Mesyuarat Pertubuhan Thalassaemia Pulau Pinang yang diadakan pada 23 Februari sempena Hari Keluarga telah memutuskan rancangan tahun 2003. Berikut adalah petikan keputusan penting pada mesyuarat tersebut.

3 Sosial dan 2 Bengkel tahun ini

Tiga aktiviti sosial dan dua bengkel dirancangkan untuk tahun 2003. Hari Keluarga pada 23 Februari menjadi aktiviti sosial pertama. Bengkel akhir tahun lepas diadakan di Hotel Crown Prince (sekarang Hotel Crown Jewel) yang dinamakan Kem Psikososial II. Dalam aktiviti tersebut, empat penceramah jemputan serta aktiviti di tepi pantai dirancang. Sila rujuk mukasurat 6 untuk maklumat lanjutan kem tersebut.

Persidangan TIF 2003 di Palermo Sicily, Itali

Persidangan Pertubuhan Antarabangsa Thalassaemia 2003 akan diadakan pada 15-19 Oktober di Palermo Sicily, Itali. Kos anggaran ke persidangan tersebut ialah RM6000, tidak termasuk kos makanan. Persatuan Pulau Pinang akan memberi subsidi sebanyak RM1000 untuk lima ahli, yang akan dipilih berdasarkan penyertaan dan sumbangan kepada persatuan. Selain itu, ahli yang dipilih haruslah mengetahui Bahasa Inggeris yang menjadi bahasa perhantaran persidangan tersebut.

Di antara topik yang yang akan dibincangkan adalah pendekatan baru perawatan thalassaemia, isu psikologikal, aspek molekular thalassaemia, keselamatan tranfusi darah, peningkatan kesedaran thalassaemia di negara-negara membangun, dan kerjasama TIF dengan Organasasi Kesihatan Antarabangsa (WHO). Untuk maklumat lanjut, sila rujuk kepada laman web <www.tif2003.org>.

Subsidi THS 50% dan 75%

Pertubuhan Thalassaemia Pulau Pinang telah memutuskan bahawa THS (Rancangan Pertolongan Perawatan – Treatment Asistance Scheme) subsidi sebanyak 50% boleh diberi jikalau rawatan sepenuhnya diambil. Selain itu, subsidi sebanyak 75% boleh diberi jika angka serum ferritin adalah 4000 ke bawah. Demikian bertujuan menggalakkan rawatan sepenuhnya diambil oleh pesakit thalassaemia.

Taken from the News Review of the United Kingdom Thalassaemia Society, and edited for space constraints:

Research and Medical News

An investigational oral drug from Novartis demonstrated favourable results in patients with excess iron from transfusion-dependent anaemias; new data featured at major uS medical meeting.

Basel, 9 December, 2002 – New data featured at a major medical meeting suggest that a once-daily oral dose of a Novartis iron-chelating investigational drug (ICL670) may be as effective as the most widely prescribed treatment, Desferal. the data, from an ongoing Phase II study in 7 patients with thalassaemia, were oresented at the annual meeting of the American Society ofHematology (ASH) in Philadelphia. In the trial, the oral iron chelator ICL670 demonstrated benefits comparable to Desferal, but via a convinient oral administration.

"While Desferal has improved patient outcomes, its injectable route of administration creates significant compliance problem. Although efficacy is the most critical consideration, we also have to take into account the convenianc e – or inconvience of – administering treatment," said lead investigator, Antonio Piga, MD, Turin Universitym Italy.

Study Details

The Phase II data featured at ASH were from an open-label, randomized, multicenter study in patients with iron overload resulting from transfusional treatment of 6-thalassaemia. the 12-month study was designed to compare the overall safety, tolerability and efficacy of ICL670 (orally, either 10 or 20mg/kg/day) relative to Desferal (40mg/kg/day sebcutaneously 5 days/week) by measuring decreases in liver iron concentrations (LIC). The LIC reflect the overall body iron burden and were measured every three months by SQUID (Superconducting QUantum Interference Device) an sophisticated and non-invasive technique that provides results quntitatively equivalent to liver biospsy.

