FROM THE DESK OF THE PRESIDENT

Many exciting things are happening to the Thalassemia Foundation of Canada that favours our crusade towards better patient care.

It has been a few months since our last newsletter and a few changes have occurred. I am proud to announce that elections were held recently and some new members were elected onto the Board of Directors this term. Congratulations to our new Board Trustees Bessie Calabria, Andre Oliveira and Frank Storino for joining our crusade; doubtless, they will bring a fresh outlook and new ideas to the Foundation. I sincerely thank and appreciate those members that have stepped down from the Board; they have dedicated much time and effort to the Thalassemia cause.

Our meetings are still being held every third Monday of each month and may be attended by patients, parents and friends of the Thalassemia community. Please feel free to come and voice your concerns and ask for help from our Foundation. We will try to help in any capacity that we can.

The Thalassemia Foundation has found a great ally in our fight for better health care for Thalassemia patients. The Anemia Institute, together with the Thalassemia Foundation of Canada, has dedicated funds towards the "Standards of Care" project. This was first conceived in the UK to implement a program specific to UK patients and their health care system and to introduce a protocol for other hematologists to follow when treating Thalassemia patients. In Canada, we have funded this pioneering project to be used for Canadian hematologists. This initiative will begin in the early spring and involves the communal expertise of many doctors across North America in order to come up with a protocol that is specific to Canadian patients and our Health Care system. We thank Durhane Wong-Rieger and the rest of her dedicated staff in helping the Thalassemia Foundation of Canada with this inaugural project. We shall keep all of you posted during the establishment of this pioneering project to ameliorate the health and care of Thalassemia patients across Canada.

Also on the funding front, we would like to thank and congratulate Dr. Volker Blank from the Lady Davis Institute at McGill University. The Medical Advisory Board, with the approval from the Board of Directors of the Thalassemia Foundation of Canada, has approved a two-year funding grant for his project entitled Balanced Gene Expression: Analysis of Regulatory Pathways. Congratulations again, Dr. Blank. We look forward to your updates on this crucial project for Thalassemia.

We have finished final touches on our new website. I would like to thank all those who participated in its design and construction. Please check updates at www.thalassemia.ca for the Swimming Pool Charity Car Wash, ROMA Fence Golf Tournament, Educational Conference and other exciting events.

I wish you and your families all the best and a very healthy and joyous summer.

Sincerest Regards,
Corrado Falcitelli, President

IN THIS ISSUE

TIF GENERAL MEETING AND ELECTION OF NEW TIF BOARD OF DIRECTORS

The biannual TIF General Meeting was held on January 7th, 2006 during the organization's conference in Dubai. The General Meeting is an open forum which is attended by many interested individuals, parents and patients from the global Thalassemia family, along with representatives of all Thalassemia associations from around the world who are members of TIF.

TIF Chairman, Mr. Panos Emgelzos, presented the activities and events of the Federation over the past two years - since the previous General Meeting in Palermo, Sicily in October 2003 - together with plans for activities for the next two years.

Chairman Emgelzos' Report included details on:

- Participation and organizing of international and national conferences and workshops
- Delegation visits to Albania, Bulgaria, Sri Lanka, Bangladesh, India and Pakistan, and plans of a delegation visit to Azerbaijan and Romania in 2006
- Participation in other educational events
- Support of the founding of national Thalassemia associations in Afghanistan, Bulgaria, Cambodia and Vietnam
- Development of TIF's educational material, including the addition of new publications and the translation of existing publications into further languages
- Data on the distribution of TIF's publications on a worldwide scale
- Updates on TIF's projects including: the MRI Project, the Educational Courses Project, the establishment of national Thalassemia associations and collaborating committees in "affected" countries of the world and the establishment of a Patients' Forum
- The Pan-European Blood Safety Allianceñaddressing the issue of safety and adequacy of blood and blood products in Europe
- Collaboration with international bodies, including the WHO, for joint activities planned for the next three years

Following the presentation of the Chairman's Report on the activities of the Federation, the Report was unanimously approved by participants at the General Meeting. The audited accounts for 2004, prepared by TIF Auditors PriceWaterHouseCoopers, were presented and unanimously approved.

The Chairman asked that the decision on when and where the next General Meeting would be held be taken by the Board during the next Board meeting. The participants of the General Meeting unanimously agreed to the Chairman's proposition.

The TIF General Meeting was attended by more than 350 members from 45 countries. Participation of voting members was 30 out of 42 in attendance. Fourteen new voting members, who were approved by majority through correspondence during the course of 2005 but also during the Board Meeting preceding the General Meeting, were all unanimously approved.

TIF voting members then elected a new Board of Directors, consisting of seven Thalassemia patients and seven non-patients. The nominees gave an introduction to themselves.

According to TIF's Constitution, 11 out of the total 14 members of the Board should be country-affiliated patients or non-patients; whereas the remaining three positions on the board should be filled by people who are non-country affiliated (and may be either patients or non-patients nominated for their work and contribution to Thalassemia on an international scale).

Immediately after the elections the newly appointed TIF Board held a brief meeting to elect officers to each of the positions on the Board. The decisions were made as follows:

Panos Englezos - (Cyprus) Chairman
Shobha Tuli - (India) President
Michael Michael - (UK) 1st Vice President
Dawn Adler - (USA) 2nd Vice President
Riyad Elbard - (Canada) Treasurer
Katrina Demetriou - (UK) Assistant Treasurer
George Constantinou - (UK) Board Member
Robert Ficarra - (USA) Board Member
Mouna Haraoui - (Lebanon) Board Member
Fatemeh Hashemi - (Iran) Board Member
Mohammed Imran - (Pakistan) Board Member
Christina Stephanidou - (Greece) Board Member
Ramli Mohd Yunus - (Malaysia) Board Member

During the course of the Dubai Conference, the TIF Board held its meeting to discuss current and future TIF projects and activities, and to approve financial reports for the fiscal year 2005 and to approve the proposed budget for 2006.

