



...continuing the fight against Thalassaemia

Government Pledges Payouts For Victims Of Hepatitis C Blood Contamination

In a press release issued on 29th August 2003 Health Secretary John Reid announced that he is establishing a scheme to give financial assistance to people in England infected with Hepatitis C as a result of being given blood by the National Health Service. Since the 1980s more than 1,000 NHS patients have died from either Hepatitis C or AIDS contracted from contaminated blood products before the introduction of virus-killing heat treatment in 1985.

The decision has apparently been made solely on compassionate grounds and there has been no admission of wrongdoing by the Department of Health. Mr. Reid states; "After becoming Secretary of State, I looked at the history of this issue and decided on compassionate grounds that this is the right thing to do in this situation. I have therefore decided in principle that English Hepatitis C sufferers

should receive ex-gratia payments from the Department of Health."

It is estimated that more than 3,000 people will be eligible to receive compensation. Patients such as thalassaemics and haemophiliacs who are regularly transfused represent the largest group of victims, although others who received one-off transfusions have also been affected. It should be pointed out, however, that at the moment the press release from the Department of Health is a statement of intent only and that no timescale or structure for the payouts has yet been worked out. When UKTS contacted the DoH for more details we were told to expect further news in early 2004. Hopefully these further details, when released, will make it clear who will be eligible to claim compensation and the amount each affected person can expect to receive. In January 2003 the Scottish

Health Executive promised payouts of up to a maximum of £45,000 per patient but so far no individuals have been compensated. Under the Scottish scheme, each patient who contracted Hepatitis C from contaminated blood would receive a payout of £20,000. The worst affected, many of which are suffering from severe cirrhosis, liver cancer or other serious illness would receive additional compensation of up to £25,000. This has been described as "derisory" by the Scottish Haemophilia Groups Forum which represents 500 affected patients. This group has been particularly vocal in demanding justice. On 18th September 2003 they protested outside the Scottish Parliament in Edinburgh; demanding a public enquiry. They claim to have evidence that senior executives within the Health Service in Scotland became aware of the risk to patients from infected blood years before officially acknowledging that it existed. Scottish Health Minister Malcolm Chisholm has pledged to examine any evidence they bring forward and we will await the outcome with interest.

In the past the Government has demonstrated a markedly different attitude to those infected with HIV in the same way from contaminated blood products. Since 1987 1,200 affected persons have been compensated under a Government-funded scheme. Perhaps the influence of the press taking up

Continues on page 3

CONTENTS

A word from our President	2	Patient News	9
Latest News	3	World News	11
News from around the Country	4	Office News	13
Medical News	8		

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A word from our President



Welcome to the autumn edition of Thalassaemia matters:

On August 29; the Department of Health released a document. This document; this statement of intent, was released without fuss, without media coverage and without the newspaper frenzy which has recently surrounded thalassaemia. It implies that the government is to establish a scheme which will compensate people who have been treated using contaminated blood or blood products and have gone on to contract the HEP C virus. And although no payment will ever truly compensate for liver cirrhosis or for the loss of a loved one I'm sure that it will go some of the way to easing the burden for sufferers and their families.

As this could affect many thalassaemics throughout the U.K. you can be sure that we will be keeping a close watch on this story.

On a different note the highlight of the thalassaemics year will soon be upon us. Yeap it's nearly conference time. This year's conference "Thalassaemia in the 21st century" aims to inform on the results of new and improved treatments for Thalassaemia. This will also include a summary of the TIF conference in Palermo by Dr Anne Yardumian. But the most important part of this whole conference will be in the afternoon.

The afternoon session will be a series of round table discussions aimed at a variety of issues relating to Thalassaemia and how it affects us in our lives/relationships/quality of life etc. Places are limited and I would advise that anyone who has not registered do so.

A few weeks back I was sitting in the clinic discussing quality of life with some younger thals. I asked them to define when they stopped being a thal. One person said "when I don't need a transfusion anymore".

This made me think. Is that true? Does the end of transfusions mean that you are no longer a thal? After all I know many people who've had successful bone marrow transplants and no longer need transfusions but still consider themselves thals. And for myself I can say that my treatment today is much better and more in tune with my lifestyle than ever before. In fact only when I go in for a transfusion do I remember that I am a thal.

Treatment today allows us a freedom that we've never had before and yet we still feel different. Even when we are released from injections and transfusions we still feel different.

Maybe one of the questions we should be asking is why do we have this image in our heads.

And finally comments have poured into the office regarding the new look and feel of the newsletter. I hope that this issue continues in the same vein.

Should you have any comments, thoughts or suggestion on how to improve this newsletter or on any of the stories within then write to me and let me know.

This Society is your Society.

Mike Michael

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

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Continues from page 1

“fashionable” causes has more than a little to do with this difference - as we all know, Governments are as susceptible as individuals to the pressures of the media in this regard.

We at UKTS naturally welcome the decision in principle to provide financial assistance to Hepatitis C sufferers. We will be lobbying the Government to ensure that the compensation structure and

subsequent payouts are released without undue delay; given the fact that so many have already died and thousands of others are suffering daily from the effects of Hepatitis C caused by transfused blood. We will also be pointing out the necessity for the payments to reflect the true scale of damage caused to quality of life and life expectancy for chronic Hepatitis C sufferers. There is also the question of

compensation for the families and dependants of those who have died as a result of this disaster in the last 20 years, which has not yet been addressed. Be sure that we will keep you posted with the news on this vital issue for thalassaemia patients in the UK.

