UNITED KINGDOM
Thalassaemia SOCIETY
matters
April 2004 ISSUE NUMBER 97
...continuing the fight against Thalassaemia

Hepatitis C ex-gratia payment scheme

– Dept of Health announces further details

Our regular readers will remember that Issue 95 (October 2003) contained details of a press release issued on 29th August 2003 by the Health Secretary John Reid; to the effect that he was establishing a scheme to provide financial assistance to those who contracted the Hepatitis C virus from contaminated blood supplied by the National Health Service.

On 23rd January 2004 another press release was issued which aimed to clarify further who would be eligible to claim. It was announced that every person in the UK who was alive on 29th August 2003 and whose Hepatitis C infection is found to be attributable to NHS treatment with blood/blood products before September 1991 will be eligible for the ex-gratia payments. For those who meet these criteria the payments will be:

- An initial lump sum payment of £20,000 for those infected with Hepatitis C.
- Further payments of £25,000 for those developing more advanced stages of liver disease such as cirrhosis or liver cancer, or who have received a liver transplant. The DoH has set up a medical team who are currently developing a protocol that will enable the existence of cirrhosis to be assessed using only existing biopsy results or the results of non-invasive tests.

Anyone who contracted Hepatitis C from someone else who was infected with the disease as a result of contaminated NHS blood products as described above will also qualify for payment. The scheme will further include those who do not currently have Hepatitis C but who have cleared the virus as a result of treatment – but not those who have cleared the virus spontaneously. The Government are currently amending social security legislation to ensure that anyone who receives the ex-gratia payment is not penalised as a result.

However, no payments will be made in respect of persons who have died before 29th August 2003 when the scheme was originally announced. If any eligible persons are found to have died between 29th August 2003 and the time when the scheme becomes operational, the payments will be made to their dependents. If any claimants have received compensation from other sources in connection with their infection, the sum received will be deducted from any award they are entitled to under the scheme. No legal costs in connection with the seeking of compensation will be reimbursed.

The payment scheme will be administered by a new independent body known as the Skipton Fund. We await further announcements which will be made by the DoH once the Fund is in a position to start processing claims. This next announcement will specify exactly what claimants need to do to make an application.

What to do if you think you may be eligible to claim – initially you should register your interest with the Dept of Health if you have not already done so. You can do this by telephoning 020 7210 4850 or emailing dhmail@doh.gsi.gov.uk and leaving your contact details. You will then be sent further information once it becomes available.

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A word from our President

Dear Members

As you may know Dr Wonke (OBE) has now retired. Since the beginning of the year patients from the Whittington were planning a surprise party for her in April.

I must congratulate the team that managed to arrange such a party; consisting of 250 guests sworn to secrecy; without the good Dr getting a sniff of what was going on, and let me say Dr Wonke is a very difficult person to keep a secret from.

As she stepped through the door she was confronted by her real family and grandchildren and her adopted family and grandchildren. Patients travelled from all over the UK and from as far away as Trinidad and Hong Kong to be there. I can not describe the range of emotions that filled the room that night, guests went from laughter to tears and back again many times and that included Dr Wonke.

Dr Wonke, a truly brilliant doctor, who in her many years of treating thalassaemia has managed to change the world that we live in, there can be no thanks great enough.

Her departure will be a truly hard act to follow. But with that in mind I ask the following questions. But first the facts, due to the work carried out by doctors around the world, thalassaemia is not the same as it was 30 – 40 years ago. From a deadly childhood disease to a condition that is preventable, treatable and manageable.

And so I ask

1. Do we need to replace Dr Wonke with another Dr Wonke or do we need doctors that help us to make the correct decisions to manage our condition.
2. Don't we really need clinicians and hospital managers to create and/or continue a truly 24 by 7 unit in hospitals up and down the country.

Finally just before we went to print we were advised by the Whittington Hospital that they have appointed Dr F Shah to the post of Consultant Haematologist. I would like to congratulate Dr Shah on her new position and look forward to working with her on many of the UKTS projects. Hopefully by the next issue we will be able to publish an interview with Dr Shah in the next issue.

Until the next issue

M. Michael
President

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
Costas Kountourou	Vice-President
Maria Gavriel	Secretary
Olga Demetriou	A Secretary
Nina Demetriou	Treasurer
George Constantinou	A Treasurer
Avraam Demetriou	Committee
Menuccia Tassone	Committee
Andreas Yiannikou	Committee

UK Thalassaemia Society Supports NHS Decision To Fund Embryo Screening

– Press Release In Response To Sunday Times Article

As many of you may have seen, on 21st March 2004 the front page of the Sunday Times carried an article entitled "NHS Pays for first "designer" baby" by Sarah-Kate Templeton. The article states that a couple, who already have a child with thalassaemia, have been granted a licence by the Human Fertility & Embryology Authority to undergo tissue typing of embryos in order to have a child who will be a compatible bone marrow donor (as in the well known case involving the Hashmi family). The Hashmis and one other couple have already been licensed for the treatment, but this is the first case in which the NHS has agreed to provide funding. The couple will receive treatment at the Centre for Assisted Reproduction at the Park Hospital in Nottingham, under the care of Dr Simon Fishel. Dr Fishel welcomed the NHS decision, stating that treatment is out of the question for many couples due to the costs involved.

