos are rapidly frozen (this is called vitrification) while the genetic test is performed on the cells taken from the embryos. Genetic testing takes two to four weeks to complete depending upon the reason for PGD.

Embryo transfer

Once the genetic test is completed, and providing the results show that there is at least one unaffected embryo available, an unaffected embryo can be selected and warmed, and transferred into the womb. A pregnancy test is carried out 12 days later to see whether the PGD treatment has been successful.

How long does it take to start treatment?

The time frame involved in preparing a couple for PGD varies depending on the reason PGD is being done.

If it is a new condition for which we have not done before it will take much longer.

For a PGD test that we already have set up: **4-10 months**
For a new PGD test: **up to 18 months**

Satellite services

Travelling to London for treatment is time consuming and sometimes expensive. We run 3 satellite PGD services in Leeds, Sheffield and Exeter. Couples start the first part of their treatment in a satellite centre and only come to London when they get to the stage of egg collection. If you are interested in this service please ask your Geneticist or Genetic Counsellor for more information.

Contacts and website

Our staff: Alison Lashwood, Genevieve Say, Sarah Ross, Frances Flinter and Sara Levene. Jas Dhesi is our PGD administrator.
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www.pgd.org.uk- this is our website. Patient leaflets, outcomes and updates.

ApoPharma Announces Health Canada Approval of Ferriprox (deferiprone)

Ferriprox®
deferiprone

Already approved in more than 65 countries worldwide, Ferriprox could become a new treatment option for Canadian patients with blood transfusion-related iron overload -

TORONTO, Feb. 17, 2015 /CNW/ - ApoPharma Inc., today announced that Health Canada has granted approval of Ferriprox (deferiprone), an oral iron chelator for the treatment of patients with transfusional iron overload due to thalassemia syndromes when current chelation therapy is inadequate.

"We are very pleased that Health Canada has responded positively to the extensive clinical data and track record associated with Ferriprox," said Dr. Michael Spino, President, ApoPharma, Inc. "This drug will provide a critically important new treatment option for individuals who have not had a good response with another therapy."

At any given time in Canada, approximately 400 patients with the inherited blood disorder thalassemia require blood transfusions for survival. While repeated blood transfusions are life-saving for many patients, they result in an accumulation of iron in blood and in organs such as the heart and liver. Without effective treatment, iron overload ensues and can lead to organ failure and early death.

Not all patients have their iron burden successfully controlled by the currently available treatment options. Approximately one quarter of thalassemia patients fall into this category, according to research conducted by the NIH- funded Thalassemia Clinical Research Network.

Clinical studies and more than 15 years of international post-marketing surveillance totaling approximately 58,000 patient years of exposure have demonstrated that Ferriprox can control the iron burden in patients who are transfusion dependent. In the pivotal clinical trial Ferriprox was twice as effective as deferoxamine in removing cardiac iron.

Analysis of studies sponsored by ApoPharma shows that one year of Ferriprox therapy met the targeted reduction of serum ferritin levels (a measure of total body iron) in approximately half of the patients who had failed previous therapy.

Ferriprox is currently approved in more than 65 countries worldwide for the treatment of iron overload in patients with thalassemia major when the standard therapy is contraindicated or inadequate. With the present approval, patients whose current therapy is unsatisfactory can be treated with Ferriprox as an established alternative.

One to two percent of Ferriprox patients develop agranulocytosis, a decline of certain white blood cells (neutrophils) that may put them at risk of serious infections. ApoPharma is introducing a program designed to mitigate the potential risks among patients taking Ferriprox, similar to a program implemented in the US in 2011.

About ApoPharma

Headquartered in Toronto, ApoPharma Inc. is a pharmaceutical company specializing in the discovery and development of new medicines for critical diseases. It is part of the Apotex Group of Companies, the largest Canadian-owned pharmaceutical company.

