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

THE UKTS ANNUAL CONFERENCE/WORKSHOP 2003

Our happy helpers preparing for the conference - Clockwise from centre; Barry Demetriou, Koula Kanias, Angelica Gavriel, Nina Demetriou, Aggie Tan, Olga Demetriou, Valerie Tan

As many of our readers will be aware, the UKTS 2003 conference/workshop took place on 16th November at the Royal Moat House Hotel, Nottingham. We were fortunate enough to welcome some of the most eminent names in the world of thalassaemia as presenters; and another 200 patients, parents and healthcare professionals as delegates.

The presentations given by healthcare professionals were as follows:

Thalassaemia International Federation Palermo Conference 2003	Dr Anne Yardumian
Planning a Family	Dr Paul Telfer
Studies on the Drug Pamidronate	Sr Emma Prescott
Pre-implantation Diagnosis for Thalassaemia	Dr Mary Petrou
Benefits of the T2* Scanner in Thalassaemia	Dr Mark Westwood
Customisation in Treatment of Thalassaemia	Dr Beatrix Wonke
The UKTS Patient-Held Record	Dr Paul Telfer
Latest Research Into Chelation (Apotex Research Inc)	Dr Fernando Tricta
Latest Research Into Chelation (Novartis Pharmaceuticals)	Dr Dietrich Hadler

(If any readers were not able to attend the conference and would like copies of the abstracts of the presentations, please contact the UKTS office.)

Most of the afternoon was devoted to the workshop discussions. For these sessions, the delegates were divided into groups of healthcare professionals, parents/relatives and patients. The reason for the division was that feedback from the Compliance Conference in 2002 told us that some patients feel slightly inhibited about expressing concerns about their treatment etc. in the same group as healthcare professionals and we wanted everyone to feel comfortable to enable free and open discussion. Our discussion facilitators found the opinions expressed interesting and often enlightening, as parents, patients and those caring for them shared their experiences. These sessions have proved very popular with delegates in the past and once again this proved to be the case, with many people expressing the view that this was the most enjoyable and beneficial part of the day. (A full evaluation of the workshop sessions will follow in the next issue of TM.)

The day closed with the presentation of

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A word from our President

Dear Member

Welcome to the first newsletter of 2004.

Last year was a very busy year for the society; but the past four months have seen a period of intense activity cumulating with December's very successful dinner and dance.

October saw the 11th International TIF Conference for Parents and Thalassaemics in Palermo, Sicily, where a host of international figures explained the latest in research and treatment for thalassaemia. While all this was going on upstairs in the main halls, downstairs, around tables and in rooms all over, the patients and parents of this society were talking to young thalassaemics and their parents from all over the world, answering their questions and re-assuring them.

One of the UKTS fundamental principles is education so with this in mind November saw the UKTS National conference,"Thalassaemia in the 21st Century". I'm very sad to report that the attendance for this conference was very poor. In fact there were more professionals than patients which is a shame. Many people have commented that the conference was held at the wrong time of the year. In fact if we ran the conference earlier than November then we would not have been able to report on any of the new theories and treatments that were unveiled at the TIF Conference.

One of the year's major projects is the Patient Held Record (unveiled at the UKTS conference). This item has been designed, by a team of patients, doctors and nurses, to act as a handy reference guide, which is constantly updated, allowing the patient to record their treatment results as well as providing information on other yearly tests. All this information is held in a handy and easy to use personal organisor which is free for patients and available from the UKTS office.

The start of the New Year has already supplied us with a major piece of news with regards to Ferriprox (L1) and the European courts ruling. More about this further on page 3.

Until the next issue

M. Michael
President

Aims & Objectives of UKTS

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

The UKTS Management Committee

Mike Michael	President
Costas Kountourou	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

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Patient workshop session at the conference hosted by UKTS Asst. Treasurer Menuccia Tassone (4th from right)

the inaugural UKTS Achievement Awards (see article on page 4) and an address from our President, Mike Michael.

The general feedback we have received so far indicates that those who attended found the conference very valuable. Most found the presentations to be well chosen and accessible and the conference packs were welcomed by all. Such positive comments made the months of hard work by UKTS personnel worthwhile. All in all we had a very enjoyable, if tiring day and look forward to welcoming as many of our members as possible to the next UKTS Conference in due course.

UKTS would like to extend our heartfelt thanks to all the volunteers who helped us to organise the conference and/or assisted on the day. Your work is greatly appreciated.

Elaine Miller

European Court decision on Ferriprox

On December 18 2003 the Court of First Instance of the European Court of Justice ruled that Dr Nancy Olivieri of Toronto, Canada, had no legal standing to challenge the approval of Ferriprox (also known as deferiprone or L1) by the European Agency for the Evaluation of Medicinal Products (EMEA). Dr Olivieri's legal challenge began in 1999 after the EMEA approved the marketing of Ferriprox for use in patients unable to use the standard therapy. The Court found that the EMEA had fully examined all relevant data and had therefore acted properly in approving Ferriprox.

The significance of this decision to thalassaemia patients is that the original approval of Ferriprox in 1999 will stand and that the drug will remain available for prescription where clinicians consider it to be the appropriate treatment. At the present time, the EMEA ruling is that Ferriprox can be prescribed "For the treatment of iron overload in patients with thalassaemia major for whom Desferrioxamine therapy is contraindicated or who present serious toxicity with Desferrioxamine therapy." However, this indication is now under review by the EMEA who are examining the current scientific data. Depending upon the conclusions the EMEA reach from the latest studies, Ferriprox may become more widely available for prescription in the future.

