UNITED KINGDOM
Thalassaemia SOCIETY
matters
October 2004 ISSUE NUMBER 99
...continuing the fight against Thalassaemia

MRSA – New NHS Guidelines and Patient Power

We have been hearing a great deal in the news lately about the MRSA virus, the "superbug" which has affected many people, particularly those who have been admitted to hospitals throughout the UK. Obviously many of our readers will be frequent visitors to the hospital environment and we therefore attempt to answer here some of the questions they may have.

The full name for MRSA is "methicillin-resistant Staphylococcus aureus" . It is actually not one but many strains of Staphylococcus aureus (commonly known as "staph") infections, which have become resistant to various antibiotics, including the commonly used penicillin-related antibiotics. In the past most serious staph infections were treated with penicillin-related antibiotics; however over the past 40 years the bacteria have become resistant and therefore far more difficult to treat.

Staph bacteria are commonly carried on the skin or in the nose of healthy people. Approximately 25-30% of people carry staph bacteria in their noses at any given time. They may occasionally cause an infection, usually of a minor character (for example, boils and pimples) but these do not usually require antibiotic treatment.

Sometimes, however, staph bacteria can cause serious infections such as wound infections, pneumonia, bone infections and severe, life-threatening bloodstream infections, among others. Especially susceptible are those who are already debilitated by illness or weakness or who have an open wound or a tube going into their body. Staph bacteria and MRSA can spread by close contact with infected people. It is almost always spread by direct physical contact but can also spread by indirect contact (e.g. touching towels, wound dressings or clothing which has been in contact with the infected skin of a person with MRSA). In normal life, practising good hygiene helps to prevent the spread of staph or MRSA – washing the hands thoroughly with soap and water, keeping cuts/abrasions clean and covered and avoiding contact with other people's wounds or dressings.

However, for those who are hospitalised there is a real danger that the infection can be carried from patient to patient by the healthcare professionals treating them. This process is known as cross-infection. Professor Pat Troop, Chief Executive of the Health Protection Agency, said "The most effective way of controlling the spread of both Staphylococcus aureus and MRSA in hospitals is through early detection and appropriate isolation and treatment. Prevention of cross-infection is of paramount importance, which will include good hand hygiene and healthcare professionals should ensure they always wash and decontaminate their hands thoroughly in between treating patients."

As part of their strategy of coping with this situation, the Dept of Health have introduced two documents – "Winning Ways, working together to reduce Healthcare Associated Infection in England" and "Towards cleaner hospitals and lower rates of infection" (both can be downloaded from the DH website at www.dh.gov.uk, then search on "MRSA"). While it is good to know that the DH seems to be taking the issue seriously, some of the guidelines seem laughably obvious. Surely it hardly needs to be stated that all hospital wards should be cleaned to a high

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A word from our President

Dear Friends,

A slight change to this issue as you can see – a different writer and a different (but equally lovely!) photograph for the President's corner of TM. Unfortunately Mike, our President, is out of action at the moment, having suffered a bad fall in September and broken his hip and elbow. The good news is that he is now out of hospital and is recovering at home, he will be back as usual in the next issue.

It seems that Autumn 2004 has been an unlucky time for the head honchos of Thalassaemia Associations – Mr Panos Englezos, Chairman of the Thalassaemia International Federation, has also been in hospital, having back surgery for a crushed disc! We all wish both gentlemen a speedy and uneventful recovery.

I would also like to mention Dr Panos Ioannou, a great friend of UKTS, who has been experiencing health problems in recent months. We thank Dr Ioannou for contributing the article on page 9 to this issue and send him our good wishes from all his friends here in the UK.

As you will see from our headline article, the increase of MRSA in our hospitals continues to be a cause for concern for thalassaemics and anyone else who has to attend hospital on a regular basis. Please take note of the advice regarding the hand hygiene of hospital staff and make sure that you heed these precautions – we all need to do whatever we can to minimise the risks.

As always, this is a busy time for UKTS with our annual dinner & dance, our main fundraising event of the year, coming up on 27th November. You will find further details on page 15. Even though distance will not permit everyone to attend, all our members can take part if they wish, by buying raffle tickets (available by telephone from the office), making a donation or putting a message of support in the brochure. There is so much work to be done and every pound we raise helps us to go on, so please give us your vital support.

The Autumn months bring the approach of festivals and celebrations for many communities and as we all know, thalassaemia is a condition which reaches across all boundaries of nationality, culture and religion. May I wish all our friends everywhere a happy time over their respective festivities from all of us here at UKTS. Look after yourselves and each other!

All the best.

Costas Kountourou
Vice-President
UK Thalassaemia Society

Aims & Objectives of UKTS

- The relief of persons suffering from thalassaemia.
- The promotion and co-ordination of research in connection with thalassaemia.
- To educate people on the problems of thalassaemia.
- To offer counselling to sufferers and carriers.
- To bring together patients, their families and well-wishers to exchange ideas and information.
- To raise by any legal means the funds required for the above activities.

The UKTS Management Committee

Mike Michael	President
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Maria Gavriel	Secretary
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Andreas Yiannikou	Committee

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standard, or, for example, "Intravenous cannula insertion will be carried out by trained and competent staff using strictly aseptic techniques." (page 13, *Winning Ways*).

