FROM THE DESK OF THE PRESIDENT

PLANNING EXERCISE INITIATED IN DEVELOPING LONG-TERM PLAN FOR SERVING ADULT THALASSEMIA AND SICKLE CELL PATIENTS, LED BY TORONTO DISTRICT HEALTH COUNCIL.

It is indeed gratifying to report that the Foundation's continuing efforts stressing the urgency of a plan to create stability and long-term quality care for our adult patients is gaining momentum.

Our first meeting with Toronto District Health Council was held April 12th, 2002. It was well attended with representatives from Thalassemia Foundation of Canada, Sickle Cell Association of Ontario, chief physicians, health planners and researchers from both The Hospital For Sick Children and the University Health Network's Toronto General Hospital. Many questions were asked and answered and we believe the district Health Council now have a clear picture of the urgency of formulating a plan for continuing quality care of adult Thalassemia and Sickle Cell patients.

We acknowledge with thanks and appreciation executive director Scott Dudgeon and his dedicated staff at the District Health Office for their time, effort and expertise in this matter. Our next meting is scheduled for June 18, 2002. And we are confident our goals will eventually come to fruition.

OUR UNSUNG HEROES

Most often we forget to recognize the people in the trenches, so to speak. We are frequently reminded by patients and parents alike about the dedicated services care and comfort that our nurses and social workers provide for our patients at both Toronto General Hospital and Sick Children's Hospital clinics.

We take this opportunity to recognize Bev Tyler, Nurse Co-ordinator at Toronto General Hospital, and Kelly Flannigan, Social Worker also at Toronto General Hospital, and Anne Chun, Nurse Co-ordinator at The Hospital For Sick Children. One would have to spend a day with them to realize the enormous contributions they make to the well being of our patients on a daily basis, our thanks always.

On a sad note we bid farewell to Social Worker Kathy Netten who for many years kept the spirits and hopes alive for parents and patients at The Hospital For Sick Children, we wish her much happiness in her future endeavours.

Our best wishes to all for a safe and happy summer.

God Bless,
Chris Bennedsen, President

IN THIS ISSUE

In 1988 Dr. Bill Francombe asked me if I would work with him to create the Adult Thalassemia Program at TGH. I accepted, not really appreciating the onerous consequences. I remember looking up the word T-H-A-L-A-S-S-E-M-I-A in the medical dictionary. I didn't know it was a blood disorder. Fortunately Dr. Francombe is a great teacher and mentor, and today that all seems like a hundred years ago!

Those early days were difficult for all of us - for the patients transferring and for me. We all had to learn, adapt and develop an effective program quickly. We set up the TGH program to be as similar as possible to the HSC program, so that the transition to TGH wouldn't be too difficult. Over the years the programs of both hospitals have changed but we are similar in our approaches, and the clinic we have today is the largest in North America and among the best in the world. Our program at TGH is well integrated with Sick Kids and the staff knows each other and communicates often. Much of the world's Thalassemia research happens here. Although it is a pain to be poked and prodded and asked the same questions over and over the reason that Thalassemia patients are doing so well and continue to do better is that medical questions are being answered and many of them answered here.

The one consistent thing about the adult clinic over the past 14 years at TGH is that it is always changing, and the improvements will continue. Old buildings are coming down and being replaced by new improved ones. By 2005 our clinic will be moved to a totally modern ambulatory center in what is now the Norman Urquhart wing. The Medical Day Unit is being renovated before moving back to its old location in October. The new transfusion room will be moved forward and will be much nicer and more accessible. The room we used will be turned into a staff room. By 2005 the Medical Day Unit will also be in the new ambulatory centre but the exact location has not yet been decided.

The ongoing interest and input by the patients and families is essential for our progress. We welcome the presence of family members in the clinic. It is obvious to all of us in the TGH Program that those patients who have ongoing support from family and friends do better and are more accepting of therapy.

Kelly Flannigan, Anne Chun and I recently went to a workshop at HSC about better supporting patients in making the transition from HSC to adult hospitals. Once we can get enough physician hours to meet the increased need, and sufficient space in the Medical Day Unit to do the transfusions, we are hoping to start taking adult patients who are still getting their care at HSC and begin to put what we learned into practice.

It is the result of many people's hard work, dedication and vision that support for the Program by the Hospital is growing. We are excited about the direction we are headed, and look forward to serving a growing and healthy community long into the future.

Bev Tyler, BScN
Coordinator
Thalassemia/Sickle Cell Program
Toronto General Hospital (University Health Network)

Hi, my name is Anne Chun, the nurse coordinator for the Thalassemia Program (a sub-specialty in the Hematology/Oncology Department) at the Hospital for Sick Children (HSC). I have been a nurse at HSC in the Hematology/Oncology Department since 1994 with experience in the Bone Marrow Transplant Unit, the in-patient Hematology/ Oncology ward and the Hematology/Oncology Clinic. I joined the Thalassemia Program in January 2000 and have had the great pleasure of working with a wonderful team of people to help deliver care to our families dealing with Thalassemia.