Leading Thalassaemia Specialist gets OBE

We at UKTS are sure that all our readers will join us in sending warmest congratulations to Dr Beatrix Wonke, Director of Thalassaemia at the Whittington Hospital, North London, who has been awarded the Order of the British Empire in the Queen's Christmas Honours List. Under the supervision of Dr Wonke, who retires in April this year, the Thalassaemia Management Centre at the Whittington has become an internationally renowned centre of excellence for the treatment of thalassaemia and the training of healthcare professionals.

The award ceremony will take place at Buckingham Palace later this year.

The UKTS Achievement Award

Mr George Constantinou UKTS Management Committee, Mr Avraam Demetriou, Mr Mike Michael UKTS President, Mr Phedias Soteriou.

Since its inception in 1976, the UKTS has managed to achieve many of the objectives envisaged by the founding members, two notable examples being; the development of the portable pump and fully funding the research into the development of the oral chelator deferiprone (L1). These projects were initiated, supported and implemented by volunteers who offered not only their time and effort but on many occasions, funds from their own incomes in order to ensure the success of the projects.

In 2003 therefore the UKTS Management Committee created the UKTS Achievement Award in order to honour and thank these commendable friends. It was decided that the first Achievement Award would be jointly presented; to two people who, by their dedication, commitment and pure energy managed to raise over one million pounds, which enabled UKTS to fund it's research projects. The Awards were presented at our National Conference/Workshop, which took place at the Royal Moat House Hotel in Nottingham on 16th November 2003. The recipients were:

Mr Phedias Sotiriou

Phedeias is aged 53 and was born in Morhou, Cyprus. He came to live in the UK in 1958 and eventually made his career in the CID. His wife Helen, sadly recently deceased, was also a supporter of UKTS. He has 2 sons and a daughter. Phedias says that he became involved in the cause of thalassaemia after seeing the needs of the patients. His most memorable day with UKTS came when he tested L1 on himself and saw iron being expelled from his own body. This convinced him that it would work for thalassaemia patients.

Mr Avraam Demetriou

Avraam is 52 and was born in Limia, Cyprus. He came to the UK in 1964 and is a dentist by profession. He is married with 3 sons. He was recruited to the cause of thalassaemia by Phedias, having already known about thalassaemia patients and their difficulties from his home village. Avraam feels that the most memorable thing about his time helping UKTS was how people who had no direct connection with thalassaemia would generously offer their financial support.

Thank you Phedias and Avraam, for everything. In honouring these two outstanding achievers, however, we do not forget the many others who gave up their time, expertise and money to help us achieve our objectives. Our heartfelt thanks to all our wonderful volunteers and supporters.

George Constantinou
UKTS Management Committee

ANNOUNCING THE UKTS

THALASSAEMIA NURSES & COUNSELLORS CONFERENCE

5TH MAY 2004

King's Fund Conference Centre,
11-13 Cavendish Square,
London W1G 0AN

Are you a nurse or counsellor working with thalassaemia patients and their families? If so don't miss this unique opportunity to get the latest information on medical and psychosocial issues.

For an application form please contact the UKTS office.

Doctors Compliance

By Bernadette Modell
Emeritus Professor of Community Genetics RF & UCMS Dept of Primary Care & Population Sciences
& UCL Centre for Health Informatics and Multiprofessional Education (CHIME)

The subject of compliance often comes up for thalassaemia patients, usually in terms of the patient complying with his/her treatment. However there is another side to this question, which is; what doctors should do to provide and comply with the treatment available. The book "What Is Thalassaemia" (published in 1995 by the Thalassaemia International Federation) states; "…. A well-treated thalassaemic at the present day can have an excellent life expectancy." Almost ten years later treatment continues to improve and no thalassaemic should be dying……so why are they?

There is no simple answer to this question. However, if we want to examine any treatment issues in a realistic way, we need a centralised source of vital information regarding treatment, from which we can obtain statistics which show us patterns and trends. A good example is the UK Thalassaemia Register, situated at the Whittington Hospital in North London. This is a database which works only with doctors who treat thalassaemic patients. The Register is in contact with every single treating clinician in the UK and regularly requests updates on the number of patients being treated, any new births of babies with thalassaemia and any deaths. Further, the Register is able to send the latest information on new developments in treatments or newly identified risk factors promptly to all the doctors.(It should be stressed that all the information held by the Register is protected by the Data Protection Act, is also subject to the same rules as all other National Health Service Information and is therefore entirely confidential.) The information collected throws up some revealing statistics. For example, in 1999 there were only 4 doctors in the UK treating in excess of 50 patients, whereas there were 71 doctors treating only one thalassaemic! The aim of the Register is to help all doctors, whether they treat 50 people or only one, to provide the best possible care to their patients.

One objective of the Register is to study deaths and causes of death. In 1999 it became clear that despite the apparent availability of effective Desferal treatment nationwide deaths still occurred from iron overload, particularly among patients in their early thirties. This information was sent urgently to all doctors. It will probably not surprise too many thalassaemics to learn that the subject of the message was that deaths continue because many patients find desferrioxamine treatment intolerable. The doctors were urged to consider new treatment options which make life easier, for example, Baxter pumps, oral chelation and combined treatment regimes. The message included the recommendation that all patients should attend an expert centre on an annual basis, to identify the treatment that works best for them. This message reached every doctor in the UK treating a thalassaemic patient one full year before the paper was published in The Lancet.