Part of the *Towards cleaner hospitals document* refers to "Giving power to patients" (page 8). Patient Forums will have a statutory function to monitor the NHS and will be invited to undertake cleanliness inspections four times a year. The results of these inspections will be reported to the public. Training for these inspections will be provided to members of the Patient Forums. The same page of the document contains the following section, which we reproduce here in full:

"Giving patients the power to challenge

The National Patient Safety Agency will launch its *cleanyourhands* campaign this summer (2004).The campaign will empower patients and their carers to challenge NHS staff to ensure they have washed their hands. All NHS patients have a right to expect all NHS staff to have very high standards of hygiene. Since MRSA transfer often comes from human contact patients must not be inhibited in asking NHS staff if they have washed their hands."

We sincerely hope that none of our readers or indeed any other NHS patients will feel inhibited and will take care to be observant that hospital staff at any level have washed their hands or, in appropriate circumstances, put on fresh sterile gloves before touching them. Part of the campaign also aims to provide alcohol hand gel at all staff-patient contact points to facilitate the process.

Please remember – *it is your right to ask* and indeed, unless you have actually seen the member of staff washing their hands – whether it is the most junior nurse or the most senior consultant – *you should ask*.

Harrow Thalassaemia Awareness Conference

– 16th September 2004

This conference, held in the Council Chambers of Harrow Civic Centre, was organised by Mrs Sonoo Malkani, parent of a thalassaemic son and a long-standing UKTS member and activist in support of thalassaemia. Unfortunately Mrs Malkani was unable to attend the conference as the previous weekend she had to travel to India due to a medical emergency in her family.

Those present included Mr Navin Shah, Leader of Harrow Council and Mr Prem Pawar of Harrow Commission for Racial Equality; as well as representatives from Harrow and Brent PCTs and various community groups.

Mrs Malkani's absence left a gap in the conference programme so UKTS Co-ordinator Elaine Miller acted as her "substitute". Elaine spoke to the delegates about thalassaemia and its treatment, the carrier state, inheritance patterns and incidence in different communities and of course the work of UKTS.

Lunch was provided and followed by a presentation from 30-year-old thalassaemia patient and UKTS member Ajay Gandhi. Ajay spoke honestly and movingly of his early experiences of living with thalassaemia and of how he made the hard decision to follow his treatment to the letter and work towards reducing his very high ferritin level. Happily his story had a fairy-tale ending as the audience heard how he is now a professional man (a chartered surveyor), a husband and is soon to become a father as he and his wife Natasha are expecting their first child in January.

After Ajay's presentation there followed a lively discussion on the subject of how families cope with having a thalassaemic son or daughter and how in some families thalassaemia is still seen as a stigma and something to be hidden. There is no doubt that where this attitude prevails in a family it is deeply damaging to the self-esteem and indeed the health of the thalassaemic son or daughter, who can be made to feel worthless, demoralised and discouraged from adhering to his/her treatment. However to debate this issue and bring it out into the light can only be positive; and the openness and frankness of the discussion gave encouragement that such unenlightened views may become obsolete in the foreseeable future.

Blood Screening at the Janmastmi Festival – Thalassaemia Carriers Identified

Family members queue up to be screened.

As in previous years, UKTS were invited to take a stall at the Janmastmi Festival, held on 5th and 6th September. This huge event, which marks the most significant date in the Hindu calendar, was held at Bhaktivedanta Manor near Watford. This magnificent estate was donated to ISKCON (the International Society for Krishna Consciousness) by the late George Harrison of Beatles fame. George Harrison became a devotee of Hindu spirituality after travelling to India in 1967 and remained so until his death in 2001.

Approximately 80,000 people from all corners of the UK visit the temple over the two days of the Festival so naturally this is a good opportunity for UKTS to fly the flag and promote the cause of awareness and blood screening for thalassaemia. Our valiant team of volunteers talked until they were hoarse to hundreds of people and gave out awareness leaflets; however, possibly even more importantly, we also offered on-the-spot blood screening to anyone who was willing to be tested for thalassaemia trait. The results have now been sent out and there are quite a few people out there who are now aware that they carry thalassaemia who were previously unaware. At the risk of preaching to the converted – **please remember that knowledge is power**. Those who know they are carriers can make informed choices for themselves and their families. In the UKTS office we frequently speak to carriers and to parents of thalassaemic children and when we ask them if their extended families have been tested for thalassaemia trait, all too often the answer is "no". How often we have heard remarks such as, "My brother won't have the test" or "My sister-in-law insists there's no illness in her family". We would ask all our readers to examine their own families and, in the strongest terms, urge everyone to be have a test if they have not already done so. The thalassaemia gene knows no boundaries - no matter where you come from, whatever your ethnicity, unless you have been tested you cannot be sure! Anyone who is not sure how to get a blood test or where to go, please contact the UKTS office and we will make every effort to assist you.

Coventry Sickle Cell & Thalassaemia Awareness Day – 17th September 2004

Some members of the Coventry Support Group.

This event was organised by the Coventry Sickle Cell & Thalassaemia Services, together with the Thalassaemia Support Group. It took place at St Peter's Community Centre, Charles Street, in the Hillfields area of Coventry.

The day was very well attended, with people including patients, family members, healthcare professionals and interested citizens of Coventry dropping in throughout the day. There were a variety of stalls to visit, providing information such as dietary advice and light relief such as massage for the weary.