My team consists of doctors, a social worker, an information coordinator, and many support staff including the nurses in the IV room and daycare/treatment room, child-life specialists, a dietician, clerical staff, and patient-service aids.

We have a very busy program, as we care for almost 200 patients and families with either b-thalassemia, a-thalassemia and a few patients with Diamond Blackfan

Anemia. Our families come from all over the Greater Toronto Area and beyond (e.g. Kitchener, London, Hamilton, Ottawa, Montreal, Alberta, British Columbia and even a few from the USA). The Thalassemia program at HSC provides comprehensive care, offering a transfusion program, iron chelation program and the necessary monitoring by coordinating access to other departments within the institution, such as audiology, ophthalmology, radiology, image guided therapy department, cardiology, the liver service, and endocrinology. Our program is also very actively involved in research to help improve the care and future treatment of our patients.

During the past 2 years, as I have worked closely with our Thalassemia families I have come to have a new appreciation for the journey that they are on and the life that they live. They face many challenges as they deal with a chronic illness. On top of all the usual twists and turns that life throws our way, they must also juggle their lives to come to the hospital monthly for transfusions and various tests. Then there are the pokes, the lumps, bumps and bruises as they do their Desferal therapy, the childhood joys and struggles of growing up, adolescence, and the journey to achieve life dreams and aspirations. I thank you for the privilege to be a part of your lives, through tears and laughter, through joys and struggles, the good times and the bad, and to be a proud witness to the celebrations and achievements of many of our patients and families.

Blessings to all,
Anne Chun
Thalassemia Nurse Coordinator, Thalassemia Program
The Hospital for Sick Children

TIF REPORT - TIF EXTRAORDINARY GENERAL MEETING

TIF started the year with some changes, and a busy agenda that will be fulfilled in the next two years. Two Board Meetings and a General Meeting were held in London, UK in January and May of this year. TIF has to implement some changes as it has expanded its activities, projects and memberships to maintain the success in meeting the expectation of the larger thalassemia community in the world.

Early this year TIF held its first Board Meeting for 2002 and a General Members Meeting in London on January 18th- 20th. Due to the cancellation of TIF activities at the Athens Conference held on October 18-19, 2001 the Extraordinary General Meeting was requested by a majority of the voting members to be held on January 19th in London, UK.

The meeting was attended by 15 voting members, four proxies and eight observers. New memberships were approved for 7 voting members, 10 provisional members and 35 associate members. Later that afternoon, elections to the Board of Directors of TIF were held. As at January 19, 2002 TIF had 24 voting members from 16 countries. Nominations included 13 patients and 10 non-patients were 7 to be elected from each category.

The elected Board of Directors selected the executives among its officers at its first meeting on Sunday, January 20th, 2002 according to TIF constitution. The current TIF Board was formed as follows:

Panos Englezos – Chairman
George Constantinou – President
Shobha Tuli – 1st Vice President
Martina Fanari- 2nd Vice President
Loizos Pericleous – TIF Secretary
Stavros Melides – Assistant Secretary
Riyad Elbard – Treasurer
Merula Steagall – Assistant Treasurer
Robert Ficarra – Board Member
Dawn Adler – Board Member
Odysseas Platis – Board Member
Mouna Haraoui – Board Member
Yousef Nawwab – Board Member
Fatemeh Hashemi – Board Member

Dr A. Aleftheriou accepted the unanimous request by TIF Board to re-appoint her as TIF Scientific Co-ordinator. Dr Aleftheriou has been a great benefit to TIF Office and a deligent contributor to all TIF Scientific activities. TIF has sent a proposal to its Medical Advisory Board Members to extend their term till the next General Meeting in 2003.

Non-elected nominees demonstrated a very positive potential in supporting TIF on all its activities, and an eagerness to continue their collaboration with TIF Board. To benefit from the efforts and contributions of these dedicated individuals TIF is considering to increase the number of its Board Members. Another suggestion is to create a role that will allow interested

individuals a more affective involvement on TIF activities and at Board Meetings.

The audited accounts reports were presented and approved for fiscal years 2000 and 2001. The proposed budget for 2002 was discussed and the decision was to increase the budget 20% from preceding year. This increase is to carry forward activities that were planed for late 2001 but were cancelled because of September 11, 2001 events.

Mr Panos Englezos, TIF Chairman, presented a report detailing TIF activities and projects carried out during the last four years. TIF has achieved remarkable success in providing education on thalassemia, and establishing clinical management and prevention programs in many affected countries in the world.

The next General Members Meeting will be held at the next TIF International Conference. TIF Board accepted a contract proposal by the Fondazione Italiana "Leonardo Giambrone" with collaboration of the Italian Ministry of Health to host the next TIF International Conference in Palermo Sicily in November 2003.

