UNITED KINGDOM
Thalassaemia SOCIETY
matters
...continuing the fight against Thalassaemia

Thalassaemia is NOT a "Terminal Disease"

– UKTS Against the Media

Yet again, little thalassaemia patient Zain Hashmi has been in the news; with April's High Court decision to determine whether the treatment his parents are seeking to produce a baby with an exact tissue match could go ahead. Zain would then be given a stem cell transplant or a bone marrow transplant with the new baby as donor. Most of you will be familiar with the story. (Please see the article by Dr. Michael Antoniou on page 7 for a user friendly explanation of the procedure.)

The case was decided on 8th April 2003 in favour of the Hashmis and the Human Fertilisation & Embryology Authority who mounted the appeal after a lower court ruled that the HFEA did not have the right to grant the Hashmis a licence for the treatment. At the outset the UKTS wish to state that we have nothing against the treatment the Hashmi family are seeking. We naturally support any advance in medical technology which gives hope to thalassaemia patients and their families. What we do object to most strenuously, however, is the gross misrepresentation of thalassaemia which has appeared in the media reports. Zain has been consistently described as "terminally ill" or "dying". Many of the reports stated that he has less than two years to live in the absence of a cure. Unfortunately, the Hashmi family seem to be perpetuating these untruths. Mrs. Hashmi, who was allowed to address the Court in the arguments which took place the week before the decision is quoted as saying; "We would like you to consider when making a decision that our son *will die a terrible painful death if we are not given permission to save him.*" (our italics). We find it extremely hard to believe that any parent of a thalassaemic child receiving modern medical treatment in this country could be so misinformed.

Our office has been besieged by calls from angry and upset patients and parents, who quite understandably wanted to know what we were doing about the misinformation in the media. Many of our callers were parents of young children with thalassaemia seeking reassurance. We would like our members to know that we have done our best to put the record straight; but unfortunately many members of the press seem disinclined to let the facts get in the way of a good story. On 1st April we issued a press release to all the major newspaper groups stating the true facts about thalassaemia and asking them to bear these in mind in their reporting of the case. Sadly this was largely ignored. We also spoke to as many journalists reporting on health/medical issues as we could possibly reach; and some of them did listen to us – for example, UKTS Secretary Katerina Read featured in a programme on BBC 3 Counties Radio on 10th April and Asst. Co-ordinator Elaine Miller featured on the Mike Dickin Show on Talksport Radio on 3rd April and again on BBC Radio 5 Live on 8th April to put our point of view. Our President, Mike Michael, wrote to a British Medical Association Ethics spokesperson objecting to the flawed media coverage and also

continues on page 3 ➡

CONTENTS

UNITED KINGDOM THALASSAEMIA SOCIETY
A Charity Organisation
Registration Number: 275107
19 The Broadway
Southgate Circus, London N14 6PH
Telephone: 0208 882 0011 • Fax: 0208 882 8618
Email: office@ukts.org • www.ukts.otg

A word from our President

Someone once said "There are three versions of the truth: The facts as group A sees them, the facts as group B sees them and the true facts which lie somewhere in the middle". This has never been truer than in the past few months. Sadly it has been the community so-called journalists who have emerged as reporters of sensationalism rather than truth.

Over the past four months the media has fed the public a diet of thalassaemia lies and half-truths. We have been subjected to the media spun story of young Zain Hashmi suffering from (as the media reports); "a deadly condition known as thalassaemia. This life threatening condition will cut young Zain down within two years unless the government grants a licence for pre-implantation diagnoses and tissue matching."

April also brought another damaging blow to thalassaemia in the shape of the Channel 4 programme "Dying for Drugs". This programme misrepresented deferiprone and categorized the controversy as one researcher being gagged by a big company rather than more accurately reporting how two sides interpreted the data differently and how the overwhelming majority of medical literature shows that concerns Dr. Olivieri initially raised against the safety and effectiveness of the drug have proven to be unsupported by the data. The UKTS has sought not to take sides in this debate but to call for objective and unbiased presentation of all the facts. As noted in this issue despite our efforts to convey our concern to the Broadcasting Commission and Channel Four over misrepresentations in the programme our concerns were not satisfactorily resolved.

Finally I would like to bring to everyone's attention the new look of our newsletter. The redesign allows us to still deliver the same quality of information in an easier to read format. We may change our design and look but never our focus on serving patients and families and providing objective information to them.

As usual we would like your comments on any of the stories in this issue or if you have any comments to do with thalassaemia in general email us office@ukts.org

M Michael

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

Mike Michael	President
Costas Kountourou	V. President
Katerina Reed	Secretary
Maria Gavriel	A. Secretary
Erol Aziz	Treasurer
Menuccia Tassone	A. Treasurer
Kyri Theodorou	Meetings Chair
Kyriacos Demetriou	Committee
George Constantinou	Committee

continues from page 1

wrote to GMTV following a programme they aired which featured the Hashmi family. An article also appeared on the Discovery Channel website putting the UKTS's case.

At the UKTS we spend a great deal of time and effort on trying to help patients and parents appreciate the fact that thalassaemia, even with it's associated problems, is no reason to abandon hope of a normal life. We feel saddened that Mr. and Mrs. Hashmi have used misinformation to publicise their case and in doing so, have made our task more difficult. Even more distressing is the fact that our office regularly receives e-mails from desperate parents overseas; whose children really are dying because no treatment is available or affordable. Little Zain, with access to the best medical treatment provided by the National Health Service, is in a far more fortunate position.