We were welcomed by Amar Swarn, a 21-year-old thalassaemia patient who hosted the meeting in the absence of the chairperson of the Thalassaemia Support Group, Jatinder Karir. UKTS was represented by Co-ordinator Elaine Miller, who was very interested to listen to the presentations by: Manjit Bath (Coventry Sickle Cell/Thalassaemia Officer), Dr Nick Jackson (Consultant Haematologist at Walsgrave Hospital), Joanne Thompson and Margaret Chidlow (of OSCAR Birmingham) and Amar, who spoke about the work of the Thalassaemia Support Group. Elaine then spoke about inheritance patterns for thalassaemia in the various communities, blood screening and the work of UKTS. Last but not least the audience heard from 18-year-old thalassaemia patient Noreen Saeed, who spoke with humour and directness about her experiences of living with thalassaemia. Noreen's 21-year-old brother Haseeb, (another thalassaemia patient) also attended the Awareness day. (We produce Noreen's personal experience on page 10).

UKTS were delighted to be invited to attend the Awareness Day to meet our friends in Coventry, particularly Mrs Karir (Jatinder's mum) Amar and his mother Mrs Swarn, Noreen and Haseeb and another brother and sister pair from the Thalassaemia Support Group, Naheed and Shazad Nawaz. We would like to offer our congratulations to Naheed, who is now engaged to be married!

It was a very enjoyable day. The Coventry Thalassaemia Group are a delightful set of young people and we look forward to bringing the UKTS Roadshow to Coventry in the near future.

news from around the world

Genetics & Population Health Conference – Western Australia

By Dr Anne Yardumian, North Middlesex Hospital

Dr Anne Yardumian

In early August, the pretty little coastal town of Fremantle near Perth in Western Australia hosted a wide ranging 3-day conference 'Genetics and Population Health'. It was of particular interest to those concerned about thalassaemia for two reasons. The first day of the formal conference was titled 'Haemoglobinopathies as a paradigm of genetic disease'; and a range of distinguished speakers were invited from 10 different countries including Australia, America, England, Hong Kong, Thailand, Indonesia and Sri Lanka to talk about aspects of the conditions in their country. Also, on the day before the main conference began, there was an educational symposium called 'World best practice in thalassaemia management';

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this was sponsored by Novartis, whose product ICL670 is shortly to be released as Exjade, an alternative oral iron chelator. Needless to say, there was a good deal of interest in what was to be discussed at this symposium!

In fact, despite its title it did not aim to pull together any sort of protocol or guidelines for management, but instead consisted of a series of talks by experts in the field, talking about the range of diagnostic and clinical problems and management options It began with Dr Nancy Olivieri from Toronto, giving a general overview of the condition and her view of the various newer chelation options. Professor John Porter from University College London expanded on the theme of the newer iron chelators in his talk later in the day. There is, of course, a good deal of interest in ICL670 which promises to be a very effective treatment, although of course longer term studies are not available, and there is no data on changes in heart iron with this drug yet. Dr Porter showed the good results his group have been achieving in recent years by optimising standard desferrioxamine treatment. Another speaker, Dr Don Bowden from Melbourne, gave a most interesting talk his centre's approach of 'individualising patient management to optimise therapy'. There were many thought provoking elements to this: for example, children and adults attending for transfusion are all treated together, so the older ones can help and reassure the younger, and the families of young children can see how well the adults are getting on. He also talked about the fact that he tends not to start transfusions until the parents can see that the child really is not well, and needs this treatment, as they find it much more acceptable at this time. In people who are struggling to adhere to standard desferrioxamine therapy, he finds some can tolerate twice daily subcutaneous injections over about 10 minutes, and views that this can be used on days when 'the pump' cannot be.

I also found fascinating a talk by Tim St Pierre from the university of Western Australia, regarding measurement of iron levels with magnetic resonance imaging. For a brief time, I even understood the physics of it! The take-home message was that, although MRI is increasing our understanding of iron distribution, and giving a window into the various organs which we have not previously had, one has to be a bit cautious in interpreting the results. For example, he showed how patchy the iron distribution in the liver is, so that an overall level may not be properly representative. He expressed concern about putting too much faith in individual measurements, especially in the heart. In his view, the 'scatter' of the technique, and the small range over which the measurements are made make them inherently error-prone. At a time when we are all very ready to embrace any new technique which offers improvement in our abilities to manage iron overload, I found this cautionary note helpful and important.

The opening day of the main conference offered some wonderful, broad insights into the problem of thalassaemia across the world. After an introduction about the human genome project and its possible impact on population health, Professor Sir David Wetherall talked about the global problem of genetic disease in general, using haemoglobin disorders as his main example. He addressed fascinating theories about why different - especially island - communities have such different carrier rates, and the possible influence of environmental factors on the clinical expression of gene types. There were talks about the burden of alpha thalassaemias and Haemoglobin H disease, a major problem in China. From Indonesia came a most interesting talk about the potential role of blood transfusion service doctors in preventing thalassaemia, and talks from clinicians in Malaysia, Cambodia, Central-East India , Sri Lanka and Mumbai were at once impressive and humbling in demonstrating what can be achieved in low resource settings, also highlighting what continued obstacles there are for patients and health care professionals in some of these areas.