TIF board members also met with various delegates from national Thalassemia associations to discuss the particular concern of each country or association. These meetings offer an opportunity to learn more about every country's issues related to prevention, management of Thalassemia, iron chelation and challenges facing patients and parents in their struggle against Thalassemia.

The treatment and management of Thalassemia on a global scale has been advanced by the participation at TIF conferences and events and the close collaboration of international Thalassemia associations on TIF activities and projects. The sharing of ideas and willingness to assist each other has proven to be a benefit to all Thalassemia patients across the world.

Riyad Elbard - Treasurer, TIF
Vice-president, Thalassemia Foundation of Canada

BLOOD DONOR DRIVE INITIATIVE

Canadian Blood Services, Dell Canada Inc. and Yahoo! Canada Co. recently teamed to create an online music game that promoted blood donation among Canadian youth. The game, which featured a three-round interactive music trivia game, taught the importance of blood donation while allowing participants to have fun with music and win prizes from Dell Canada Inc. and Yahoo! Canada Co. The game could be played via the website www.dontmissabeat.ca.

Eighty-seven percent of young Canadians recently polled by Ipsos-Reid ranked blood donation as one of the ways to make a significant contribution to their community, which created further incentive for this education drive, which ran all through April and May. "Young Canadians are socially conscious and want to make a difference," said Steve Harding, Executive Director of Marketing and Communications for Canadian Blood Services, on the day of the game's launch. "Blood donation is often referred to as a 'rite of passage' for Canadians turning 17. It is a way for youth to express their individuality while still satisfying the desire to make a difference in society. Through just one blood donation, our unique and individual gift has the potential to save up to three lives, and make a direct and positive impact on your community."

When one hears of the statistics of blood donation, there is little wonder why donors are constantly sought. It takes about 50 donors to collect enough blood for the victim of a car accident, and it takes about 100 donors to collect enough blood for a liver transplant. Compounding the requirement problem is the fact that blood has a shelf life of only 42 days.

In other donor news, Canadian Blood Services, HÈma-QuÈbec and the Toronto Blue Jays celebrated World Blood Donor Day 2006 on June 14th with a baseball game dedicated to all blood donors. Four thousand donors and blood recipients were gifted with free tickets to watch the Blue Jays play against the Baltimore Orioles at the Rogers Centre in Toronto.

According to Lorna Tessier, the Director of Public Relations for Canadian Blood Services, the true purpose of the event was to thank donors for their dedication and commitment to saving lives and have the donors meet some of the grateful recipients; however, the event was also meant to raise awareness of the need for donors.

A flyer for the event offered some staggering statistics. The Roger Centre holds approximately fifty-thousand people, which means that:

- Canada could fill eleven stadiums with people who gave blood last year
- Every year, Canada must recruit two full stadiums of new donors to meet the the needs of patients
- An estimated seventeen million Canadians (340 stadiums full of people) have been touched by the need for blood during their lifetime

Canadians interested in becoming blood donors are encouraged to contact Canadian Blood Services at 1-888-2-DONATE for blood donor clinic information, eligibility information or to book an appointment.

Stefanie Polsinelli

THE HOSPITAL FOR SICK CHILDREN'S HEMOGLOBINOPATHY RESEARCH PROGRAM: CURRENT AND UPCOMING STUDIES IN THALASSEMIA

Dr. Melanie Kirby is the physician responsible for the Hemoglobinopathy Program at the Hospital for Sick Children; she joined the Hematology/Oncology program at the Hospital for Sick Children in early 2000. Dr. Kirby was the recipient of the Hour Glass Award from the Thalassemia Foundation of Canada in 1998.

Within our program at the Hospital for Sick Children we have four nurses: Anne Chun, the Thalassemia Coordinator, Marcia Palmer and Doris Baxter, both of whom are the Sickle Cell Coordinators and Manuela Merelles-Pulcini, the Thalassemia/Sickle Cell Research Coordinator.

We are currently following 791 patients in our haemoglobinopathy program; 597 of the children have severe Sickle Cell Syndrome, 194 children have Thalassemia (beta Thalassemia major, beta Thalassemia Intermedia, alpha Thalassemia major, E/beta Thalassemia, Hemoglobin EE Thalassemia or hemoglobin H disease) and 13 have severe congenital anemias.

The program currently has six active studies, three of which focus on Thalassemia. In addition, we have six new studies which are being considered and should begin in the near future. Below is a summary of the current and upcoming Thalassemia trials at the Hospital for Sick Children.

Porter The purpose of this study is to examine how quickly a very toxic form of iron, called non-transferrinbound plasma iron (or NTBPI), accumulates in the blood of transfused children during the first years of his or her life.

Thalassemia Registry To gather information from patients with Thalassemia and other related blood disorders into a centralized registry to help doctors learn more about the disease and its complications.

Iron Overload Study The purpose of this study is to examine patients with Sickle Cell Disease and beta Thalassemia major to see if their bodies handle iron accumulation from transfusions differently.

Novartis ICL2203 To provide expanded access of Exjade (a new oral chelator) to patients with congenital disorders of red blood cells and chronic iron overload from blood transfusions who cannot be treated with other locally approved iron chelators.

Health-Related Quality of Life in Patients Requiring Chronic Red Cell Transfusions: Developing a New Disease-Specific Measure. The purpose of this study is to develop a disease-specific quality of life measure for patients receiving chronic transfusions, focusing on children with beta Thalassemia major and adults with both Thalassemia and Myelodysplastic syndrome.

Should you have any questions regarding our program, current and/or upcoming studies, please do not hesitate to contact the program Clinical Research Nurse Coordinator, Manuela Merelles-Pulcini, at 416-813-5643.