On 12th April Mrs. Hashmi featured on a BBC Radio 5 programme in which the presenter put the Society's points to her – that thalassaemia is not "terminal" where treatment is available and that there are many adult thalassaemics in the UK etc. Mrs. Hashmi responded that she was "not aware of any" and that all the statistics she has seen indicate that thalassaemia is fatal by the age of 20. (This is misleading – of course, it would be correct if statistics are used which include all the countries where many thousands of thalassaemics have no access to proper treatment.) If Mrs. Hashmi would care to meet some adult thalassaemics she is very welcome to contact the UKTS office – we would be pleased to introduce her to many, among them most of the UKTS Management Committee! In light of this case and the strong feelings of our members, our President has decided to publish an open letter to Mr. and Mrs. Hashmi in this Newsletter (see below). Although they are not and never have been members of UKTS, we hope very much that they will have the opportunity to read it.

Elaine Miller

Mr. & Mrs. R. Hashmi
3rd April 2003

Dear Mr. And Mrs. Hashmi,

As President of the UK Thalassaemia Society I feel compelled to write to you in light of the publicity surrounding your Court proceedings in conjunction with the HFEA.

First of all let me say that the UKTS does not and never has taken any stance against what you are trying to do. Our position is that this is a personal choice which only you should make. I feel bound to point out, however, that the media coverage of this case causes great offence to other thalassaemics. We see Zain constantly described as being "terminally ill" or "dying". It is reported in the press that Mrs. Hashmi told the Court that Zain "will die a terrible painful death" if no transplant is carried out; everywhere it is reported that he has only two more years to live in the absence of a cure.

As parents of a thalassaemic child you must be aware that all the above is untrue. Obviously you are trying to whip up media and public sympathy; but must you do this by resorting to untruths? Why can you not represent the facts as they are – that thalassaemia is a serious but *treatable* disorder? If you had a diabetic child would you regard him/her as terminally ill (like thalassaemia, insulin dependent diabetes is ultimately fatal in the absence of any medical treatment)? Do you not realise how distressing it is for parents of other small children with thalassaemia to read such reports in the press? Not to mention the offence given to many thalassaemics like myself and many of my friends; who are well into our forties (and even fifties). Most of us have full time jobs, many are married and more and more thalassaemics are becoming parents themselves. No-one is belittling the difficulties associated with the disorder and the treatment; but to suggest that it is terminal and hopeless is unacceptable. Please note that we are considering mounting our own press campaign to counter the negative and false impression of thalassaemia which you are propagating.

Once again I reiterate that the UKTS is not against your efforts to have a child which will be a match for Zain, indeed we wish you every success – but please consider the effect you are having and the feelings of the parents and patients who share your problems and your son's condition. There are approximately 800 thalassaemics in the UK and thousands more worldwide. At the UKTS we receive frequent communications from desperate parents of children in the Third World who really are dying because no treatment is available. In this country, however, we are fortunate enough to have access to the best medical care which enables us to lead normal lives.

Our lives are far from being joyless and hopeless. Please consider that if no cure is found for Zain, we could one day be his role models – showing him that, notwithstanding the difficulties we face, thalassaemics can and do lead productive, full and happy lives.

Yours sincerely,

Mike Michael
President, UK Thalassaemia Society

Dying for Drugs

April has been THE month for controversy surrounding thalassaemia! No sooner had our office begun to recover from the many 'phone calls, letters and e-mails surrounding the case of the Hashmi family than we were once again taking issue with the media.

On 27th April 2003 at 8 pm Channel 4 aired a programme entitled; "Dying for Drugs". This programme had the apparently laudable aim of exposing the tactics of unscrupulous drug companies; who are allegedly using their financial muscle to discredit research scientists who cast doubts on their products.

One of the main focuses of the programme was Dr. Nancy Olivieri, a name which may be familiar to many of you. Dr. Olivieri is a haematologist practising in Toronto, Canada, who treats a number of thalassaemic patients; and was one of the doctors involved in the initial testing phase for the oral chelator L1 (also known as deferiprone or Ferriprox®,). Dr. Olivieri initially supported the introduction of L1, indeed at the TIF meeting in Cyprus in 1993 she presented studies which indicated that L1 was more efficient in removing iron from the heart than desferal. However, in later years Dr. Olivieri's further studies appeared to associate a significant degree of liver fibrosis with the use of L1. As a result, Dr. Olivieri ceased the use of L1 in her patients. At around the same time Dr. Olivieri experienced problems in her employment with the Toronto Hospital for Sick Children.

The Channel 4 programme focused extensively on this dispute, implying that Dr. Olivieri's employment problems were a direct result of Apotex, the company which manufactures and markets L1 in Canada, putting pressure on the hospital in an attempt to discredit her findings. Dr. Olivieri, who was interviewed at length in the programme, remains adamant that her research indicates that L1 should not be given to thalassaemia patients rather than desferal. She is at present challenging the European Commission's 1999 granting of a restricted license for the prescription of L1. The general tone of the programme was to present an image of a concerned doctor fighting alone against the financial might of the profit-driven drug company.

