



Thalassaemia
International
Federation

**Workshop on Haemoglobinopathies for
health professionals and patients/parents
in Guangzhou**

22 June 2009

**Guangzhou City – Guangdong Province
People's Republic of China**

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1. Introduction



Picture 1: Map of Southern China: Guangdong and Guangxi Provinces

Guangdong Province

Guangdong faces the South China Sea to the south and has a total of 4,300 km of coastline. The province is geographically separated from the north by a few mountain ranges collectively called the Southern Mountain range. Guangdong borders Fujian province to the northeast, JiangXi and Hunan provinces to the north, Guangxi autonomous region to the west, and Hong Kong and Macau special administrative regions to the south. Hainan province is offshore across from the Leizhou Peninsula. The province has a population of over 110 million.

Guangxi Province

Guangxi province is bordered by Yunnan to the west, Guizhou to the north, Hunan to the northeast, and Guangdong to the southeast. It is also bounded by Vietnam in the southwest and the Gulf of Tonkin in the south. In 1949 was reformed as one of China's five minority autonomous regions. The province has a high concentration of Zhuang, over 14 million, one of the major minority ethnicities of China. Over 90% of Zhuang in China live in Guangxi, especially in the central and western regions. There is also a significant number of both Dong and Miao minority peoples. Other ethnic groups include: Yao, Hui, Yi (Lolo), Shui, and Gin (Vietnamese). The total population of Nanning is 6.48 million

2. Workshop in Guangzhou

The workshop on Haemoglobinopathies gathered over 140 participants from the Guangdong and Guangxi provinces in Guangzhou City, Guangdong Dasha Hotel, on 22 June 2009. This was organised by the Thalassaemia International Federation in collaboration with its medical collaborators in China, namely Dr Chi Kong Li, Chief of Paediatrics, Prince of Wales Hospital, Hong Kong, acting as Regional Coordinator on behalf of TIF; Prof Li Chunfu, Head of the Department of Paediatrics, Nanfang Hospital/Southern Medical University, Guangzhou, as the Guangzhou Coordinator; and Prof Zhang Xinhua,

Department of Haematology, the 303 Hospital of PLA, NanNing, as the Nanning coordinator.

This was the third visit of TIF to China and the second workshop organised in this southern region of China.

We have recognised that there are many healthcare challenges are specific to individual provinces within the country, due to the great variety of health systems and difference in the quality of health services. Nevertheless, the southern Chinese provinces share certain problems in the management and prevention of haemoglobin (Hb) disorders.

In the People's Republic of China, haemoglobin disorders and their importance have long been under-recognised by the central government because of a lack of reliable epidemiological information on the frequency of the diseases and their real medical, economic and psycho-social impact. Other factors contributing to this relative neglect include weak health infrastructures, unable for services to support such a demanding, multi-faceted disease, other overriding health priorities, poor health literacy of the populations, and the tremendously high costs of adopting appropriate treatment protocols.

The objective of this second workshop on haemoglobinopathies was to follow progress from the previous visits and work of TIF in China (2000 and 2003), to raise the profile of haemoglobin disorders and gather relevant updated information for the southern Chinese provinces – a necessary step in understanding better the causes of the lack of significant progress in establishing effective control programmes. In addition, this workshop also served as a forum to identify specific ways and areas where the Thalassaemia International Federation (TIF) can provide support and achieve a measurable impact.

The workshop was a one-day long educational event which was divided into a scientific programme and a patients' and parents' programme. The scientific programme covered in depth the current state-of-the-art in the prevention and clinical management of haemoglobin disorders, as well as the latest research data on bone marrow transplantation and gene therapy. The faculty was comprised of internationally, regionally and nationally recognised authorities in each field (see below).

The organisers sponsored 141 participants, with 45 health specialists, and 35 patients and 61 parents from the Guangdong and Guangxi provinces.

2.1 Translation

Translation facilities from English to Chinese and from Chinese to English were provided for both the patients' and health professionals' programmes.

2.2 Educational material

A total of 660 copies of TIF's educational books were distributed in the course of the workshop to patients and health professionals:

- 140 *Guidelines for the Clinical Management of Thalassaemia*, 2nd edition revised (2008) in English
- 100 *About Thalassaemia* in Chinese
- 150 educational booklet sets in Chinese ("About β -thalassaemia", "About α -thalassaemia", "About sickle cell disorders")
- 100 *Prevention of Thalassaemias and other haemoglobinopathies Vol. I* in Chinese
- 50 *Prevention of Thalassaemias and other haemoglobinopathies Vol. II* in English

- 70 *Patients' Rights* in English
- 50 *Guide to Establishing a Non-Profit Patient Support Organisation* in English

2.3 Information questionnaires

Three types of questionnaires were prepared for the workshop:

- a) Questionnaires for health professionals: Two questionnaires were distributed to health professionals – one for obtaining information on the status of prevention programmes in their centre/city/province country and a second one for collecting detailed information on treatment in their country.
- b) Questionnaire for Patients/Parents: Patients and parents were asked to fill in a special patients' information questionnaire which included questions on their treatment regimes. These were translated into the Chinese language.