This year (2003) the Register updated information on deaths. There has been a dramatic fall since 1999 from an average of almost 10 deaths per year to less than 3 deaths per year. This is probably due to a concerted attack on the problem by everyone concerned. There are probably many different causes including (a) new possibilities for iron chelation therapy (Baxter pumps, the oral chelator Deferiprone); (b) new ways to identify patients with unacceptably high levels of iron in their heart (MRI technique); (c) the fact that the UK Thalassaemia Register informs doctors immediately about important new developments; (d) doctors' willingness to act on new information and refer patients; (e) the UK Thalassaemia Society's role in organising meetings of doctors, patients and parents and actively promoting the information. In addition, we can conclude from the new figures that L1 does not increase mortality, at least in the short term. Most thalassaemics will be aware that there has been bitter and public disagreement about the use of L1 among experts in thalassaemia. Our profession has not handled this problem effectively. We must recognise that we have failed to send patients the clear messages they needed and to apologise for the anxiety this has caused among both patients and doctors. For patients, the basic problem has been the failure of the medical profession to recognise the difference between Dr Olivieri's bitter disagreement with Apotex (the firm that manufactures L1 as Ferriprox), and the evidence about the value of the drug itself. Involvement of the media only increased the general confusion. Even now the harm persists. Though L1 is licensed for marketing in 32 countries it is still not available for many patients who cannot afford Desferrioxamine.

So what do doctors do when "experts" disagree? Firstly, they try not to become personally involved because it can seriously affect their work. They usually focus on treating their patients and producing objective scientific data as fast as possible. But is this enough? Do us doctors need

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help from you patients?

Patients may feel that they cannot possibly decide where doctors disagree; but you are more powerful than you think. You can use various tools, for example, the Internet to find out about new treatment options. You have the right to challenge authoritative opinion and ask doctors for their credentials (e.g. how many patients do they care for regularly? What is their clinical experience with L1?) You have the right to an open discussion that you can understand and you have the right to ask your support associations to arrange this and publicise the results. Patients can, with the help of support organisations like the UKTS, organise sufficiently to assert their rights. Some doctors may need to adjust to cope with "empowered" patients; but any person who has, or who cares for someone else with, a chronic condition is entitled to (and indeed should) take responsibility by negotiating their treatment options rather than merely obeying commands.

Finally, then, we can conclude from the information provided by the Register that people with thalassaemia need regular contact with an expert centre to ensure that they receive appropriate treatment and medical tests. They need to be able to negotiate an iron chelation regimen that will work for them and to know and be convinced that their treatment greatly reduces the risk of death from iron overload. This is not to say that risks do not remain, e.g. increased risk of infection. However, at last, in 2003 we can conclude with the optimistic message, that well-treated thalassaemics should now expect a nearly normal length of life.

The Psychosocial Burden of Thalassaemia

By Dr Evgenia Georganda

One of the goals of this conference, as mentioned in the program, is "to stimulate thalassemia patients to pose questions about their problems, doubts and expectancies". Thus, my effort will be, not only to summarize the previous presentations, but also to add a few personal remarks that will help us pose some serious questions.

In the opening ceremony Dr. Hershko talked about the importance of compliance to DFO treatment. I am certain that for most doctors patient compliance is the most important problem and obstacle to the "correct" treatment. I put "correct" in brackets because I believe that the correct treatment must take into consideration the psychological well being of the individual. This for me refers to the fact that we all have to keep a certain inner balance so that we can cope with the stresses of living. This means that one individual, for example, may be able to cope with the use of the pump on an every day basis for 24 hours a day and another one may be able to achieve the best results for his/her inner balance using it 5/6 days a week for 10/12 hours. So, I prefer to use the term ideal treatment to refer to what the books and the theory in general propose to be the best approach, i. e. daily 24hr usage, and correct treatment to refer to that which is feasible and realistic for the individual at hand.

Although there is a greater open-mindedness with regard to the importance of psychological issues I believe that we still have a long way to go before we understand how the inner psychic state of the person affects his/her physical well being. It would also be of great benefit to thalassemics to know what are the means for achieving a better psychological well being. Although research in the field of health psychology is ample for other diseases in thalassemia units research in this direction is scarce.

One of the biggest and most important questions that we could address, for example, is: "what makes us do all the things that we do?" Transfusions, chelation, appointments with doctors, check-ups, biopsies, operations, interferon and insulin treatments, and on and on goes the list. So for me the question is not why we do not comply but why do we comply? What is it that gives us the strength and the stamina to keep on going? How do we manage to integrate everything that is required of us into our busy schedules?

Thalassemics are no longer the poor children who died young, where hidden in the closet, and had no prospects for the future--although unfortunately there are still parts of the world where this may still be true. We have among us plenty of thalassemics who are professionals, who are married, who have families and who are doing very well. It would be very interesting to learn from them how they have succeeded in achieving all that and also to hear more about their needs.

For example, while talking with fellow patients I often hear how upset they feel about wasting a lot of unnecessary time. The element of time is important not only because we always thought we wouldn't have enough but also because time is the most valuable commodity and must not be wasted in hospital corridors. Doctors and staff must be sensitive to this important need of patients, to be able to finish with all they have to do in the hospital without unnecessary delays. Waiting for hours for appointments, tests, etc. is not only a waste but is also

extremely disrespectful of the patient and his/her need to move on with life and life's demands. Chronic patients who have to do all these things continuously are a very different category from those patients who get sick once and have to deal with something that has a known end. In our case this is a story with no end.

Another important issue for success in life and its demands is self-discipline and strength. We seem to have both. On the one hand psychic strength is something that needs exercising—like muscular strength—and life has given us ample opportunity to exercise. On the other hand self-discipline is another important ingredient of success. Setting a goal and having the discipline to follow through to completion requires perseverance and determination. Again my observation is that we are very determined and strong willed. However, we often times use this strength for self-destructive purposes rather than for our well being. Here again we come to an important issue. Do we really love ourselves? Do we care enough to do what is good for us? How can we achieve self-acceptance and self-esteem?