Manuela Merelles-Pulcini

STEM CELL THERAPY UPDATE

Thalassemia affects three million people worldwide and according to an article in the American journal Nature Biotechnology (www.nature.com), there may be hope for a cure. As reported on the Italian news website, www.ansa.it, a "Trojan horse" stem-cell therapy process may be the key to halting the function of the Thalassemia gene.

Researchers at Cervello Hospital in Palermo, Italy, along with members of the Memorial Sloan-Kettering Cancer Center in New York, have created a new gene therapy for the disease. The process works by inserting a "Trojan horse" virus into the stem-cell's DNA to turn off the Thalassemia gene. The therapy has been successfully tested on mice, primates and laboratory-cultivated stem-cells; if all goes as the Italo-American team plans, it may just be a matter of months before human trials commence.

Stefanie Polsinelli

TIF 2006 CONFERENCE, DUBAI, UNITED ARAB EMIRATES

The 2006 TIF Conference was hosted at the Dubai World Trade Centre - one of the best conference facilities in the world - and was one of the most successful events for the organization. It is estimated that over 700 health professionals and almost 1000 patients and parents attended the conference.

As usual, both the scientific conference and the patients' and parents' conference were held jointly over four days, from January 7-10. Delegates had the opportunity to learn the latest developments on the treatment of Thalassemia, its related complications and future treatments. Lecture topics included: cardiac complications, endocrine, hepatic and liver disease, Thalassemia intermedia, Sickle Cell Disease, blood transfusion, blood safety, gene therapy, bone marrow transplantation and cord blood transplantation.

Interactive sessions on prevention and psychosocial aspects of Thalassemia were a priority of the conference program. An overwhelming number of participants from various countries - most particularly from regions of high Thalassemia incidents - attended the interactive discussions. These sessions were very successful in achieving their objectives of raising hope for parents and encouraging a positive outlook toward life among patients. Patients went away with a high level of confidence in self-management and determination of being in control of their own treatment.

Similarly interactive sessions for scientific discussion on patient cases were extremely useful and interesting. The wide range of expertise from various countries made it an exciting discussion on clinical management of Thalassemia. Presentations of data on patient survival and quality of life also provided encouraging results on improving both the quantity and quality of life for patients.

Iron chelation therapy remains the most important topic at any Thalassemia conference. Presentations on Exjade (ICL 670) indicated that the new oral chelator is well tolerated, with few cases of mild side effects. The drug is used once daily and is effective over a 24-hour period, with potential protection from non-transferrin-bound iron. The current evaluation studies are conducted in various countries across the world and include over 1000 participating patients.

On the other hand, evaluations of Deferiprone (L1) have been continuously and consistently showing that the drug is the most effective chelator in removing iron from the heart. Also, combination therapy of Deferiprone (L1) and Desferal remains to be very effective iron chelation therapy.

Unfortunately, all ceremonies were cancelled due to the state of mourning over the sad death of the Prime Minister of the United Arab Emirates, which occurred at the time of the conference. Because of this, the two TIF awards presented at every conference were handed out during a brief closing session. Mr. Mahesh Kotecha received the George Englezos award, which is presented to an individual for his or her outstanding contribution to the promotion of awareness and control of Thalassemia around the world. Mr. Andreas Ioannou accepted the Panos Englezos award on behalf of his late father, Dr. Panos Ioannou. This award is presented to a scientist for his or her exceptional contribution in the field of Thalassemia research.

The TIF bi-annual conference facilitates a forum for patients, parents and all delegates to interact amongst themselves and exchange ideas, knowledge and experience. Such events promote unity and collaborations among Thalassemia patients and Thalassemia associations around the globe. This will certainly enhance the availability of new drugs to all patients in all countries with the hope for the provision of optimal treatment for all patients. The Dubai conference will always be remembered as one of the most successful TIF events. It is a conference that brought together delegates from all parts of the world to join in the fight against Thalassemia.

Riyad Elbard

MEMBERSHIP ANNOUNCEMENT

Dear Friends,

We are hoping to increase our membership to assist in the fight against Thalassemia and continue the quality of care for Thalassemia patients. Please help us in finding a cure. Take a few minutes to fill out the enclosed membership card and mail it our new address. Membership costs $10 per year and provides you with the Foundation's newsletters. It also allows you to attend the Foundation's annual general meeting and have a say in the organization's actions. We thank you in advance for your support!

Angela Costa

THALASSEMIA FOUNDATION OF CANADA
VALENTINE'S DAY DANCE 2006

Our 17th Annual Valentine's Day Dance was a great success. This year's gala was held at Renaissance Parque Banquet Hall on February 11th, 2006. Everyone in attendance enjoyed a wonderful meal followed by fantastic live music by New Image Band. Thanks to a special Abba tribute performed by the group as well as a guest appearance by singer Carlo Coppola, guests were well entertained. A performance by dancers Jason and Kimberly from Violetta's Dance School was another wonderful treat.

Once again, we were lucky to have our Masters of Ceremonies, Michael Ciccolini and Andrea Trentadue, join us in conducting our evening. Many thanks go to Dr. Jacob Pendergrast, of the adult patient clinic at the Toronto General Hospital, for speaking at our event.

We had much representation and support from the Hospital for Sick Children, Canadian Blood Services, the Anemia Institute, and both Apotex and Novartis Pharmaceuticals.

With over 650 guests in attendance, the Foundation was able to present a cheque in the amount of $110,000 towards Thalassemia research and patient care. The organization would like to express its gratitude to all of the dance guests and corporate sponsors for continuing to support the initiatives of the Thalassemia Foundation of Canada.

The next Valentine's dance is scheduled for February 10th, 2007. Please feel free to contact me for further details at cmarra@romafence.com.

Christina Marra

ADULT PATIENT DINNER

A few months ago, a survey was distributed to all the adult Thalassemia patients at the Toronto General Hospital. The main purpose of the questionnaire was for the Thalassemia Foundation of Canada to get an understanding of the patients' views on the Foundation and how it represents and interacts with the patient community.