The article contained opinions from several senior doctors, some in support of the decision but some critical, suggesting that the concept of creating a child as a donor is unethical and should not be supported by the NHS. It was also suggested that primary care trusts would decide to fund this procedure for purely economic reasons (the embryo screening process costs approximately £4,000 per attempt, compared with up to £50,000 per annum to treat a thalassaemia patient).

Given the prominence of the article UKTS felt compelled to issue a press release, reproduced in part below (we have not reproduced the first paragraph as it is a summary of thalassaemia and its treatment and we imagine that our members already have this information! However, if any readers would like the full text of the press release please contact the UKTS office).

"The UK Thalassaemia Society welcomes the decision of the NHS to fund embryo screening to produce a cord blood/bone marrow donor for an affected sibling. We feel the term "designer baby" which has been frequently used is offensive when applied to this situation as these babies are not chosen for "cosmetic" reasons. There are ethical considerations in the use of this technique as there are in many other areas of medicine. However, the relevant authorities have already taken these on board in their decision to allow the HFEA to grant licences for this procedure. Each case is examined by an ethical panel before granting a licence and this is sufficient safeguard of the ethical use of the procedure.

There are concerns that the donor child would be somehow less loved and valued than any other. The fact is that people have children for all kinds of reasons and there is no way of policing this as long as it is a natural conception. Bone marrow transplant is not a risk free procedure and families do not make these decisions lightly. It does not follow that a child would be less loved because it was created to help a sick sibling, but such a child indeed takes a very special place in the family.

It is profoundly unfair to restrict the hope of a cure to those able to pay for private treatment. To prevent people from seeking a cure in this manner would be to ignore the voices of the thalassaemia patients and their families who all suffer physical, emotional and financial hardship from having a family member with a chronic condition. The UK Thalassaemia Society congratulates the Government for its' vision and courage in this decision, which will help to ensure that the UK stays at the cutting edge of genetic research."

New blood safety measures disqualify 52,000 donors

On March 16th 2004 the Health Secretary John Reid announced that from April 5th 2004, anyone who had received a blood transfusion in the UK since 1st January 1980 would no longer be eligible to donate their blood. This follows the announcement in December 2003 of the first report of a possible transmission of variant Creutzfeldt Jakob Disease (vCJD, known commonly in the past as "mad cow disease") from person to person via blood. Those who have received transfusions before 1st January 1980 will remain eligible as it is accepted that there was no exposure to BSE (bovine spongiform encephalitis, the form of the disease which affects cows) in the UK before that date.

The Department of Health wish to stress that there is no proven link between vCJD and blood transfusion and that the measure is being taken as a precaution. The National Blood Service estimates that this will lead to a loss of 52,000 blood donors. The DoH have pledged to counteract this loss by their current initiative "Better Blood Transfusion – More Appropriate Use"; securing improvements in the conservation of blood stocks by encouraging hospitals to make the best possible use of donated blood.

Naturally, blood safety is of vital importance to our members and we are pleased that the issue is taken so seriously; however the loss of so many donors is a cause for concern. It is too early to tell what the real effects will be on the National Blood Service – hopefully blood supplies will not be affected but we would be interested to hear if any of our readers subsequently experience any difficulties.

UKTS meet the Leeds & Bradford patients

By Maserat Lal, Leeds Thalassaemia Patient Support Group

On Sunday 29th February 2004 UKTS attended a thalassaemia support group meeting in Leeds. The aim of the meeting was for the Leeds and Bradford thalassaemia patients and their families to meet UKTS members, hear about their work and generally get acquainted.

We were honoured to welcome Mike, Costas, Menuccia and Neelam from UKTS, not forgetting Sister Emma Prescott from the Whittington Hospital who generously gave up her Sunday to help answer our queries and provide valuable help and information on day to day care and transfusion protocol. Some of the other issues discussed were MRI scans, bone marrow transplants and tablet alternatives to Desferal.

The event was a great success. Patients who are normally too shy to ask questions or to even attend the UKTS national conferences got a huge boost from being able to talk to more knowledgeable thal patients. We were all encouraged not to give up on the daily grind of living with thalassaemia and the pump and were inspired to do more. While enjoying the delicious food during the buffet lunch, patients talked on a one-to-one basis with Mike, Costas, Menuccia, Neelam and Emma and felt they had made new friends. It was a very informal, relaxed afternoon.

A big thank you to UKTS – thank you for caring enough to give up your Sunday and travel all the way to Leeds to talk to us. Thank you to all who made this meeting a success and to the families who provided the excellent food. Thank you to Fiaz, Tracey, Melissa and Josh for their invaluable help, it couldn't have been done without you guys! Thank you to Julie Hart, Haematology Nurse from St. James's Hospital Leeds, who gave up her much needed day off, it was really appreciated. And special thanks to Zeb-un Nisa (Specialist Nurse Counsellor from Leeds Thalassaemia Centre), who keeps pushing us to achieve more. Without a doubt you are the heart of our group. Thank you from us all.

And thank you to Maserat for her kind words. We were delighted to meet the group and hope to revisit them in the near future. Do you have a patient support group who would like a visit from UKTS? We would love to meet you – please contact our office if you wish to discuss.