The responses obtained are currently being translated into English by TIF collaborators in China.

2.4 Recognition by World Health Organisation (WHO) and at national level

The workshop was placed under the auspices of the WHO country office in Beijing. However, due to reasons beyond his control, Dr Cristobal Tunon, the WHO country representative, was unable to participate in person in the workshop.

The opening ceremony gained the necessary political weight from the presence and contribution of the Deputy Director General of Health Services of the Guangdong Province, Prof (Ms) Peng Wei. In her address she stated that the Guangdong Province health authorities appreciated TIF's long-term efforts in her country and more specifically in this region. She remarked on the recognition of haemoglobin disorders by the central and regional governments, and the pressure they exert on the national resources, and expressed her commitment on behalf of the provincial government for progress on the development and implementation of an effective national control programme.

Moreover, the participation of the Honourable Minister of Health of Cyprus demonstrated Cyprus's commitment to supporting the efforts of the Chinese government, particularly through close collaboration with the Thalassaemia International Federation.

3. Committees and faculty

The organising and the scientific committees were led by Dr Chi Kong Li, Regional co-ordinator, Chief of Paediatrics, Prince of Wales Hospital, Hong Kong; Prof Li Chunfu, Guangdong Province coordinator, Department of Paediatrics Nanfang Hospital/Southern Medical University; Prof Zhang Xinhua, Guangxi Province Coordinator, Department of Haematology, the 303 Hospital of PLA, NanNing; Prof John B. Porter, Professor & Consultant Haematology, University College London Hospitals, UCL School of Medicine and Dr Androulla Eleftheriou, TIF Executive director.

The faculty of speakers was comprised of 8 regional/national and international medical and scientific specialists. These were:

Chi Kong Li, MD

Li Chunfu, MD

Zhang Xinhua, MD

John B Porter, MD

Louis Low, MD- Department of Paediatrics & Adolescent Medicine, University of Hong Kong

Xiu Xiang Ming, MD - Southern Medical University, Guangzhou

Nie Yong Mei, MD - Guangzhou Blood Centre, Guangzhou

Androulla Eleftheriou, PhD

4. TIF's past activities in China

TIF has organised two delegation visits to China, in 2000 and in 2002 in Nanning and Guangzhou, and a workshop in Nanning in 2002. At the time TIF urged the medical and scientific communities to actively get involved in the establishment of thalassaemia associations in their respective provinces of Guangdong and Guangxi, and supported the establishment of two thalassaemia associations.

Since then, another one association was created in Sichuan province (2006), which is based at the 2nd Hospital of Sichuan University.

TIF has sponsored the participation of health professionals and thalassaemia association representatives in TIF's educational conferences, such as in Dubai in 2006.

With the support of TIF collaborators in Taiwan (Prof Ching Tien Peng and Dr Watson Li) and Guangzhou (Dr Peiling Tian) it has been possible to translate and print several TIF publications in the Chinese language, including:

- (i) About Thalassaemia – a book addressing the needs of the patients;
- (ii) Prevention of Thalassaemias and Other Haemoglobinopathies Vol. I – a book providing basic information for developing effective prevention strategies;
- (iii) Booklets 'About β - and α -thalassaemia and sickle cell disorders' – booklets addressing the needs of the community in relation to haemoglobin disorders;
- (iv) 'Prevention of Thalassaemias and Other Haemoglobinopathies Vol. II' has been completed and ready to go to print (Pending), and;
- (v) 'Guidelines for the clinical management of the thalassaemia' – 2nd revised edition': the translation is expected to be completed by the end of 2009 (Pending).

However, the progress observed is not a true reflection on the efforts of TIF in China. Developments have been much slower than TIF had anticipated with regard to the establishment of effective prevention programmes. The lack of resources to put forward activities on chronic conditions on the whole and more specifically on haemoglobin disorders, the underestimation by the central and provincial governments of the magnitude of problem posed by haemoglobin disorders to public health, and other disease priorities may have constituted the most likely reasons for this lack of progress.