Some respondents feel that the Foundation - in the midst of trying to advocate for the patients and raise funds - has lost touch with them. In response to this, the Foundation decided to host more patient-related events and spearheaded the project with a dinner.

Held on March 11th at Acrobat Lounge in Toronto, the free buffet was open to each adult patient and a guest (any guests beyond that were asked to pay $25 each). The affair was kept simple, as the Foundation wanted to test patient response (to better plan future functions). Although flyers announcing the event were posted in the TGH clinic and emails were sent to individuals months before, attendance for the dinner was surprisingly low. (Guests included, just over thirty people came.) However, those who were able to attend enjoyed themselves immensely, as the evening gave them a chance to share food, drinks and laughs with people they might only see if their hospital visits happen to coincide. Many in attendance expressed interest in future events, and in fact, the Foundation is already working on plans for a second, even bigger function. It will take place in the fall, so stay tuned in the next few months for more details.

These events can only continue if a large enough number of patients take part in them. The Foundation has taken the survey results to heart and is trying to remedy the matter of its interaction with patients; now, it needs the patients to reciprocate. We have a vibrant, diverse Thalassemia community - let's celebrate it together!

Stefanie Polsinelli

THALASSEMIA FOUNDATION OF CANADA'S RESEARCH GRANT COMPETITION

Congratulations, Dr. Volker Blank!

Dr. Blank is this year's recipient of the Thalassemia Foundation of Canada's Research Grant; his research study is being funded for 2 years.

Dr. Blank received his undergraduate education, including a Masters, at the University of Konstanz in Germany; his PhD at the Institut Pasteur; and did post-doctoral training in Pharmacology at Stanford University. He also worked at the Department of Hematology at Harvard University for several years. Since 1999, he has been at McGill University in Montreal, where he is an Assistant Professor of Medicine and Project Director at the Lady Davis Institute.

His project, entitled "Balanced Globin Gene Expression: Analysis of Regulatory Pathways," focuses on red blood cells - also called erythrocytes - which give blood its red color. Red blood cells are required to carry oxygen from the lungs to other organs and tissues in the body. During their final maturation stages these cells produce large amounts of hemoglobin, the protein needed for their oxygen-carrying function. The coordinated expression of hemoglobin components is crucial for the normal functioning of red cell precursors to avoid the accumulation of excess globin chains, toxic heme biosynthesis intermediates and unbound iron. The primary defect in patients with Thalassemia is an imbalance between alpha and beta globin chain synthesis. Dr. Blank's recent experiments have uncovered that the NF-E2 protein is required for the induction of globin gene expression by heme. This is of interest: heme is considered a possible treatment option for people with thalassemia, as it has been shown to have a positive effect on globin synthesis. There is also evidence that signalling molecules, called MAP kinases, may play an important role in hemoglobin production. His research team will use a series of molecular approaches to investigate how MAP kinases modulate globin and heme synthesis via NF-E2. Dr. Blank hopes that this study will lead to further insights into the mechanisms of erythroid-specific gene regulation, opening up new avenues to manipulate globin expression - using, for example, drug- or gene-therapy based approaches - in patients with Thalassemia.

The Thalassemia Foundation of Canada congratulates Dr. Blank and wishes him continued success in his research endeavours.

Angela Covato

GRANT COMPETITION INFORMATION

The Thalassemia Foundation of Canada was founded almost 25 years ago by a group of patients, their relatives and friends coming together for support, encouragement and fundraising initiatives. Over the last decade, this group has grown and become instrumental in supporting patient care, research, and education directly related to the field of Thalassemia. One of the most productive initiatives has been the annual Research Grant Competition. Since 1995, the Thalassemia Foundation of Canada has awarded approximately $400,000 to support research, and offered another $150,000 for direct patient care.

The Thalassemia Foundation of Canada's Grant Research Competition supports basic, clinical, laboratory, and psycho-social research broadly related to Thalassemia. The Foundation also considers operating grant applications, applications to supplement partial funding from other agencies, or applications for seed money to support initial study on sound proposals.

The Research Fellowship is given to a young investigator under the mentorship of an established investigator, for those who have received their MD degree since 1997 or PhD degree since 2000 are the first priority of the Foundation's research support program. The Thalassemia Foundation encourages young faculty investigators to apply. In general, the amount funded for each grant is $30,000 to $40,000 per annum. In the case of fellowships, it is expected that most of the awarded sum will go towards the fellow's salary, with most direct costs of the research being covered by other sources. The research must be carried out in a recognized Canadian institution, and the primary investigator applicant must be a citizen or permanent resident of Canada.

The grant applications must be relevant to the mandate of the Thalassemia Foundation of Canada and receive scientific peer review by a five-member Medical Advisory Board, chaired by Douglas Templeton, Ph.D.,

M.D., Professor of Laboratory Medicine and Pathobiology at the University of Toronto.

A new initiative the Foundation is undertaking for this upcoming grant year is that it will be partnering with Canadian Institutes of Health Research, Small Health Organizations Partnership Program (SHOPP). The mandate of this program is to foster partnership opportunities with small health charities and not-for-profit organizations (i.e. the Thalassemia Foundation of Canada) with modest health research funding capacity by co-funding training and salary awards. The Thalassemia Foundation has identified the several areas of health research relevant to its mission and CIHR provides an internationally recognized peer-review process and administrative program support.

For more information on the Foundation's grant competition, please visit its website at www.thalassemia.ca.