TIF ACTIVITIES

During the last two Board Meetings, discussions on constitutional changes has been a primary item on the agenda. Mrs S. Tuli was selected chairperson for the committee responsible for the constitutional ammendments, the committee will complete the project within established deadlines. TIF legal advisors will review the final draft of the proposed changes before presenting it to the voting members at the next General Members Meeting in 2003.

Mr R. Ficarra accepted the responsibility of the production of a new educational video on Thalassemia and TIF activities. The video will include patients, parents, health care providers and experts on Thalassemia. Mr Stavros Melides was elected as chair of a fundraising committee that will explore new venues to generate funds for supporting various TIF activities.

Education and awareness on thalassemia has been one of the important commitments in which TIF achieved great success. TIF Office is working on various projects to maintain its status as the reliable source of information on thalassemia across the globe. TIF is currently updating its web site to include more scientific and medical information on the latest research. TIF's most recent publication is a book on the prevention of Thalassemia. This book is at its final stages and will be ready for distribution before the end of summer this year. Also "What is Thalassemia?" is being rewritten to include the latest developments on the treatment of thalassemia and to include patient perspective and psychological and social aspects. TIF has also contributed partial sponsorship for Dr Weatherall's latest publication on thalassemia.

Workshops on Thalassemia and compliance to Desferal were organized during the month of January in Egypt and Iraq, and in Birmingham, UK and Sao Paolo, Brazil in March 2002. Future workshops will be held in China in June and Saudi Arabia in October. Also delegation visits to Trinidad, Indonesia, Argentina, Pakistan, Saudi Arabia, Brazil, and Bangladesh are planed for 2002 and 2003.

In response to the difficult life conditions and the pressing need for thalassemia patients in the troubled regions of the world TIF donated blood filters to Palestine, and butterfly needles to Iraq earlier this year. Cooley's Anemia Foundation has donated funds to purchase desferal for thalassemia patients in Argentine. TIF has arranged for the purchase and shipment of Desferal at a discounted price from Novartis.

Mr R. Ficarra presented an update on current developments of L1 licensing in the USA. He said that the Cooley's Anemia Foundation is asking the NIH to look into results of MRI star 2 tests for assessing the combination therapy of L1 and Desferal. He also mentioned that a public relations firm is advocating for L1 approval on merit, and that an application to the FDA will be made in October to give L1 a fair Trial.

The next TIF Board Meeting will be in Cyprus on September 28th-29th preceded by Associations Workshop on September 26th – 27th of this year. All Thalassemia associations are invited to attend the workshop. The workshop will bring thalassemia associations across the world to join their efforts in the fight against this debilitating disease. Only through active participation by all we can achieve our goal.

Riyad Elbard,
Trustee, Thalassemia Foundation of Canada
Treasurer, Thalassemia International Federation

THALASSEMIA ACTION GROUP ANNUAL PATIENT/PARENT CONFERENCE: PHILADELPHIA PA "A REAL EYE OPENER"

April 5th 2002

As a parent attending my first Thalassemia conference, I looked forward to attending the Annual Patient/Parent conference in Philadelphia, Pennsylvania, and being in a room full of parents and patients who have the same issues and concerns that I do. When my daughter was first diagnosed with Thalassemia, I went through a lot of different emotions, ranging from confusion, hurt, disappointment and mostly isolation because I had no idea where to turn for answers or even support. Months of treatments and clinic visits allowed me the opportunity to talk with other parents and patients and adjust and cope with all the changes that are to be faced now and in the future (as I'm sure it has with other parents). But to be in a room full of parents voicing these same feelings and concerns was something I had yet to experience—and looked forward to.

I went to the conference for a variety of reasons: to hear other parents and patient's concerns, to find out what hope we all had for a cure, etc. But one important thing I kept looking for while in the sessions was a similarity. I'd seen numerous parents before while at clinic visits at Sick Kids, but this time, I wanted to see parents from the U.S. and see if they had any similarities to me and other Canadian parents. The answer I found was both yes and no.

The answer was yes; my concerns were very similar to parents in the United States. The discussions evolved primarily around one main topic, Thalassemia, namely "What are our chances for a cure?" "What are the best treatments available? "What research is being conducted?" among other vital questions. The nurses and physicians discussed our hopes for the future and included many guest speakers such as Dr. Cohen from Children's Hospital of Philadelphia, and Dr. Wonke from London, England. The afternoon was dedicated to the various speakers including nurses, cardiologists, hematologists, and patients. I found my similarity between other parents when it came to these issues.