At the nine month checkpoint reported, LIC in 63 patients taking 10 or 20mg/kg of ICL670 decreased by 5.61% and 26.3% on average, respectively, compared with 13.9% of 20 patients in te Desferal group. The average liver decrease was greater in patients treated with 20mg/kg/day of ICL670 (- 2.2mg/Fe/g liver) than those treated with Desferal (- 1.2mg/Fe/g liver) or 10mh/kg/day of ICL670 (- 0.6 mg/Fe/g liver).

Contraindications and Adverse Effects

In studies to date, overall the drug has been well tolerated with some nausea, vomiting and skin rashes seen at higher doses, howevern no unmanageable toxicities have been observed. Safety will be monitored carefully during the clinical trials.

ICL670 Development

ICL670 was granted orphan drug status in the European Union and in November 2002 in the US. In the U, the term "orphan drug" refers to a product that treats a seriousand debilitating disease that affects fewer than five people per 10,000 population.
Global Phase III trials will be initiated in January 2003.

The foregoing release contains forward-looking statements that can be identified by terminology such as"suggest", "to start", "may be", "will be initiated" or similar expressions.

Taken and edited for space contraints from the December 2002 issue of TIF Magazine, originally published in the newsletter of the Thalassaemia Society of the United Kingdom:

The joys of parenthood

I was 19 when I married my husband in 1978. While we were still going out, I sat him down and explained that because I had the menopause at the age of 17, the only hope for m to have a child would be to have fertility treatment; and if that didn't work, we would have to see if we could adopt.

Our big day came and we settled down to married life. Five or six years later we decided to try for a baby. We approached my heamatologist who explained all the pros and cons, advising us that I would need various tests to determine whether I was fit enough and my heart strong enough to cope with the pregnancy.

Luckily, the results came back fine. At this time I would like to say that I'm so glad that doctors' attitudes have changed for the better since the mid-80s. My endocrinologist at the time was totally against any thalassaemic having fertility treatment; and obvioulsy this sent me home very upset, annoyed and bewildered. However, my haematologist gave me permission to carry on. I sought a second opinion and with the support of other doctors and my own perseverance, I had my first attempt at fertility treatment. Unfortunately, I had no luck even after thre attempts and the doctors advised us to take a break from treatment before trying again. It was 1986. With each attempt you go on an emotional roller-coaster ride: up with the hope then down when it falls,

We decided to have another try at the end of 1989. After four or five attempts we still had no luck. In 1994 we tried again. By now I was getting used to it but it was still as stressful as ever, especially because I continued working throughout all the attempts. After four attempts and four failures, I was beginning to think that perhaps someone 'up there' was trying to tell me something. But I wasn't taking the hint – hope never goe away when you want something so badly.

In 1996 I had another course of treatment. Once again four attempts – or perhaps even five – and NO it didn't work. I finally came to accept the fact that I couldn't have children, a fact confirmed by the doctor treating me at the time. Apparently, my genotype showed that the type of thalassaemia major I had was making it impossible for me to become pregnant. Even though I had never heard of this before I didn't question it or request a second opinion, as I had become tired and emotionally drained from all the years.

Then, while we were away on holiday, my husband and I discussed our second option – adoption. Whn we got back I rang our local borough and spoke to the social services department. I informed the social worker that I had thalassaemia major, and she assured me that as long as I passed the medical she did not believe that there would be a problem. There were some forms left for us to read, complete and return to her office. We followed the instructions, enclosed a letter from my consultant and the letter was forwarded to the doctor who sat on the adoption panel.We waited for his verdict and finally he said, YES, to go ahead.

The next hurdle was the police check, which we passed. Now it was time for the evaluation, where we attended a meeting with other hopefuls, a social worker spoke to us, and a group workshop. Then, the social workers make a decision regarding which hopefuls they will assess (in other words, they elimate some of the hopefuls). Thank God we passed this hurdle.

The next step was the home visit with our own allocated social worker. It felt as though our life was put under a microscope – but then this was a small price to pay for what we dreamed of.