I was sorry to have to leave to return to the UK after the main thalassaemia sessions were over - but not before enjoying an especially interesting morning on human migration and histories as illuminated by certain genetic markers, and the effect of religion, cultural and social identity on population genetics.

This might sound as if we spent our entire time in the lecture hall; but far from it! There was a very welcoming opening reception, at which it was a great pleasure to meet some people with thalassaemia, from Western and Eastern Australia, all looking in very good health and in positive spirit. A treat also was to see the beautifully preserved wreck of the 'Batavia', a Dutch ship which was wrecked on the islands off the coast near to Fremantle in 1629, and which is housed in a small dedicated museum a hundred yards from the conference hotel. We were given a most erudite talk about the happening and ensuing mutiny, followed by an demonstration of how the skull bones found from the wreck can be accurately reconstructed to give an idea of what the men would actually have looked like. As this was accompanied by a wine-tasting and chance to meet patients and colleagues from all over the globe, it really was a very pleasant and sociable occasion. In all, the conference organisers Professor Alan Bittles and Dr Wendy Erber, had done a fantastic job and gave us a most educational, thought provoking and thoroughly enjoyable programme.

Dr Anne Yardumian,
North Middlesex Hospital

News About Deferiprone (L1)

The following relates to a news decision by the European Medicines Agency to extend the indication for Ferriprox ™. UKTS gratefully acknowledges that the following is reproduced from Issue No 42 of the TIF magazine.

On 7th May 2004, the European Commission adopted the decision of the European Medicines Agency to extend the indication for the oral iron chelator Ferriprox (deferiprone), saying, "Ferriprox is indicated for the treatment of iron overload in patients with thalassaemia major when Desferrioxamine therapy is contraindicated or inadequate. Determination of what constitutes "inadequate therapy" will be the responsibility of the prescribing physician but, based on the opinion of scientific assessors of the European Medicines Agency, it includes not only those patients for whom efficacy of Desferrioxamine is unsatisfactory, but also "those patients for whom Desferrioxamine is intolerable or unacceptable", explained Dr Michael Spino, President of Apotex Innovative Drugs Division.

According to Dr Fernando Tricta, Vice-President of Medical Affairs at Apotex, under this expanded indication physicians may prescribe Ferriprox for those persons who have been unable to adequately remove enough iron stored in the heart or other critical organs, or those who may be experiencing compliance difficulties.

Many haematologists and other leaders in the thalassaemia community throughout Europe have expressed the view that the expanded indication is an important development, welcomed both by patients with thalassaemia and by their physicians. Now that clinicians can make an informed choice in the use of iron chelators, there should be an overall improvement in the care of patients with life-threatening iron overload.

Ferriprox has already been approved in more than 40 countries, including the European Union, China, Hong Kong, Malaysia, Singapore, Jordan, Kuwait, Oman, Turkey, Australia, Brazil and Tunisia. The United States' Food & Drug Administration will be reviewing the drug for approval in early 2005.

Further prescribing information, along with publications addressing the safety and efficacy of Ferriprox can be found at; www.ferriprox.com.

ICL 670 (Deferasirox)

An Investigational Compound for the Treatment of Chronic Iron Overload

WHAT IS ICL 670?

- ICL670 is a Novartis compound that is currently under investigation and is available only in clinical trials. It is an oral iron chelator that is being studied as a treatment for chronic iron overload caused by repeated blood transfusions.
- Administered orally as once-daily, dispersible tablet, ICL 670 works by selectively mobilizing and promoting the excretion of chelated iron mainly through faeces.
- If approved by health authorities, it is intended to be marketed under the brand name EXJADE.

ICL 670 CLINICAL DEVELOPMENT

- ICL 670 is currently in phase III clinical trials. This is one of the largest programs ever implemented for an investigational iron chelator. The clinical trials program includes about 900 patients from 12 countries spanning across four continents.
- Trials with ICL 670 include patients with beta-thalassaemia, sickle cell anaemia, myelodysplastic syndrome and other rare anaemias who require frequent blood transfusions.

THALASSEMIA COMMUNITY SUPPORT

- Novartis has supported the thalassaemia community since the introduction of Desferal® (desferrioxamine) more than 30 years ago, now considered the standard of treatment for patients with iron overload. Desferal is indicated for the treatment of acute iron intoxication and of chronic iron overload due to transfusion-dependent anaemias. Desferal is administered as a subcutaneous infusion of 8-12 hours. The most common side effects of Desferal include allergic reactions and local reactions at the injection site.
- Over the course of the last ten years, in support and collaboration with the Thalassaemia International Foundation (TIF), Novartis has worked to meet the specific needs of both the patient and professional thalassaemia communities. Novartis has supplied educational materials and pump equipment to thalassaemia patients in many countries around the world. Also, through this joint effort, thalassaemia physicians, technicians and nurses have been able to attend medical training workshops to further their understanding of the disease and treatment options.

Wheat Grass Juice and Thalassaemia

There has been recently much discussion on the potential benefits of wheat grass juice in relation to thalassaemia. The interest in wheat grass juice has been instigated by a pilot study from India reporting significant benefit in some patients (RK Marwaha et al. Wheat grass juice reduces transfusion requirement in patients with b-thalassemia major: a pilot study. Indian Pediatrics 2004, in press). The original article should hopefully be published very soon. For anybody interested to look at the original article, it should become available through the web site of the Indian Pediatrics journal (http://www.indianpediatrics.net/), as soon as it is published.