5. Epidemiology of haemoglobin disorders in Southern China

Current status and challenges

For decades haemoglobin disorders did not constitute a priority on the agenda of the World Health Organization. Resolution WHA 57.13 on genomics, adopted at the 57th World Health Assembly in 2004, Resolution WHA 59.20 on sickle Cell Anaemia adopted by the 59th WHA in May 2006 and the Resolution EB118R1 recommended by the 118th WHO Executive Board meeting in May 2006, formed an important milestone: the WHO urged its member states to focus attention and mobilise resources for action on control programmes for haemoglobin disorders and to prioritise them in their national health agendas. In addition, the Ministry of Health of China has recently urged the WHO to hold discussions on birth defects, in the course of the 125th Executive Board meeting in May 2009, in order to formulate policies that would be most effective in the control of congenital defects, including thalassaemia and sickle cell disease.

Not only is there wide variation in the frequency of β - and α -thalassaemias and sickle cell disease within the southern China provinces, but there is also variation between different geographical compartments within the same province. The estimated carrier rates of thalassaemias in five out of the seven provinces heavily affected by these disorders are shown in the table below.

Table I: Frequency of carrier rates for various haemoglobin disorders:

Name of province	Carrier rate for α -thalassaemia (%)	Carrier rate for β -thalassaemia (%)	Carrier rate for sickle cell disease (%)
Guangdong	8.53*	2.54*	NA
Guangxi	14.95*	6.78*	NA
Hong Kong	4.5**	3.4**	NA
Sichuan	1.92*	2.18*	NA
Guizhou	4.20*	1.10*	NA
Jiang Xi	NA	NA	NA
Hainan	NA	NA	NA

* = Data obtained from presentation of Dr Xiangmin Xu

** = Data obtained from WHO-TIF joint meeting report 2007

Appropriate national registries and reliable, up-to-date epidemiological data are still lacking in all seven provinces, shown above. These are necessary steps to plan and focus on the needs of southern China effectively. Only Hong Kong has published information on the economic burden of Hb disorders. Prevention programmes, where they exist in the country, are mostly ineffective and services are fragmented. It is therefore evident that there is a need to update the quality and coordination of services in the context of a comprehensive national plan. Reliable data are therefore urgently needed to provide evidence of the public health burden, in order to develop or improve national control programmes. It is recognised that the development and maintenance of effective national control programmes in the provinces rely heavily on political commitment and support.

6. Health system for thalassaemia and other chronic diseases in china

Until the 1980s, the health system in China was basically a national health system and patients' medical expenses were covered by the government. Since the early 1980s, there was a change in the health insurance system in that the hospitals only received a small percentage of the annual expenditure from the government. Most of the hospital expenses, in staff salaries, drug costs, capital investment, buildings and equipment, were coming from the hospital income, i.e. patients paying for their medical treatment. Today, only patients who are government employees are covered by their organization, whereas others, including children, have to pay for the in-medical expenses from their own pockets. There are patients whose families do not have the financial capacity to pay for expensive treatment, and therefore they cannot receive appropriate treatment. One example is the treatment of β -thalassaemia major, where some families cannot afford to pay for regular blood transfusions, and of course iron chelation treatment, which is even more costly. Thus only a small proportion of thalassaemia patients can receive appropriate treatment in China.

Current situation

With the improvement of the economic status of China, more families can now afford to pay for blood transfusion and partially for iron chelation treatment. However there are still many families that are not able to afford the appropriate treatment. The Central Government has identified the subsidisation of medical treatment across the entire country as one of its top priorities. In addition, the government has drawn up new regulations on the new health insurance system aiming at implementation across the country in the coming years. There are two systems covering the urban and rural areas. According to various reports from China, the recent developments in past years are as follows:

Guangzhou City

1. Children will be covered if they pay a nominal insurance fee (<10 US dollars per year), i.e. coverage is not 100%.
2. Pre-marital thalassaemia screening: free in Guangzhou.
3. Out-patient: For drugs under basic drug formulary, reimbursement is 40-70%. Desferrioxamine is included in the basic formulary. For community clinics or hospitals, the reimbursement rate is 70%, while for tertiary hospital only 40%. The monthly reimbursement is capped at RMB 300, i.e. only 11 vials of Desferrioxamine can be purchased. Some towns in Guangdong province do not even have reimbursement procedures in place for this drug.
4. Blood transfusion fee cannot be reimbursed at out-patient clinics, i.e. they have to receive transfusion as in-patients.
5. In-patient: The patient has to pay the minimum charge for every admission. The minimum charge varies with the region. Once the expense exceeds the minimum charge, then the patient can have partial reimbursement of the fee. For example, the minimal charge is set at RMB 600 for one admission for blood transfusion; together with 7 days of Desferrioxamine, it may cost RMB 1000. The reimbursement rate is 60%. Thus, the patient can actually only be reimbursed for RMB 240 (RMB 1000 – 600, then x 60%). The patient still has to pay large proportion of the cost.
6. Bone marrow transplantation: this will be reimbursed as the maximum level, and the amount also varies according to the economic situation of the town. It is usually two times of the average annual income for a citizen of the town, for example Guangzhou

which is estimated approximately at RMB 80,000 per year. There are also alternative sources that patients may apply for funding, such as the home affairs department for treatment of serious illnesses.