The murky story of deferiprone

Once again, the acrimonious conflict between the clinical investigator Professor Nancy Olivieri and the drug company Apotex (producers of deferiprone under the name Ferriprox) has burst into flame on the pages of a major medical journal (British Medical Journal 2004; 328:358. The full text of the correspondence is accessable at http://bmj.bmjjournals.com/cgi/eletters/328/7436/358) Anyone coming to this debate for the first time, pure and innocent, will be rubbing their eyes in disbelief. Others may have read similar hot exchanges in the New England Journal of Medicine last year and will read with weary familiarity. How can respected and experienced doctors and scientists come to such opposite conclusions on the safety and efficacy of this drug, after so many trials, and so many years of experience with it in thalassaemia clinics all over the world?

Confusion arises from a number of sources, and is not made any easier by the differences in factual accounts given by the different players. It also depends on how one assesses the published literature in medical journals, as it seems that objectively reported facts can be seen from two different angles to provide support for alternative views. I suppose it is the essence of intellectual debate, but seems unusually vehement and personal in this case. All involved have to be very clear about their motives, and the force with which they express themselves, as the consequence of their influential views are important for the life and livelihood of many thousands of thalassaemics.

However it is essential not to confuse the two different debates going on here. One is a general issue about the freedom and right of a doctor or scientist to express concerns about the safety and efficacy of a drug during a clinical trial, and the procedures for investigating and addressing these concerns. Obviously a drug company will not want to abandon a promising drug unless these concerns are fully substantiated, and neither will the patient group who stands to benefit from the drug. On the other hand, if concerns are genuine and patients are being put at risk, the trial needs to be modified or stopped. No drug company would seriously want to continue backing a drug under these circumstances, for obvious reasons.

The second is the debate on the safety and efficacy of deferiprone. The clinical scientist at the centre of the debate, Dr Nancy Olivieri, believes that the drug is not effective in removing iron, and has serious side effects. A group of well respected doctors and scientists agree with her, and have made their views well known in the medical literature, suggesting more clinical trials to address these concerns before the drug can be recommended at all. Such is the strength of her feeling, that in 1999 she launched a challenge to the European licensing for deferiprone which was dismissed in the European Court. (In fact, the indications for use of deferiprone under European licensing have actually been extended).

A large number of respected doctors and clinical scientists, probably representing the majority of specialists treating Thalassaemia, believe something rather different. They accept that deferiprone does not remove as much iron as desferrioxamine at recommended doses, but know that many patients are not able to adhere to the recommended treatment with desferrioxamine, either because they cannot afford it, or because of the practical problems of compliance. They believe that deferiprone can be an effective chelator, that adherence to therapy is easier, that deferiprone alone or in combination with desferrioxamine have saved large numbers of lives and improved quality of life beyond recognition for thalassaemics, that the range of side effects at standard dosage are now well understood from trials and long-term clinical experience, and can be managed effectively, and that deferiprone is probably the only hope for affordable treatment for the vast majority of thalassaemics in the developing world. Conducting the further clinical trials demanded by Professor Oliveri and her supporters will delay the acceptance of the drug in many parts of the world and expose the trial patients to multiple liver biopsies unnecessarily.

The Editorial in the British Medical Journal, which provoked the flaming arrows, was by the clinical ethicist Dr Julian Savulescu. He was writing after a recent series of articles 'the Oliveri symposium' was published in The Journal of Medical Ethics. He makes two points of interest. Firstly, that there is another ethical issue which cannot be ignored: the medical community is ethically obliged to resolve as soon as possible whether deferiprone is a life saving drug which is currently being denied to many patients in the developed and developing world, or whether it is an ineffective and dangerous drug which should not be recommended at all. In other words 'A moral imperative exists to conduct potentially lifesaving research properly and

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as quickly as possible'. Secondly, that the medical ethics committees which review the design and conduct of clinical trials in our medical schools and academic institutions have a duty to resolve these sorts of disagreements at their outset, independently of doctor or drug company bias.

There have been (so far) five responses to the initial article, and three further responses. One of the most interesting of these 'The disappearing patient' by Mr George Constantinou, draws attention to the notable lack of consideration for the actual, rather than perceived, views of the patients. After all, it is the thalassaemics who are suffering the most from the prolongation of this dispute.

I have permission to reproduce the article, and have selected some of the important passages which illustrate this viewpoint:

'Julian Savulescu suggests that the ethical committee is the closest advocate for patients because 'no one group has the responsibility for representing the interests of people affected with thalassaemia'. But patients have voices, there are many active support associations, and all concerned should keep in mind that the thalassaemic people of the 21st century are educated, married with children of their own, successful businessmen and women, scientists, doctors, active politicians, but above all very knowledgeable about the economics and politics of their treatment.'

'It was a patient group, the UK Thalassaemia Society, which supported the introduction of deferiprone for thalassaemia in the UK for a total cost of £750,000. In 1992, the Thalassaemia International Federation, requested Ciba-Geigy (then the only firm interested in iron chelation) to support clinical trials, largely because of the hope deferiprone offered for patients in developing countries. This was eventually declined, and without financial support for quality clinical trials, evidence had to be collected piecemeal by dedicated professionals'.

'Though authoritative reviews have concluded that its safety and efficacy is well within the usual range for commonly used drugs, in many low-resourced countries it is still not licenced, and so not available to patients. This is (a) because it has not been licenced by the American FDA and (b) because of professional insecurity created by the Olivieri dispute'.

'The Olivieri debate is contributing to the 2000-4000 annual deaths worldwide from iron overload by 'subordinating medical to political issues, and imposing a narrow North American perspective on a global problem'.