Elaine Miller

Myths about beta thalassaemia

Dear UKTS,
I was delighted to read that UKTS are putting the record straight regarding information about thalassaemia. I am not even affected by beta thalassaemia (except through the involvement I have with my patients) and it cut me to the core to hear the condition being described as “terminal” and causing death in childhood etc. People with thalassaemia have enough to deal with in their lives without being demoralised and upset by inaccurate reporting.

I too have every sympathy with the Hashmi family in their determination to find a cure for Zain, but not at the expense of upset to hundreds of families affected by beta thalassaemia in the UK and many more worldwide. I do hope that the Hashmis read your letter. It is a pity that they were not put in touch with you from the very beginning so that you could work together to present an accurate and just as compelling case in favour of PGD. They have chosen a “road to travel” that may not have been everybody’s choice and I just hope and pray that it all turns out for the best for all concerned, particularly young Zain.

Thank you.

Pippa Gillham

Haemoglobinopathy Specialist Counsellor
Royal Berkshire Hospital

“Designer” babies – some questions answered

We have had very positive feedback from our readers on our attempts to correct the misinformation about thalassaemia surrounding the Hashmi case. Thank you to everyone who wrote, emailed or telephoned our office. However, there still seem to be a number of misunderstandings regarding the stance of the Human Fertilisation and Embryology Authority, which need to be cleared up. The HFEA initially agreed to grant a licence for the preimplantation diagnosis/tissue matching of embryos to Mr. and Mrs. Hashmi to enable them to have a child which could be a stem cell or bone marrow donor for their thalassaemic son, Zain. The subsequent legal proceedings were initiated by CORE (Comment on Reproductive Ethics), a “pro-life” organisation which challenged the right of the HFEA to grant such a licence.

Many people have been confused over why the HFEA agreed to grant a licence to the Hashmis but turned down the similar application from Michelle and Jayson Whitaker, whose young son Charlie (now 4) has Diamond-Blackfan anaemia. In this syndrome, the bone marrow produces little or no red blood cells. It is sometimes treatable by steroids; but often the treatment, as for thalassaemia, is regular transfusions and chelation therapy. The condition is far rarer than thalassaemia,

with only 600-700 cases worldwide. Again like thalassaemia, a bone marrow transplant from a compatible donor can provide a cure. Following the rejection of their application by the HFEA, Mr. and Mrs. Whitaker subsequently travelled to the Reproductive Genetics Institute in Chicago, USA, where Mrs. Whitaker successfully underwent IVF/PGD. Happily, as a result of this procedure a son was born to the Whitakers on 16th June 2003 in the Royal Hallamshire Hospital, Sheffield.

At first sight it is hard to see why the Whitakers’ application failed with the HFEA where the Hashmis succeeded. The answer is that no pre-implantation diagnosis is available for Diamond-Blackfan anaemia; which can be passed on genetically but also occurs sporadically. In the case of the Hashmis, however, the embryo providing the tissue match for Zain would also be screened for thalassaemia, and this is the reason that permission was granted in their case. Screening the embryos for thalassaemia implies a benefit for the unborn child as well as providing a possible donor for Zain. If there had been no potential benefit to the unborn child no licence would have been granted, regardless of the severity or otherwise of Zain’s condition. This is why there was very

Continues on page 7 ➡

UKTS at Asian Festivals, Summer 2003



*Some of our team at the Plumstead mela.
L to R: UKTS Vice-President Costas Kountourou, Asst. Co-ordinator Elaine Miller, phlebotomist Amina Ishaq-Khan, volunteer Angelica Gavriel, Asst. Secretary Maria Gavriel*

Over the Summer months the UKTS attended 2 prominent Asian festivals, with the usual dual purpose of raising awareness and offering free blood screening to those present.

Firstly, we attended the Mega-Mela which was held on Plumstead Common on 6th July 2003. (For any readers who

have never attended a mela, it is a multi-cultural Asian festival which includes music, dancing, displays, stalls of goods for sale and, needless to say, a huge variety of delicious dishes to sample.) Barclays Bank had kindly invited us to share their marquee. This was organised by their representatives Ajay Chowdhary



Our youngest blood screening volunteer, Nayan Dhokia (aged 6), at the Hare Krishna Festival.

and Steve Rogers, who were participating in a Barclays staff charitable scheme. They ran a raffle and other fund raising activities during the day for our benefit and Barclays agreed to match whatever they raised. (The total benefit to UKTS from the event came to almost £300. We are very grateful to Barclays and their staff for their help; with particular thanks to Ajay and Steve for inviting us.)

The sun was shining and we had an enjoyable day distributing our leaflets and encouraging the youngsters present to have their blood screened (some of those we spoke to were very concerned that the blood test for thalassaemia trait would involve them giving about a pint of blood!!! Let us set everyone's mind at rest on this point, only a tiny amount is taken!).