Nanning

1. Introduced the prevention and treatment of thalassaemia in the "road to health" programme, in 2004.
2. Free pre-marital thalassaemia screening services are available since 2005 in Guangxi Province.
3. 10,000 samples have been examined using prenatal diagnosis technology from 1982 to 2009.
4. There are 3 Day care thalassaemia centres at
 - (i) 303 Hospital of PLA
 - (ii) First Affiliated Hospital of GX Medical University
 - (iii) People's Hospital of LiuZhou City
5. About 800 patients regularly receive transfusion and chelation each month at the centres, but there are still many patients who cannot afford regular transfusion and chelation treatment.
6. Blood transfusion and iron chelation regimes with Desferrioxamine or Deferiprone are provided to patients.
7. Exjade is currently undergoing clinical trials.
8. Blood transfusion and iron chelation services are not included in the reimbursement procedures.
9. The rural region in Guangxi province has started re-imbursement procedures for up to 30%, for covering blood transfusion and iron chelation treatment, while reimbursement for patients dwelling in Nanning City has not yet started.

7. Programme

The scientific programme ran throughout the morning until lunchtime and covered the current state-of-the-art in the control of haemoglobin disorders, including prevention and clinical management, as well as the latest research data for bone marrow transplantation at Nanfang Medical University, and gene therapy. The faculty was comprised of a number of national and international experts in the various specialities (see p.4).

The official opening ceremony of the workshop included an opening statement from Prof. Li Chunfu, Guangdong coordinator, a welcoming statement from Prof (Ms) Peng Wei, Deputy Director General; Department of Health Guangdong Province and a welcoming address from Mr Panos Englezos, President of the Thalassaemia International Federation (see Annex I). Finally, the Honourable Minister of Health of Cyprus, Dr Christos Patsalides, gave a brief thanking statement to all those involved in the facilitation of the Cyprus delegation visit to China. He briefly described the synergy between the various stakeholders in Cyprus that had resulted in the successful control of affected births in Cyprus. Finally, he expressed the interest of his Ministry to assist the national and provincial authorities in China in their efforts to control haemoglobinopathies

In the last part of this introductory session, Dr Andreas Polynikis, Chief medical officer of the Ministry of Health of Cyprus, gave a brief overview of the health system and the role it played in the control (prevention and management) of haemoglobinopathies in Cyprus. Finally, Dr Androulla Eleftheriou gave a brief overview of the activities of the Thalassaemia International Federation on a global scale, its mission and objectives and how these are achieved through its various educational and other activities. She explained the kind of support that TIF offers to national health authorities of affected countries in improving pre-existing or implementing new control policies. She also described the collaboration of the Federation with other health-related institutions and patient-oriented national and international associations (see Annex II, scientific and patients/parents' programmes), and introduced the speakers (see Annex III).