SOURCE Apotex Inc.
For further information: Mike Woolcock, 416-401-7571 , mwoolcoc@apopharma.com

Shortened URL htpp://cnw.ca/JB8B

Nepal Thalassaemia Society – appeal

Dear friends

When we heard the news of the appalling tragedy in Nepal we had just been about to publish an update from our old friend Wendy Pinker, who works with the thalassaemia children of Nepal. Sadly the happy news of Wendy's recent visit to the thalassaemia clinic to bring gifts and essential supplies for all the children has been overtaken by the dreadful news of the earthquake and the devastation it has caused to the already desperately poor people of Nepal. Wendy herself had only been back in the UK for a few days when the earthquake struck on 25th April 2015. Since then she has been trying to raise funds to help the Nepal Thalassaemia Society so that they can provide assistance to vulnerable families affected by thalassaemia. UKTS circulated the appeal below and many of our members have responded in heartwarming fashion. A huge ***THANK YOU*** *to all those who have already donated – we will be sending round bulletins by email and in the next issue of TM to keep you informed of how your donations are being used to help the thalassaemia children of Nepal.*

Appeal

We have all seen the news about the devastating earthquake in Nepal. There are many charity appeals going on at the moment and they are all worthwhile. However there is one charity very close to home and close to our hearts and that is the Nepal Thalassaemia Society. Long-standing UKTS members will be familiar with the story of NTS and how it was founded by a British woman, Wendy Pinker, living in Nepal. This lady, who is not a healthcare professional and has no personal connection with thalassaemia, has single-handedly raised enough money to not only open a thalassaemia transfusion clinic in Kathmandu, but to keep it open and running since 2009. The clinic provides free transfusions for over 120 very poor children on a fortnightly basis.

The clinic building has miraculously survived the earthquake, but may need some structural work. However many of the thalassaemia children (who travel many hours to Kathmandu for their transfusions) live in the epicentre of the earthquake and have lost their homes, some are spending the freezing nights in the open, some are in tents or meagre shelters and many are in very remote areas. They are in desperate need of our help. They also urgently need blood and medical supplies.

Many of us want to donate money to help the earthquake victims; but by donating to the Nepal Thalassaemia Society we can make sure that our donations are going directly to help families affected by thalassaemia. The relief efforts are being coordinated by Wendy Pinker in the UK and Durga Pathak, the President of NTS, in Nepal. Please, if you have a spare couple of pounds, consider sending them to NTS for the benefit of the children – a very little money goes a long way in Nepal and you can be sure that your donations are going directly to those in need in our own "thalassaemia family".

EVERY SINGLE PENNY DONATED WILL GO DIRECTLY TO NEPAL THALASSAEMIA SOCIETY

Bank details
Nepal Thalassaemia Society
Account No : 71463209
Sort Code : 40 47 34

Email : pinkyland_2000@yahoo.co.uk

Address for cheques: Wendy Pinker, 13 Phoenix Way, Portishead, Bristol BS20 7FG

Some of the children having their transfusions in the open air after the earthquake (in case of aftershocks).

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Wendy with Harimaya Upreti, who was the first thalassaemic child she met in Nepal. Harimaya's two older sisters both sadly died of thalassaemia without ever having received a diagnosis or treatment. Wendy was volunteering at the school in the town of Pokhara when she met this frail little girl who seemed to be wasting away. She was told by the local people that the children of this family got weaker and weaker and no-one understood why. Wendy took Harimaya to Kathmandu (a 9-hour bus journey) where she was told the little girl had thalassaemia and that she would inevitably die. So began Wendy's amazing quest to learn more about thalassaemia and its treatment.

Sadly Harimaya and her parents are currently homeless as their modest home and all their possessions were completely destroyed by the earthquake. Their only form of shelter is a half-collapsed animal shed which they share with their buffalo.

Update from Nepal by Wendy Pinker

Some of the Nepali families have more than one child with thalassaemia….

Sarasuti and Niru are two sisters who come from a very poor family. Their father is a porter and earns just 500rs (£4.00) per day… he works 14 hour days and is often away from home for weeks at a time leaving his wife to manage the girls' treatment. Having free treatment at the clinic is a massive help to them but even just paying for the journey there is a strain and many times the girls have to miss their transfusion so their parents can put rice on the table. We would very much like to be able to offer the girls and their parents some extra help so that they never have to miss their life saving treatment.