It is in adolescence that we start to form our own identity and to take the control of our life into our hands. Are we well prepared to face the responsibilities of adult life? Can we stand on our own two feet? Adolescence is also the time to rebel and express our own mind. This is why non-compliance is highest at this time. Slowly, however, we have to decide that we want to do what we have to do because we want to live. The desire for life is what keeps us alive. If the self-destructive instincts, which we all have, take reign then it is very likely that we will not survive for long. It is this desire to live, to want to do things with our life that will give us the stamina and the self-discipline to follow through with whatever treatments are necessary.

What makes some of us have the desire to live and others not? Why some give up and others not? How do we see ourselves? What is our self-image? Do we like ourselves? Do we believe we are worth loving? Can we love and be loved? Can we give and take? Do we trust others and ourselves? Can we get close and not be scared of being hurt? Can we be touched and feel pleasure or is our body used to pain and our soul is afraid of being hurt again? What do we expect of ourselves and of others? Why were we born with this illness? What does it mean to live always dependent on somebody else's blood? Are we angry? What do we do with our anger? Do we let it out on others or do we let it out on ourselves? Are we sad and discouraged? When so whom do we speak to? Who is there to help us with all these feelings and questions? Hopefully TIF will continue to pursue the quest for answers to these questions and convince the medical community that these issues are as important as the "correct" treatment is.

Dr Georganda invites any readers who wish to respond to her article to contact her by email on: egeorganda@panafonet.gr .

Response to Intravenous Pamidronate in the Treatment of Osteoporosis In Beta Thalassaemia

Sr. Emma Prescott, Thalassaemia Nurse Specialist, Whittington Hospital

Original study: E.E. Prescott, J.J. Hanslip, S.M. Tuck, J.E. Agnew, D.J.McCol, K.B. Raja, M. Griffin & B. Wonke.

Osteoporosis is becoming an increasingly debilitating problem among beta thalassaemia patients, and if not treated, deteriorates with time. The clinical consequences of osteoporosis are severe backaches, fractures with minimal trauma, femoral head necrosis and vertebral compression fractures.

We have treated 40 osteoporotic thalassaemia patients, 25 males and 15 females (mean age of 25 years) with monthly intravenous (i.v.) infusions of pamidronate, in doses of

30-60 mg for a mean period of 41 months. The treatment was well tolerated in all patients, with gradual improvement of back and neck pain and no new fractures were observed during the study period.

Bone mineral density (BMD) improved in 33 (82.5%) of patients, both in the spine and femoral neck, with a mean BMD increment of 32% and 42% respectively. Five patients showed improvements in the femoral BMD only; with a mean increment of 22%, they were classified as partial responders. One patient's BMD deteriorated in the lumbar and femoral bones, and one patient's BMD remained unchanged.

The dose of i.v. pamidronate was the only factor significantly associated with response, other factors such as gender, age, erythoid activity, iron loading, mode of iron chelation, hypothyroidism, hypogonadal hypogonadism, diabetes and liver cirrhosis did not influence the response to i.v. pamidronate treatment.

The results of this study show that despite the severity of osteoporosis found in this group of patients, significant improvement in spine and femoral neck BMD can be achieved through the use of monthly intravenous pamidronate. This regimen is well tolerated with minimal side effects. We have observed a marked improvement of symptoms such as chronic back pain and fracture rates.

Patient Experiences

Thalassaemia International Federation 11th International Conference for Parents and Thalassaemics

15th-19th October 2003, Palermo, Sicily

First Experience (1)

I didn't know what to expect going to a TIF Conference for the first time. I had an idea of what was in store as I had asked other patients who had been to the TIF conferences in the past.

The first day we arrived in Sicily, the hotel was filling up with parents, patients and medical professionals from all over the world. It was very strange that even though we were all complete strangers, we all had one thing in common - it was Thalassaemia that brought us all together. It seemed as if there was a special bond there.

Over the next few days, I had the opportunity to sit and listen to talks given by doctors, parents and also patients. It was very interesting to listen to new developments on research and the treatment available throughout the world for all Thalassaemics.

The most unforgettable experience during the four days of the Conference was the Patient and Parent session with our friends from Saudi Arabia. There was a Questions and Answers session and I was extremely surprised to find that there is a lack of knowledge on Thalassaemia by medical staff and patients themselves in a country where funding for treatment isn't generally a problem. A lot of our Saudi friends had stopped using their Desferal pumps due to painful scarring and discomfort. This was because they had never been shown how to put the needle in correctly. After the session was over, myself and a few of the UK and Australian patients showed the Saudi patients how to put the needle in correctly to make it more comfortable.

UKTS Co-opted Committee member Olga Demetriou, UKTS Asst. Secretary Maria Gavriel & UKTS Vice-President Costas Kountourou with some of our friends from Saudi Arabia.

We also showed them the treatments that are available in the UK and Internationally and which could possibly be available in their country. The main reason they had stopped using their pumps was due to the painful butterfly needles. When we showed them the thumbtack needles and how to use them they were willing to try them out and a few of the Saudi patients noticed the difference straight away. The expression on their faces said it all.

After the session the Saudi patients seemed more positive and determined to start using their pumps again and realised that having Thalassaemia is not that bad and that you can lead a normal life, working, being in a relationship and having a family.

The last day was very emotional and memorable. Even though the Conference was only for a few days it seemed that the friends I had made I had known all my life. It's a bond that's unexplainable.