However, the answer was also no; I didn't see a similarity between parents and myself from the United States. The largest contrast I saw was that of the health care systems in the United States and the Canadian system. During the session targeted solely towards parents, I listened as U.S. parents voiced their worries and concerns over ways to pay for treatments. They discussed different types of insurance, the necessity of "reading the fine print" when choosing certain policies, (because some policies have a cap on the amount of money available for treatments), and numerous other financial worries. In the U.S. they have to worry about health care coverage on top of dealing with Thalassemia. I can't imagine having to do that as well as learning about transfusions, properly mixing Desferal, not to mention dealing with the array of emotions that come along with the diagnosis. As I listened to U.S. parents discuss their concerns, I realized how lucky we are in Toronto, Canada to have a Thalassemia Program within the University Health Network.

We, as Canadians are quick to judge the health care system and for me, attending the conference was really an eye opener in because I learned that as Canadians we need take a step back and appreciate what we have accessible to us. In the same breath, however, we must realize that we are at the government's mercy when it comes to programs such as the Thalassemia program. We should keep in perspective that our health care system is beginning to deteriorate. Privatization and user-fees are terms that we fear. If they are put into practice, what would this mean for the Thalassemia patients at Hospital for Sick Children and Toronto General Hospital? Essentially, what will this mean for you and me—and our children? Will we have to fight for the Thalassemia Program to continue?

As parents we need to be concerned about the future of the health care in Canada. I am very grateful and appreciative that my government looks out for my daughter and me but we need to make sure this continues. As parents of children with Thalassemia, we can all do our part by staying informed about the current status of these programs and when necessary, voicing our concerns.

The TAG conference opened my eyes to a lot of things. But what I learned the most is how much parents from the U.S. to Canada, need to not only support one another but also keep our eyes open to the changes that affect the Thalassemia programs. So I urge you to join your child's physicians and nurses as they advocate for the best possible care for our children. After all, your child's strongest advocate is you.

Angela Covato
blueseptember73@yahoo.com

ANEMIA CONFERENCE - MONTREAL

The weekend of April 12th was a busy one in Montreal. The city played host to the Conference on Anemia. Members from the Thalassemia Foundation of Canada, Sickle Cell Society of Ontario, Canadian Sickle Cell Society (Montreal), Sickle Cell Parents Support Group (Ottawa), Aplastic Anemia & Myelodysplasia Association of Canada, and Canadian Celiac Association showed up to take part of the conference.

The conference began with the Canadian Hematology Society meeting at the Hotel Bonaventure on Friday, April 12th. This was the annual scientific symposium for Canadian hematologists. The CHS President, Dr. Gail Rock, extended a kind welcome to all the representatives from anemia patient groups and acknowledged the special opportunity to have patients and specialists together for this year's meeting.

After presentations of three resident abstracts, Dr. David Chui (of McMaster University) opened the main program with an inspiring overview of hemoglobinopathies entitled "Hemoglobin Disorders in Canada: A Mirror of the World." He left his audience with the strong message that we cannot minimize the seriousness of anemia in Canada: "Anemia is a Canadian Disease!"

He was followed by Dr. Ian Quirt (of Princess Margaret Hospital) who spoke on "Current and Future Management of Patients with Sickle Cell Disease." The final speaker was Dr. John Doyle (of the Hospital for Sick Children) who covered "Management of Patients with Fanconi Anemia." Unfortunately, Dr. Eric Nisbet-Brown (of the Boston Children's Hospital) was unable to make his scheduled appearance to present on the topic of Iron Overload.

It was great to see representatives standing up during the question period to pose questions to the presenting hematologists. More extended discussions between patient reps and specialists took place after the session closed.

After a group luncheon, the conference continued at Hotel du Fort with a recap of the morning sessions followed by an "Ask the Experts" Game Show Panel. This session pitted two teams against each other (the "Maple Leafs" vs. the "Canadiens"), with each team consisting of two physicians and one patient expert. For each question asked by the audience, the teams competed to give the most clear and complete answer. Thanks goes out to Dr. Richard Woodman (Calgary), Dr. Kent Stobart (Manitoba), Dr. Wendy Graham (North Bay) and Dr. David Chui for participating as physician/specialist panel members. Thanks must also be given to Josie Sirna (Thalassemia Foundation) and Caroline Laughlin (Aplastic Anemia & Myelodysplasia Association) for serving as patient experts. They had to be patient, considering the long-winded answers given by some of the physicians! The panel was moderated by Durhane Wong-Rieger of the Anemia Institute and, due to very diplomatic score-keepers, ended in a tie.

On the second day of the Anemia Conference, Annie Capua (Administrative Technician/Coordinator, Biochemical Genetics Unit, Montreal Children's Hospital) gave a very interesting presentation about the Montreal Thalassemia Screening program. This consists of a team that travels to Montreal-area high schools to present information to students and allows them optional screening for Thalassemia and Sickle Cell disease trait. Conference attendees were very interested in learning about this program and hope to bring screening programs for anemia to other parts of the country.