Sunil and Anil Rai are brothers from Chitwan 8 hours from our clinic in Kathmandu. Their father is a simple farmer but has no land of his own, he is a labourer and earns just 300 (£2.50) per day. Sunil and Anil have now had to leave their family home to live with their aunty and uncle in Kathmandu to be near the clinic. It is heart breaking for both the children and their parents as they can only come together as a family at festival times. We would desperately like to be able to offer some help for transport costs so that the family could be together where they belong.

Kamal is the oldest Thalassaemic in Nepal at 34 years old. He walked through our gates on Christmas day 3 years ago having travelled over 600km for 3 days in a leap of faith that he might be able to get help in Kathmandu. He is now the secretary at the clinic and is having regular transfusions. Kamal has some financialhelp with his transportation from a lovely lady called Jill in the UK; but he is now urgently in need of regular chelation treatment.... as it's clear to see Kamal is very poorly but his spirit is strong and I know that with proper chelation treatment Kamal's health could be much improved.... It is my mission this year to try and secure the cost of his treatment for him.

Thalassaemia and self-image

By Tom Koukoulis

I remember the frustrations around puberty and coming of age, when I was in high school. We were turning from kids to teenagers. The boys would start growing facial hair and their voices would deepen. The girls' bodies would also begin changing. And everyone was a mess of their raging hormones. We guys were obsessing over who would be next to start growing facial hair. We'd talk about the girls and how they were starting to look different. We were turning from children to young adults.

Each day had me painfully looking at the mirror for any signs of puberty. I was watching all of my classmates grow body hair, but I wasn't; I couldn't wait to catch up with them. I have thalassaemia and like many other people with thalassaemia I experienced delayed puberty. While my friends were dating, I didn't feel attractive enough to date. It actually became so severe that I started to hate looking at my own reflection. I was even avoiding going anywhere near windows or glass doors for fear of seeing my own reflection. Each time I would catch a glimpse of myself, I would cringe inside. The person I would see reflected in the window did not look like the person I was in my mind. Looking at myself was too painful. In my mind I looked different… handsome. But that was not who I would see in the windows.

And then there were the scars, physical as well as emotional. I have scars on my veins from transfusions, scars on my tummy from nightly iron chelation injections of Desferal, and a big scar that runs the length of my abdomen from surgery to remove my spleen. In my twenties, when I had heart failure, I refused the insertion of a port-a-cath, a permanent tube in my chest to administer the iron chelation medication straight into my heart. This was a potentially fatal decision, but I was dreading yet another scar. I chose to take the risk of dying over having my body scarred again.

In addition, many people with thalassaemia have diabetes or pre-diabetes, which makes the individual accumulate more fat than normal. Also, because of hormonal imbalances men can develop a condition called gynaecomastia, which means they can grow breasts, not necessarily as large as a woman's but certainly big enough to be visible under clothing and when naked. Gynaecomastia is treatable with plastic surgery, but it's not without complications and where present adds yet another layer to one's body image issues. At the very extreme end, people who receive inadequate treatment for thalassaemia also have noticeable bone deformations such as short arms, spinal curvature, and protruding facial bones. I was lucky enough not to have any major bone deformations.

As feeling attractive to other people goes hand-in-hand with body image, it's not illogical that I felt very unattractive. It's also not illogical that I felt unworthy of being wanted. I did not feel like an attractive person. I felt I did not deserve to be seen as a person worthy of being attracted by and attracted to other people.

Both men and women with thalassaemia who experience delayed puberty can be left feeling like this. In these situations, comparisons with our peers often make us feel inadequate; and this is made even worse when people around us treat us as though we are much younger than our actual age. This is why it is so important that thalassaemia patients are regularly checked by an endocrinologist when they are young, so that any hormonal deficiencies or imbalances can be corrected immediately.

Currently blood transfusions in the UK are as safe as they can be using current scientific methods; but that was not the case two decades ago. Some people have contracted hepatitis C and HIV from blood transfusions, which apart from the physical health implications, can affect intimate relationships as well as that person's perception of their own attractiveness. Even though both of those conditions are treatable and the risk of transmission can become negligible, their constant presence still impacts a person's emotions as well as their relationships.

When I talk to my friends who have thalassaemia, they more often than not mention some of the above and how they feel it is impacting their love lives and relationships.