The study has involved 16 patients who satisfied the strict requirements of taking 100 ml of wheat grass extract every day for at least 18 months. Patients were monitored only by measuring the frequency and amount of blood transfused.

In the course of the study 50% of the patients showed a reduction in blood consumption, with 3 of them showing a much stronger benefit. However, it is important to emphasise that all patients continue to be transfusion dependent.

Unfortunately the paper does not include any information on the types of mutations found in these patients, or their iron chelation or whether the reduced consumption of blood was accompanied by an increase in fetal hemoglobin. These are all important questions that need to be carefully documented, in order to help us understand the mechanism by which some patients are deriving benefit and others are not responding.

Prompted by this study, we hypothesised that wheat grass juice might be exerting its beneficial effect by increasing the production of fetal hemoglobin. To address this question, we have recently examined in our lab whether wheat grass concentrate can increase the production of fetal hemoglobin. The method of our assay was published earlier this year (Human Molec Genet 13 (2004) 223-233. Vadolas J, Wardan H, Orford M, Williamson R and Ioannou PA. Stable cellular genomic reporter assays for screening and evaluation of inducers of fetal hemoglobin) and depends on using a sensitive fluorescent protein to detect production of fetal hemoglobin in human erythroleukaemic cell cultures. The wheat grass concentrate we have used is of course prepared in a very different way from the wheat grass juice that was taken by patients in India. Nonetheless, we were very encouraged to see in our preliminary studies that wheat grass concentrate has a significant effect on fetal hemoglobin production. I cannot say much more at this stage, except that we are planning to extend our studies to hopefully identify the factor(s) responsible for this induction.

I understand that wheat grass extract is already being promoted as an elixir for many diseases without any solid scientific evidence, so I want to caution people from rushing to buy it from natural product stores as an elixir for thalassaemia. We have no information which patients can respond to it and which patients may not benefit from it. Similarly, it is not possible to predict from the Indian study what dosage of wheat grass extract or concentrate may be most effective for those patients that could benefit from it. Further studies are clearly necessary and warranted by these initial observations. It is only through careful and systematic studies that we will eventually get an effective therapy for this disease and not by patients experimenting individually without proper assessment.

In the meantime, we are also interested to examine any other natural products which may have beneficial effects on thalassaemia. We would therefore be pleased to hear from any patient who may have "experimented" with other natural products and noted a significant difference in their transfusion requirements.

Dr Panos Ioannou,
Head,
Cell & Gene Therapy Research Group
Murdoch Childrens Research Institute
Flemington Road, VIC 3052
Australia

My Life…

Hi, my name is Noreen; I'm 18 years old and have lived with Thalassaemia Major for all of my life. I've had to grow up with it whether I like it or not. It's difficult coping with it. I am a member of the Coventry support group for thalassaemics and I am also the secretary.

Once a month I go for a blood transfusion, which takes about a day. I have to just sit there whilst the blood is going through. The nurses have to keep checking my temperature, blood pressure and heart rate to make sure everything is ok and to see that I don't get a reaction to the blood, which can happen.

Because of the blood transfusion I get iron overload. If the iron level gets too high it can cause problems in my organs. To keep the iron under control I'm supposed to take Desferal injections every day and Ferriprox tablets, 2 three times a day. But, I find it really hard to cope with and hate having the injections, and so I don't take the injections, I know this may cause problems in the future but It's just too much for me to take, especially at my age.

Thalassaemia can cause other problems too, not just iron overload. It can also cause problems elsewhere such as to my eyesight, hearing, growth and damage to my organs. So, everything needs to be observed regularly especially now as I'm getting older – it can be more risky. This means more hospital appointments.

When I was at school most of my mates didn't even know about my illness, I never used to tell people about it. I didn't tell them because I just wanted to be 'normal' and hated the fact that I had this condition in the first place. I thought if they knew they would be different around me. But, as I'm growing older I'm starting to come to terms with it and accepting it. I think this is because I am more confident within myself and I know that it is a part of me. It's weird to think that thalassaemia is a big part of my life and yet the people around me didn't even know I had it. The people that did know were my teachers who were told by my mum as she thought it was best that they knew and a few close mates knew that was only because when they came to my house they saw my medication and injections and so I had to explain to them. But, I suppose it is better if people know about it. I remember one time when my science teacher had just found out about my condition, I think she kind of felt sorry for me. Because what happened was, I was in class and I wasn't doing any work just because I was being lazy and I didn't realise she was watching me. And so she came up to me and I remember thinking oh no I haven't done any work she's gong to go mad. But, instead she just asked me if I was feeling ok. And she told me to go outside and get some fresh air. And then when I went outside she brought me a mug of milk and she gave me some biscuits, I found it all funny.

I always thought that it would get me down; whenever I applied for a job I didn't mention my illness or put it on the application form. But, now I do. I make sure I tell the companies that I'm applying to. And so far it hasn't caused me any problems. I went to an interview on Tuesday and I explained to them that once every month I will need to go to hospital and I was successful in getting that job.