The second event we attended was different in character, being the Hare Krishna (Janmastmi) Festival on Sunday 24th August. This event, held at Bhaktivedanta Manor near Watford, is a Hindu religious festival attended by thousands of people from all over the UK. UKTS were invited by the organisers to occupy a space in the Health Tent. Once again the weather was good and the response even better, as we had people of all ages queuing up to have their blood taken! When we left to take the blood samples to the lab for processing, the festivities continued late into the night.

Thank you to all the volunteers who helped us at the festivals and to the laboratory at the North Middlesex Hospital for processing the blood samples.

Elaine Miller

Manchester Awareness Day, 4th July 2003



L to R: Mrs. Zanib Rasul, Elaine Miller, Dr. Andrew Will, the Mayoress of Trafford, the Mayor of Trafford, Dr. Allyson Hague, Dr. Asa'ah Nkohkwo, Verna Angus-Davies.

The 4th of July is of course American Independence Day; more importantly to us however, in 2003 it brought an excellent Awareness Day, organised by Manchester Sickle Cell & Thalassaemia Centre. The event was held at the Centre, located in Oxford Road, Manchester. There were displays by UKTS, the Sickle Cell Society, Pendlebury Paediatric Team, Play Therapy, Reflexology and many others.

Throughout the day entertainment was provided by the drumming band of St. Thomas Aquinas School and displays of African, Asian and Egyptian dancing. Speeches were made by many, including: the Mayor of Trafford, Cllr. Whit Stennett,

the Chair of Central Manchester PCT, Ms. Evelyn Asante-Mensah and the Director of the Sickle Cell Society, Dr. Asa'ah Nkohkwo. UKTS Asst. Co-ordinator Elaine Miller spoke about the work of the Society in raising awareness of thalassaemia.

The day was very well attended and it was encouraging to see such a large gathering. For Elaine it was a good opportunity to meet a few "telephone friends"; and a particular pleasure to meet at last Mrs. Zanib Rasul, Co-ordinator of the North of England Bone Marrow and Thalassaemia Association. (Many of our members in the North will be familiar with Mrs. Rasul, who has been campaigning for

the cause of thalassaemia for many years.)

All in all, the day was a great success and a great source of information and fun for all who attended.

The Centre has been open since 1984 and offers free and confidential blood screening, genetic and prenatal counselling, supportive counselling and a weekly haematology clinic. Any enquiries, please contact:

**Manchester Sickle Cell & Thalassaemia Centre,
352 Oxford Road,
Manchester
M13 9NL**

Telephone: 0161 274 3322

A year in the life of the Sickle Cell and Thalassaemia Service in Reading, Berkshire

The Sickle Cell and Thalassaemia Service in Reading was introduced in 1989. This was considered a major breakthrough as West Berkshire then had an ethnic minority population of only 8 – 9%. Many other areas would not have considered this high enough to warrant the cost of running such a service. So how did it come about? Enlightened and pro-active health professionals and ‘people power’ – strong voices within the community pushed for a better level of care and greater understanding of sickle cell and thalassaemia amongst health professionals and within the community. The introduction of National Haemoglobinopathy Cards in 1988 further highlighted a need to provide support and counselling for those found to be carriers of an unusual haemoglobin.

This is a hospital based service and involves a designated Consultant Haematologist, Specialist Registrar (Paediatrics), Counsellor/Service Co-ordinator, Staff nurse (specialising in sickle cell and thalassaemia), 2 Biomedical Scientists and an Assistant Counsellor/Biomedical Scientist.

Year 2002 People in Reading with Beta thalassaemia

There are 3 young adults in Reading with Beta Thalassaemia Major, 7 children with Beta Thalassaemia Intermedia and 2 with Haemoglobin E/Beta thalassaemia. Their routine care and management is provided here in Reading with periodic reviews at The Whittington Hospital. Contact is maintained not only when they

attend the hospital for transfusions or clinic appointments but by home visits when appropriate. Blood transfusions are arranged according to individual need and can be provided in the Paediatric Day Bed Unit, Adult Haematology Day Bed Unit or overnight on a designated ward where staff have extra training in care and management of people with Beta thalassaemia.

Two social events are also planned each year to further support the families as a whole. In 2002, the summer event was a trip to the seaside at Bournemouth and at Christmas there was a party held at the hospital with food, drink (non alcoholic naturally), music and a magician. The Sickle Cell and Thalassaemia Service Office is also used as an informal ‘drop-in’ centre.

Antenatal Screening to detect carriers of sickle cell and thalassaemia

is currently being offered to women if they or their partner are of non-Northern European origin. This year, 5,687 women were booked for ante-natal care by midwives in West Berkshire and 991 were screened. 93 carriers were detected and 9 couples identified as being at risk of having a baby with Sickle Cell disease (4), Beta thalassaemia major (2) or Haemoglobin H Disease (3). These couples were offered the opportunity for pre-natal diagnosis to determine if their baby had inherited a major blood disorder. Only one couple chose pre-natal diagnosis and subsequently terminated the pregnancy when they found their baby had beta thalassaemia major. Fortunately, none of the other pregnancies resulted in a baby

with sickle cell disease or beta thalassaemia major.