Olga Demetriou

First Experience (2)

I have always been curious about the Thalassaemia international conference and this year after plenty of encouragement from other patients who were attending I decided to go to this years conference in Sicily.

I feel the experience has been a valuable one and one I would like to share.

Initially one half of me was looking forward to the conference and meeting other patients from other parts of the world. On the other hand there was a certain amount of fear of seeing things that would be upsetting and I suppose a fear of not really knowing what to expect.

Looking back I feel on all fronts the experience has been a rewarding one and one that I would recommend to others.

Firstly meeting other patients from all over the world and seeing them do so well makes you realise how big and strong the Thalassaemia community is and generally makes you feel proud to be part of it. Even though most of us had never met before, a strong bond, a friendship, a understanding, a caring was instantly there and this grew stronger over the few days that we spent together. For me, spending time with so many other likeminded patients and sharing thoughts, ideas experiences was a very good feeling.

The conference was also a opportunity to meet numerous patients from other parts of the world where treatment for Thalassaemia was poor, in some cases not even regular blood transfusions or medication could be guaranteed. This was upsetting and made me realise how much progress is still needed to deal with Thalassaemia adequately in these parts of the world. On the same note meeting these patients made me realise how fortunate we are in the UK to be able to receive the treatment that we do and be able to see the necessary specialists when required. The differences in treatment in some cases was shocking.

Presentation to patients and families by Professor Bernadette Modell

On a knowledge basis the conference offered a good opportunity to listen to numerous medical experts from all over the world talking about their specialist area of Thalassaemia. Although much of this information at times was very technical and went over my head, speaking to specialists over a coffee or a drink throughout the conference was a good opportunity to ask questions. Meeting so many doctors and specialists working on improving Thalassaemia treatment throughout the world is also very encouraging, as you feel confident that improvements to the current treatment can be made.

All in all my first conference has been a very rewarding and emotional experience providing a good opportunity to meet other patients and share experiences, learn more about my treatment and become more aware of problems faced but other patients in certain parts of the world.

Philip

CELEBRATING A NEW ARRIVAL!

UKTS would like to offer many congratulations to new parents Amanda and Mario Nicola (both thalassaemia major patients!) who are celebrating the birth of their son Costandino. The little one weighed in at 8lbs 1oz at 3.31 pm on 7th January 2004 at University College Hospital in London. We are very grateful to Amanda and Mario for allowing us to print their details and for letting us have the lovely photograph of their baby son. It is a joy to us to have such good news to report, which can only give encouragement to other patients and their families.

Employment and Career Matters

by Neelam Thapar

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

In this issue, I have looked at using networking for your career development. If there are any other areas you would like me to cover, please do not hesitate to contact me via the UKTS office.

What is networking

Networking is all about making contacts that may be able to help you as well as you being able to help them. All of us have already got informal networks that we call upon all the time in everyday life but may not have thought about how they can be used for career development or indeed how to create new networks.

Over 70% of recruitment vacancies are never advertised yet get filled - it is important to know how to create your own vacancies and for that you need to be able to network. You may also want to start working in an area that you do not have experience in - for this you need to know about the profession/industry before you start making any applications. Networking is asking for information and advice and allowing others to help you achieve your goals. Its not about telling people to give you a job but about creating knowledge for yourself to make informed choices and then targeted applications. People do not necessarily mind giving you half an hour of their time to give you the benefit of their experience.

Networking can be done at any age - whether you are still at school, college, University, starting out your career, in the middle of it or even coming to the end of it.

How do you network

You need to think about what information you are looking to gain and then think about who you can ask. It is important that you develop a list of questions that you can ask them so that you do not feel awkward when contacting them. You may also want to have a CV handy, just in case!

You need to draw up a list of people you know. These could include friends, family, teachers/tutors if still in education, former/present colleagues, people you meet through everyday activities, people in your community. Think of what you are hoping to learn about. Each one of the people you know will also have their own contacts that they may not mind putting you in touch with.

REMEMBER WE ALL HAVE NETWORKS TO TAP INTO

Collect business cards of people especially if you go to conferences or exhibitions. You never know when they may be useful. Go through your long list and think who could possibly help you - keep the initial network list of people you will contact small as it becomes more manageable.

Initially, a good way of making contact to arrange a meeting is through telephone, letter or email. You may find that people may be busy but be quite happy to advise you over email, rather than meeting you face to face. Tell the "network contact" the name of the person who has recommended that you speak to them and at this stage give a little information about yourself and how the "network contact" could help you.

Even at this stage you want to create a good impression - you never know how this person could help you. If they are unable to help, ask them if they know anyone else that may be able to give you more information. Keep in contact with your networks.

Keep a detailed record of who you have talked to and what was said. Record what action you need to take next so that you can build up a plan to work towards. Help others as well as getting information for yourself. You will have lots of skills and experience that may be useful for someone else.

What questions can you ask your contacts?

These are some examples of some questions that you could select from to ask someone:

About their Work Role:

- Please can you describe a typical working day?
- What are your main responsibilities?
- What skills are needed for your job/in the industry?
- What do you enjoy the most/least?
- Has it met your expectations?

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Getting in:

- How did you get in?
- What do you think recruiters are looking for?
- What would you recommend as a useful stepping stone, e.g. voluntary work?
- What do you think are the barriers to overcome? How did you do that?
- Would you be able to look at my CV and give me the benefit of your opinion?

About the Organisation:

- How is the job changing?
- What kind of jobs do people move to?
- What are the key factors in progressing with the organisation?

Other questions:

- Can you suggest other people I should be talking to?
- Can you suggest courses that would be useful?
- Are there specialist publications I should be looking at?