The story of the dispute between Dr. Olivieri, the Toronto Hospital for Sick Children and Apotex is complex; but does not answer the only question which interests thalassaemia patients worldwide – "How safe is L1?" It would have helped the programme to present a balanced view if it had included the opinions of other haematologists experienced in treating thalassaemic patients with L1. However, the programme's producers chose not to interview any other doctors currently treating thalassaemia patients.

Needless to say, the programme caused concern and distress to patients taking L1. Many of them rang our office to ask our opinion of the programme and whether their medication was really safe. (We repeat here the advice we gave over the 'phone – *if you have any concerns whatsoever about your medication, SEE YOUR HAEMATOLOGIST and talk the matter over with him/her!*) Many of our members have been taking L1 for some years, indeed some have no other option as they are intolerant of desferal.

This being so, there are strong feelings of resentment and anger about the one-sided nature of the "Dying for Drugs" programme; and even more so over Dr. Olivieri's attempt through the European Commission to prevent other doctors from prescribing L1. Patients currently doing well on the drug most definitely see this as acting against their interests. However, there are many other studies available showing a very positive risk/benefit ratio for L1; and we are confident that these will be fully taken into account in the deliberations of the European Commission.

Quite a few of our members wrote strongly worded letters of complaint to Channel 4; expressing their disappointment at the biased nature of the programme and reiterating the fact that L1 is the *only* chelation treatment option for patients unable to tolerate desferal. Quite naturally, they also wanted to know what UKTS had done. We are therefore printing in this issue a letter sent by our President, Mike Michael (Mike has been busy this month!!) to Channel 4 (with copies also going to the Independent Television Commission and the Broadcasting Standards Commission).

Elaine Miller

Channel 4 Television
Public Relations Dept.
124 Horseferry Road
London SW1P 2TX

6th May 2003

Dear Sir/Madam,

Re: "Dying for Drugs" 8pm 27.4.03, Channel 4

We wish to comment on the above television programme; which contained a feature on Dr. Nancy Olivieri and her dispute with the pharmaceutical company Apotex; who manufacture the drug "L1" which is used in the treatment of beta thalassaemia major. We wish to point out that we are the only UK charity dedicated to the support of thalassaemia patients and their carers. We represent the 827 thalassaemics in the UK and also represent the UK on the Board of Directors of the Thalassaemia International Federation.

Dr. Olivieri was interviewed at length in the programme; explaining her reservations about the use of L1 and the fact that she no longer prescribes it. However, this gave only a very biased view of the situation; as none of the other doctors shown who supported her are actively involved in the treatment of thalassaemia. Had the producers wished to present a balanced view, they could have found many doctors in the UK and worldwide who have equal or far more experience than Dr. Olivieri in the treatment of thalassaemia and specifically L1 who do not share her views. Why were none of the many other doctors who took part in the studies on L1 who did *not* find the problems she found with L1 given a chance to respond?

Between 200-300 thalassaemia patients in the UK (and many thousands worldwide) are currently taking L1 and have been for many years. Many of them are allergic to the traditional treatment with desferal and therefore L1 is their only hope of achieving their optimum life expectancy. This programme has caused distress and confusion to many; we have been inundated with calls and enquiries from members who are now worried about their treatment.

This is the second programme aired by C4 which has circulated confused and frankly incorrect information about thalassaemia and it's treatment (you also showed a programme on the Hashmi family of the recent "designer baby" Court case which presented thalassaemia as a terminal illness. Where treatment is available this is far from the case; more than 500 of the 827 UK thalassaemics are adults aged over 25 of whom over 200 are professionals, married with children etc.). We are disappointed that once again C4 has not given the only national association for thalassaemia an opportunity to comment. It is very distressing to our members that the 2 programmes aired by C4 have created insecurity, mistrust and total confusion for the thalassaemics in the UK.

Perhaps a fair way to redress the situation would be to commission a programme about the lives of people with thalassaemia showing the difficulties and the realities. If you would like more information about the medical treatment and/or living with thalassaemia please do not hesitate to contact our office.

Yours sincerely,
Mike Michael
President, UK Thalassaemia Society

cc Independent Television Commission, Broadcasting Standards Commission

ITC and Channel 4 have responded that they regret any distress or confusion caused by the programme, but do not feel that any broadcasting standards were breached.

UKTS v GMTV

Our office received yet more complaints from our members following the appearance of Mrs. Shahana Hashmi on GMTV on 11th April 2003. Once again, this lady represented her little boy as terminally ill. Disappointingly, GMTV's resident medical expert, Dr. Hilary Jones, allowed Mrs. Hashmi's comments to go unchallenged.

In the circumstances, Mike our President once again sat down at his word processor and wrote a letter of objection to Dr. Jones, setting down the correct facts about the life expectancy of thalassaemia patients. He also pointed out that, as a medical practitioner, Dr. Jones was actually validating the misrepresentations in the programme by failing to give the true facts to the viewers.

We are pleased to report that we have had a polite response from Dr. Hilary Jones giving an assurance that if GMTV cover the subject in the future, "in any shape or form", UKTS will be notified and invited to contribute. We sincerely hope that this opportunity will arise before long.

Elaine Miller

NEWS FROM AROUND THE COUNTRY

Icing on the cake!

UKTS Secretary Katerina Read greets the Earl and Countess of Wessex.

That's how Lynne Mathers, Haemoglobinopathy Nurse Specialist described the official opening of the new Haemoglobinopathy Unit at the Children's Hospital in the Birmingham. The Earl and Countess of Wessex visited the new unit on the 1st of May, spending time with patients, parents, staff and representatives of those whose fund raising made the unit possible.