Many couples may not have chosen to have pre-natal diagnosis as the risk was detected too late in pregnancy. Only 35% of women were offered screening before the 12th week of pregnancy. Understandably, screening any later than this has been shown to dramatically reduce the number of couples willing to consider pre-natal diagnosis. This delay in screening is ‘historical’ as some midwives misguidedly delay booking bloods until 16 weeks when the AFP test is done (a test to detect spinal abnormalities). Steps are currently underway to further educate GP’s and midwives. The ‘Gold Standard’ would be pre-conceptual screening which relies heavily on the support of GP’s.

The couple with Beta thalassaemia trait who declined pre-natal diagnosis in 2002 subsequently accepted it with their second pregnancy in 2003 and happily, the baby was found to be unaffected.

Screening is also carried out pre-operatively, primarily to detect sickle cell but it will also detect other unusual haemoglobins or thalassaemia. This is opportunistic screening.

Information leaflets are produced ‘in-house’ to ensure that people are aware of why they are being offered screening and possible outcomes. Once a ‘trait’ is detected, specific written information and the offer of an appointment with the service’s counsellor is then provided

Education and awareness raising are key issues for the service and any opportunity to ‘spread the word’ is grasped with both



hands. Talks and poster presentations were given at 5 schools, 2 colleges of higher education, Thames Valley University, University of Reading, West Berks. Primary Care Trust, Royal College of Nursing Conference on Sickle Cell and Thalassaemia, 2 Young Offenders Institutions, 2 Church Groups, WOMAD (music festival). Information about the service can be found on the GIG (Genetic Interest Group) website www.gig.org.uk and the STAC (Sickle and Thalassaemia Association of Counsellors) website www.stacuk.org

Teaching sessions were also arranged for hospital staff. Invited speakers were: Professor Graham Serjeant (Internationally renowned speaker on care and management of sickle cell disease) Dr Anne Yardumian (Consultant Haematologist) Emma Prescott

(Thalassaemia Nurse Specialist).

Pippa Gillham (Counsellor) and Dr Melanie Pollitzer (Specialist registrar-Paediatrics) were fortunate to be accepted on the 8th International Educational Course on Clinical Management of Thalassaemia in Cyprus in November (a written review of this experience can be obtained by contacting Pippa via email – pippa.gillham@rbbh-tr.nhs.uk) This was arranged by TIF (Thalassaemia International Federation) who were perfect hosts. It was truly an experience of a lifetime.

Plans for 2003

- To arrange a number of workshops for 6th form students to cover the practical implications of rapid advances in the study of genetics and the governments decision to introduce a national linked ante-natal and neo-natal screening

programme for sickle cell and thalassaemia.

- To produce a set of educational posters about Beta thalassaemia
- To maintain a level of awareness within the hospital and the community in support of people affected directly or indirectly by Sickle Cell or Beta Thalassaemia Major – probably the hardest thing to achieve.
- A selection of books, posters and videos are available for loan to schools and also for individual students to support project work.

Pippa Gillham

Specialist Haemoglobinopathy Counsellor

Contact details:

Reading Sickle Cell & Thalassaemia Service
Haematology Dept., Royal Berkshire Hospital
London Road, Reading, Berkshire RG1 5AN.
Tel. 0118 987 7689

Calling all families with under-5's in Birmingham!

Contact a Family would like to hear from anyone who lives in Birmingham and has a child under 5 with a rare disorder (such as thalassaemia).

They have secured funding until March 2004 from Birmingham Early Years partnership, to work with families of children under 5 years with rare disorders. They need to hear from families which fall into this category to find out about their experience of services and their views about the support they need.

- Did they have difficulty getting a diagnosis?
- Do they find it hard to find information?
- How do they access services?
- What experience do they have of using mainstream services?

They would really like to hear from families, both positive and negative views.

Contact Sarah or Kirsty at Contact a Family West Midlands on **0121 455 0655** or email to: westmids@cafamily.org.uk

Continues from page 3

"Designer" babies – some questions answered

little mention of thalassaemia in the legal proceedings.

Some readers have expressed surprise that UKTS were not in Court or represented; but as we were not parties to the case we naturally had no right of representation. Having said that, however, UKTS were asked by the solicitors representing CORE to make a written submission to the Court which would prove the Hashmi's claims regarding thalassaemia being terminal etc. to be false. However, we declined to do so. As a policy decision, we have adopted a deliberate stance of non-interference with the legal proceedings as we have no desire to obstruct any developments, medical or legal, which could assist thalassaemia patients and their families. We still urgently desire, however, to see that the media understand and print the facts about thalassaemia, its treatment and prognosis. We are sending copies of our last issue of Thalassaemia Matters to all the journalists we are aware of who wrote ill-informed articles about the Hashmi case. We will continue to do whatever we can whenever we can to ensure that the sensationalism of the past few months is substituted by the plain unadorned truth.

Elaine Miller

A New Oral Iron Chelator (ICL670) Is Able To Promote Iron Excretion

A safe and effective iron chelator to rid the body of accumulated iron, and which can be taken by mouth has been the goal of thalassaemia research for decades. Now, a recent publication in a leading journal (The Lancet) describes encouraging results for a new agent developed by clinical experts and the Novartis Company. This article summarizes the results.