8. Recommendations

1. Chronic illnesses need to receive priority on the national health agenda -in particular haemoglobin disorders, including thalassaemia. National prevention programmes should be considered a priority and should include:
 - a) Nation-wide carrier screening programmes
 - b) Availability of genetic counselling services for 'at-risk couples' and psychological support to patients and their families
 - c) Pre-natal diagnosis.Prevention programmes, once implemented, can contribute to saving and re-allocation of public funds. To improve the quality of life of patients, increasing the re-imburement rates from the current 30%-50% to cover all patients entirely (100%) is essential.
2. Raising public awareness about these diseases is a priority. It may be advisable for central and local governments to introduce a special module on haemoglobinopathies, their prevention and control in the high school and medical university curricula.
3. It is essential to provide support in as many ways as possible through the establishment and running of parents/patients nongovernmental organisations. Therefore it is important to have more flexible regulations.
4. Both prevention and treatment should be integrated into the primary health system in order to spread knowledge amongst primary health medical professionals, as well as increasing awareness about these diseases among the general public.
5. All three iron chelation drugs should be registered as essential medicines and should be included in the Chinese 'basic drug formulary'. This would make the iron chelators more accessible to doctors in order to tailor treatment according to patients' needs, which will effectively promote the adherence of patients to treatment, and therefore better health outcomes. Novartis Pharma should be contacted in order to discuss the distribution of Exjade (Deferasirox), in the context of the Asunra project or a similar one, like in India and other developing countries. China is still in a transition phase, and as such it should be considered a candidate for such a programme, particularly with regard to the highly affected provinces.
6. Production of Deferiprone (or L1) by a local pharmaceutical company should be investigated carefully to ensure that the quality of the product is up to the standards of the parent company. Patients who receive this drug must have access to clinical laboratories for frequent and accurate monitoring of severe side effects.
7. For supporting consistent treatment throughout the country, the Guidelines of TIF could be adopted by the Ministry of Health and the medical community. These should be translated into the Chinese language and widely distributed to health professionals.
8. For providing consistent and updated information to the patients, the 'About Thalassaemia' book should be distributed to patients.
9. A three-year plan of action (see below) developed as an outcome resulting from the workshop, from the high level discussions with Central Chinese Health Authorities, and the available data, has already been delivered to the central and provincial Chinese health authorities.

8.1 3-year joint plan of action

A 3-year joint plan of action agreed between the WHO (WHO-HQ), WHO/WPRO, TIF and the Chinese health authorities to strengthen the management of haemoglobin disorders: prevention and clinical care.

Chinese National Health Authorities and the Thalassaemia International Federation				
GOAL	2009	2010	2011	2012
1: Meeting with the Minister of Health of China and other key Ministry of Health Officials	√	-	-	-
2: 1 st Workshop on Haemoglobinopathies in Guangzhou, Guangdong Province	√	-	-	-
3: Preparation of report with recommendations and suggestions	√	-	-	-
4: TIF publication already translated into the Chinese language and ready to be distributed in China: a) About Thalassaemia b) About β -thalassaemia booklet c) About α -thalassaemia booklet d) About sickle cell disorders booklet e) Prevention of Thalassaemia and Other Haemoglobin Disorders Vol. I	√	-	-	-
Chinese National Health Authorities, Medical Community and the Thalassaemia International Federation – COLLECTION OF INFORMATION				
5: Reviewing the current status of epidemiology and control services for haemoglobin (Hb) disorders in China	√	√	-	-
6: Identification of local and provincial problems, needs and priorities for improving control policies	√	√	-	-
Medical and Scientific Communities, Patients/Parents Associations and the Thalassaemia International Federation – EDUCATION FOR HEALTH PROFESSIONALS AND PATIENTS/PARENTS				
7: 2 nd workshop on haemoglobinopathies in Nanning, Guangxi Province	-	√	-	-
8: Promotion and strengthening of the activities of old and the establishment of new thalassaemia associations in every affected Chinese province	√	√	-	-
9: The establishment of a Chinese Federation of Thalassaemia Associations	-	√	√	-
10: Translation and publication of Guidelines for the clinical management of thalassaemia in Chinese	√	√	-	-
11: Preparation, translation into Chinese and publication of patient-friendly guidelines for the management of	-	√	√	-

thalassaemia				
Medical and Scientific Community with the Support of the Chinese Health Authorities and in Collaboration with the Thalassaemia International Federation and the World Health Organisation –West Pacific Regional Office (WHO/WPRO)				
12: Identification of centres that can be promoted to expert centres – support through providing European and international criteria.	-	√	√	√
13: Establishment of a twinning training programme for health professionals and scientists with neighbouring countries, e.g., Thailand and Malaysia	-	√	√	√
14: Promotion of the establishment of a Chinese expert advisory group and participation in the Asian Collaboration Network, already existing	-	√	√	-
14: Promotion of e-MSc in Haemoglobinopathies	√	√	√	√

More detailed information using time-frames, wherever possible, for achieving each goal is given below, although it should be recognized that the majority of goals need continuing efforts to be developed and sustained:

8.2 Next steps

Epidemiology:

1. Reviewing the current status of epidemiology and control services for haemoglobin (Hb) disorders globally:
Time-line: Reviewed at the end of the delegation visit – (July 2009)
Complete this through published data by the end of 2009.
Responsible: Chinese health authorities, medical and scientific community, WHO/WPRO and TIF

2. Identification of local and regional problems, needs and priorities for improving control policies:
 - a) Identified through various personal communications and published data;
Time-line: December 2009
Responsible: Medical and scientific collaborators, local Chinese health authorities.
 - b) Review published data for additional information from participating health professionals;
Time-line: December 2009
Responsible: Medical and scientific collaborators, local Chinese health authorities.
 - c) Information on the Chinese health care system (both national and provincial):
Are patients getting reimbursed?
Time-line: October 2009
Responsible: Medical and scientific collaborators, local Chinese health authorities.
 - d) Review of local and regional problems in care management:

- (i) Blood supply and safety
- (ii) Availability of essential drugs
- (iii) The necessity of multidisciplinary care provision
- (iv) Expert centres – do they exist?
- (v) Are patients treated in hospital wards, in centres or in outpatient departments

Time-line: December 2009

Responsible: Medical and scientific collaborators, local Chinese health authorities.