The dedicated purpose built unit aims to provide comprehensive multi-professional care for 240 patients from birth through to 16 years of age. This will include clinic appointments, blood transfusions, Community Liaison and a variety of support groups.

Many of the current patients chatted to Sophie and Edward discussing various topics including the conditions, treatment and outfits! Former patient Salma Bi said they were genuinely interested to find out more about her and her condition, even discussing her studies at Coventry University. Sadly Harris Islam was unable to see the Royal couple as he arrived on the unit with a posy of flowers and spots! He did leave a picture for the Royal Couple, who promised he would receive a Royal Thank You!

Over lunch in the conservatory their Royal Highnesses then met fundraisers who have raised over £60,000 for the Unit, and the key people who have been involved in the building and establishment of the new Unit.

Lynne said, "It was a wonderful visit and the children were so excited to see the Royal couple – they were absolutely lovely and really compassionate. The Unit is all about bringing together children with blood disorders into one dedicated centre, and the royal opening recognised the importance of this. It also acknowledges the commitment and hard work of the staff here that have contributed to the unit- and my thanks go out to them.

Consultant Haematologist Dr. Philip J. Darbyshire said, "This Unit will enhance our current service by ensuring that young patients with this lifelong blood disorders and their families can be cared for in a dedicated Unit".

Lynne Mathers

Using Pre-implantation Genetic Diagnosis (PGD) to Select Children with a Tissue-Type Match for a Potential Cord Blood or Bone Marrow Transplant

Dr Michael Antoniou, Division of Medical and Molecular Genetics, GKT School of Medicine, Guy's Hospital, London.

As I am sure all those with thalassaemia in their family know, a transplant of blood stem cells obtained from either bone marrow or the umbilical cord of a newly born child, is at present the only means of curing thalassaemia. The first thing that is required for this procedure to be carried out is to find a bone marrow or umbilical cord blood donor with the same tissue-type as the affected person, otherwise the stem cell graft will be rejected. In addition, the graft will attack the person receiving the treatment causing what is known as "graft verses host disease" (GVHD). The donor of course must also be free of thalassaemia! The ideal donor is a tissue-type matched brother or sister as stem cell grafts from a more distant relative or an unrelated donor run a much higher risk of rejection and GVHD complications. What are the chances of having such a person in the family who is disease-free and of the right tissue-type? The chances of brothers/sisters having the same tissue-type are 1 in 4 (25%); the chances of being disease-free (that is, without thalassaemia) are 3 in 4 (75%); the chances of being a tissue-type match and disease-free are just under 20% or about 1 in 5. So it is quite possible for a family to have several children who are disease-free but who will not have the same tissue-type. A variation on a procedure known as pre-implantation genetic diagnosis (PGD) is a potential way of overcoming this limitation by helping couples to have a normal child with a tissue-type match for a thalassaemia-affected member of their family.

PGD is an add-on procedure to normal in vitro fertilisation (IVF). It is used in cases where a couple carry a risk of having a child that is affected by a genetic disease. Indeed, no doubt some couples have used this procedure to avoid having a child with thalassaemia. How does all this work?

The first step is IVF, which I'm sure you've all heard about and is mostly used by couples with infertility problems to help them conceive. Simply put this is what is involved. A woman is given injections of various hormones to stimulate her to mature and release about 10 eggs from her ovaries, rather than the usual one, as part of her monthly cycle. These eggs are collected through a surgical procedure and fertilised with the man's sperm in the laboratory. Under normal IVF conditions, the eggs that have been successfully fertilised are allowed to grow for a couple of days and after examination under the microscope, up to a maximum of 3 of the healthiest looking of these embryos are then implanted in the womb of the woman. Hopefully one or more of the embryos will implant in the womb successfully and lead to a healthy child or children (!) being born 9 months later. The thing to note here is that in this regular IVF procedure with people who do not carry a fatal or debilitating genetic disorder, there are no genetic tests of the embryos before implantation.

PGD carries IVF a step further. The eggs after IVF are allowed to grow for a few days until they have become an embryo of a group of 8 cells. At this stage one or two of these 8 cells is removed and its DNA analysed to check to see which embryos are normal and which carry the disease-causing genetic defects. Again, up to a maximum of 3 embryos that are found to be genetically normal and healthy looking are implanted in the prospective mother's womb to grow into a baby. This procedure is only available to couples that are carriers of a genetic disorder.

Until recently, fertility clinics were only licensed to genetically screen embryos by PGD for disease-causing genes such as those that result in thalassaemia, muscular dystrophy or cystic fibrosis. The recent court ruling in favour of the Human Embryology and Fertilisation Authority (HFEA) and Hashmi family has changed this. Embryos produced through IVF in this case will not only be screened by PGD for the absence of thalassaemia but also for tissue-type in the hope of finding a match with a boy with thalassaemia already in the family.

What are the chances of success? After the IVF stage, there are usually 4-6 eggs that are in good shape and can be further analysed by PGD. Whether an embryo will be found that is free of thalassaemia and a tissue-type match is simply a numbers game; in theory, any one of the surviving embryos has about a 1 in 5 chance of having these desired properties. In other words there are no guarantees of finding a match in any given round of IVF-PGD treatment. Mrs Hashmi is currently undergoing her third cycle of IVF-PGD to find a matched embryo for her son Zain.

continues ➡

continued from page 7

(Just in case you were wondering it costs about £4,500 per IVF-PGD treatment cycle).