The study's aim was to evaluate the clinical effectiveness of ICL670 (product code) in promoting the excretion of iron accumulated in the body from blood transfusions. Another aspect was to assess whether the treatment would be well-tolerated and acceptable to patients with transfusional dependent iron overload. Indeed, it is well known that at least one third of the thalassaemia patients who have access to treatment find it difficult to comply with current iron chelation infusion therapy, which may typically last 8-10 hours a day, five days a week. Improved convenience and tolerability is therefore to be expected with an effective drug taken by mouth rather than by infusion, which would be a significant and long awaited advance for patients with thalassaemia.

Three North American hospitals participated in the trial which consisted of both males and females, age 16 and older. All 24 participants showed iron overload

due to regular blood transfusions. Their blood ferritin levels were between 1000 to 8000 ng/ml. The study lasted 12 days and was placebo-controlled. Patients were divided up into three groups to be able to examine three different dosage levels per day: one group took 10 mg/kg/day, the second, 20 mg/kg/day, and the third, 40 mg/kg/day.

Results

Twenty-one patients concluded the study and thus provided results that could be analyzed. The elimination of iron from the body was observed to be proportional to the dose taken. For most patients the 20 mg/kg/day dosage eliminated the amount of iron that would normally have been expected to accumulate from their regular blood transfusion therapy.

Tolerability of the drug was also good. Three patients dropped out of the study because of drug-related adverse events after about eight to ten days of treatment. The adverse events were primarily rashes. Otherwise, no clinically relevant biochemical blood value changes were observed. In addition, the blood values for rare metals such as copper and zinc did not change.

The pharmacokinetics of the new drug was linear. This means that the drug's

absorption and distribution in the body, as well as its elimination proceeded in proportion to the dose taken. Oral doses were rapidly absorbed and then slowly eliminated over about 24 hours. This slow elimination indicates that the drug can probably be taken once a day. It takes the body about three days to reach a so-called 'steady-state', whereby levels of drug in the blood remain relatively constant as long as doses are taken regularly by the patient.

The investigators of the study found the new drug to be well tolerated over the short study period and therefore to show promise for future clinical studies. Given the fact that:

- ICL670 is quite potent in eliminating iron from the body
- it appears well tolerated,
- a once-a-day dosage by mouth is possible

This new drug, if successfully developed in larger, long-term clinical studies, may replace the demanding dosage schedule that current infusional iron chelation therapy entails. These pivotal studies, involving 800 patients in 12 countries over 4 continents have already started.

Dr Christopher Adams
Novartis Pharma

From a proud mother

Dear Friends,

I am writing this letter about my daughter, in the hope that it shows the other thalassaemics that with their strength and courage they can achieve almost anything. Secondly, I am a very proud parent and also very humbled by my daughter's achievement.

My daughter was diagnosed with beta thalassaemia major when she was 18 months old. At a very early age (4-5) she decided that she was going to become a doctor, when she was undergoing painful treatment in hospital. She excelled in school and on her own merit gained admission to University to study medicine. She has just completed her third year. Year two was with a Merit and this year with a Distinction.

I do not have to tell you what this

means to a normal student, but for her to achieve this against all the odds stacked against her is truly remarkable.

All her growing years, her father and I tried to wrap her in cotton wool and protect her, but she was determined not to be different from the other children and wanted to be treated on an equal footing in all fields. To her, her illness was incidental; something to be dealt with and I think this attitude has helped her achieve her goals. We were against her studying medicine because of the physical demands this course and career would put on her, but she was adamant and she is excelling in her chosen field.

It has not been easy for my daughter and the first year was particularly tough and even now there is some medical problem or the other, but she seems to manage to put this behind her and carry

on without complaining or feeling sorry for herself.

I hope that this letter will help some patients and show them that determination can overcome almost anything.

Yours sincerely,

A very proud mother.

We are very grateful to this lady for writing to us and letting us know about her daughter, surely an inspiration to other young thalassaemics and an example of what can be achieved when good medical treatment is combined with a determined and independent attitude. For reasons of privacy, names etc have been omitted at the request of the writer.

Congratulations to Maria and Aris

UKTS are delighted to announce the engagement of Asst. Secretary Maria Gavriel; seen here with her fiancé Aris Giourgas and their little dog Mia. We wish Maria and Aris every happiness in their life together and look forward to printing their wedding photographs in due course!





Employment and Career Matters

by Neelam Thapar

Neelam is a Careers Adviser at London Metropolitan University (City) and also has thalassaemia. She welcomes feedback from our readers and you can contact her via UKTS.

Here is some information that may be relevant to you. I hope you find this section useful but remember if there are any specific issues you would like covered, do not hesitate to contact me c/o of the UKTS.

National Minimum Wage

From 1st October 2003 the National Minimum Wage is set to increase with the rates being:

- Main (adult) rate for workers aged 22 and over **£4.50 per hour**
- Development rate for workers aged 18-21 inclusive **£3.80 per hour**

If you would like to check on how the National Minimum Wage applies to you the TIGER interactive website is a useful starting point at www.tiger.gov.uk or telephone the National Minimum Wage Helpline on 0845 6000 678.