'When professionals cannot retain their objectivity, they need help from the patients, who have nothing to lose but their lives. We have the right to an open discussion that we can understand. We have the right to challenge opinions and ask authorities for their credentials. We have the right to ask our associations to support us and publicise results. Exercising these rights helps both professionals and patients. It also facilitates growing medical receptiveness to 'expert patients' and to joint decision-making. Though some doctors may need to adjust to cope with these developments any person who has, or who cares for someone with a chronic condition is entitled to, and indeed should, share responsibility by negotiating their treatment options rather than merely obeying orders.'

'We do not believe that new regulations including further involvement of ethical committees can help in such complex and fluid situations. We expect out doctors 'to cure sometimes, to relieve often, to comfort always' and believe to do so needs closer collaboration with patients.'

'As we see it, the deferiprone story has brought out many weaknesses of the medical research system, and of the human beings who work within it. Its message for the developing world is both depressing and challenging. It reflects the inexorable economic laws that govern drug firms, the difficulty in disentangling scientific, personal and commercial issues, and the neglect of patients in developed and developing countries.'

Dr Oliveri responds to this letter at length, re-iterating her views on the problems with deferiprone, and stating that these patients' advisors should feel deeply ashamed for misleading patients about the true priorities for thalassaemia management. Later on she urges patients to examine critically the data regarding deferiprone, with the help of individuals of 'integrity and independence', rather than to accept opinions expressed in discussions at selected meetings. In answer to the plight of thalassaemics in the developing world, who are inadequately chelated, she states that physicians in the developed world, rather than supporting use of deferiprone, have a moral responsibility to help these patients gain access to standard desferrioxamine treatment.

Where does all this leave the patients in the developed and developing world? Many will be feeling insecure, confused and distrustful about the whole medical/scientific/pharamaceutical setup. However, new information is continually accumulating, including animal studies, clinical trials and the experience of large numbers of thalassaemics who are taking deferiprone, some for many years. The credibility of the different arguments is not constant, but changes as new information is published. In my view, the emerging picture is that deferiprone has a very important role to play in management of iron overload. I suggest that everyone stays informed, continues to discuss treatment options objectively, and attends the relevant thalassaemia meetings.

Dr Paul Telfer, Senior Lecturer in Haematology and Honorary Consultant Haematologist Queen Mary University of London, Barts and the London NHS Trust

International Conference on Oral Iron Chelators

Utrecht, Holland. 14th –17th April 2004

The conference took the form of three workshops within the 38th Annual Scientific Meeting of the European Society for Clinical Investigation. The subjects covered were: Cardiovascular diseases: New horizons for iron chelator treatment; Nitric Oxide, metals and endothelial function; and Oral iron chelators in the treatment of thalassaemia and other diseases.

Spring is a lovely season in Utrecht. The sun shines continuously (at least it did during the conference), flowers are coming into bloom, ducks and geese nest building in the canals and dikes, and flocks of locals out and about on their bicycles.

What about the conference itself? The attendance was rather low, there was only one parent or patient on the delegates list, the scientific content was variable, and there were some very notable omissions from the programme. One can question whether it makes sense to continue these oral iron chelator conferences every year, particularly when there are several other larger conferences where the same data may be presented to larger and more comprehensive audiences. These workshops would have been better if there were truly an opportunity for in-depth discussion of clinical and scientific aspects of chelation. For this to happen, the attendance needs to be more representative of the spectrum of the clinical and scientific community working in this field.

It was particularly disappointing that there was no presentation on the Novartis Oral iron chelator ICL670. It is understood that the clinical data from Phase III studies are not yet mature, but surely, at an oral iron chelator conference there should have been at least one presentation giving an update to reassure us that things are on-track.

It was only by talking to the Novartis representative who attended, that I obtained this information that the studies are continuing satisfactorally.

Was there anything new to report? The group from Genzyme reported early studies on the oral chelator GT 56-252 (Deferetrin), which they are developing. So far, the pre-clinical and Phase 1 studies in thalassaemics look promising. There is still a long way to go of course.

It is very good news that there is another large drug company looking seriously at iron chelators, and I suspect that others may follow if it is shown that iron chelators have a role in preventing tissue damage due to 'free iron' and 'free radicals' in other medical situations, including cardiovascular disease.

By Dr Paul Telfer, Senior Lecturer in Haematology & Honorary Consultant Haematologist, Queen Mary University of London, Barts & The London NHS Trust

Employment and Career Matters

by Neelam Thapar

(Neelam is a Careers Adviser at London Metropolitan University and also a thalassaemia major patient at Whittington Hospital, London)

In this issue, we will look at devising CV and cover letters when applying for vacancies. Please don't hesitate to contact me if there are any particular questions you have. All correspondence can be sent via the UKTS office.

Making Applications

Applications are used for many different purposes; for example full time employment, temporary work, voluntary work and training courses. However, all written applications will have some similarities whether you are asked to use a CV, letter or application form.

You need to spend time preparing your applications. The employer will have to select people to interview based on what you have written. When faced with numerous applications to look at, the employer will be looking to see that you have done your research about the position and company. By doing this you will be able to relate your skills and experience to the employer's needs. This is known as targeting your applications. If the employer has mentioned that they are looking for particular skills, make sure that you address this by changing your CV and letter accordingly for each position you apply to.