Dr. Penny Chan presented on the "Current Status of the Blood System" and covered the risks associated with blood transfusions in today's blood supply. The conference ended with a Business Session of the Anemia Joint Working Group. The business session was very productive and many members stepped forward to take on projects for the next year, including planning another joint Anemia conference for 2003. Tentatively, this conference will take place in Toronto, April 25-26, 2003 – again, in association with the Canadian Hematology Symposium.

Summary
Business meeting of Anemia Joint Working Group
Saturday, April 13, 2002, Hotel du Fort, Montreal

Ideas for collaboration:

- Medical Education
- Public Education
- Links among groups – e.g. links in websites; joint conferences; letter writing with respect to common drugs.
- Screening programs
- Dependence on the Health Care System
- Access to Health Care
- Special Access to medications, orphan drugs
- Think nationally – while dealing with provincial systems
- Funding
- Practice Guidelines – evidence-based review & development
- Patient Registries
- Blood Products/Blood Safety
- Unrelated Bone Marrow Donor Registry

- Genetic Therapy & Research (pre-implantation genetic diagnosis, studies with embryos)
- Research – e.g. relating to iron overload
- Centers of excellence
- Compassionate "person-oriented" approach
- Finding new resources rather than appropriating other groups' existing resources
- Information Sharing

We expanded on some of these topics:

LINKING GROUPS
- Websites referencing other groups (already in place for most groups)
- Brochures referencing other groups
- New informational pieces that reference all the groups
- Yearly joint conferences
- Mechanisms for sharing new information & international information
- Use Anemia Institute Review as an overall newsletter for anemia groups?
- Create simple summary of all the Canadian anemia patient groups to provide to physicians as a reference (include website & contact information)
- Create CDs for remote medical education

Action Step - Committee to work on increasing connections among groups: Caroline Laughlin (AAMAC), Salim Amlani (Thalassemia); Cathy Wiggins (Sickle Cell); Margery Konan (Anemia Institute)

Action - Caroline Laughlin will also work on planning the next joint Anemia Conference. Suggestion to schedule it around next year's Canadian Hematology Meeting, in Toronto, April 25-26.

ADVOCACY
- Educating politicians
- Message (as Dr. Chui said): "Anemia is a Canadian Disease!"

RESEARCH
- Collaborate to co-promote the respective research competitions relating to anemia
- Invest in training individuals who will become experts in the field; training fellowships

Action Step - Dr. Ric Woodman will go through the research program summaries from each group to look for opportunities to collaborate

SCREENING
- Newborn screening: add sickle cell/thalassemia screening to existing newborn screening programs
- Nationwide programs

Action Step - Committee (Dr. David Chui; Rosetta Cadogan; Dr. Ola Kassim; Ani Capua) will put a proposal together with the objective of achieving MCV category on all obstetrics prenatal forms. Will begin by gathering information; find rationale for best place/province to start.

PRACTICE GUIDELINES
- Access to appropriate standards of care

Margery Konan and Stefanie Polsinelli

CANADIAN BLOOD SERVICES

Donor Selection Criteria Working Group

My affiliation with the Foundation has permitted me to become a member with this new branch of the CBS. This group is known as the Donor Selection Criteria Working Group. I have been regularly attending their quarterly meetings since June 2000. This group meets on a quarterly basis at the Canadian Blood Services Headquarters in Ottawa. This committee consists of several medical, ethical and legal professionals that establish the guidelines supplying citizens with the safest possible blood and blood products. The last meeting that I attended was held on May 15, 2002.

There are several blood retrieval centers across Canada that fax inquiries to the CBS. Some of the questions posed refer to deferral of donors on certain medications or vaccines. Other topics discussed during meetings are: updating the List of Unacceptable Medications, Therapeutic blood donations (Hemachromatosis), and age limit for donors. There was also some talk about revising the donor questionnaire and having a self-administered questionnaire or asking all questions verbally. This will be studied and discussed further.

These meetings, held four times a year, provide an opportunity to become involved with questions about our blood system and actually have them answered at the source. It is a committee dedicated to improve quality of donors and thus effectively improving the blood supply for recipients.

Corrado Falcitelli

TORONTO HEMOGLOBINOPATHY RESEARCH PROGRAM: CURRENT AND UPCOMING STUDIES IN THALASSEMIA

Fifteen years have passed since the arrival of Dr. Nancy Olivieri at the Hospital for Sick Children in 1987. Since this time the Toronto Hemoglobino-pathy Research Program has expanded to become the largest in North America. The Program has overcome numerous challenges to reach its current position as a world-renowned centre in Thalassemia and Sickle Cell research. Currently, the Program has thirteen active trials. Eight of these trials focus specifically on medical progress in Thalassemia. In addition, several new trials are being considered and should begin in the new future. Below is a brief summary of all the current Thalassemia trials carried out by the Hemoglobinopathy Research Program at the Toronto General and Sick Children's Hospitals.