- e) Bone Marrow Transplantation – Availability? Cost and places?

Time-line: December 2009

Responsible: Medical and scientific collaborators, local Chinese health authorities.

- f) Information on prevention:

- (i) Are there national or provincial prevention programme?
- (ii) Beyond local surveys, what screening programmes are ongoing?
- (iii) Are pre-natal testing and pre-implantation genetic diagnosis services available?

Time-line: October 2009

Responsible: Medical and scientific collaborators, local Chinese health authorities.

As much as possible of the above information should be collected in order to identify needs and potential weaknesses. This information will assist in setting goals and formulate strategies.

Efforts should be focused at harmonizing the prevention and management policies through China.

- 3. Identification of centres that can be promoted to expert centres:

- (i) Information on the available services provided by these centres
- (ii) Identification of potential new centres within highly affected areas in China

Time-line: Throughout the 3 year period

Responsible: WHO regional and Chinese country representative office and national health authorities.

Public awareness and education for parents/patients and health professionals:

- 4. Promotion and strengthening of the activities of old and the establishment of new thalassaemia associations in every affected Chinese province.

- a) Creation of a network of health professionals in every affected province;
- b) Establishment of parents/patients thalassaemia association in every affected province and becoming members of TIF – TIF to support for raising public awareness;
 - (i) Guangxhi Thalassaemia Association – Already a General Member of TIF
 - (ii) Guangdong Thalassaemia Association – Already a General Member of TIF
 - (iii) Children’s Thalassaemia foundation in Hong Kong – TIF Voting Member

- (iv) Need to re-establish contact with the association in Shihuan Province
- (v) Need to establish an association in Fujian province

Time-line: Within 2010.

Responsible: TIF and local scientific and medical communities

c) Establishment of Chinese Federation of Thalassaemia Associations:

Time-line: 2011

Responsible: TIF and established national thalassaemia associations in China

5. Translation and publication of Guidelines for the Clinical Management of Thalassaemia in Chinese:

- a) Translation into the Chinese language is currently underway.

Time-line: Expected time of completion December 2009.

Responsible: Dr Peiling Tian – Institute of Family Planning of Guangdong province.

- b) Preparation, translation into Chinese and publication of patients' friendly Guidelines for the management of thalassaemia.

Time-line: expected time of completion end of 2010.

Responsible: TIF

Education of health professionals, parents/patients and participation in regional programmes:

6. Promotion of the establishment of Chinese national expert advisory group and potential participation the South East Asia Network:

- a) Identification of local and national experts – in collaboration with the Chinese health authorities;
- b) Establishment of the national expert group on haemoglobinopathies
- c) Support to participation in the South East Asia network meetings.
- d) Promotion of twinning programmes with established centres for example in Thailand and Malaysia with new or less well resourced centres in different areas in China.
 - (i) Between patients/family driven organisations;
 - (ii) Between centres of excellence and other centres e.g., from Thailand and Malaysia, and;
 - (iii) Between other health-related national and international institutions.

Time-line: End of 2011.

Responsible: WHO regional office, Prof. Fucharoen, Prof Weatherall and TIF.

7. Promotion of the UCL-TIF e-MSc course in Haemoglobinopathies:

Time-line: ongoing throughout the 3 year period and well beyond.

Responsible: TIF and Chinese Ministry of Health

8. Collaboration between potential stakeholders, established by the end of 2009, but continues to expand and strengthen throughout the 3-year period and beyond.

Networking between medical specialists and patients' associations

There is a general absence of effective communication among patients' associations and between patients' associations and doctors, if any at all.

The objectives of such a network are:

- (i) to improve awareness among medical professionals about haemoglobin disorders;
- (ii) to gain a more accurate picture of the available services and any existing problems;
- (iii) to gather up-to-date epidemiological information, including numbers and locations of patients in the region;
- (iv) to raise awareness among patients and parents for these disorders;
- (v) to create networks of collaboration and close contact between patients and medical professionals within and between countries.