Curriculum Vitae

A CV can be used to apply for advertised or speculative vacancies. To help you draft a CV, think back and make a list of all your accomplishments and experience. When you are applying to a particular vacancy, you can see at a glance what you will need to include in your CV

Writing Your CV

- Your CV should not be more than 2 sides of A4 paper and should be word processed.
- It is an organised summary of all your personal details and experience and should be targeted to the position or company you are apply. Be concise and do not use long complicated sentences.

Personal Details
Name Address Telephone numbers/email address Nationality if appropriate. If the job is away from your hometown, it may be useful to put that relocation is possible.
Education
This will include dates and places such as University if appropriate and school career with your qualifications. Add your grades as far as possible. (If your grades are not very good, it would probably be better to just mention the subjects) GCSEs only need a brief listing e.g. 8 GCSEs including 2 at Grade A
Employment Experience
All past experience should include dates of employment, name of the organisation, job title and responsibilities. Think about all your vacation and part time employment. Even if you have done unpaid work e.g. voluntary work, this may be relevant. Employers want to know. Recognise what you have gained from these e.g. leadership skills, management skills, Target your duties and responsibilities according to the job you are applying to.
Achievements
This would include any positions of responsibility, awards etc.
Activities/Interests
Think about what you put down -you may be asked at an interview. Try and not use words such as socialising.
Additional Information
This will covers things such as: Computer skills - list the packages that you can use. Language skills -If you can speak another language, add this. You may want to mention that you have a driving licence
Referees
Check that you can put their names down from them. You should use two referees. If you know someone who works in the sector you are applying to, ask him or her. Alternatively, you can put that references are available on request.

- CVs can be done in chronological or reverse chronological order (most recent date first) but remember whichever style you choose, follow it through for the whole CV.
- Use good quality A4 paper
- Keep a copy of the CV you send
- Always remember to include a cover letter

CV Headings

There are many different formats and designs of CVs but in general all CVs should cover the following basic sections. This will give you a basis to start with when you are considering the sections to include but the contents and layout/style should be changed according to the job that you are applying for.

Cover Letters

A covering letter is essential whenever you are enclosing Curriculum Vitae to an employer whether in response to an advertisement or applying speculatively. It is also advisable to use a covering letter when forwarding an application form to an employer.

Guidelines for Cover letters

- It should only be on one side of A4 and should be written as a business letter
- The letter can be typed or hand written. Some employers will ask for a hand written cover letter
- It should preferably be to a named person and therefore end with "Yours sincerely". If it is to Dear Sir/Madam, it should end with "Yours faithfully"
- Print your name under the signature
- Do not forget to enclose your CV

What a good covering letter should include

- Make clear the job for which you are applying
- Mention where you saw the advertisement or learnt of the vacancy
- Emphasise points of special relevance to the job e.g. previous work experience, skills, interests or any other reasons why the employer should consider you
- Add any relevant information that was not included in your CV or the application form
- Target the letter to the employer – provide him/her with information about why you are interested in their organisation.
- Mention when you are available for interview.
- Try drafting your letter using action verbs e.g. achieved, initiated, planned, advised, implemented, established, supported etc.

Always check and double check your applications.

Congratulations to Mena and Paul

UKTS would like to offer our warmest congratulations to Mena and Paul Shervill, who will shortly be celebrating their first wedding anniversary. Mena, a beta thalassaemia major patient, is the daughter of UKTS members Mr and Mrs Bharat Nathwani of Wembley, Middlesex. Mena is a programme manager for an IT software house and her husband Paul is a network administrator for a law firm. Their wedding took place on 3rd May 2003 at the Grims Dyke Hotel in Harrow, Middlesex.

Thank you to Mena, Paul and their families for allowing us to print their details and the lovely photograph of their special day.

A parent's experience

By Aggie Tan, President, Singapore Patients Association & mother of 15-year-old Valerie, a beta thalassaemia major patient (Aggie is also the fiancée of our President, Mike Michael).

I was quite reluctant when asked to write my thoughts and comments on the UK Thalassaemia Society during my 3-month stay in London. After all, being engaged to the President of the Society, I would have nothing but compliments wouldn't I? But, to not say anything at all would be injustice to the group of people working hard behind the scene to keep the society going from strength to strength.

For every celebrity walking down the red carpet, there's a whole unit of hairdressers, make-up artists, fashion consultants, shoe fitters and personal trainers backing them up; putting the whole package together so that the celebrity looks good from the moment s/he emerges from the limousine to sitting down in the grand ballroom. It's the same for UKTS. A team of nine people from diverse professions make up the group of 9 committee members, who have volunteered to work for the benefit of all Thalassaemics in the UK and indirectly, the rest of the world.

Since the World Wide Web has become THE window of information to the world, I was introduced to the power of positive thinking in the world of Thalassaemia. What the little screens have shown me from the various Thalassaemia websites were just the tip of the iceberg. Coming from an environment where adult Thalassaemics are afraid of long term commitments; hearing announcements about marriages and new births by Thalassaemics was encouraging, but it seemed somewhat mythical and faraway from us.

My ex-husband and I have very different outlooks on Thalassaemia. As the number of candles on Valerie's birthday cakes mounted, we found ourselves drifting further apart. We love her in our own very different ways. While he continues to find her having to live with Beta-Thalassaemia Major very depressing; I, on the other hand, was encouraged by every motivating article or bit of news that came my way. It was not easy, fighting a battle both for and against loved ones. At the end of the day, something had to give.