If ultimately successful at the IVF-PGD embryo selection stage, there is also the chance of failure during the subsequent phases of the procedure. Firstly, there is a 50-60% chance that none of the selected eggs will implant successfully in the womb. Secondly, the cord blood stem cell transplant may also fail. If the cord blood graft fails, then one could wait until the donor child is older and repeat the transplant with a bone marrow stem cell graft (which may also fail again), although this is highly undesirable since the recipient (Zain) will then have to undergo two highly stressful, painful and risky operations where his own bone marrow has to first be destroyed ("ablated") to allow the graft to take over. The ablation of bone marrow before donor stem cell transplantation is carried out with powerful chemotherapy drugs that have their own undesirable and damaging side effects. So you do not want to put a person through this procedure more than once if at all possible. So there are many technical issues to consider before embarking on such a procedure. Given all of this, it is perhaps fortunate that Zain does not have to rely on this procedure for his survival as transfusions and good old Desferal will keep him going if all else fails!

Finally, in addition to the technical issues there are a number of ethical and moral concerns and questions. For example, is it acceptable that in all likelihood large numbers of perfectly normal embryos that do not have the desired tissue-type match will be discarded? What will be the emotional and psychological effect on the donor child selected through IVF-PGD when they find out that they may have only been conceived to provide a stem cell graft for a sibling rather than been wanted in their own right? Does this type of IVF-PGD screening for genes that are not involved in causing disease, lead to "designer babies"?

No doubt these are difficult issues for all of us to consider and with no sure fire, definitive answer.

PATIENT NEWS

Give us your good news!

Are you a thalassaemia 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 stories from our patient members and we are therefore thinking of including a new "Congratulations" feature in the News Review. The good news can be anything 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 whether there is anything you would like to share with our readers – for example, any of the following:

- Success at school – passing exams or getting an excellent report
- Gaining admission to a University course (or any other further or higher education)
- Gaining a degree or other, for example, vocational qualifications or similar
- Getting engaged or married
- Birth of a baby
- Starting a business
- Starting a job / gaining a promotion at work
- Taking part in voluntary work / helping in your community
- Taking part in sporting events (remember, taking part is the important thing, *not* winning)
- Doing something positive for your health, e.g. giving up smoking

There must be dozens of other things we haven't thought of; so if your personal success is not listed above don't be put off but let us have it anyway – every achievement we can print will be a source of encouragement to other thalassaemia patients and their families. Accompanying photographs would also be very welcome.

N.B. A PLEA FROM TIF – The Thalassaemia International federation have requested photographs of happy events in the lives of thalassaemia patients for a new DVD they are producing. If anyone has any suitable family/wedding/graduation photos etc please send them to our office – we will copy the photos here and guarantee that they will be returned to you!

Many thanks – we look forward to hearing from you.

Elaine Miller

Welcome to the Careers Page

by Neelam Thapar

I work as a Careers Adviser for London Metropolitan University, City Campus. I know from my work and own personal experiences of having Thalassaemia and talking to friends with Thalassaemia, the whole work/career world can sometimes seems daunting for many people. I thought it would be useful to give some general information for you to think about.

If there are specific career related queries linked to having Thalassaemia or you would just generally like to give some feedback on this section, you can contact me by emailing Neelam c/o office@ukts.org All information remains confidential.

How do we start looking at our own self development or career?

At any stage in life, there are several questions that we should be asking ourselves when thinking of starting, developing or managing your career.

- What are my main abilities?
- How can I assess myself?
- What is the range of options open to me?
- What do specific jobs involve and what are the skills necessary to perform them?
- How do I make a decision?

The process of making a career choice is similar to the process of completing a jigsaw puzzle without knowing the picture you are trying to make! So, how do you start to create this picture? To do this, you will need to:

- Assess yourself – what experience do you have? What are your priorities, abilities, values, interests, temperament, and needs?
- Develop some idea of aims and priorities.
- Take note of any constraints e.g. health, location, finance.
- Find out about the range of options available, and what they involve. This will include looking at jobs, under/post-graduate study, professional training, voluntary work, self-employment and taking time out.
- Decide which you want to aim for. Remember, you have more than one choice.
- Find out about sources of vacancies and how to apply- look at the hidden job market – 80% of jobs are not actually advertised but you can learn the skills in networking.
- Fill in application forms and attend interviews – have some mock interviews to help you.

Your initial choice does not commit you forever more, although some moves can be more difficult with time. Increasingly, these days, the concept of job for life has been replaced by people aware that they may be taking temporary contracts and having several employers in their lifetime.

What is a Disability?

At some point or another in their lives, people with Thalassaemia are faced with the question "Do I have a disability? Having Thalassaemia will affect people in different ways. Whilst some people have little or no trouble from having Thalassaemia, there are others whose lives are impacted in a more serious way. To help with the legal jargon, I have given some information below which you would need to think about. It is important to remember that while one person with Thalassaemia may be successful in getting for example a Blue Disabled Car Badge, someone else applying may be turned down. This is because of the interpretation and application of these definitions.

This definition is taken from the Disability Rights Commission (www.drc.org.uk)

What counts as a disability according to the law?