The daily management of thalassaemia and the constant hospital visits, nightly infusions, needles, etc. may also affect interpersonal relationships and challenge a person's confidence and self-worth. I don't use Desferal anymore and some of the scars have healed, some scars though, like the surgical ones, are still there. And I guess some of the emotional ones too. I have come a long way since I was a teenager and I've worked with these issues. One event I can remember that sparked off a process of overcoming the issue about my physical scars was when I was on holiday on a Greek island and saw a guy on the beach with a scar more prominent than mine, and he obviously didn't give 2p about it. I thought if he doesn't worry about it, why should I? And that really helped set the process of healing in motion.

In the years that followed I have had psychotherapy and even though it may not be for everyone, it has helped me to some degree. I have also read some good personal improvement books and done quite a bit of awareness work. I have

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learned to have compassion for myself. I don't avoid glass doors or windows any more - sometimes nowadays I even think I look cute when I catch a glimpse of my reflection!

But I don't think I have completely overcome these issues. They are still there somewhere and they crop up every now and then. I've acknowledged them and embraced them and they are part of who I am. What makes me myself. They have played a major part in how I have defined my self-worth and how I behave when I'm with intimate with someone. A very important part of the healing process is to acknowledge the effect of a long term condition on your psyche; and to also acknowledge the fact that someone with thalassaemia can deservedly be a loved and loving person.

Tom Koukoulis lives with beta thalassaemia major. He lives in London, UK and works as a software engineer. He also works with thalassaemia charities in the UK and abroad to promote awareness of the condition, and improve treatment for people with thalassaemia and sickle cell anaemia.

Life is Sunshine!

By Androulla Andreou-Panayis

My name is Androulla and I was born in March 1963. I have two younger brothers, Mario who is two years younger and Andro who is 9 years younger. We were born and brought up in Hackney in London until I was 11 years old, when my parents decided to buy a house and move to Palmers Green.

I was born healthy and rosy cheeked as my mother puts it! But after a year my mother could see I was not the same, I lost my appetite slept all the time and my rosy cheeks had disappeared. After a visit to a GP who advised my mother to take me straight to the hospital, I was admitted to The Queen Elizabeth Hospital for children. After a few weeks of tests and not knowing what was wrong I was finally diagnosed with thalassemia major – or so they thought! I was sixteen when they realised I was an intermedia but had been treated as a major.

My parents had heard of thalassemia because where we were living at the time they knew a family who lived below us who had two children with thalassemia. The two families become very good friends as you may imagine.

So began my journey living with thalassemia; and my brother Mario joined me. We went to the Queen Elizabeth Hospital together every month. I remember getting excited to go and play with the toys they had on the ward - or was it a way to hide from my mother how scared and how desperately we did not want her to go and leave us? In those days our mother was not allowed to stay with us, so she would leave us crying our hearts out. I remember the blood came in glass bottles and the horrible butterfly needles that still give me nightmares now!

At the age of five my parents had a visit from a social worker who arranged for my brother and me to attend a school for 'special needs children,' my mum was told it would be better for me because the school was all on one level and I could have a sleep during the day. So my parents agreed thinking they had made the right choice, later on my brother joined me.

I left school with no qualifications so I applied to go college not really knowing what I wanted to work as. I went on do a BTEC (business course). I found the course extremely hard as I did not know how to apply myself to study, so my first year was a complete failure. My tutor back then advised me to go on and do a course working with children - maybe she recognised something in me and she was absolutely right, I definitely was not a business woman! Taking my tutor's advice was the best thing I did. My learning journey had begun. I went on to do a year's community course and from there I went on to do a two year social care course. I left college and began to job search, having difficulty in finding a job working with children because of my lack of qualifications. I took a job working in Marks and Spencer in Oxford Street. Working in retail made me even more determined that I was not going to stay in this line of work. When I came across an article advertising for an apprentice in child care, I was over the moon. With 400 applicants I thought I had no chance, but I tried not to let that put me off. I went for the one-hour interview which involved a written essay and being interviewed by a panel of four. I was called back for a second interview and was offered the position. The NNEB was a 2 year programme and I completed the course and passed with distinction. After I completed the course I went for my first interview in a nursery in Hackney called Sunbabies; while in this setting during inspections I had very positive feedback, encouraging me to move on and go forward to do a foundation

degree. At the time I did not really have the confidence, so I continued my career in Hackney working at various nurseries (Children's Centres) for 18 years. After this time I decided it was time to move on as I felt that after all these years I had learnt everything there was to learn in Children's Centres.