Angela Covato, Coordinator,
Medical Advisory Board
acovato@thalassemia.ca

CONSULTANT APPOINTMENT ISSUES

There is a growing concern among health care providers regarding adult Thalassemia patients at the Toronto General Hospital not showing up for their specialist appointments (i.e. cardiology, ophthalmology, etc.). The consultants themselves have contacted the Thalassemia clinic regarding this issue. Many patients are choosing not to attend their appointments; often, they don't even have the courtesy to call and cancel or reschedule their visits. Because of this, some of the consultants are threatening to refuse seeing all Thalassemia patients. On behalf of the patients who routinely attend their appointments, the Thalassemia clinic is asking that you be kind enough to cancel or reschedule any appointments that you are unable to attend. If you cannot reach the consultant's office personally, call the Thalassemia clinic and someone there may be able to assist you. It is crucial that we as patients attend these appointments, as it is very difficult to find specialists who are familiar with Thalassemia and the effects it has on the body.

Marygrace Bancheri

BLOOD DONOR APPRECIATION

On June 14, 2006, a crowd of people that filled the Rogers Centre in Toronto cheered on blood donors - the wonderful individuals who have given the gift of life to others. On behalf of the Thalassemia Foundation of Canada and the entire Thalassemia community, I'd like to express my appreciation to Canadian Blood Services (CBS) and the Toronto Blue Jays for honouring Canada's blood donors.

CBS held this event on Wednesday June 14, 2006 because it is World Blood Donor Day - an occasion organized annually for 192 World Health Organization members and over 200 voluntary blood-donor organizations, to recognize the selfless act of blood, plasma, platelet and bone marrow donation. Giving the date even more significance is the fact that June 14th was the birthday of Lark Landsteiner, the Nobel Prize winner who discovered the ABO blood group system.

The act of blood donation is unique, and blood donors are special people. We should all salute these everyday heroes, who rarely get recognized for their selfless acts of kindness.

Angela Covato

World Blood Donor Day @ Blue Jays Game with Dr. Graham Sher CBS Chief Executive Officer

Network of Rare Blood Disorder Organizations (NRBDO)

COMPREHENSIVE CARE FOR RARE BLOOD DISORDERS TORONTO, FEBRUARY 3-5, 2006. BANK OF MONTREAL INSTITUTE FOR LEARNING

The Network of Rare Blood Disorders held its first conference on Comprehensive Care in Toronto on February 3-5, 2006. The conference was an impressive meeting which achieved resounding success. One hundred and fifty participants attended the conference, including thirty speakers from six countries (the U.S., the U.K., Sweden, Germany, Italy and Canada). The event was a remarkable gathering of patients, patient organizations, physicians, scientists, allied health care professionals, pharmaceutical companies, and representatives from Canada's blood system operators as well as representatives from provincial governments, who came to discuss the improvements needed for delivery of care for patients with rare blood disorders.

The conference was made possible by a Sector Development Grant from Health Canada's National Voluntary Health Organizations, and by unrestricted educational grants from ApoPharma, Baxter, Bayer, Canadian Blood Services, Clegene, Genzyme, Hema-Quebec, Novartis, Pharming, the University of Calgary and ZLB Behring.

The goals of the conference were to provide a forum to present existing national and international models of comprehensive health care for rare blood disorders (Hemophilia, primary immune deficiencies, hereditary Angioedema, Thalassemia, Sickle Cell Anemia, Aplastic Anemia and Myelodysplasia), and to develop original and feasible models to propose to provincial health authorities.

Conference sessions covered the following topics:

- Existing models of comprehensive care
- The challenge of self/family care in the context of rare blood disorders
- Transition from pediatric to adult care
- National patient registries as an essential element of comprehensive care and access to drug trials
- Collaboration among patients, physicians and among provinces
- Systems to ensure access to state-of the art diagnosis and therapies
- Proposed models of comprehensive care

Presentation on the Hemoglobinopathies:

It was certainly a great pleasure and most interesting to listen to presentations by two of the internationally renowned lead experts on Thalassemia. Dr. Paul Telfer from the Department of Haematology, Royal London Hospital, UK, made two presentations - the first entitled Iron Chelation Therapy and the second called The

Network of Comprehensive Care Centres to Treat Thalassemia and Sickle Cell Disease in the U.K. Dr. Allan Cohen, M.D., Chair, Department of Pediatrics, University of Pennsylvania School of Medicine, gave an informative talk on Professional Collaboration in the Care of People with Thalassemia.

The talk Topics Which Are Most Relevant to Our Current Situation of Care was presented by Dr. Isaac Odame, M.D., Chair of the Hemoglobinopathy Group of Ontario (HemGO), M.D., Associate Professor and Staff Hematologist/Oncologist, McMaster Children's Hospital. Dr. Odame spoke on two topics: The Prevention and Management of Hemoglobinopathies during the Scientific Session, and A Proposal for the Comprehensive Care of Hemoglobinopathies in Ontario, delivered during the concluding session of the conference.

Dr. Molly Warner, M.D., McGill University Health Centre, Montreal, shared the success of her experience while presenting Facilitating the Transition from Pediatric to Adult Care in Thalassemia, Sickle Cell Anemia and Hemophilia, which is an ongoing project in Montreal.

To give a patient's perspective, Josie Sirna prepared a presentation on The Challenges of Self/Family Care in the Treatment of Hemoglobinopathies. Mr. Howard Leung delivered the presentation on Josie's behalf, as she was not able to attend the conference. I was very pleased to be given the opportunity to make a presentation on The Challenges of the Transition from Pediatric to Adult Thalassemia Care in Toronto.

At the conclusion of the meeting the following motions were debated, voted on and adopted unanimously by all participants:

COMPREHENSIVE CARE

The Network of Rare Blood Disorder Organizations, collectively, and its member organizations, individually, will advocate with provincial/territorial governments for comprehensive care for rare blood disorders. The Network recommends that the following components, in principle, be considered essential to comprehensive care:

- Provincial designation
- National patient registries
- Self/family administration of therapeutics
- Patient, family and association involvement in care
- Education of patients, families and health care providers
- Standards of care and portability
- Decentralization through outreach
- Multi-disciplinary care
- Defined core services delivered by a comprehensive care team
- Program evaluation and accreditation
- National collaboration among health care professionals and patient organizations
- Post-marketing surveillance including blood-borne pathogen surveillance
- Collaborative research
- Flexibility in organization

CONTINUED SUPPORT FOR NETWORK

The Network of Rare Blood Disorder Organizations recommends that:

Health Canada/PHAC, CIHR and Provincial and Territorial Health Ministries continue to support the work of the Network of Rare Blood Disorder Organizations.