To encourage collaborative networking, TIF has pledged some financial assistance to Guangdong and Guangxi thalassaemia associations, provided that they begin to collect more accurate epidemiological data and begin to create a patient database. In addition, the thalassaemia associations (mainly health professionals) have promised to begin to involve parents and patients in their activities, especially as these relate to non-remunerated voluntary blood donor recruitment.

Through the collection of data, a solid evidence base will be built to help focus TIF's joint activities with the WHO on the special needs of the Southern China, eventually producing a report.

Time-line: end of 2011

Responsible: TIF and the national and regional medical and scientific collaborators

Annex I: President's address

It is a great privilege and a real pleasure to address this audience of friends, patients and parents, scientific and medical collaborators from Guangzhou and Nanning and other provinces – some of whom are long-term members of TIF's global thalassaemia family.

Thalassaemia International Federation (TIF) is the global umbrella organisation of thalassaemia patients' associations. TIF is an official partner of WHO and is dedicated to promoting equal access to appropriate care for all patients with thalassaemia. Its extensive educational programme includes a series of educational publications as well as events aiming to spread awareness and promote effective control programmes across the world. As one single body with a very strong voice, we aim to achieve improvement in the survival and quality of life of our patients: to enable each and every one to have equal access to quality health care, which is not only the fundamental right of every patient across the globe but the mission and reason of existence of this Federation.

Today, thalassaemia and sickle cell disease are no longer fatal; there is no limit in the length of life each patient can have, and no limit as to the quality of life each patient can enjoy. There is no reason today to put on hold the dreams and hopes of our patients, no reason to keep them in the margin of our societies. Therefore, education of both health professionals and patients is essential to achieve this.

TIF was actively planning to visit China in 2009, and it was an opportune moment for our Federation, when the Ministry of Health of Cyprus invited TIF to participate in an official delegation visit in China, whereby thalassaemia constitutes part of the agenda to be discussed at the level of the Chinese national health authorities. Indeed, a few days ago the official Cyprus delegation group, headed by His Excellency the Minister of Health, Dr Christos Patsalides, met with His Excellency the Chinese Minister of Health and other key official, where a fruitful interactive discussion and useful exchange of information, knowledge and expertise pertaining to haemoglobinopathies took place. The above demonstrate the commitment of the Government of the People's Republic of China to further reinforce its actions in this field and particularly in the area of prevention.

The Thalassaemia International Federation is reiterating its efforts, as a follow-up to its previous visit in 2003, which included amongst others the establishment of 2 parents/patients associations, one in Guangzhou and one in Nanning. It is unfortunate that progress from this former visit has been much slower than what TIF had expected. Lack of resources to put forward activities, underestimation of the magnitude of the contribution of the haemoglobin disorders to public health by the China governments, and other disease priorities constituted the most likely reasons for this lack of progress. We are pleased, however, that after the WHO resolutions on Thalassaemia and Sickle Cell Diseases, WHO member states, including China, have placed these disorders on the priority health agenda, seeing the evidence of its medico-socio-economic impact, if control is not addressed effectively. Health infrastructure and public health improvements as well as allocation of more resources now allow more countries to put haemoglobin disorder on their health agendas. We are delighted that China has already included the haemoglobinopathies in the context of its 'Disability Programme', as a suggestion in the last World Health Assembly (WHA No.62 – May 2009). TIF is fully committed to work with the Chinese health authorities, the Chinese medical and scientific communities, the Cyprus Government and our global thalassaemia family, including our international advisory panel to support the efforts of the Chinese government, in as many ways as possible.

The very presence of the WHO country office representative, here today, Dr Cristobal Tunon, reflects the commitment and recognition of WHO, which has also placed this event under its auspices, towards supporting the development and implementation of appropriate control programmes of Hb disorders in China.

This workshop constitutes the first in a series of national and regional educational events that TIF hopes to materialize through its joint 3-year plan of activities, as presented to the Chinese Health Authorities.

The objective of this workshop is to bring together health professionals and patients/parents from various highly affected regions in China, to educate them, to create a network of collaborations between them, and to provide a forum for exchanging information, knowledge and experiences.

The contribution of medical specialists of international and regional expertise and recognition in the programme provides the guarantee for a successful educational event of the highest scientific level.

In addition, we are proud to announce that in cooperation with our eminent Chinese collaborators, Dr Peiling Tien- Guandong family Planning Institute, Prof CHING-TIEN PENG - China Medical University and Hospital, Taiwan and Dr Watson Lin – Thalassaemia Association in Taichung-Taiwan, we have been able to translate several of TIF reference publications, such as 'About Thalassaemia', Prevention of Thalassaemia and other Haemoglobinopathies Volumes I and II etc, into the Chinese language, hoping that these will be of great value and support to the work of the health professionals, but also to the patients.