Flexible Working

From 6 April 2003 eligible parents of children aged under six, or of disabled children aged under eighteen, have the right to apply to work flexibly (eg flexible hours, job sharing, home working) providing they have a qualifying length of service (currently completed 26 weeks continuous service at the date of the request to work flexibly). Employers will have a statutory duty to consider their applications seriously.

This new right will enable mothers and fathers to request to work flexibly and aims to encourage both employees and employers to find solutions that suit them both.

The right does not provide an automatic right to work flexibly, as there will always be circumstances when the employer is unable to accommodate the employee's desired work pattern. More information can be obtained from www.tiger.gov.uk or telephone the ACAS National Helpline on 08457 47 47 47

Access To Work

Access to Work (AtW) provides advice and practical support to disabled people and their employers to help overcome work related obstacles resulting from disability. Remember that each case will be looked at on its own individual merit. Even though you may not choose to use the word disability to describe Thalassaemia, the legal definition of disability may include it, depending on your individual treatment and long term affects and as a result you may be entitled to this help.

As well as giving advice and information to disabled people and employers, Access to Work pays a grant, through Jobcentre Plus, towards any extra employment costs which result from disability.

Eligibility

If your disability or health condition affects the type of work you do, and it is likely to last for 12 months or longer, you should contact the Access to Work Business Centre to check whether you are eligible for any help. If you have a disability and are in a job, or self employed, Access to Work could also be for you. It applies to any paid job, part-time or full-time, permanent or temporary. Type of

assistance to those in help include adaptations to premises or to existing equipment for example back supports for chairs and also help with the additional costs of travel to, or in, work for people who are unable to use public transport for example near transfusion times or because of mobility difficulties.

The above is for guidance and does not mean every application will be accepted. You need to contact your local access to work business centre too get more information. This can be done by contacting your local job centre and asking to speak to the disability employment adviser.

Getting Experience

Did you know 75% of 200 British businesses surveyed stated a preference for applicants with voluntary work experience
– Source: Reed Employment Agency

Getting experience is a vital part of career development and volunteering is an excellent way to develop your Curriculum Vitae. You can get involved in charities (eg UKTS!) or local community organisations. To see a range of volunteering opportunities in your local area you can start by looking at www.timebank.co.uk/. This would be a good way for people currently not working to develop their skills and confidence before returning to the world of work.

Continues on page 12 ➔

Blood Crisis Hits New York

This summer has brought real problems for the beleaguered New York Blood Center. Stocks of blood have been dwindling for some time as the number of donors coming forward continues to fall. Apparently concerns regarding disease transmission are deterring donors from coming forward; further, new criteria for giving blood have been introduced, which has led to fewer potential donors being available. This has resulted in blood shortages at 200 hospitals in the New York and New Jersey areas. Donations in June 2003 were 50% lower than in June 2002. Consequently, the supply of certain blood groups such as O Negative have been cut back and even rationed; when necessary being released on a day to day basis only in cases of medical emergency. As supplies fall, the Blood Center is contemplating further rationing of A Negative and B Negative types.

The problems experienced by the New York Blood Center are far from being a case in isolation. In July blood banks across the USA issued urgent appeals for donors. Efforts are being made, however, to address the crisis, notably the Save a Life Tour 2003 organised by the American Red Cross. Two convoys of mobile blood donation centres will travel across the USA, starting in Los Angeles in June and terminating in Washington DC in November. The object of the tour is to raise 3 million units of blood; at the same time as making the public aware of the ongoing need for donors. We wish them luck in their efforts.

Elaine Miller

A Teenage Thalassaemic in Singapore

by Valerie Kum



I am like any other teenage girl in Singapore. In fact no one would think that I have Thalassaemia Major.

In Singapore Thalassaemia is not widely recognised as a condition and in some cases it's still mistaken for a disease. Because of this and various other reasons most Thals in Singapore feel ashamed of their 'life long friend', and feel they need to hide their condition.

When I look at the Thals in Singapore; I feel disappointed and angry because most of them have really low self-esteem. So much so that they end up relying on their parents for everything to the extent that generally, the parents feel if they were 'gone', the Thals would not survive on their own. This is why Thals are very stressed out here.

In most cases parents became over protective. We would not be allowed to do almost anything as we are "not capable enough". How, if we do not scrape our knees in our youth will we

learn to deal with the problems of adulthood? I admit I once felt like that. But thankfully, my parents taught me to become more self-reliant and learn to take control of my condition.

The environment where we are treated in Singapore is good and comfortable. The wards where we have our blood transfusions are air-conditioned, with beds and sofa chairs that can recline fully, and TVs for every one. But the treatment schedules are not flexible. We have to follow the appointments and transfusion dates that the hospital sets; and should we need to change these dates then this becomes a very difficult process, because either the doctor's appointment slots are full or there is not enough space to go around. Eventually, most of us would rather stick to the given schedules and everything else gets pushed to the back, regardless of importance or conveniences. For the past year, I have had the reputation of being a 'trouble maker' because if I need to rearrange my transfusion schedules to fit my ever increasing activities, I will do so - even if it means lots of phone calls to the various departments and getting a earful from the nurses on duty!