The Disability Discrimination Act (DDA) protects disabled people. The Act sets out the circumstances in which a person is "disabled". It says you are disabled if you have:

- a mental or physical impairment
- this has an adverse effect on your
- ability to carry out normal day-to-day activities
- the adverse effect is substantial

continues ➡

continued from page 9

- the adverse effect is long-term (meaning it has lasted for 12 months, or is likely to last for more than 12 months or for the rest of your life).

There are some special provisions, for example:

- if your disability has badly affected your ability to carry out normal day-to-day activities, but doesn't any more, it will still be counted as having that effect if it is likely to do so again
- if you have a progressive condition such as HIV or multiple sclerosis or arthritis, and it will badly affect your ability to carry out normal day-to-day activities in the future, it will be treated as having a bad effect on you now
- past disabilities are covered.

What are "normal day-to-day activities"? At least one of these areas must be badly affected:

- mobility
- manual dexterity
- physical co-ordination
- continence
- ability to lift, carry or move everyday objects
- speech, hearing or eyesight
- memory or ability to concentrate, learn or understand
- understanding of the risk of physical danger.

It's really important to think about the effect of your disability without treatment. The Act says that any treatment or correction should not be taken into account, including medical treatment or the use of a prosthesis or other aid (for example, a hearing aid). The only things which are taken into account are glasses or contact lenses. The important thing is to work out exactly how your disability affects you.

Remember to concentrate on what you can't do, or find difficult, rather than what you can do. For example, if you have a hearing disability, being unable to hold a conversation with someone talking normally in a moderately noisy place would be a bad effect. Being unable to hold a conversation in a very noisy place such as a factory floor would not.

If your disability affects your mobility, being unable to travel a short journey as a passenger in a vehicle would be a bad effect. So would only being able to walk slowly or with unsteady or jerky movements. But having difficulty walking without help for about 1.5 kilometres or a mile without having to stop would not.

The above is for information only and intended to help people make their own decisions to get more advice.

Disclosure

For a number of people, the fear of disclosing their health condition or disability to potential employers can mean that they choose to give up and not pursue their preferred career ambitions.

Disclosure is the process of informing a potential employer that you have a health problem, illness or disability. Many people choose not to disclose because of fear or bad experiences in the past. It is often difficult to know whether to tell an employer and also to know when and how information should be given. The decision is a personal one but the following points may help you in this.

Should you disclose or not?

- You may not want to disclose your health or disability, as you may be concerned of being rejected automatically
- You may feel that your health or disability does not actually affect your ability to do the job that you have applied for.

Reasons for Disclosure

- The Disability Discrimination Act 1995 covers employment. If you have declared your disability, the employer cannot dismiss your application on this basis if "reasonable adjustment" can be made in the work place. However, if you do not declare your disability, an employer may have grounds for dismissal. Reasonable adjustment can mean a variety of things eg back support adaptations, flexible working hours.
- Many employers are committed to employing disabled people. Look for the Employment Service 'two ticks' symbol. Many employers also have an equal opportunities policy.
- You may be asked to complete a medical form and if so you must do so truthfully.
- There may be a health and safety implication, or the need for work-place adaptations.

How to Disclose – Marketing Yourself Effectively

It is important to think about all the skills that you can offer an employer. Living with your health problem or disability has in fact have given you transferable skills that an employer is looking for e.g. doing well in your studies and having to manage treatment can be considered a strength.

There are several appropriate times you may need to disclose your health or disability to a potential employer.

Application

There may be a section on the form that asks about any serious health conditions or disabilities. Do not just put Thalassaemia or Diabetes etc – you need to give a very simple explanation how the condition/disability will **not** restrict your ability to work drawing on your achievements in the past. Remember not everyone knows what Thalassaemia is about.

Interview

Be relaxed and always present yourself in a positive manner. If you have disclosed any health condition or disability, the interviewer may be unsure and want clarification. Acknowledge this and clarify things in a very positive light highlighting your strengths. The employee is looking for reassurance that you can do the job. For example:

"having to manage studying, working part time and combining my hospital treatment, I feel I have excellent time management skills that can be transferable to your organisation"

Do:

- Be very positive about skills and abilities and not allow room for doubts
- Provide factual information that is related to your ability to do the job but do not use complicated medical terminology. Remember, YOU know what your health problem or disability means and how it affects you; others may not.
- Be prepared that the interviewer may ask you questions about your health if you have mentioned the illness
- Do give positive examples of how you have met challenges in the past

Don't:

- Do not let your health or disability become the focus of the interview
- Assume that an employer will view you in a negative way.

General labour market news – for interest

UK job prospects weaken

UK employment prospects are expected to drop in the second quarter, according to the latest Manpower Quarterly Survey of Employment Prospects.

The survey asks 2,000 UK companies if they expect an increase, decrease or no change in their staffing levels for the quarter ahead. A 'net balance' of job gains is calculated by subtracting the employers planning to decrease staffing levels from the number of employers planning to take on staff. The study found that a net balance of 11% of UK employers will be taking on staff in the period April-June 2003, compared with 12% for Q1.

At the bottom of the sector league table is finance, where job losses are predicted for the first time in seven years. In addition, high street retailers have reported their lowest Q2 result since 1993 with a net 7% of employers anticipating taking on more staff in the second quarter. The public sector, however, continues to report significant increases in staff, with a net balance of 17% this quarter, well above the national average. Health and education show net job gains of 24% and 16% respectively.