PATIENTS REGISTRIES

The Network of Rare Blood Disorder Organizations recommends that:

The Public Health Agency of Canada establish a national working group to coordinate and support the development of national data base registries, including quality of life measures, for the rare blood disorder disease groups including, but not limited to:

- Primary immune deficiency
- Hereditary angioedema
- Rare blood disorders
- Hemoglobinopathies
- Bone marrow disorders
- Porphyria
- Hemophilia/bleeding disorders
- Dr. Tom Bowen be mandated to represent the Network of Rare Blood Disorder Organizations for this initiative.

Official proceedings of the conference and speakers' presentations are available on the Thalassemia Foundation of Canada website (www.thalassemia.ca). Or, visit the Network of Rare Blood Disorder Organization website at http://www.hemophilia.ca/nrbdo/en/home.php.

Riyad Elbard

2005 NATIONAL ANEMIA CONFERENCE

Like people met for a like cause when patients and caregivers from Canada's numerous anemia associations met on September 24th and 25th for the 2005 National Anemia Conference. The event was organized by members of the Anemia Institute for Research and Education, Canadian Blood Services, the Aplastic Anemia and Myelodysplasia Association of Canada, The Canadian Sickle Cell Society, Fanconi Canada, the Sickle Cell Association of Ontario and the Thalassemia Foundation of Canada.

Held at the Novotel Toronto Centre in the core of the city and introduced by NDP leader Howard Hampton, the conference was a busy affair, with presentations and seminars held one after the other on the Saturday, followed by further presentations and forums on the Sunday. Due to low attendance by each of the patient groups involved, many of the seminars originally scheduled had to be cancelled or offered in one time slot only, meaning that there were sometimes limitations as to which seminars people could attend. When asked why they had not attended the conference, many Thalassemia patients said there was nothing new they could learn about their illness or the treatments for it. Although no announcements were made of miracle drugs or treatments, the conference was still a great refresher course (i.e. Do you really understand exactly what happens in your body when you are born with Thalassemia?). It was also a way to unite all the anemia groups; if nothing else the conference let you see that you could and should be grateful for your lot in life.

Guests invited to give talks at the conference came from as far away as England and the United States. Saturday morning's presentations included the following:

- Quality of Life and Chronic Anemia, given by Dawn Adler, a social worker from the Children's Hospital in Oakland
- Living with Anemia: Past, Present & Future, given by Dr. Blanche Alter, with the National Cancer Institute in Maryland
- Iron Chelation Therapy, given by Dr. Ian Quirt of the University Health Network in Toronto
- Bone Marrow Transplant and Stem Cell Research, given by Dr. Richard Wells, from Sunnybrook & Women's College Health Sciences Centre

The talks were informative and well-presented; the topics discussed pertained to all the illnesses, lending each guest speaker a rapt audience. Dr. Quirt's session about the status of iron chelators was the biggest draw for many Thalassemia patients. He mentioned that, thanks to a campaign by the drug company Novartis and support from anemia groups like the Thalassemia Foundation of Canada, approval for ICL670 - the most promising drug - has been fast-tracked. At last check, the drug should become available in September. Following all the presentations there was a panel discussion entitled Emerging Treatments and New Technologies Including Developments in Iron Chelation Therapy, Stem Cell Research and New Medications, with the above specialists as well as Dr. Yigal Dror, of the Hospital for Sick Children in Toronto.

After lunch, the various anemia groups broke off and attended seminars that dealt with needs specific to the different illnesses. This method of presentation worked out well except for when seminars were held concurrently. (This happened only once and it was due to an unavoidable lack of time.) Luckily, many people brought family members with them, enabling them to each attend a seminar. The seminars presented to Thalassemia patients were:

- Principles of Patient Self-Management: Healthy Living with Chronic Disease, given by Durhane Wong-Rieger, of the Anemia Institute for Research and Education
- Reproductive Choices and Family Planning, given by Cecile Loiselle (a family planning counselor)
- Transition from Pediatric to Adult Care, given by Dawn Adler
- Complementary Therapies, given by Aliya Kabani (a patient/student) and David Lescheid (a naturopathic doctor)
- Psychological Issues Facing Adult Thalassemia Patients, given by social worker Helen Antoniades and Dr. Brian Cho, both from the Toronto General Hospital
- Thalassemia Q & A Session, headed by Chris Sotirelis, of the United Kingdom Thalassemia Society (UKTS)

The first seminar, about patient self-management, was not only educational but it also offered the opportunity for patients to sign up for two initiatives put out by the Anemia Institute; the first, a survey about the impact of iron chelation on quality of life (the results of which may help open doors for oral

chelators so that patients will have further chelation options); the second, a leadership training course called Optimizing Life-Patient Self-Management. The second seminar, about family planning, was disappointing because the information given was not Thalassemia-specific; nothing was said regarding the troubles patients may face with fertility, iron chelation during pregnancy, or child care after birth. The third seminar about the transition from pediatric to adult care was well-done, but not very useful to the mainly adult audience that had already made the move. The last two presentations were pertinent to patient needs now - especially the Q & A session, which was mainly a discussion of the UK Thalassemia clinic and illustrated just how many improvements can be made to the clinics and patient care in Canada.