I went on to work in a school nursery which was slightly different to where I was before. After working at this school for four years I decided to do my Foundation Degree for my own development, the school approved and allowed me the time off I would need to attend university.

Off I went to do my degree at Middlesex University! I loved university life and could only imagine how it must feel to be young and living at a university. The atmosphere was buzzing and as a student I could feel that life here was fun but could also be stressful – it was an experience that you can never replace in your life. The friends and people you meet are something you take with you for the rest of your life. I passed my two years and I then had another surprise, my manager offered me to work as an unqualified teacher in the nursery - I was over the moon. I was finally doing what I had always wanted to do. Although I was thrilled I now felt the pressure even more!

I now had to study for my GCSEs in maths and science in order to be able to complete the fourth year to get my teaching qualification, so during my six weeks' summer holiday I spent all my time studying science which I knew nothing about. I had never heard of atoms! After weeks of reading I took the exam and passed. I could not believe it but now I had to study maths - I needed a little break before I could start again!

So without any thought I applied to continue with my studies and went on to do a BA Hons in Education at South Bank University. I graduated in October 2014 with a 2:1 degree, a very emotional but proud day for me. Finally, after many months of revising I passed my maths GCSE and achieved a grade B in December 2014.

I am currently still working as an unqualified teacher in my new school (Hazelbury) which I joined in September 2014; and have now applied to do my teacher training which starts in September 2015. Just a few more hurdles to overcome and I should reach my goal - anyone can be a winner, you just need the determination!

TSY – new thalassaemia support group in South Yorkshire

By Nighat Khan

Cllr Nicky Bond cuts a ribbon to symbolise the opening of the support group; assisted on either side by thalassaemia consultants Dr Josh Wright (Royal Hallamshire Hospital) and Dr Jenny Welch (Sheffield Children's Hospital). Also in the front row are sponsors Shabir Mugal of Imaan Radio and ex-Cllr Maroof. Nighat is on the far right (in red headscarf).

I have recently launched a small support group for people who are affected by thalassaemia.

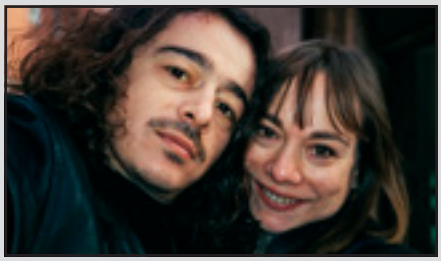
This has come into existence due to the closure of Sheffield Sickle Cell and Thalassaemia Foundation where I worked for 14 years as a community development worker. The clients still needed support as there was no service; so I continued to offer support on a voluntary basis. I felt that I just couldn't let these people down as they already have a lot on their plate through the illness they have. This led to the establishment of the support group TSY (Thalassaemia South Yorkshire) based in Sheffield.

On 4th March 2015 we held an event to celebrate the opening of the support group at St Peter's Church in Netheredge, Sheffield. The event was attended by community leaders and workers, local councillors, health care professionals and of course thalassaemia patients and carers. (Elaine Miller, National Coordinator of UKTS attended on behalf of the Society.) We heard presentations from Raqia Udin who talked about the challenges she faces in caring for someone who has thalassaemia; and Shabana Hussain who talked about her experience of living with thalassaemia. A group of young people also performed a role-play about marriage and testing for thalassaemia trait.

TSY contact details: 07988 033 534, tsysheffield@gmail.com

In Loving Memory of Athena (Tina) Sergides (née Paraskeva)

27.7.61 – 23.1.15



Tina with her beloved husband Mario (12.10.70 – 27.7.11). May they rest in peace and love together.

This tribute was given by Neelam Thapar, one of Tina's friends, on behalf of the UK Thalassaemia Society at a memorial service held on 1st March 2015 at Golders Green Church. Thank you to Neelam, for allowing us to publish these lovely words; which bring the memory of our dear friend so vividly to life.