After the divorce, with my newfound freedom, I travelled to countries where conferences for Thalassaemia were being organized by the Thalassaemia International Federation.

My first life-changing encounter was in Bangkok, Thailand, in the year 1999. There, I witnessed the confident and assertive "Mr Thalassaemia" – George Constantinou (of UKTS), talking to a group of doctors just a few yards from me. It suddenly dawned on me that marriage and family life for Thalassaemics was no longer a myth, but a reality! It was the dawn of a huge battleground.

Upon returning to Singapore, I began my fight against local doctors' outdated Thalassaemia treatments. The countless arguments with the blood bank to give Valerie the blood she required to live instead of just enough to survive. The nagging at Valerie, making sure she did her pump every night. Accepting interviews by reporters, aiming to raise awareness and thus changing the mindsets the public have on Thalassaemia. Learning to write articles and give speeches. In an oriental society, no one talks about illness or hereditary conditions. Divorce and single-parenthood is taboo, women can't lead or change laws, and if one is poor and uneducated one just keeps the mouth shut. The scariest part was to fight with myself to get up and disregard the rules – to unite all Thalassaemics in my country to move towards recognizing our strengths, to lead a life just like every other person – complete education, find a job, establish a career, raise a family, live to a ripe old age, retire to look after grandchildren or backpack around the world.

I look forward to every opportunity to attend Thalassaemia Conferences. It is a huge moral boost, and also an opportunity to hear complex medical information presented in an accessible way.

The most memorable conference was the one held in Athens, Greece in the year 2001. It was shortly after the 911 terrorist attacks, a time when everyone was afraid to travel, yet the attendance was overwhelming. Sitting amongst participants from countries involved in the war, the tagline "Thalassaemia has no borders." was indeed well chosen. As in all the conferences, I was just one of the many informed parents/patients. Not Chinese, not uneducated, not poor, not ignorant. Skin colour, language barrier, race and background, ceased to exist as we sat in the same function room. Almost every day at the conference I would find myself moved to tears by the bravery, selflessness and attitudes of professionals working with Thalassaemics, and Thalassaemics who became professionals.

There I befriended the Italian beauty - Martina Fanari. I can still remember our first conversation, in which I asked how she was related to Thalassaemia. With a brilliant smile she replied, "I'm a patient." I was dumbfounded! Such openness and confidence! Where I come from, it's unheard of.

I used to attend every clinical presentation during the conferences. Where I would diligently note down all new updates on Thalassaemia treatments, talk to doctors if there were questions, and bring home the wealth of information to share with my support group. This was food for the brain, feeding the knowledge of how to prolong the lives of Thalassaemics, what to look out for, what are the complications, what are the new drugs, how to tackle the side effects, etc.

However, it was at the workshop in Cyprus, where I found my soup for the soul.

To be continued in next issue.

A Singapore Wedding

Another wedding to report – this time from the other side of the world! On 7th June 2003 Wahida, a beta thalassaemia major patient and human resource administrator by profession, celebrated her wedding to Nasir, a ramp serviceman with Singapore SATS. When they met Nasir had never even heard of thalassaemia and had no idea that Wahida was a patient. When he declared his feelings for her she invited him along to one of her transfusions to see how he would react. When Nasir saw the bag of blood however he did not run but stayed, talked to Wahida and convinced her that he loved her for herself and wanted to marry her. We do not have to say more, their wedding photograph speaks for itself!

UKTS are very grateful to Aggie Tan, President of the Thalassaemia Society (Singapore) for sending us this information and photograph.

GIVE US YOUR GOOD NEWS!

Are you a thalssaemia patient (or a parent) who has some good news to tell us? At UKTS we are always keen to hear of any achievements and success stoires from our patient members and we are therefore thinking of including a new "Congratulations" feature in Thalassaemia Matters. The good news can be abything at all, as all success is relative and what would be routine for one person can be a great achievement for another! So please ask yourself if there is anything you would like to share with our readers – every achievement we can print will be a source of encouragement to other thalassaemia patients and their families. Accompanying photographs will also be very welcome.

Many thanks – we look forward to hearing from you.

AGM at the Holiday Inn

UKTS President Mike Michael and retiring Secretary Katerina Read

The UKTS Annual General Meeting took place at the Holiday Inn Hotel, Brent Cross, North London on 7th March 2004. The meeting was attended by 23 members in addition to the Committee. Outgoing Secretary Katerina Read chaired the meeting. Mike Michael read the President's report. This included an overview of some of the major projects undertaken by UKTS during the last term. Mike added his thanks to the outgoing Committee and all UKTS volunteers for their help over the past year. As Treasurer Erol Aziz resigned in mid-term the accounts were presented by George Constantinou.

As only 9 nominees put their names forward for election to the Management Committee they were automatically appointed without the need for a vote. Each nominee submitted a short "biography" and these are reproduced below. Once the general business was concluded, Dr Anna Mandeville (Clinical Psychologist, University College Hospital, London) gave a very interesting presentation on "The psychosocial integration of thalassaemics in the 21st century".

Introducing The UKTS Management Committee 2004-5

(in alphabetical order)

George Constantinou

George is a beta thalassaemia major patient. He is a founder member of the UKTS, having served on the Management Committee from 1976-1985 and again from 1999 to the present day. George has been a tireless campaigner on behalf of thalassaemia all his adult life and has conceived and been involved with many UKTS projects including the Compliance Workshop and Doctors' Workshop in 2002; also the thalassaemia patients' personal organiser. George is a hotel manager by profession and is married and has a daughter.