Sunday's talks were just as interesting as those on the previous day, but some of them were geared to specific anemias. The presentations offered were:

- Gene Therapy, given by Dr. Hans Messner of the University Health Network in Toronto
- Blood and Transfusion in Canada, given by Dr. Heather Hume of Canadian Blood Services
- The Myelodysplasia Program at Sunnybrook and Women's College Health Sciences Centre, given by Dr. Wells
- Health Canada's Drug Approval Process, given by Supriya Sharma of Health Canada
- Iron Chelation and Quality of Life Research, given by Durhane Wong-Rieger
- Panel Discussion: Taking Action to Maximize Health for Chronic Anemia, with Dr. Messner, Dr. Hume, Dr. Wells, Dr. John Waye (of McMaster University), Dr. Jacob Pendergrast (a hematology fellow at TGH), Dr. Robert Klaassen (of the Children's Hospital of Eastern Ontario) and Dotty Nicholas (of the Sickle Cell Association of Ontario)
- Open Forum and Call to Action: Newborn Screening, Standards of Care, Clinic Status, Quality of Life, headed by Durhane Wong-Rieger

There are two things that need to be said about Sunday's presentations. First, the panel discussion was supremely helpful but far too short (due to the fact that some of the morning's talks ran long); second, the open forum would have been much more useful if the panel members were available afterwards to answer to questions and concerns put forth by audience members.

After all is said and done, the conference was a success and those who attended eagerly await the next one (especially considering that surveys were given out at the end of the weekend, ensuring that any glitches in the program will be ironed out before then). However, the success of events like this one rises exponentially with attendance; the more interest shown by patients and caregivers, the more information which can be provided to them by the various associations. For those who were unable to attend this year's event, a detailed description of the talks will be offered on the Anemia Institute web site (www.anemiainstitute.org) as well as the web site for the Thalassemia Foundation of Canada (www.thalassemia.ca). A thank you goes out to everyone who put the conference together.

Stefanie Polsinelli

CHRISTMAS GIFT FUND

The Christmas Committee would like to take this opportunity to extend our appreciation and warmest thanks to everyone who contributed in making Christmas 2005 a magical and memorable holiday for our patients at the Hospital for Sick Children. Giving these children a moment to forget their pain and replacing it with a smile at Christmas is always our goal. The continued support of all of our friends and families is crucial in our fight against Thalassemia.

We have already launched our 2006 campaign and welcome any suggestions and input that you may have. You are welcome to contact us at: jewely_00@hotmail.com. We hope that all our patients have a healthy and happy summer!

With our warmest and heartfelt good wishes, the Christmas Committee: Julie Vizza, Lina Pedota, Anna Maiorano and Anna Vizza.

STANDARDS OF CARE FOR THALASSEMIA PATIENTS IN CANADA

Over the past two decades, medical advances and the modern clinical treatment of Thalassemia have vastly improved the health of Thalassemia patients and extended their life expectancy. However, in recent years, access to optimal treatment for Thalassemia patients and delivery of care have been facing serious challenges due to hemoglobinopathy programs not being a priority for health institutions and governments.

Compared to other countries, care in Canada continues to be defined by local expertise and the limits of the institutional support. In Toronto, specifically, the provision of care for adult Thalassemia patients has been deteriorating drastically over the past 6 years. The Thalassemia Foundation of Canada has been concentrating on a continuous effort of exhausting processes in search of a solution to this ongoing problem. The Foundation believes that Thalassemia care programs in Canada must be established based on similar models of care for Thalassemia that exist in other countries such as the United Kingdom, the United States, and Italy. The successes of such comprehensive care programs - increased life expectancy and improved quality of life - serve as optimal models for care for adults and children living with this disorder.

There is a clear need for Standards of Care for Thalassemia patients in Canada to promote and ensure optimal care for patients and families living with Thalassemia. While there have been major advances in diagnosis, transfusion therapy, chelation therapy and disease management, patients in Canada do not necessarily receive the best possible treatment and care. The purpose of the proposed document (entitled Standards of Care for Thalassemia Patients in Canada) is to bring together the most up-to-date knowledge in Thalassemia prevention, diagnosis, treatment and care and to formulate these into national practice guidelines and resource requirements. The Standards will serve as the basis for the development of centers of excellence and care programs at non-specialty sites; as practice guidelines for the provision of treatment and care; as resources for the training of healthcare professionals; as justifications for resource allocations; and as benchmarks for the evaluation of program delivery and outcomes. The document will provide a national standard of care that will help to ensure consistency and continuity of care across provinces and institutions treating patients with Thalassemia. These standards will also serve to promote and develop similar standards of care for other hemoglobinopathies, including Sickle Cell Disease and Myelodysplasia.

A working group has been formed of physicians representing the major adult and pediatric Thalassemia programs across Canada - namely Toronto, Ottawa, Montreal, and Vancouver. Other members of the advisory will include patient representatives (adult patients and parents) from the Thalassemia community, nurses, social workers, and other allied professionals. In addition, an external expert panel of key Thalassemia clinicians from the United Kingdom, the United States and other countries will serve as reviewers. The topics that will be covered are:

- Model of Care
- Red Cell Transfusion
- Monitoring and Treatment of Iron Overload
- Psycho-social Issues
- Bone Marrow Transplantation
- Splenectomy
- Transition from Pediatric Care to Management of Adults
- Cardiac Complications
- Endocrine Complications
- Liver Complications
- Bone Problems
- Fertility and Pregnancy
- Genetic Counseling

The project will be supervised by the Anemia Institute for Research & Education with the collaboration of the Thalassemia Foundation of Canada. The project will be carried out in several steps. The starting points are the UK Standards of Care (2005), other published guidelines from the Thalassemia International Foundation and "working" standards in use at various clinics in the United States and other countries. Dr. Durhane Wong-Rieger, President and CEO of the Anemia Institute for Research & Education, presented the project proposal at the Canadian Hematology Society Annual Meeting on March 30, 2006. Her presentation was fitting because this year's meeting was focused around the treatment of hemoglobinopathies in Canada. The initiative and project proposal has received wide support among the hematology communities across Canada.