I have been asked by the UK Thalassaemia Society to say a few words to pay tribute to Tina's charitable contribution to the Society and the thalassaemia family. Tina touched so many people and we will all have a kaleidoscope of memories that we will hold dear. She was an extremely loyal supporter of the Society being involved from very early on and serving several terms on the Management Committee in the 90s before becoming Vice-President in 2001 -2003.

She made many lifelong friendships through the Society and there will be many stories shared today about Tina from the early years; a time when groups of young people got to know others, sharing common experiences and through that having fun.

Tina was involved in many different aspects of the Society and very much known in the thalassaemia family, not only in the UK and Cyprus but internationally and there will be many here today that will remember Tina at Conferences. Tina became a protective friend, buddy and mentor to many over the years and showed warmth and love that gave others their own strength and confidence, showing that thalassaemia did not have to dominate life and everyone had a voice.

She was passionate about working in a team to provide a better future for thalassaemics and their families and during her tenure at UKTS, was involved in many projects that raised awareness of thalassaemia and along with her husband, Mario provided inspiration to others.

She worked on a team to develop and implement the first ever UKTS Compliance Workshop in 2002 held in Birmingham to help challenges in patients complying with arduous treatment. She would give time to those who did not feel positive to educate them and most importantly to listen to them.

In her time with UKTS, Tina was always willing and available to deliver talks and attend events to represent the charity in a professional capacity. Many a day were spent often in the rain, when volunteers were needed during a high profile awareness campaign and I have fond memories of Tina trying to attract members of the public to engage with UKTS which was often a difficult task but a challenge that she rose to.

Tina used her creative skills and talent in dinner dances where she would for several years, provide table decorations with a huge amount of love and attention to detail. She also used to successfully negotiate reductions in cost of booking venues for UKTS with her natural ability to network and powers of persuasion.

She was intelligent and articulate and her contributions to meetings were always valuable. Tina spoke her mind and that made her an excellent team member as she challenged people and their thinking, leading to open decision making. Her loyalty, integrity and honesty to UKTS were some of her greatest strengths. She was adaptable and able to change the way she was with people in response to their needs; a skill totally necessary in her career as a florist and that held her in good stead at UKTS where she would meet a cross cultural diverse group of patients, families and medical professionals and bring in new volunteers.

Tina and Mario used to open their home and create special times and many a committee sub group used to get together in Finchley where a two hour meeting would extend into a social evening with their open hospitality.

Nothing was too much trouble for Tina - UKTS National Coordinator Elaine Miller shares a particular story during the time Tina was Vice-President and Elaine was getting married. When Tina asked Elaine who was doing her flowers, Elaine told her she was having a registry office wedding and wasn't having any – Tina's reply was "Oh yes you are" and she made an exquisite bouquet as a gift. I think this just is a perfect illustration of one of many examples where Tina's generosity, thoughtfulness and sweet nature touched so many people.

Words do not do justice to say what a beautiful couple Tina and Mario made. It was self- evident how much happiness they brought each other and together they faced everything unconditionally bringing each other strength and above all true love.

Even in the face of insurmountable difficulties, Tina showed us that humans can be remarkable and selfless. Over the years she never ceased to amaze so many with her zest for life, courage and compassion.

In recent years, despite moving to Cyprus, Tina still maintained her friendships with her thalassaemia family in the UK whether it be in person or through the wonders of technology which lessened distances. Her own health deteriorated but that would not stop her and she derived immense pleasure from time with others.

Tina is sorely missed and has left a void is so many lives. On behalf of all the "thalassaemia family" members at the UKTS, we are grateful and feel blessed for the time that we have had with her. She is now reunited with Mario and they both will always be remembered with love, fondness and affection.

Thank you

UKTS hosts East Midlands Roadshow meeting, 29 November 2014

King Power Stadium Leicester

Prof Simon Dyson

Further to our last visit to Leicester and the surrounding area in September 2011, UKTS organised a follow-up "Roadshow" meeting for the thalassaemia patients and families in the East Midland area. The Roadshows are a series of informal meetings organised by UKTS. The aim is that the UKTS team and the families in the local area can get to know each other learn from each other. Families can let us know about any local issues they may have and UKTS delivers updates on the work of the Society and any important developments in research and/or treatment.