Send a thank you letter to your contact after you have spoken - create that good impression. Remember people may not be able to help and you should not take that personally but instead think of other people that you could contact.

Any readers wishing to contact Neelam for personal advice may do so care of the UKTS office.

THE UKTS 2003 PATIENT SURVEY PRIZE DRAW - Announcing the winner!

As many of you will remember, in June 2003 UKTS launched a comprehensive survey. We wanted to find out about variations in treatment, how satisfied patients are in general with their treatment and what specific concerns and issues they wished to raise. The survey was, of course, anonymous; but as an incentive to return the form, a sheet was attached which gave contributors the option of sending their name and address for entry into a prize draw to win a Playstation 2. (These sheets were detached from the survey on receipt so the information given will not be linked with the name and address.)

The prize draw was made at our office on 5th January 2004 and we are delighted to announce the lucky winner – 15 year old thalassaemia patient Daud Daud from Bristol. Said Daud, who attends the Bristol Children's Hospital for his thalassaemia treatment and is a student at St Mary Redcliffe & Temple Secondary School in Bristol, "I was amazed to hear that I had won the prize!"

Congratulations to Daud who by now should have his Playstation 2 and a couple of games courtesy of UKTS. Many thanks to all of you who sent in your survey forms.

Elaine Miller

UKTS Welcomes NEW MEMBERS

Annual

Ms Farzana Hussain
Mr Khalid Hussain
Mr Hamid Peryie
Mrs Laleh Peryie
Ms Renuka Mardia
Ms Elizabeth Shaw
Ms Mavis Durant
Dr Alexander Molassiotis
Mr Surinder Singh
Ms Sunitha Featherstone
Ms Sobia Khan
Ms Rukhsana Khan
Mr Majid Naz
Ms Rahia Naz
Ms Sara Bibi
Mrs Pinky Kava
Mr Viresh Kataria
Mr Sanjay Amarchand
Mrs Binta Amarchand
Mr Lefteris Karatzas
Mrs Loukia Karatzas
Ms Sarla Patel
Mr Sajid
Mr David Chisling
Mr Kheirollah Roodashtyam
Mr Payam Roodashtyam
Mr Shamim Akhtar
Mr Haseeb Saeed
Ms Noreen Saeed
Ms Inshani Bandou
Ms Zaqia Bi Ayub
Ms Noureen Fareed
Mrs Zeb-un Nisa
Ms Nazia Begum
Ms Zanab Ibrahim
Mr Cem Kuman
Dr Kate Ryan
Mr Milan Savjani
Ms Yvonne Elliott
Mr Tejash Suba
Mr Vinesh Kava
Ms Manjit Bath
Ms S Tangai
Ms Hema Jandu
Ms Sheila Daley
Ms Collette Stainforth
Ms Hilda Castillo-Binger
Ms Shabana Hussain
Ms Hansa Khan
Ms Oya Yiakoup

Life

Mrs F Mumuni
Mr George Diamantaras

Glitz At The Regency!

Once again our annual Christmas dinner and dance was here upon us!

I was rushed with excitement of "what was I going to wear", and with helping to organise it.

"I think I will wear my little black number with my stilettoes".

Just about able to walk down the road I managed to drive to my friend Costas Kountourou's house..

Once there, I was informed that we would be going in style this year. Very excited at this point, I step out of the front door to hear, " Your chariot awaits, my dear." I look around expecting to see a black limo to go with my slick chic black dress and all I can see parked outside the door is a white van...

"What! You expect me to go to the dance in a van?" Costas replies, " Yeah, we need to make sure we bring back the remainder of the drinks. Why, are you disappointed?"

"No way I'm game for a laugh…"

I managed to get into the van with great difficulty as my heels were getting in the way of the step.

Once we were at the banqueting suite, the table arrangements were in the spirit of Christmas with balloons and crackers. The guests started to arrive looking very glam, dressed up to the nines. The night began with style, our band Jason and the Argonauts, also Maria with her lovely seductive voice got the party going. The atmosphere was electric, everyone was beginning to get into the festive Christmas mood….

Dr Beatrix Wonke & Mr Peter Keeping with UKTS President Mike Michael and his Fiancee Aggie Tan, President, Thalassaemia Association (Singapore).

Dr Beatrix Wonke and George Constantinou took over the dance floor with the sousta and the horo tis giyas (belly dance in other words).

Our two charming helpers Angelica and Olga made their way round the hall selling raffle tickets, which went like mince pies…

Costas Kountourou worked his usual PR charm with the guests, making sure everyone was happy and enjoying themselves..

Katie Read and Elaine held the fort out front making sure that everything was running smoothly...

Later Michael Michael welcomed everyone with his annual Christmas speech (and looked very smart in his black dinner suit...)

We had Chris Paul and Barry Paris behind the bar serving our guests with the liquid refreshments....

Finally, we had our lovely Menuccia preparing the sold raffle ticket counterfoils ready for the grand draw!

The dinner and dance was once again a success and full of spirit... a time where we can all get together and have fun!!

We raised approximately £3,500 this year. Next year we are hoping to raise the total….. so folks get your thinking caps on and please write in to the society suggesting any ideas for our future dances, no matter how eccentric they may be!!

The Committee would like to say thank you to Chris Neophytou who provided us with his van and who helped Costas Kountourou and Philip Agathangelou take the drinks up to the Regency. Special thanks also go the band Jason and the Argonauts for donating their time and talent. We are very grateful to everyone who helped us to make this another successful event!!!

MARIA GAVRIEL Asst Secretary

Young Revellers at the Regency.