Lepore Study

Purpose - to determine if patients with b-thalassemia (intermedia or major) can be treated with oral medicine instead of with regular transfusions to increase total hemoglobin.

E-Thal. Treatment Study

Purpose - to determine if patients with E/b-thalassemia (intermedia or major) can be treated with oral medicine instead of with regular transfusions to increase total hemoglobin

E-Thal. Natural History Study

Purpose - to gather information on patients with Hemoglobin E/b-thalassemia in order to better understand the natural course of the disease

Porter I Study

Purpose - to examine how quickly children with thalassemia build up a very toxic form of iron, called non-transferrin-bound plasma iron (NTBPI), which is thought to cause organ damage

Porter II Study

Purpose - to examine the factors that control a very toxic form of iron, called non-transferrin-bound plasma iron (NTBPI) in Vitamin C replete b-thalassemia patients

Porter III Study

Purpose - to examine the factors that control a very toxic form of iron, called non-transferrin-bound plasma iron (NTBPI) in Vitamin C deplete b-thalassemia patients

Thal. Registry

Purpose - to gather information from patients with thalassemia and other related blood disorders into a centralized registry to help doctor's learn more about the disease and its complications

Iron Overload Study

Purpose - to identify if SCD patients handle transfusions and increasing iron levels differently than b-thalassemia patients (ie. are they experiencing fewer and/or less severe complications)

Should you have any questions regarding the Program, its current and/or upcoming trials please do not hesitate to contact the Program Research Manager, Laura Merson, at 416-340-4800 ext. 3979.

UPDATE FROM THE WINNIPEG CHAPTER

The Winnipeg Chapter of Thalassemia Foundation of Canada successfully completed its second fundraising 'Chocolate Drive' in November 2001. Donations were collected on behalf of the Thalassemia Foundation of Canada to help fund research funded by the foundation.

Back in June 2001, Josie Sirna visited Winnipeg where she spoke with members of the Winnipeg Chapter as well as nurses and care givers involved with Thalassemia to address related issues. The Winnipeg Chapter wishes to thank Josie Sirna for taking the time to visit us and providing us with information.

Chris Bennedsen accepting the donation cheque from Rose Palone

Thank you,
God Bless,
President
Winnipeg Chapter,
Thalassemia Foundation of Canada

NATIONAL LIAISON COMMITTEE (CANADIAN BLOOD SERVICE)

Canadian Blood Services (CBS) hosted the inaugural meeting in Ottawa on October 22 & 23, 2001 of the National Liaison Committee (NLC). The impetus for the establishment of the NLC was a desire to engage stakeholders in active and meaningful ways to ensure the ability to cope with future difficulties by working together. The NLC will ensure that Canadians, particularly those who have a direct interest in the blood system, contribute to decision making on issues affecting the blood system. The NLC is intended to identify issues, and offer ideas, opinions and concerns from across Canada. The NLC members discussed the key topics on day one and developed a presentation to be given to the CBS Board of Directors on day two. The following paper was presented to the Board and their C.E.O. Dr. Graham Sher.

What NLC is

- Potential partner to CBS to work towards providing a "better blood service"
- Bridge between "Stakeholders" and the Board
- Opportunity to harness a diverse range of stakeholders who are passionate about the blood system

What the Board can expect from the NLC

- Outside insights
- Raise issues that can/may influence policy
- Access a network of many community organizations and interests
- A framework for advocacy

The NLC will provide a different perspective to help work in policy, to provide a framework for advocacy, using the committee as a means of bringing forward varied interests in a meaningful way.

What the NLC expects of the Board

- Opportunity to provide input on issues important to stakeholders with respect to priorities and policies
- Opportunity to receive feedback in a timely manner

The committee recognizes that it will not have input on every issue however wishes to emphasize the need to provide input on issues of major importance. It welcomes ability to provide feedback on draft policies, annual plans and believes it can act as an advisory committee and a sounding board.

Major themes

- Communication (Managing perception, education, access to information, marketing)
- Recruitment and retention of donors (Access to subsets of donors e.g. youth and ethnic groups, plasma self-sufficiency)
- Utilization and alternatives
- Safety of the blood supply

The committee has many interests but sees a need to focus on meaningful contributions. Transparency is seen as a part of communications. There is emphasis on the importance of openness, trust, and ease of access to important information.