We were fortunate to be joined by some key members of the medical and nursing staff in the region, including Dr Claire Chapman (Consultant Haematologist, Leicester Royal Infirmary), Dr Sarah Nicolle (Consultant Haematologist, Walsgrave Hospital Coventry) and Professor Simon Dyson (Professor of Sociology, De Montfort University, Leicester). Prof Dyson (pictured) gave a presentation on his recent study into the social implications of being diagnosed as a carrier of thalassaemia or sickle cell disease. UKTS National Coordinator Elaine Miller gave a summary of news from the TIF conference in Athens at the beginning of November 2014 and UKTS Vice-President Anand Ghattaura spoke about his personal experience of living with thalassaemia. In the discussion group after the presentations, we heard from Louis, the young son of thalassaemia patient Giuseppe Cetera (readers of the last issue of TM may remember Louis' spider-taming exploits from the Birmingham Roadshow of August 2014!). Louis spoke from his own experience about living with a parent who has thalassaemia major – no doubt this is an aspect of thalassaemia that we will be discussing much more often in the years to come as more and more thalassaemics are becoming parents.

Would you like UKTS to organise a Roadshow in your area? Contact us on office@ukts.org

NHSBT award ceremony

L-R John Richardson, Vasos Melides, Glyn Botfield

NHSBT held an award ceremony on 23rd January 2015 at the Bentley Hotel, Lincoln to honour long-standing blood donors. Lincoln thalassaemia patient Vasos Melides presented awards to John Richardson and Glyn Botfield, who have both given over 100 blood donations. Vasos spoke to the audience about his personal experience of living with thalassaemia and UKTS National Coordinator Elaine Miller gave an awareness presentation at the ceremony. We were only too delighted to be given this opportunity to thank blood donors, whose selfless generosity means so much to the thalassaemia community.

Recent Events & Meetings

Those who attended meeting on behalf of the UK Thalassaemia Society are: Gabriel Theophanous President, Anand Singh Ghattaura Vice-President, George Constantinou Secretary, Chris Fassis Asst. Secretary, Raj Klair Committee Member, Elaine Miller National Coordinator, Katerina Loizi-Read Office Administrator, Dr Christos Sotirelis Trustee Advisor, Roanna Maharaj patient member, Stavros Melides parent member, Vasos Melides patient member

Acronyms

APPG – All Party Parliamentary Group for Sickle Cell & Thalassaemia
HCC – Hepatitis C Coalition
NEBATA – North of England Bone Marrow and Thalassaemia Association
NHSBT – NHS Blood & Transplant
RDMCC – Roald Dahl Marvellous Children's Charity
RDUK – Rare Diseases UK
SCTSP – NHS Sickle Cell & Thalassaemia Screening Programme
SHCA – Specialised Health Care Alliance
TIF – Thalassaemia International Federation
UKFHD – UK Forum on Haemoglobin Disorders