Diwali – event in Brent

UKTS were delighted to receive an invitation to a Diwali Dinner and Dance, organised by Rajesh Kerai of the Kutchi World Group, a community group for youngsters within the Gujarati community in London, and Depesh Vekria of Asian Dynamix, a group of talented young dancers who blend modern bollywood and bhangra with traditional culture. The event, which was entitled "Bollywood Fire & Ice" took place at Brent Town Hall on October 17th 2003.

The Mayor of Brent, Cllr Peter Lemmon was present and other special guests included Don Dee, Juggy D and music producer Rishi Rich, who was voted best producer of 2003 at the Asian Music Awards and has worked with many international artists, including Craig David and Britney Spears. UKTS Secretary Katerina Read and Mrs Rita Paul attended on behalf of the Society and had a wonderful time. Information leaflets to raise awareness of the need for blood screening for thalassaemia were distributed to the guests. At the end of the evening Mrs Read was overjoyed to accept a donation to UKTS of £1,001 from the proceeds of the event. Many thanks to our kind friends at Kutchi World and Asian Dynamix for their wonderful support.

For further information on Kutchi World and Asian Dynamix visit their websites on:
www.Kutchiworld.com
www.asiandynamix.co.uk

Elaine Miller

Back row left to right, Juggy D, Don Dee, Rishi Rich, front row, left to right Depesh Vekria of Asian Dynamix & Raj Kerai of Kutchi World.

THE UKTS ANNUAL GENERAL MEETING

This will take place on 7th March 2004 at the Holiday Inn Hotel Brent Cross, North London.
Please see article on page 14

14TH INTERNATIONAL CONFERENCE ON ORAL CHELATION (ICOC)

14th-17th April 2004, Utrecht, the Netherlands
For further information contact:
Dr N A Georgiou, N.Georgiou@azu.nl or
Dr A Kolnagou, koranita@cytanet.com.cy

THALASSAEMIA INTERNATIONAL FEDERATION ASSOCIATIONS WORKSHOP & BOARD MEETING

Please contact TIF for further details.
tifhq@spidernet.com.cy

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The views expressed are not necessarily that of the Society.

UKTS AGM 2004

The UK Thalassaemia Society would like to announce that this year's Annual General Meeting will take place on the 7th March 2004. As last year, the venue will be: Room 101, The Amaryllis Suite, Holiday Inn Brent Cross, Tilling Road, Brent Cross, London NW2 1LT Tel No 0208 210 8686. The meeting will commence at 3.30 pm and will close at 5 pm when refreshments will be served. (If anyone needs a map and/or instructions on how to reach the venue, please contact the UKTS office.) All our members are welcome.

Professor John B. Porter and Dr Anna Mandeville of University College of London Hospital have kindly agreed to come along and give their presentation on the psychosocial integration of thalassaemics in the 21st century; which was first presented at the Thalassaemia International Federation Conference in Palermo, Sicily, in October 2003. Prof Porter will also be giving an update on the trials he is currently conducting on the new oral chelator ICL670, so don't miss this unique opportunity to hear the latest news on an issue of vital importance to thalassaemics everywhere.

This is also an ideal opportunity for anyone who wants to become more involved with the work of the Society to make a start. Come along, meet other members and the Committee and find out what you can do to help. If you are already involved in our work and would be interested in standing as a Management Committee member for the forthcoming year, now is the time to act! You should already have received a letter explaining who is eligible to stand and how nomination works together with a nomination form. If you would like to join the Committee and contribute to the running of your Society we would be delighted to hear from you. (Please note that Committee members meet fortnightly on Tuesday evenings at the UKTS office and anyone wishing to stand must be prepared to commit this amount of time as the absolute minimum.)

We look forward to seeing you on 7th March.

Elaine Miller

UKTS says "Au Revoir" to Costas Paul

Mr Costas Paul, who has been a mainstay of the Society since he joined in the late 70's, has decided to retire after serving the cause of thalassaemia for over 25 years. He will be greatly missed by all his colleagues at UKTS. Costas retired from full time employment with the Society in 1999 but has been helping us on a part time basis until the end of the December 2003.

Costas ran the office as the Society's Co-ordinator and has represented UKTS at international and national conferences and workshops and is a well-known figure in the thal community worldwide. He has been actively involved in fund raising since the early 1980s and his dedication and commitment to the Asian Awareness Campaign will forever be referred to. Costas' total commitment to running the Society in the highest standards of clarity, ethics and fairness is largely what has made UKTS one of the best (if not the best) run charities in the UK, as well as being the most respected thalassaemia association worldwide.

Finally, Costas will be remembered and thanked by the thalassaemics of the UK for being the first person who truly believed that a thalassaemic is an ordinary person first and a thalassaemic second; and for treating them with respect and support in accordance with this belief.

We wish him all the best in his retirement; but we are sure that his commitment and support towards UKTS and thalassaemia will continue throughout his life.