How the NLC plans to work

- We will meet quarterly: two face-to-face meetings and two teleconference meetings
- Agenda will be set participative between the Board and the NLC
- Meeting summary will be approved by the NLC participants and then posted on the web site together with the action plan
- The group will raise emerging issues
- The group will begin by focusing on a couple of key issues and priorities

A summary of meetings will be kept as a permanent record. Minutes of committee meetings should also be posted on the CBS web site at http://www.bloodservices.ca

Process

- How are we going to address these issues?
- Next meeting we will do a SWOT (strengths/weaknesses/opportunities/threats) analysis of communication, retention and recruitment
- The NLC would like the Board to provide background information related to these two topics

Short term issues

- Ensure maximum donor recognition in the "Roll Up Your Sleeves" campaign
- Ensure recipient stories are told
- Extend best practices Canada-wide
- Promote community ownership/partnership
- Think of targeting different communities and ethnic groups

- Communicate consistently with all stakeholders on safety and product issues
- Facilitate and improve ongoing one-on-one dialogue with CBS administration (example: feedback on the Blood Education Resource Group)

The Board questioned whether committee members represented themselves or their organizations/publics, and what role advocacy plays. The committee responded that at this early stage it was difficult to say. Members do speak for their nominating agencies or organizations and for themselves as well. The committee understands that part of its role is to take issues back to the organizations that are represented on the committee for further feedback. It was stated that there would be an attempt to balance advocacy with diverse views.

It was asked what was meant, in the NLC presentation, by the committee providing a framework for advocacy. The committee responded that it would act as an initial filter or sounding board for input on matters in which outside views were important. The NLC emphasized that it is important to recognize what is currently being done well and to share best practices across the country. It was also stated that CBS should improve ownership and partnership with communities, target different communities and groups to become donors, and communicate consistently with all stakeholders.

There was some discussion of the nature of the committee's intentions around advocacy. It was asked whether the committee intended to advocate for specific areas or was discussing advocacy in a general sense. The committee responded that advocacy was viewed as an important process. The committee would be used to make the views of the community known to the Board. There was some debate about whether the committee should present advice or recommendations to the Board as a consensus or whether minority views should be included. It was determined that the committee would debate and analyze issues and report on the results of its analysis, including reasoning and majority and minority views.

The committee stated that if it attempts to deal with all problems and views it might be seen as ineffective, hence its decision to look at specific things the Board can usefully act upon, based on building relationships and communication. The Board requested that the committee also reflect on ways in which the Board can improve the affordability of the blood system, one issue that had not yet been discussed. The committee agreed that this was an important priority that would not be overlooked. For example, the committee suggested that it could provide input on how to take greater advantage of the volunteer cadre.

The CBS Chair expressed his personal appreciation for the work of the committee and the appreciation of the Board. He expressed the belief that both the Board and the committee would be pleased with the results of this important work. After these comments, the meeting was officially adjourned. There was a subsequent teleconference meeting on January 30, 2002 and the details of which will be posted once all the National Liaison Committee members have approved the minutes of said NLC meeting. There will be an upcoming NLC meeting in Ottawa on April 15, 2002. A report, similar to the one that you have read, will follow.

Howard Leung

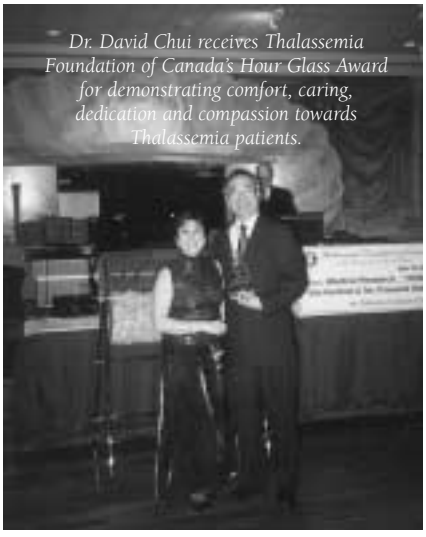
VALENTINE'S DINNER DANCE 2002

As it was billed by the president of the Foundation, the 13th Annual Valentine's Dinner Dance was a "night to remember". Held on Saturday February 16, the evening put the "fun" in fundraising.

Tenor Rosario D'Amico serenaded people as they ate their meal, which was a traditional, satisfying Italian dinner. Sam Ciccolini hosted the event, which was held at La Perla Banquet Hall in Vaughan. Dr. David Chui, of McMaster University, gave a compelling speech about the need for research funding, especially for future genetic testing.

The Volkswagen Beetle was won by Brian Sequeira of Toronto. Not able to attend the dance, Mr. Sequeira was called from the hall by a rep, allowing him to hear the enthusiastic congratulations of everyone there. A new addition to this year's event was a live auction, held by Vriesen Auctions. The biggest draws of the evening were a hockey stick autographed by the Toronto Maple Leafs, a framed and signed photo of Tiger Woods, and a Grandfather Clock.

The silent auction was very successful, with many items up for bidding. Thanks to the dinner tickets, raffle tickets, two auctions, and the car giveaway, the event raised approximately $30,000 for the Foundation.



Dr. David Chui receives Thalassemia Foundation of Canada's Hour Glass Award for demonstrating comfort, caring, dedication and compassion towards Thalassemia patients.