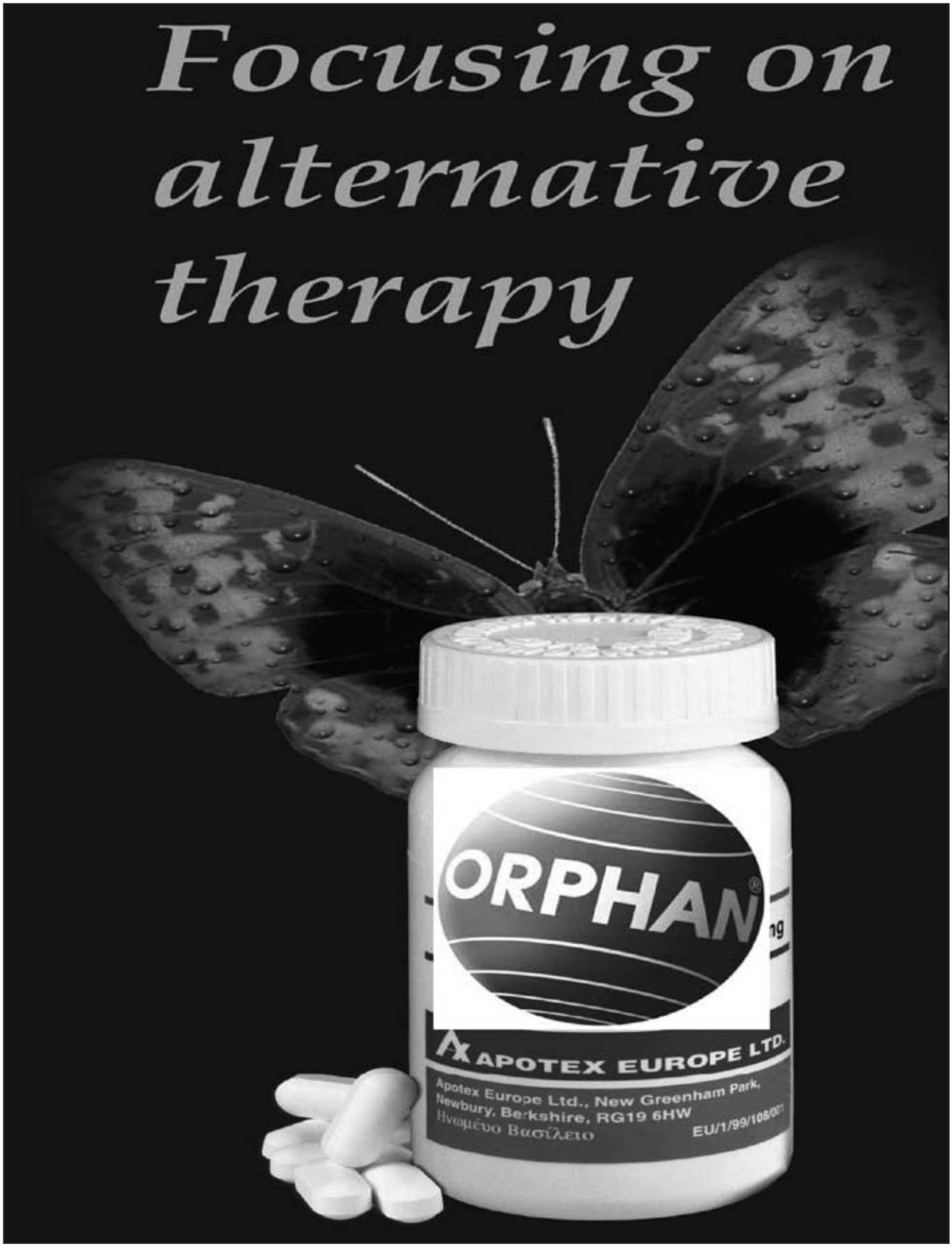
One advantage of having thalassaemia is that you get treated very well sometimes! For example, when I used to go visit my grandparents in Birmingham. At night when I had my injection on, my grandma used to be really careful; she wouldn't let my cousins share a bed with me, so I got the whole double bed to myself - even if it meant all the other kids were squashed into one bed. However, she used to wake me up really early in the morning to tell me to take my injection off so I could sleep properly. It used to really annoy me though when she did that because it was really hard to go back to sleep again!

My cousins and aunties all thought I was really brave because I was really young when I started to put my own injection on. I was probably about 4 years old. I used to be putting my injection on and I'd have a big crowd around me watching me. It does get really hard sometimes, though, because when I go to see my grandparents in Pakistan I can only stay for a maximum of 4 weeks because of my transfusion. It's the same wherever I go on holiday. It's really sad because I know my grandparents wish that I could stay for longer with them but I can't. 4 weeks seem to go really fast.

Because of thalassaemia I've been on the news and in the newspaper to make other people aware of this condition. So thalassaemia has made me sort of famous, don't know if that's a good thing though! I'm not sure what I want to do in the future yet. But what I do know is I'm not going to let thalassaemia hold me back. I have to consider all the possibilities whatever decision I make. Because for example, if I wanted to live abroad it would be very difficult for me as I would have to check out what treatment was available for me, if any. I would have to be sure of the doctors and how much knowledge they had of thalassaemia. I would also have to consider that my medical treatment might not be free as it is in the UK.