Finally the day of our decision had arrived. My husband went off to work as normal and I went out but made sure I was home for that very importnat call from the social worker. The phone call came and – YES! – we had been approved to adopt. From start to finish the whole process took two years – until July 2000 whn our seven-and-a-half year old boy moved in with us. What's he like? He's birght, funny, noisy, saucy, cheeky and OURS. Best of all is the feeling we get when he cuddles us and calls us 'Mum' and 'Dad', or his face lights up when we enter the room.

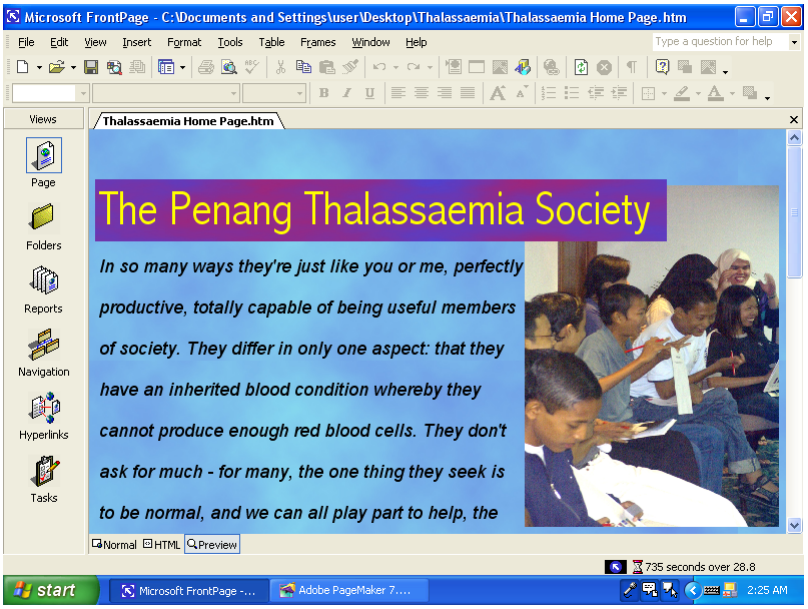
The moral of this story is we can achieve ANYTHING if we keep pumping and try ro stay as healthy as possible. DON'T ever give up hope and keep trying because DREAMS DO COME TRUE. I am a true believer that things happen for a reason.

Love and God bless, A happy mother.

Laman Web tidak lama lagi

Pertubuhan Thalassaemia Pulau Pinang sedang berusaha menyediakan laman web sendiri. Projek ini dicadang akan dilancarkan sebelum pertengahan tahun ini. Di antara fungsi rancangan ini adalah komunikasi yang lebih rapat di arena antarabangsa dengan pertubuhan-pertubuhan thalassaemia serta persatuan-persatuan perubatan yang berkaitan. Selain itu, adalah diharapkan bahawa adanya laman web akan menyediakan akses maklumat yang lebih senang kepada orang ramai, dan dengan itu meluaskan kesedaran awam mengenai sindrom thalassaemia.

Pada peringkat ahli-ahli Pertubuahan Thalassaemia Pulau Pinang, terdapat fungsi-fungsi lain yang dapat dilaksanakan. Jason Nicholas, yang sedang menyediakan ruang Internet bagi menubuhkan laman web, telah mencadangkan penyediaan forum di antara para ahli pertubuhan. Namun demikian, program demikian bergantung kepada sokongan dan akses para ahli kepada laman web ini.



Mengimbas kembali Kem Psikososial II

Dr Lai

"Saya tidak mahu beri syarahan - syarahan biasanya buat orang tidur."

Saya lebih daripada pesakit Thalassaemia

Aktiviti Visualisasi

Dr See

Dr Goh

Walaupun anda menghadapi Thalassaemia, jangan biar ia menentukan kehidupan anda

"The aim is to live!"

Khoo Swee Hong & Dr Balveer Kaur

En. Mohd. Idrus

"Success depends on what you do with you."

"Bezanya suka dan sukar adalah satu r sahaja"