Once dinner was over, people danced to the music of DJ Innerphase. Thanks go out to everyone involved in the event, from the attendees to the workers at the hall and all the people who donated gifts. Special thanks go

out to Angela Polsinelli and the other members of the dance committee for all their hard work, without which the event could not have taken place.

Not pictured - the Appreciation Award went to Tony Genova for outstanding support and contributions to the Thalassemia Foundation of Canada and for always being ready to lend a hand. The Alex Georgakopoulos Memorial Award went to Kathy Netten for outstanding dedication and service in promoting the work of the Thalassemia Foundation of Canada.

Stefanie Polsinelli

The Gino Fortunato Memorial Hope Award went to Howard Leung for showing tremendous strength, courage and determination in the fight against Thalassemia.

Connie Bennedsen receives the Presidents Award for continued dedication and service in promoting the work of the Thalassemia Foundation of Canada.

The Heart Award went to Order Sons of Italy of Canada for displaying continued generosity and financial support.

Cheque presentation for research presented at the Valentine Dinner Dance 2002.

1ST ANNUAL CHILDREN'S CHRISTMAS PARTY 2001

Thalassemia Foundation of Canada hosted its first annual children's Christmas party on December 9, 2001. Many attendees participated in the party, making it a huge success. The party was held in the Black Wing of The Hospital for Sick Children.

Complete with a clown, balloons, and pizza, the party set a definite standard for future parties to come. The children were overjoyed by the sound of sleigh bells, signaling the arrival of none other than, Santa Claus. Jolly Old Saint Nicholas was decked out in his bright red attire, lined with white trim. And of course his cheeks were like cherries and his belly shook like a bowl full of Jell-O when he handed out a sack full of gifts to the children.

They say a picture is worth a thousand words, and that's exactly what was captured as the children crowded around Santa Claus. The children were also entertained by a clown performing a wide array of magic tricks, while they enjoyed a variety of cookies and snacks.

The first Christmas party was a fun event for all that attended and the first of its kind to include the younger children affected with Thalassemia. The event gave children and parents alike, a chance to get to know one another in a comfortable atmosphere.

Thanks to all the parents and volunteers who helped to make this event a success. We will look forward to seeing you there next year!

Angela Covato
blueseptember73@yahoo.com

CORRADO FALCITELLI'S CHARITY BIRTHDAY PARTY 2002

On Saturday, March 18, 2002, the fourth annual Birthday/ Fundraiser was held at Thorncrest Homes Association Clubhouse. Friends and family attended Corrado's 30th Birthday party and help raise money for a worthy cause. It was a successful event with music provided by DJ Hedonizm and time to catch up with old friends, meet new friends and raise money for the Thalassemia Foundation of Canada. Special thanks to those that helped decorate and prepare for the event. Hope to see you all next year.

ONTARIO CONFEDERATION OF SICILY - Gala Dinner Dance

On March 2nd 2002, the President of Thalassemia Foundation of Canada (Chris Bennedsen and Mrs. Bennedsen) were invited to attend the Gala Dinner Dance which was held at the Regency Banquet Centre.

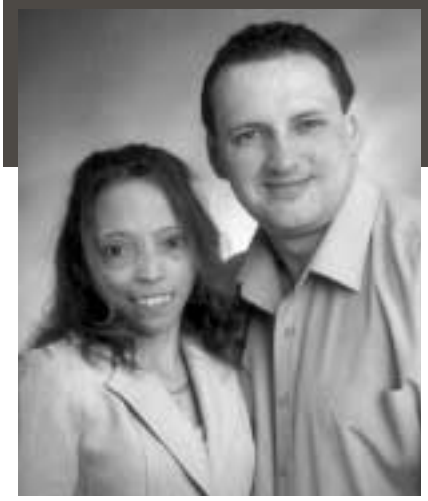
In attendance were many dignitaries who were honoured during the evening. The food was excellent and the music provided by Promises was great. Everyone present had a very enjoyable evening.

The highlight of the evening for us was the cheque presentation to Thalassemia Foundation of Canada which was presented by the President of Ontario Confederation of Sicily Cav. Angelo Balsamo.

Connie Bennedsen

UPCOMING EVENTS, FUNDRAISERS AND CONFERENCES

- Roma Fence Golf Tournament -July 24 2002
- Thalassemia Patients and Parents National Conference - October 05 2002
- Sons of Italy Dinner Dance - Villa Monaco, October 26 2002
- Guelph Chapters 9th Annual Fundraiser Dinner Dance - November 2, 2002
- 2nd Children's Christmas Party - December 2002
- For more details contact the Thalassemia Foundation of Canada.



Our congratulations to Rose and Leo on their engagement on June 22/02.

Warm congratulations to Josephine Sirna and Damiano Conte for celebrating their marriage on May 4th 2002. Thalassemia Foundation of Canada wishes Josie and Damiano a fruitful and prosperous life.

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