In ending, I would like to express my most sincere appreciation and gratitude to Dr Chi Kong Li – Chief of Service, Department of Paediatrics, Co-ordinator (Clinical Service), Prince of Wales Hospital, Hong Kong, TIF Medical collaborator, who has acted as a coordinator on behalf of TIF for this and a number of other events in the region, to Prof Li Chunfu – Department of Paediatrics, Nanfang Hospital -Southern Medical University and Guangzhou Organising Committee and Dr Zhang Xinhua –Department of Haematology, The 303 Hospital of PLA, Nanning, who have supported the coordination of this event together with Dr Chi Kong Li. Their contribution the materialization of this workshop has been invaluable. In addition, many thanks to each one of the local experts who are today presenting Prof Xiu Xiang Ming, Prof Nie Yong Mei and Prof Louis Low. Last, but by no means least, I would like to express my gratitude to Professor John Porter- Department of Haematology, Head of the Red Cell Unit at University College London, for long-standing his commitment and multi-faceted support to TIF's educational activities around the globe, including this workshop.

Finally, our deep gratitude goes to our sponsors, Novartis Pharma Services in China, and in particular Mr Kevin Zou, Head of Marketing, Oncology Business Unit and Ms Wendy Yong Wang - Communications Manager for their support and close collaboration without which this educational event would have never been realised.

I take this opportunity on behalf of TIF to wish every participant a successful and productive event.

Annex II: Workshop programme

1st Workshop on haemoglobinopathies Guangzhou City, Guangdong Province Monday 22 June 2009

- 8:30-8:32 Opening Speech - Meeting host: Li Chunfu (CN)
8:32-8:35 Welcome speech - Ms Peng Wei - Department of Health of GD
8:35 – 8:45 Introduction of TIF by TIF President - Panos Englezos (TIF)
8.45 – 8.55 Address by His Excellency the Minister of Health - Christos Patsalides (Cyprus-MOH)
8.55 – 9.00 Working Together for Better Patient Care – TIF activities across the world – Androulla Eleftheriou (TIF)
9.00 – 9.05 The Cyprus Health System: National Thalassaemia Control Programme - Andreas Polynikis (First Higher Medical Officer - Cyprus- MOH)

Scientific Programme

Part I: Epidemiology & Prevention

- 9.05 – 9:20 The role of effective prevention of Hb disorders - Androulla Eleftheriou (TIF)
9:20 – 9:35 Preventive programme in China: experience in Nanning and Guangdong - Zhang Xinhua (CN)
9.35 – 9.50 Preventive programme in China: experience in Guangdong - Xiu Xiang Ming (CN)

Part II: Blood Donation and Transfusion Practices

- 9:50 – 10:05 Blood Safety and voluntary Blood Donation - Nie Yongmei (CN)
10.05 – 10:25 Blood Transfusion Therapy - Chi Kong Li (HK-CN)

Part III: Iron Chelation Therapy

- 10:45 – 11:15 Iron Chelation and recent advances - John B. Porter (UK)

Part IV: Endocrine Complications

- 11:15 – 11:35 Growth and endocrinological problems - Louis Low (HK-CN)

Part V: Thalassaemia Intermedia

- 11:35 – 11:55 Management of thalassaemia intermedia and HbE -Chi Kong Li (HK-CN)

Part VI: Cardiac Complications

- 11:55 – 12:15 Overview of iron overload and cardiac complication - John B. Porter (UK)

Part VII: Reference Thalassaemia Centres

- 12:15 – 12:35 Role and importance of establishing Reference centres - Androulla Eleftheriou (TIF)

Part VIII: Stem Cell Transplantation

- 12:35 – 12:55 Haematopoietic stem cell transplantation - Li Chunfu (CN)

Patients/Parents' Programme

- 14:00 – 14:20 Blood transfusion - Chi Kong Li (HK-CN)
14:20 – 14:50 Iron Chelation - John B Porter (UK)
14:50 – 15:20 Growth in thalassaemia and endocrine complications - Louis Low (HK-CN)
16:00 – 16:20 Cardiac complications and liver diseases - John Porter (UK)
16:20 – 18:00 Interactive Discussion: John B. Porter (UK), Chi Kong Li (Hk-CN), Louis Low (HG-CN) and Panos Englezos (TIF)

Annex III: Presentations from key speakers

Attached separately in pdf format.