The UK's strongest employment prospects are in media & sport, with a net balance of 29%. Other strong sector performers include construction, utilities, and telecommunications, which has recorded one of the largest year-on-year gains.

All UK regions are planning to take on more staff in the second quarter. However, evidence of a North/South employment divide is emerging. The North West is now the best region for jobs, with a net balance of 18% of employers set to recruit staff this quarter. The North East has also reported its highest Q2 balance in 10 years. Wales, too, is in good shape with a net balance of 16% of employers planning to hire in the coming quarter.

The outlook is gloomier further south. The South West and South East are both below the national average. Greater London, with a net balance of 7%, lies joint bottom, with Scotland, and is still suffering from a lack of confidence and the impact of results in the troubled financial sector, says the report.

(Quarterly Survey of Employment Prospects – Q2 2003, Manpower. The report and the accompanying press release can be downloaded from www.manpower.co.uk.)

Connexions Partnerships

Connexions is a service for you if you are aged 13-19 and want advice on getting to where you want to be in life.

Connexions personal advisers can give you information, advice and practical help with all sorts of things, like choosing subjects at school or mapping out your future career options. They can help you with anything which might be affecting you at school, college, work or in your personal or family life.

For more information, see www.connexions.gov.uk

Don't hesitate to get in touch and let me know if there are other topics you would like me to cover in further issues.

Flora London Marathon

Four of our runners completed this year's Marathon. They are Sally Wood (3. 48. 06), Floros Flouris (5. 51. 40), Martyn Bevan (5. 25.15) and Maqsood Raja (5. 08. 54). Our fifth runner Marcia Osalemo had to pull out as she had an operation and was recovering. We thank them all in their noble effort in raising badly needed funds for our Society.

Donations raised so far from the Marathon –

M. Raja £1,174.30
F. Flouris £1,012.00
M. Bevan £509.00
S. Wood £1,226.00

Light Flora Women's Challenge.

This will take place on Sunday 14th September 03 in both Hyde Park in London and for the first time in Birmingham City Centre. We have been allocated 10 places for this event and any ladies interested please contact the office for a fund raising form which has to be approved by our Committee, before the official entry form is sent to the prospective runner together with the sponsor forms. Each runner has to pay an entry fee of £12, £5 of which is returned to our Society. All entry forms must reach the organisers by 15th August 03.

Runner Maqsood Raja

Runner Sally Wood

Costas Paul

2003 TIF CONFERENCE

Palermo, Sicily 15th – 19th October 2003

Registration fees (post 30th June deadline)

Medical staff & scientists €450, Students & Nurses €250
Accompanying persons €350, Patients & Parents €60

UKTS will make a contribution to assist our patient members who attend. Please contact office for details.

Accommodation per night (B & B)

Single room 50/81.18 euros, double room 83/123.76

(lower price Hotel Citta del Mare, higher price Hotel Florio Park).

Triple (102 euros) & quadruple (136 euros) rooms also available at Hotel Citta del Mare.

Booking

please contact the agents Eurocongressi.

Address

Via Liberta, 78-90143 Palermo, Sicily.
Tel: 0039 091 302655,
Fax: 0039 091 341533
e-mail: eurocongressi@libero.it
or visit the official website on www.tif2003.org

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. Watch this space for more details in the next issue

We need your help!

Take part in the UKTS patient survey

(you could win a Sony Playstation 2!)

At the UKTS we are constantly working to assist and persuade the various Government agencies and National Health Service providers of the necessity to increase support and services for thalassaemia patients. However, to make our arguments convincing, we need the figures and statistics to back them up. Therefore in 2003 we are undertaking a detailed patient survey in order to acquire the relevant information (some of you may remember taking part in a similar pilot survey in 2002). The UKTS are asking for the help of all our members in ensuring that we get as complete a picture as possible of the quality of services provided in the various regions.

If you are a patient or a parent of a child with thalassaemia you should receive the form (printed on yellow paper) by the end of July. **Please** complete the form as fully as possible and return it to us – we are enclosing stamped addressed envelopes for this purpose – no expense spared to minimise the inconvenience to yourselves(!). Yes, the form is long and you may wonder why we have found it necessary to ask so many questions. However, the questionnaire was formulated after extensive research and evaluation in order to enable us to produce evidence of the real experiences of thalassaemia patients as service consumers. Furthermore, the information you give will not be linked with your contact details. **The UK Thalassaemia Society would like to stress that the information will remain entirely confidential and will under no circumstances be shared or given out to any other body or person.** Our only aim in acquiring this information is to improve services for thalassaemia patients in the UK. We would ask you to remember that by providing this information you will be helping everyone in the thal community. As if that were not enough, with every form which is returned there is the additional incentive of having the opportunity to enter a free prize draw to win a Playstation 2.

So… we hope you are persuaded of the importance of the survey! If you have not received a form by the end of July (or if you have already received one and thrown it away!) please contact our office and we will be pleased to forward another. If you know other patients or parents who have not completed forms, please urge them to contact us.

We are grateful for every form returned!

UKTS wishes to gratefully acknowledge the help of the following people for their input into this project:

Dr. Beatrix Wonke, Dr. Philip Darbyshire, Dr. Andrew Will, Dr. Kornelia Cinkotai, Dr. Anna Mandeville, Ms. Neelam Thapar, Mr. Chris Sotirelis, Mr. Raj Singh.