Avraam Demetriou

Avraam has been a UKTS Committee member and fundraiser in the past; and now returns to the Committee after a break of several years. His past achievements include the raising of funds for the development of the oral chelator L1 and in 2003 he was the co-recipient of the first UKTS Achievement Award for this outstanding contribution. Avraam has always supported the cause of thalassaemia and by rejoining the Committee wishes to renew his efforts on behalf of the patients and families affected. He is a dentist by profession.

Katerina (Nina) Demetriou

Nina is a Haemoglobin H disease patient and was diagnosed with this problem at the age of 27. She has previously served on the UKTS Management Committee for several terms as the Treasurer. In the past year she has been involved in the sub-committee organising the conference/ workshop and is always willing to help where possible. Nina's involvement with the UKTS has included the management of the accounts and she is keen to see that funds received through hard work are used efficiently to meet the objectives of the Society. She is a finance officer by profession.

Olga Demetriou

Olga is a beta thalassaemia major patient. During the past year she has been a co-opted Committee member and has been actively involved in the organisation and execution of all UKTS events throughout 2003. She has attended Committee meetings on a regular basis throughout the past term and has made valuable contributions to many of our projects, including the redesign of our quarterly magazine Thalassaemia Matters. Olga is particularly keen to help young patients having difficulty with treatment and is always willing to give them support on a personal level. She is an IT manager by profession.

Maria Gavriel

Maria is a beta thalassaemia major patient. This is her second nomination to the Management Committee. She has served in the post of Assistant Secretary during her first term and has been actively involved with the work of the UKTS for several years. She regularly does voluntary

work for the Society by helping in the office and has also devised and organised fund raising events. Maria is keen to continue her service on the Committee as she feels that as a thalassaemia patient she can relate to and understand the issues patients deal with in their daily lives.

Costas Kountourou

Costas is a beta thalassaemia major patient. He has been a member of the UKTS Management Committee for many years, being actively involved in fund raising, events organising and the administration of the Society. During the 2003/2004 term Costas has served UKTS as Vice-President and has been very involved in the restructuring and redesign of the UKTS quarterly magazine Thalassaemia Matters. Costas feels that his many years on the Committee have given him valuable experience which will help to carry forward the aims of the Society. He is a travel agent by profession.

Mike Michael

Mike is a beta thalassaemia major patient. He has been President of the UKTS for the last three years and has served on the Management Committee for several terms in the past. He has represented the Society at many national and international conferences and functions and attends Board meetings of the Thalassaemia International Federation. Mike also provides invaluable IT support to the UKTS by installing and maintaining our office computers. He is an IT consultant by profession.

Menuccia Tassone

Menuccia is a former beta thalassaemia major patient who underwent a successful bone marrow transplant at the age of 22. She gave a presentation on this subject at the UKTS national conference in 1999. This is her third nomination to the UKTS Management Committee. In the past year she has served as Assistant/Acting Treasurer and has been involved in many sub-committees organising conferences and fund raising events. She has also been very active in the redesign and editing of Thalassaemia Matters. In her work for the Society, Menuccia aims to serve the UKTS to work towards the objectives of research, fundraising and improvements in the current standard of care for thalassaemia patients.

Some of the UKTS members at the AGM

Andreas Yiannikou

Andreas is a parent of two beta thalassaemia patients, Stella and Katie. (Sadly, Stella passed away recently.) He has been an active member of the UKTS since the Society was established in 1976 and was a member of the Management Committee for many of those years, mainly serving as Assistant Treasurer. Andreas has also been actively involved in fundraising events during this time and would like to continue putting his efforts to valuable use, in order to help the UKTS with their valuable work

UKTS Thanks the Bank of Cyprus

The Bank of Cyprus has an excellent policy of making charitable donations in lieu of spending money on Christmas cards; and as in previous years UKTS have been one of the lucky recipients. The donation of £500 was gratefully accepted at the Palmers Green, North London branch on 22nd March 2004 by Maria Gavriel (Secretary, UKTS), seen here with the Manager, Andy Symeou.

Thank you to all our friends and supporters at the Bank of Cyprus.

Thank you to the Cypriot Golf Society

Once again we thank our kind friends at the Cypriot Golf Society for their generous and continued support. Their donation of £1,685 is greatly appreciated. Here we see the retiring captain of the Cypriot Golf Society, Mr Chris Georgiou, presenting the donation to Ms Maria Couppas on behalf of UKTS.

Travel Insurance For Thalassaemia Patients

When travelling abroad it is important to feel secure and have the peace of mind that will allow you to fully relax and unwind. Freedom Travel Insurance has worked in conjunction with the United Kingdom Thalassaemia Society and leading clinicians in the field to offer people living with thalassaemia the benefit of an A1 insurance product.

Freedom already works with other medical charity groups and our expertise spans many conditions from diabetes to cancers. Our aim is to provide a wide range of benefits with an excellent level of security: this is achieved by the policy being 100 per cent underwritten by AXA, one of the largest insurance companies in the world.