Having this condition does worry me though, about the future and what if I get any complications. Its not easy having thalassaemia. It scares me sometimes.

By Noreen Saeed,
Secretary, Coventry Support Group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Congratulations to Haseeb and Azra

We are delighted to have another wedding celebration to report. Our congratulations and best wishes to Coventry thalassaemia patient Haseeb Saeed and his bride Azra, who were married on 13th April 2004 in AMB village in the Dadyal area of Pakistan.

Thank you to Haseeb, Azra and their families for letting us have one of their wedding photographs. We wish them every happiness for the future.

(You can see an article by Haseeb's sister Noreen on page 10).

Azra and Haseeb on their wedding day.

Letter from Dr Beatrix Wonke

Following Dr Wonke's retirement party and her farewell tribute in the last issue of TM, we were thrilled to hear from her again when we recently received the following delightful letter. We thank Dr Wonke for her kind permission to publish the letter and once again wish her a long, healthy and happy retirement.

30th September 2004

Dear All in the UK Thalassaemia Society!!!

My surprise retirement party on the 23rd of April was an occasion I shall never forget and indeed every day I think of you all. In my house every room has a picture, sculpture, vase or others to remind me of all of you.

The farewell was not easy and to "save my soul" and recover I left the country and only just returned to have further surprises. Opening my mail I found that the July issue of the UK Thal Society dedicated a large part of the magazine to me. I am very touched and grateful for this honour.

I would like to express my thanks and wishing you all the very best future!! Please send me further issues so that I keep up with the developments, even if it is from a distance.
With love,

Beatrix Wonke

Hepatitis C Payments – The Skipton Fund

Could You Be Eligible?

The Skipton Fund, the body set up to administer the UK-wide ex-gratia payment scheme for people infected with Hepatitis C from NHS blood or blood products, **began processing applications on July 5 2004.**

You can **now register** your details with the Skipton Fund to ensure that you are sent application forms & guidance on how the scheme will work.

People wishing to take forward an application and who are not already registered on the Department of Health's confidential mailing list, can contact the Skipton Fund for a copy of the Registration Form or download it from the Fund's website. **Details of how to contact the Skipton Fund can be found at the end of this article.**

Those registered on the mailing list will be sent a Registration Form shortly, and need do nothing in the meantime. The application form comes with comprehensive guidance on how the scheme works and how to use the form.

Details and Conditions

- The scheme will make lump sum payments of £20,000 to all those who now have Hepatitis C from blood, with a further £25,000 when people reach a more advanced stage of illness.
- The 'advanced stage' of illness that triggers eligibility for the £25,000 is defined as when a patient develops cirrhosis, liver cancer or if they have received a liver transplant.
- Legislation affecting social security benefits and residential care charging has been amended to ensure that people receiving payments from the scheme are not penalised as a result.
- General eligibility is defined in terms of having received blood, blood products or tissue from the NHS before September 1991.
- No payments will be made in respect of those who have died before 29 August 2003 or to people who have cleared the virus spontaneously in the acute phase of the disease.
- In the case of eligible people who die between 29 August 2003 and 5 July 2004, the payments will be made to their estate.
- Where eligible persons who die after 5 July 2004, payments will only be made to their estate if the eligible person had applied to the Skipton Fund whilst they were still alive.
- People who have been infected with HIV through blood, blood products or tissue on in the past, and have in addition contracted Hepatitis C in the same way, will be eligible for payments from the scheme in the same way as those who have only been infected with Hepatitis C.
- People who have cleared the virus as a result of treatment or who have cleared it spontaneously after a period of chronic infection will be eligible for payments from the scheme.
- It will be assumed that people who have developed Hepatitis C after being treated with Factor VIII or Factor IX blood clotting factor concentrates were infected as a result of that treatment. Virtually all haemophiliacs will fall into this category.
- If people have received compensation from other sources in connection with their infection, Skipton Fund will not make any deduction from any award to take account of this. [**Please note** that this position has been revised since the publication of the original details of the scheme on 23 January 2004]
- Applicants will only need to provide basic personal details to the Skipton Fund, but will need to ask their doctor to complete the main section of the application form which details information to support their eligibility.
- If the Skipton Fund decides that an applicant is not eligible for payment they will write explaining the reason for this decision. The applicant can then apply to an independent appeals panel, which will most likely be chaired by a QC.
- Applicants will not need legal advice when completing the application form and they will not be asked to sign any waiver. The scheme will not reimburse legal costs incurred in making a claim or in appealing against decision by the Skipton Fund.

Further information

Skipton Fund
PO Box 50107
London
SW1H 0YF
Registration Helpline - 020 7233 0057
E mail: apply@skiptonfund.org
DH web pages: www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/HepatitisC/fs/en

IF YOU THINK YOU COULD BE ELIGIBLE APPLY NOW!

The Roald Dahl Foundation – Helping Haematology Patients

Roald Dahl, one of the best-loved children's authors of modern times, left a wonderful legacy to the world in his delightful books such as *Charlie and the Chocolate Factory, Matilda* and *James and the Giant Peach*. This, however, is not the only benefit he left to children. Since his death in 1990, the Roald Dahl Foundation has provided grants in the three areas which interested Roald most – haematology, neurology and literacy. One of their most outstanding projects is the funding of paediatric nurse specialists within the fields of haematology and neurology.