- 1 October 2014 – awareness presentation, Guy's & St Thomas's annual haemoglobinopathy conference, London. *Anand Singh Ghattaura*
- 11 October 2014 – awareness event, Manchester Dashehra Diwali Mela *Elaine Miller*
- 18 October 2014 – awareness drive, Sikh Gurdwara, Wimbledon *Anand Singh Ghattaura*
- 1 November 2014 - UKTS held an Extraordinary General Meeting to cover administrative issues raised by the changing of the Society's financial year (UKTS office).
- 4 November 2014 – awareness presentation, University of Northamptonshire *Elaine Miller*
- 7-9 November 2014 – TIF Pan-European conference Athens (inc. TIF Board meeting) *Gabriel Theophanous, Anand Singh Ghattaura, Chris Fassis, Raj Klair, Elaine Miller, Katerina Loizi-Read*
- 15 November 2014 – awareness presentation, Bordesley Centre Birmingham *Elaine Miller*
- 19 November 2014 - Rare Disease UK APPG summit meeting on transition, Westminster. *Roanna Maharaj*
- 20 November 2014 – UKFHD academic meeting, London *Dr Christos Sotirelis*
- 28 November 2014 – awareness presentation, Harrow Sikh network *Anand Singh Ghattaura*
- 29 November 2014 - UKTS held a local Roadshow meeting/workshop for the East Midlands families affected by thalassaemia at the King Power Stadium, Leicester. Families from all parts of the East Midlands were invited to hear medical presentations and take part in workshops/discussions.
- 2 December 2014 – APPG strategy meeting, London *George Constantinou*
- 4 December 2014 - Haemoglobinopathy voluntary sector round table meeting, African-Caribbean Centre, Leicester. *Elaine Miller*
- 11 December 2014 – awareness presentation, Rotary club of Lincoln *Stavros Melides*
- 15 December 2014 – UKFHD committee meeting, British Society for Haematology, London. *Elaine Miller*
- 13 January 2015 – SHCA commissioning breakfast meeting, London *Dr Christos Sotirelis*
- 14 January 2015 - SHCA commissioning quarterly meeting, London *Dr Christos Sotirelis*
- 15 January 2015 – Westminster debate on specialised commissioning *Dr Christos Sotirelis*
- 16 January 2014 – Voluntary sector meeting, National Institute of Health Research, London *Elaine Miller*
- 19 January 2015 – Meeting with Glenda Augustine, new Chair of the SCTSP Advisory Group, London *George Constantinou, Elaine Miller*
- 22 January 2015 - peer review of haemoglobinopathy services, Southampton *Elaine Miller*
- 23 January 2015 – awareness presentation, NHSBT donor ceremony, Lincoln *Elaine Miller, Vasos Melides*
- 26 January 2015 – SCTSP newborn information governance & clinical advisory group *Elaine Miller*
- 29 January 2015 – Meeting of the thalassaemia clinical standards writing group, London *George Constantinou, Elaine Miller (with Scientific Advisory Panel members)*
- 2 February 2014 – Hepatitis C Coalition meeting London *George Constantinou*
- 4 & 5 February 2015 – peer review of haemoglobinopathy services, Barts Health *Elaine Miller, Dr Christos Sotirelis*
- 9 February 2015 – APPG meeting London *Dr Christos Sotirelis*
- 23 February 2014 – dinner meeting with Bradford patient group E*laine Miller, Dr Christos Sotirelis*
- 24 February 2014 – peer review of haemoglobinopathy services, Bradford *Elaine Miller, Dr Christos Sotirelis*
- 26 February 2014 - peer review of haemoglobinopathy services, Leeds *Elaine Miller*
- 27 February 2015 – awareness event, Holloway University London *Katerina Loizi-Read*
- 28 February 2015 – awareness event, Pakistani Muslim Centre Sheffield *Elaine Miller*
- 4 March 2014 – inaugural meeting of Thalassaemia South Yorkshire, Sheffield *Elaine Miller*
- 5 March 2015 – SCTSP advisory group meeting, London *Elaine Miller*
- 6 March 2015 – Genetic Disorders Symposium dinner, London *Anand Singh Ghattaura*
- 14 March 2015 – awareness event, health mela, University of Bolton *Elaine Miller*
- 15-16 March 2015 – Novartis iron overload advisory board, Berlin *George Constantinou*
- 17 March 2015 - Specialised Services Prioritisation Processes Consultation Event, London *Dr Christos Sotirelis*
- 18 March 2015 - peer review of haemoglobinopathy services, Bristol *Dr Christos Sotirelis*
- 26 March 2015 - peer review of haemoglobinopathy services, Sheffield *Dr Christos Sotirelis*
- 1 April 2015 – Hepatitis C Coalition meeting London *George Constantinou, Dr Christos Sotirelis*
- 9 April 2015 – Hepatitis C Coalition quarterly meeting London Dr Christos Sotirelis
- 14 April 2015 – SHCA quarterly meeting London *Dr Christos Sotirelis*
- 18 April 2015 - awareness event, health mela, University of Central Lancashire, Preston *Elaine Miller*
- 26 April 2015 – awareness event, Vaisakhi Birmingham *Elaine Miller*
- 26 April 2015 – awareness event, Vaisakhi Slough *Anand Singh Ghattaura*

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

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membership application form

UK Thalassaemia Society, 19 The Broadway, London N14 6PH
Charity Reg No. 275107

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If you however do not wish your details kept on our computers please tick this box ☐

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Surname:

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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 _____

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