It is anticipated that the project will be completed by June 1, 2007. It will be primarily funded by the Thalassemia Foundation of Canada and supported with generous contributions from Novartis, ApoPharma,

and KPMG Inc. I would like to thank the UKTS and its Executive Committee for their continued support and for allowing their Standards of Care to be used as a model for Canadian Thalassemia patients. I would like to conclude by expressing sincere appreciation to the Anemia Institute for Research & Education for partnering with the Thalassemia Foundation of Canada on this highly important project. On behalf of the Foundation I thank all the physicians, health care professionals, parents, patients and all other participants who will contribute to the success of developing the Standards of Care for Thalassemia Patients in Canada.

Riyad Elbard

2006 MERCEDES SMART WINNER

Congratulations to our 2006 Car Raffle Grand Prize winner: Dan Jeffries - ticket #0210 - of Toronto, seen in picture with President Corrado Falcitelli and the Executive Board Members of the Thalassemia Foundation of Canada. I would like to thank all who participated and made this event a success. The winning ticket was purchased at Bass Pro Shops at the Vaughan Mills Mall; I would like to thank Dave Jessop, Bass Pro Shops Manager, and his staff for all their support in this charitable endeavor.

Special appreciation to all corporate sponsors who helped to sell tickets at their locations including:

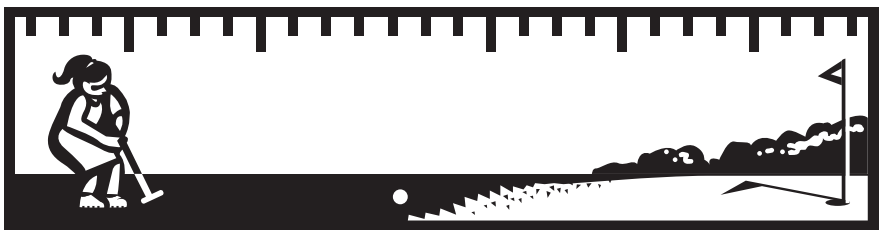
- Apotex Inc.
- Bass Pro Shops (Vaughan Mills Mall)
- CHIN International Radio TV (622 College Street)
- Li'ly Appetizer Bar (656 College Street)
- Norwest Precision Ltd. (460 Signet Drive)
- Poolside Tanning Spa (3250 Dufferin Street and 2943 Major MacKenzie Dr.)
- Roma Fence (24 Cadetta Road)
- Swimming Pool Restaurant (3200 Dufferin Street)
- TD Bank (4499 Hwy #7)

Many thanks to everyone involved in our fundraising efforts. This was a successful endeavor for the Foundation; I am pleased to say that we sold over 4300 tickets for the SMART Car draw. Good Luck next year!

Corrado Falcitelli

THE ROMA FENCE 10TH ANNUAL GOLF TOURNAMENT

The Roma Fence 10th Annual Golf Tournament will be held on Thursday September 21st, 2006. Details will be posted on www.thalassemia.ca or please contact Christina Marra at 416-798-7566 for more information.



BLOOD CHARACTER ANALYSIS "WHAT'S YOUR TYPE?"

Type O

Roughly 38% of the population is O+ and 6% O-.

Traits - Confident and strong-willed, proud, dedicated, sociable, energetic, extroverted, frank, realist, showy, flighty, generalist, positive, independent, and are risk-takers. Dislike taking orders, insecure, stubborn and self-centered. Make friends easily and go with flow and grasp opportunity. Quick to start a project or chase an idea. Good at organizing activities. May have short attention span, and express strong emotions. May quickly take opposite views that are deep but not always durable. Classic entrepreneurs and movers and shakers.

Express their emotions but can be swayed by other blood types. Have an intrinsic elegance. Sociable and showy. May be good at adapting to circumstances. Words come easily to them. Not self conscious and will frankly reveal inner feelings. Ambitious, but may have issues with detail.

Type A

Roughly 34% of the population is A+ and 6% A-.

Traits - Obedient, careful, sympathetic, self-sacrificing, polite, honest, loyal, emotional, introverted and nervous. Reserved calm and even tempered. Sensitive to public opinion. May be introverted, shy and nervous or ill at ease with others. May be pessimistic. Value relationships and are loyal. Hesitant to change. Nature lovers and dislike crowds - need a private place or secret hideaway. Can be indecisive. Good at team work and obey rules.

Type B

Roughly 9% of the population is B+ and 2% B-.

Traits - Cheerful, optimistic, active, sensitive, kind, forgetful, unorganized, noisy, egocentric, energetic and have the drive to reach towards goals. May be workaholics. Not the best team players and are individualistic. Do things at one's own pace. Strong personality and adventurous. Like to get one's own way. Are sociable and enjoy entertaining.

Type AB

Roughly 4% of the population is AB+ and 1% AB-.

Traits - Social, easy-going, sympathetic, diplomatic, outgoing, laid-back, creative, unpredictable, artistic, flexible, and moody.†Blend of opposites. Shy with some and bold with some. Introvert and extrovert. Unpredictable and may seem to have calm exterior. Strong creative strain. Good at spotting problems and skirting them. Like city environment. Get bored easily. Everything they do is compelling. Never take things for granted. Appear mysterious. Contribute harmoniously to society.

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Thalassemia Foundation of Canada
338 Falstaff Ave., North York, ON M6L 3E7

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New Address _____

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Contact Us

Thalassemia Foundation of Canada

338 Falstaff Ave. North York, ON M6L 3E7

Phone: (416) 242-8425 Fax: (416) 425-6354

Email: info@thalassemia.ca

Website: http://www.thalassemia.ca

Editors: Stefanie Polsinelli - s_polsinelli@yahoo.ca

Angela Covato - acovato@thalassemia.ca

Special thanks to all who contributed articles
and pictures for this newsletter.