Premiums are individually calculated and dependent on such factors as when and for how long you are travelling, your intended destination, your age and how well your condition or conditions are managed. Medical screening and policy document issue are carried out over the telephone with trained staff in our head office. Freedom is not a call centre operation. **There is a policy excess of only £35.00 including for claims relating to conditions which we have screened and agreed to cover.** By way of illustration here are some example screenings and related premiums. The premiums are shown inclusive of Insurance Premium Tax which is charged at 17.5%.

Traveler 1

Age 34, non-smoker travelling to Pakistan

Beta thalassaemia major – no heart failure – no stem cell or bone marrow transplant

Osteoporosis – Two fractures in the last five years

Diet controlled diabetes

Premium 17 Days – £114.16
24 Days – £122.72

Traveler 2

Age 24, non smoker travelling to Cyprus

Beta thalassaemia major – no heart failure – no stem cell or bone marrow transplant

Insulin dependent diabetes

Premium 17Days – £49.54
24 Days - £53.01

Traveler 3 Age 43, smoker traveling to Italy
Beta thalassaemia major - no transplant, degree of heart failure

Premium 15 Days – £61.93
21 Days - £65.40

NB Quotations will vary subject to medical screening

Price is one thing but the true value of an insurance contract is often realised if a claim is made. Our programme is backed up by a team of clinical staff, claims experts and linguists available round the clock and planes fitted with specialist equipment in case of the need for medical evacuation or repatriation.

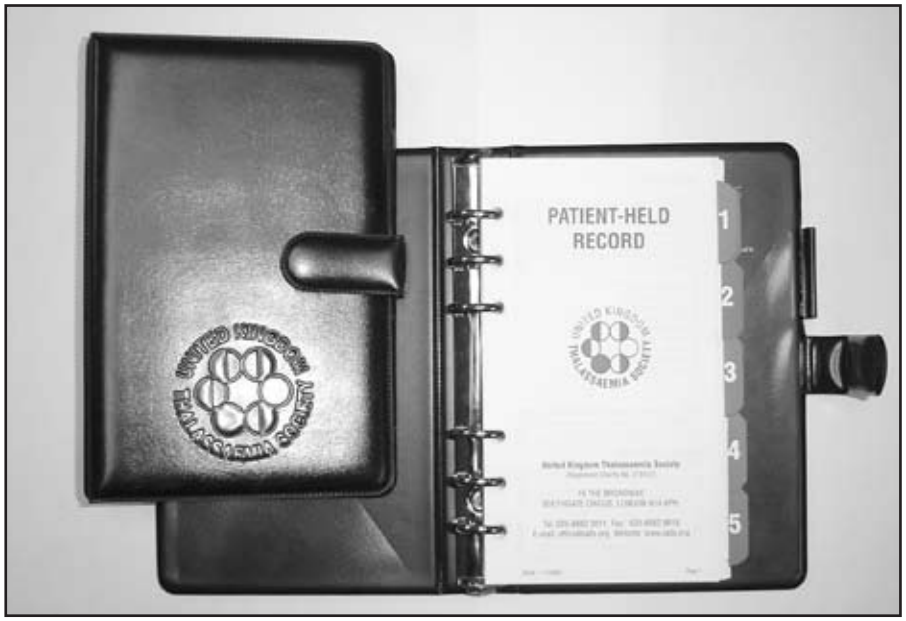
We do not claim to be able to help everybody with their insurance requirements however we are hopeful of providing a solution in the majority of cases.

For a quotation call 0870 774 3760

International Thalassaemia Day – 8th May 2004

Did you run any events to coincide with International Thalassaemia Day? If you would like to send us information/photographs of any such events to be included in the next edition of ***Thalassaemia Matters***, please let us have them by the end of May 2004. UKTS is running the first national conference for thalassaemia nurses and counsellors on Wednesday 5th May (as International Thalassaemia Day falls on a Saturday).

The UKTS Personal Organiser



- Are you a thalassaemia patient/ parent of a thalassaemic child?
- Do you have the UKTS specially designed personal organiser for thalassaemia patients?

If not why not – all it takes is a call to our office.

This valuable aid to keeping your own patient – held medical record is **FREE** to patients and parents/carers of children with thalassaemia.

Call 0208 882 0011 to order your copy now!

Donations

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

Bank of Cyprus	£500.00
Mrs B Daglish	£5.00
Mr S Gandhi	£200.00
Mrs M Kyriakides	£10.00
Mr V Constantia	£5.00
Ms M Purvis	£10.00
Mr R M Brook	£10.00
Ms K Howells	£5.00
Cypriot Golf Society	£1,685.00
Mr A Yiannikou	£10.00
All Global	£60.00
Mr M J Burton	£10.00
Mr K Papamichael	£40.00
Mr A W Coombs	£15.00
Ms D Ptohopoulos	£50.00
Mrs B Lysandrou	£50.00
Mrs & Mrs Soni	£46.00
Mr R Ensan	£20.00

THALASSAEMIA INTERNATIONAL FEDERATION ASSOCIATIONS WORKSHOP & BOARD MEETING

Please contact TIF for further details on:

tifhq@spidernet.com.cy

UKTS Welcomes NEW-MEMBERS

Annual

Mrs X Kantaris
Mrs S Tangai
Ms O Yiakoup
Mr Ashfaq
Mrs A Lewis
Mr P E Obike
Mr T Jawad
Mr C J Wight
Ms P Daly

Life

Mrs S Chebbi
Mr G Diamantaras

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The views expressed are not

membership application form

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Charity Reg No. 275107

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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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