A special vote of thanks goes to Mr. Matthew Darlison BA MA, Senior Research Fellow in Clinical & Applied Bioinformatics, University College of London; for his dedication and commitment in the development and implementation of the questionnaire.

Elaine Miller

Primary Care Exhibition 2003, 8th/9th May 2003

Early May this year saw the UKTS flying the flag at the Primary Care Exhibition 2003, held in Birmingham's NEC. By a happy coincidence, the first day of the exhibition (8th May) was International Thalassaemia Day (as designated by TIF). UKTS Secretary Katerina Read and Asst. Co-ordinator Elaine Miller manned the stand throughout the two days and found an encouraging level of interest among the many GPs, midwives and other healthcare professionals attending as delegates. We distributed our information videos and factsheets to all and sundry and talked about thalassaemia until we were hoarse! The delegates were on the whole very receptive and most were keen to learn more, apart from the odd over-complacent GP ("I don't need educating thank you"). There's always one! Of course, those with this attitude are usually the ones who *do* need educating; thankfully, however, they are in the minority these days.

All in all we spent a tiring two days at the exhibition; but will count it as time well spent if a few more GPs screen for thalassaemia trait as a result of our information.

UKTS would like to thank the exhibition organisers, Sterling Events, for donating the stand space free of charge.

Elaine Miller

London Greek Radio Programme, 8th May 2003

The other event organised By UKTS for International Thalassaemia Day was a live radio phone-in about thalassaemia on LGR, in which patients, parents and doctors were represented. Participants in the programme were: Dr. Beatrix Wonke from the Whittington Hospital, Dr. Mary Petrou from University College Hospital Perinatal Centre, our President Mike Michael and UKTS North of England Liaison Officer Stavros Melides.

We thank all the participants for taking time out of their busy schedules for the broadcast.

Thalassaemia Study Day

On 21st May 2003 our Study Day on Thalassaemia was held at the George Marsh Centre. We had 19 participants consisting of midwives, nurses, counsellors, health workers and biochemists.

Dr Anne Yardumian started the day off with a detailed talk on beta-thal and its management to be followed by a talk on prenatal diagnosis and counselling by Josephine Edlington standing in for Despina Karretti who was unwell. Personal experiences were given by Katerina Read as a patient and Sapfo Kypreos as a parent. Costas Paul talked about the role of our Society to be followed by our video "Blood Ties" and discussion.

From the evaluation forms it is so very clear that the day was enjoyed by all the participants.

We would like to express our thanks to all the speakers, the George Marsh Centre for their hospitality and all the participants.

Costas Paul

Donations

Dr. R.P. Tahalani	£150.00
Bank of Cyprus	£500.00
Mrs. M. Taylor	£5.00
Mrs. B. Lysandrou	£50.00
Mr. A. Hamit	£300.00
Mr. W. Buckley	£5.00
Ms. J. Quintavalle	£100.00
Mr. S. Gandhi	£170.00
Mrs. A. Katsouris	£50.00
Barts & London Hospital Asian Society	£4,023.81
Hellenic College of London	£372.88
Metropolitan Police Greek Staff Association	£1,000.00
Mrs. M. Kyriakides	£20.00

UKTS Welcomes NEW MEMBERS

Annual

Mrs. M. Fakhry

Ms. L. Smith

Mr. V. Tsaptsalis

Ms. B. Gemidjioglu

Mrs. S. Kistow

Ms. L. Michaelides

Life

Mrs. S. Kapoor

Mrs. S. Toros

Birmingham City Hospital Sickle Cell & Thalassaemia Centre

Mrs. T. Delgado

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.

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

ALL DETAILS AND INFORMATION WILL BE KEPT ON OUR COMPUTERS AND WILL REMAIN IN THE OFFICE AND WILL NOT BE MADE AVAILABLE TO ANYBODY OUTSIDE OF THE UKTS.
If you however do not wish your details kept on our computers please tick this box ☐

Your Personal Details

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

First Name(s):

Surname:

Address:

Post Code:

Occupation:

Ethnic Origin: *(Optional)*

Contact Details

Telephone: *Home:*

Work:

Mobile:

Fax:

Email:

Are you a:

☐ Patient ☐ Parent/Relative
☐ Healthcare Professional ☐ Association
☐ Other (Please state)

Membership Required *(please tick)*

☐ ANNUAL **(£10.00)** ☐ LIFE **(£100.00)** *(Please make your cheque payable to **U.K.T. Society**)*

If you are a patient or parent of a patient please complete the section below

Patient's Name(s):

Date of Birth

Sex: ☐ Male ☐ Female

Type of thalassaemia: *(e.g. Major, Intermedia, Haemoglobin H etc)*

Hospital where treated:

Address:

Consultant's Name:

Consultant's Telephone:

GP's Name:

Address:

Telephone:

Blood Transfused *(please tick)*

☐ Whole ☐ Washed ☐ Frozen ☐ Filtered

Chelation *(please tick)*

☐ Desferal ☐ Deferiprone ☐ Desferal & Deferiprone

Transfusion Frequency:

Units received at each transfusion

Blood Type

OFFICE USE: Date Paid _____ Receipt No. _____ Approval Date _____

Designed and printed by Orion Design & Print Ltd. Tel: 020 8351 3222 Email: Sales@Orion.gb.com Paper kindly donated by Antalis