Thals blood transfusions are mostly scheduled on Saturdays. We share the Children's Day Therapy unit with the oncology patients, but the oncology patients are often prioritised. This unit is not a 24 hours, 7 days a week unit. We need to be there by 8 in the morning and

Continues on page 12 ➔

Continues from page 11

must finish the transfusion by 5 in the evening. Those who get to the ward late get scolded by the nurses. I am one of the Thals who gets scolded by the nurses more often than not. Our plugs (needles) are set by Medical Officers, but if our body is in shock after one try too many, they will then ask their superior to set for us. What annoys me most of all is that most Medical Officers, who tremble when holding the needle, say things like, "It's not painful, relax." Yeah, right!

During blood transfusions, I sometimes go round to chat with other Thals and parents to find out how they are doing. Sometimes I talk to the nurses and doctors on duty when they come around. Sometimes it can be really boring and all we can do is to lie back and watch TV. Sometimes I make myself stay up really late the night before so that I can sleep through the transfusion; but because the nurses have to take our temperature, pulse and blood pressure every 4 hours it can be frustrating.

I remember when we were younger there were a couple of nurses who were fun to be with. We could gather at a bed and play board games, or crack silly jokes and laughter would be heard across the ward. Then we would quieten down and nap by the second bag of blood. Later, one of them went on to teach nursing school and the other emigrated to Australia. Now the nurses tend to discipline us like we are still kids. We have to be quiet and lie still until we have finished.

As meals are not included in our transfusion bills, unless we have someone staying with us during the transfusion we either buy lunch before going into the ward, make sure that someone is dropping by to buy food for us, or ask a favour from the nurses on duty. So if I forget to buy lunch before going into the ward and sleep throughout, I go hungry and thirsty until I'm finished. Rather than

get scolded by the nurses for asking them to do extra work. After my transfusion, I either go to church to perform usher duties or go home to fight with my younger brother.

The blood stock in Singapore is really bad, as out of a total population of 4 million only about 2% are regular blood donors, which is a real disadvantage to us. While the doctors call the blood bank, we cross our fingers and pray that there will be enough blood for us. It can be really depressing because Thals are usually the lowest priority and the blood bank think we can wait. That's why our pre-transfusion Hb can sometimes go as low as 6.0g/dl. Nowadays I talk to as many people as possible about donating blood regularly. Hopefully this will help raise awareness for the blood bank and benefit everybody, Thals especially.

In school I am always protected by the teachers because to them I'm a weak girl and I cannot strain myself for fear of my fainting spells. I think this is totally ridiculous. I have also found out that being a "sick girl" means they expect me to always be on my best behaviour and not cause trouble. But what a shock they got when I started mixing with some bad company. I started playing truant and was caught. This shocked my form teacher the most. She went on and on about how she always thought I was a good girl and stuff. Sometimes, I feel that they stereotype me, thinking that as long as I am sick, I will be obedient and won't break the rules. I think I am the only 'sick' girl that has not conformed to type in their years of teaching because they behave as if I planted a bomb in school.

This year, my class decided to set up a supermarket to help raise funds at the annual school funfair. On the day before the funfair I decided to go to school to help out in setting up the supermarket, even though my teachers told me I didn't have to. Much as I expected, I was treated

like a weak girl. I was not allowed to carry any cartons or boxes like the rest of my classmates; I was to just arrange them when they had been stacked up properly. Not wanting to be left out, I helped to carry the cartons just like the rest of the girls. My classmates helped me look out for any teachers in case they passed by. Still, I got caught and was lectured severely on how I was not taking good care of myself. But of course my classmates were teasing me and I just laughed with them.

What I think is, no matter what kind of illness we have, we are still normal people on this planet earth and chasing the destiny that lies ahead of us. As for me I'll never give up bringing more awareness in Singapore for thalassaemia.

Continues from page 10

Employment and Career Matters

In addition, for those of you at school, college and University, remember that employers are always looking for people who have done over and above their academic studies and show a willingness to get involved. Different ways of getting experience apart from volunteering could include:

Internships – these are common in larger firms and students will normally work on specific projects

Industrial placements - this involves taking a year out of your degree course and working for a company. This can sometimes be counted towards your final degree and will enable you to use your skills and make useful contacts

Work Shadowing - this allows you to just have short term experience to get an insight into the day to day duties in different occupations.

Contact with past students/graduates - speak to your Careers Service

Focus on Your strengths, Decide What you want, Unlock your potential.

Working With UKTS

– words from a young volunteer

I have worked closely with people who suffer with thalassaemia over the past few months and I feel I have made a close relationship with them all. I have learnt about the difficulties that they face every day and it can be upsetting to see. Before I started working at the society I thought that everybody who had thalassaemia dealt with it and that they all had supporting families, but that wasn't the case. After dealing with different people and cultures I've realized that some

people don't want to have anything to do with it or they feel afraid to tell their friends and families; but you do need support. I've made a lot of new friends through working here and every single one of them is unique in their own special way and I feel proud to know every single one of them. The UKTS is my second family and I hope that everyone will realize how much work and effort the office staff, committee and sub-committee members put in. Most of these people have other day jobs that have nothing to do with UKTS and they use up their free time to help people all around the world. So I would like to thank everyone who has helped me whilst I was working here.