George Constantinou

Donations

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

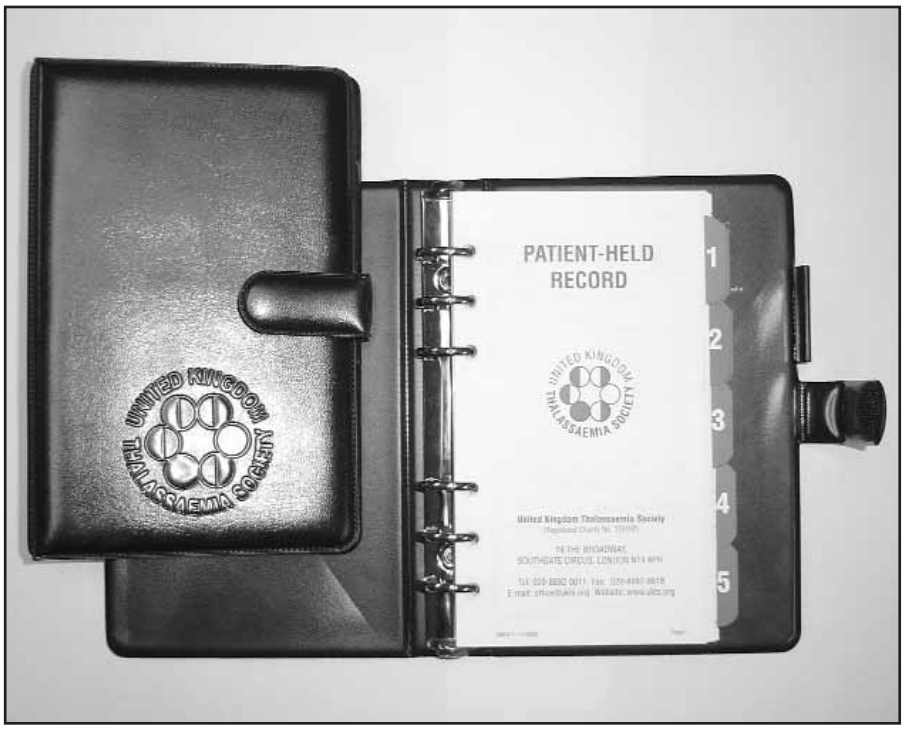
Mr F Flouris	£410.00
San Antonio Festival	£200.00
Asian Dynamix/Kutchi World	£1,001.00
Mrs L. D. Gray (in memory of Heni Soteriou)	£30.00
Mr Dinesh Patel	£50.00
Smiths Detection Ltd	£50.00
Mr N Apodiacos	£10.00
Hiten, Navita & Deepa Shah	£50.00
IMS Hospital Group Ltd	£50.00
TRS Foundation	£500.00
Kantou family	£40.00
Ms D Ptohopoulos	£50.00
Nathwani family	£75.00
Ms C Paouros	£30.00
Ms S Psaromitis	£160.00
Ms T Fedele	£30.00
Ms O Yiakoup	£5.00
Anonymous	£100.00
RAF Brize Norton Thrift Shop	£500.00

Relaunch of the UKTS Personal Organiser

The first UKTS personal organiser was introduced in 2002 and was welcomed by doctors and patients alike as being a valuable aid in keeping track of the important aspects of treatment. In addition, having their own personal treatment record helps patients to feel more in control when they visit the hospital. Due to feedback we received in 2003 we decided to redesign the organiser to make it more convenient to use; and at our annual conference in November 2003 we introduced the new, updated version. So far the response from healthcare professionals and patients has been excellent; and we are confident that this is the best, all-singing, all-dancing patient held record available to thalassaemia patients!

Throughout this project, which was ongoing throughout 2003, we were assisted by a team of doctors, nurse specialists and patients. Extensive consultations took place to ensure that the new design would be better, easier to use and more comprehensive. The end result has bigger and easier-to-read print, sections explaining the important aspects of treatment and charts which enable patients to keep track of when they should be having vital medical checks and to record their test results. There is also a handy diary section.

By taking the organiser along to your hospital appointments you can have your own set of medical records which will give you more sense of involvement in your treatment and could also help those caring for you. For example, imagine the scenario where a thal patient is taken to an unfamiliar hospital as an emergency



admission – this does happen occasionally! You could be dealing with medical staff completely unfamiliar with your condition. In such a situation it would be extremely helpful to be able to present the staff with your personal record. We have made the sections as user-friendly as possible but if you are unsure at first, ask your doctor or nurse specialist to help you fill in the various records. The organiser will be updated as necessary and any new or redesigned sections will be mailed to recipients as they are produced.

The organiser is available FREE to all thalassaemia patients (or parents/carers of a child with thalassaemia). To claim your copy you need simply telephone our office and it will be dispatched to you. Sounds too good to be true? Phone today for your copy and see for yourself. As always, we welcome your comments and suggestions.

The UKTS would like to thank all those who have given up their time and expertise to contribute to this project. We would particularly like to thank the following:
Dr Paul Telfer and Sr Emma Prescott,
Dr Vasili Berdoukas, Dr Philip Darbyshire,
Dr Bernard Davis, Dr Sally Kinsey,
Dr Melanie Pollitzer, Prof. John Porter,
Dr Beatrix Wonke, Dr Christine Wright,
Dr Anne Yardumian
We would also like to express our gratitude to the sponsors of the organiser:
Apotex Research Inc.
Novartis Pharmaceuticals

Elaine Miller

membership application form

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

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

Your Personal Details

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

First Name(s):

Surname:

Address:

Post Code:

Occupation:

Ethnic Origin: *(Optional)*

Contact Details

Telephone: *Home:*

Work:

Mobile:

Fax:

Email:

Are you a:

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

Membership Required *(please tick)*

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

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

Patient's Name(s):

Date of Birth

Sex: ☐ Male ☐ Female

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

Hospital where treated:

Address:

Consultant's Name:

Consultant's Telephone:

GP's Name:

Address:

Telephone:

Blood Transfused *(please tick)*

☐ Whole ☐ Washed ☐ Frozen ☐ Filtered

Chelation *(please tick)*

☐ Desferal ☐ Deferiprone ☐ Desferal & Deferiprone

Transfusion Frequency:

Units received at each transfusion

Blood Type

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

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