However, the Foundation also provides assistance to individuals under their Small Grants scheme. The aim is to help families to cope with financial difficulties when faced with caring for a sick child (or young person up to the age of 25) suffering from one of a range of conditions, which include thalassaemia and sickle cell disorder. Grants can be up to £500 and in the past have been provided for the following;

- Subsistence expenses when a child is admitted to hospital away from the home town.
- Travel expenses to and from hospital.
- Specialist furniture, car seats, walkers, bicycles.
- Appliances, i.e. washing machines, refrigerators, freezers, heaters, cookers.
- Beds, bedding, clothing, toys.
- Payment of utility bills i.e. telephone, gas and electricity.
- Specialist equipment i.e. alarms, sensory toys, Medic Alert bracelets and necklaces.

In exceptional circumstances grants may be awarded for holidays provided that the holiday is taken in the UK.

To qualify for a grant a family must be in receipt of one or more of the following State benefits – Income Support, Housing Benefit or Working Tax Credit; OR have an earned income of less than £16,000 per year.

Please note that applications MUST be made through a social worker or professional health worker, e.g. health visitor or nurse specialist. This person must be willing to see an application through to its completion and be prepared to supply and confirm information required for the grant to be processed. No direct applications will be considered.

If you think you would be eligible to apply for a grant, please ask your representative (social worker or healthcare professional) to contact the Small Grants Manager at the Roald Dahl Foundation, Gipsy House, Whitefield Lane, Bucks HP16 0BP - Telephone 01494 864912. Forms and information can be downloaded from the Foundation's website at: www.roalddahlfoundation.org.uk. If you are unsure of whether you may be eligible or have any queries please feel free to contact the UKTS office.

Upcoming events in 2005 – watch this space

- **UKTS 2nd National Doctors' Conference** – 14th June 2005, King's Fund, London
- **TIF 10th International Conference for Parents & Thalassaemics**, Dubai, 30th September – 4th October 2005

THE UK THALASSAEMIA SOCIETY ANNUAL DINNER & DANCE

will be held on

Saturday 27th November 2004

at

The Brewery
Chiswell Street, London EC1Y 4SD

TICKETS £40
Available from the UKTS office

N.B. For security reasons all tickets must be paid for in advance. No places will be reserved unless payment has been received.

Attention All Our Readers – We Need Your Help!

October 2004

Dear Friend,

UK THALASSAEMIA SOCIETY ANNUAL DINNER DANCE, 27TH NOVEMBER 2004

This year the UK Thalassaemia Society will be holding their annual dinner dance on the above date at **The Brewery, Chiswell Street, London EC1.**

It will be a fun-packed evening of great food (vegetarian meals available on request), music, dancing and a raffle with fabulous prizes including holidays and airline tickets. This is our major fund raising event of the year and we are hoping that all those who have any connection with thalassaemia will want to be involved. Please remember that UKTS, the only national UK charity devoted to thalassaemia, receives no funding or income from the Government, NHS or any other source. We are therefore entirely dependent on what we can raise by events of this kind.

In the past year we have produced a specially designed personal organiser for thalassaemia patients, which enables them to keep their own set of medical records (if you are a patient and don't already have it, contact our office for your FREE copy now!). We also organised the first national UK conference for thalassaemia nurses and counsellors to make them aware of the issues which most concern the patients in their care. Further, we have put together a working group of thalassaemia specialists who are writing national treatment standards, to ensure that all patients have access to good quality treatment and specialist referrals regardless of where they live. Then of course there is the never-ending work of printing and distributing literature to raise awareness of the importance of blood screening and, last but not least, we produce our quarterly magazine Thalassaemia Matters.

As you can imagine, the costs involved in our work are far from trivial and increase by the year. This is why I am writing to ask for your help. Remember that UKTS is YOUR Society and we need your support and generosity. Tickets are available from our office at £40 each. If you are not able to join us, you could take part in the raffle and again tickets are available from our office. Alternatively, any donations you are able to send to sponsor the evening would be most gratefully received and will be listed in the programme for the evening (unless you instruct us otherwise).

I thank you for your time and hope to see you on the evening.

With very best wishes.

Yours sincerely,

Mike Michael, President,
UK Thalassaemia Society

Message From Our Careers Advisor Neelam Thapar – "I'll Be Back!"

Our regular readers will notice the absence of Neelam's popular careers advice column. Due to extreme pressure of work Neelam has been unable to prepare her usual article; but don't despair – she will return in the next issue!

DONATIONS

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

San Antonio Festival	£200
Dr R Tahalani	£125
Alpha Bank of London	£100
The Iron Bed Co	£20
Carol & John Challis	£50
Lighthouse Internet Ltd	£20
NBG Bank	£50
Mrs B Roche	£15
Ms M Americanos	£123
Ms D Ptohopoulos	£25
The Map Partnership	£27.65
Ms S Toumazis	£50
Mr S Gandhi	£100
Mrs M Sherville	£50
Mr Shahi Ghani	£200

UKTS Welcomes NEW-MEMBERS

Annual

Dr O.B. Wilkey
Miss E. Isaac
Mrs M. Khan
Mr B. Tejani

Life

Miss M. Masood

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The views expressed are not necessarily that of the Society.

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 _____

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