Whilst I have been working here I have helped redesign a leaflet aimed at the younger audience to try and create awareness in teenagers; and being one myself not everybody wants to listen. I really enjoyed it and I hope you enjoy the

leaflet which will be out in the near future.

Thank you for having me, it's been a wonderful experience.

Angelica Gavriel (age 16)

Thank you Angelica, for your help in our office and at other events over the summer. It is heartwarming to know that there are still young people who are prepared to give up their time to help a good cause!

UKTS thanks Mrs. Sonoo Malkani (life member who has a thalassaemic son), who visited the Healthy Living Group at Atkins House, West Harrow, to give a talk on "Why You Need to Know About Thalassaemia" to the group. Mrs. Malkani is a frequent UKTS volunteer and constant awareness campaigner; and we are very much obliged to her for giving the presentation on our behalf.

Interview – Amina Ishaq-Khan



Helping UKTS at the Plumstead Mela, 6th July '03

Those in the general population might have their blood taken occasionally while pregnant or undergoing medical investigations; but for thalassaemics blood tests are part of their normal routine. For this reason, thalassaemics appreciate more than most the skill which a good phlebotomist possesses. We would like to introduce Amina Ishaq-Khan, a friend of UKTS who works as a phlebotomist at the North Middlesex Hospital. In recent months Amina has accompanied us to melas and festivals where we have offered

free blood screening for thalassaemia trait. Amina's cheerful ability to put people of all ages at their ease is invaluable on these occasions; as is her ability to speak Urdu, Punjabi and Hindi!

Amina's family originally came from Pakistan, but moved to East London in the late fifties, where Amina was born in 1966. She enjoyed sciences at school and did a Btec Diploma in medical sciences at Waltham Forest College. Her first job was at King George's Hospital in Essex, where she learned about haematology and biochemistry and how to take blood. She has been working at the North Middlesex Hospital since 1995, where she is a familiar face to the thalassaemia patients.

Amina was brought up by her sisters after her parents died within a few months of each other. Her sisters arranged her marriage to her husband Ikram; but even then Amina was conscious of the need to screen for thalassaemia trait. Says Amina, "As I had worked in the field of haematology I wanted to make sure that

the man I married was tested for thalassaemia. When he came to visit me I asked if he wanted his cholesterol level checked. I took his blood and made sure it was tested for thalassaemia at the same time. I told him after I had done this and he did not mind!"

Since working with UKTS Amina has become even more aware of the need for screening for thalassaemia and actively encourages people to be tested whenever possible. Whenever she has to take blood from young Asians for any reason she automatically asks their permission to screen their blood for thalassaemia at the same time. Just think of the increased screening which would come about if all phlebotomists took this line! Perhaps all our thal readers (or parents of thals) could suggest this course of action to the phlebotomists in their own hospitals?

We at UKTS thank Amina for her help and look forward to working with her in the future.

Elaine Miller



A DATE FOR YOUR DIARY

**UKTS
ANNUAL DINNER/DANCE
2003!!**

This year's annual dinner & dance will take place on
Saturday 13th December 2003

at the

Regency Banqueting Suite, Bruce Grove, London N17.

We are planning a few changes this year, firstly changing the day from Sunday to Saturday. This will enable us to continue the revels for an extra hour and will hopefully avoid half North London having to go to work with sore heads on the Monday! So don't forget to keep the 13th December free for an evening of having great fun for a great cause.

Tickets available from the UKTS office from 27th October
– book your table now to avoid disappointment!

UKTS Welcomes NEW MEMBERS

- | | | |
|------------------------------|---------------------------|-------------------------|
| Annual | Mrs Susan Davidson | Mrs Nkechi Anyanwu |
| Mr John Darbyshire | Mrs Beata Xenophontes | Ms Lorna Bennett |
| Mrs Sharbat Darbyshire | Ms Rachael Walker | Mr Peng Hoe Wong |
| Mrs Susan Crawford | Mr. Mark Walby | Ms Wendy Beckles |
| Mrs Rosy P S Wong | Mrs Elizabeth Quarcoopome | Miss Christabel Pinto |
| Mr Haidar Abdali | Mrs Pamela Jones | Life |
| Mr Sukhjinder Singh Sidhu | Mr Javed Khan | Mr Panicos Kyriacou |
| Master Gurjinder Singh Sidhu | Mrs Sarriya Begum | Mrs Dipika Shah |
| | Mrs Smriti Vig | |

Donations

Mr S Gandhi	£380.00
Anthony's Deli	£14.48
Mrs D Photopoulos	£50.00



Announcing the UK Thalassaemia Society Annual Conference/Workshop

“Thalassaemia in the 21st Century”

UKTS are pleased to announce that our annual
Conference/Workshop will take place on

Sunday 16th November 2003

at the

Royal Moat House Hotel,
Nottingham

The workshop is **FREE** to all members and registration, conference
packs, lunch, refreshments and transportation are all included.

Please see the flyer enclosed with this issue for further details.

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Special Thanks

**Thank you to the patients,
parents, doctors, scientists
and all who contributed in this
issue of**

Thalassaemia Matters



membership application form

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

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

Your Personal Details

Title (Mr/Mrs/Miss/Ms/Other):

First Name(s):

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Occupation:

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Contact Details

Telephone: Home:

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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 _____