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CHAPTERS

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FROM THE DESK OF THE PRESIDENT

It has been 6 short months since our last newsletter in the summer and several events and conferences have happened in the mean time.

The new Executive Board has settled in nicely to their new positions and has rearranged to take on new tasks and improve on present tasks. We have also welcomed a few other non Board members to the roster that have been invaluable in their input and background help with the Foundation. I openly invite anyone interested in helping our Foundation to come out to our office on the 3rd Monday of every month at 7:30pm and participate in our open Board meetings, and perhaps also volunteer few hours a week to the Foundation and its numerous activities that require much help. If you are interested, please feel to contact me or any other Board member (corrado@thalassemia.ca). We are located in Suite 204

at 338 Falstaff Ave. just off the 401 at Keele Street. We openly welcome patients, parents and affiliates to share your concerns and help us better lives of patients, which of course, is our primary mandate.

Our patient conference held at Novotel Downtown on September 24th and 25th hosted by the Anemia Institute was very successful. It attracted physicians from around the globe and patients and parents from across Canada. Thalassemia patients and parents attended the conference free of charge, thanks to sponsorship efforts by the Thalassemia Foundation of Canada and the Anemia Institute. A great many thanks go out to Dr. Durhane Wong-Rieger and associates for spear-heading the conference and to the Thalassemia Foundation of Canada volunteers that made this event possible. The Foundation



looks forward to many more joint ventures with the Anemia Institute, who have been the cohesive force behind many health care initiatives for Thalassemia patient care.

I am proud to announce the launch of our revamped website www.thalassemia.ca where information on our Foundation can be found and also events and initiatives that we are presently planning. Please email us with any suggestions and/ or posting you would like us to place on the website.

This time of year usually marks the beginning of our annual car raffle, I am proud to introduce the 2006 Mercedes SMART Car as the Grand Prize in the raffle draw. More information can be found in our newsletter.

In closing the 2005 year, I would sincerely like to thank the Thalassemia Foundation of Canada's Executive Board and associates for their dedication, loyalty and selflessness in helping a great cause. I wish all of you and your families a safe and healthy holiday season. May the New Year bring us closer to our goals.

Sincerely, Corrado Falcitelli, President



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THALASSEMIA INTERNATIONAL FEDERATION (TIF)

TIF's next big event, the bi-annual parents and patients conference, will be hosted in Dubai, United Arab Emirates at the Dubai World Trade Centre in Dubai on January 7th -10th 2006. The joint event of the 10th International Conference on Thalassemia and Haemoglobinopathies, and the 12th International TIF Patients and Parents Conference promises an exciting programme.

Hosting a major event such as the TIF 2006 Conference in the Middle East will promote more improvements of treatment for thalassemia patients in countries of the region and will help bring the level of care to optimal standards. In this developing part of the world which has a high incident rate of thalassemia the treatment of the disease has improved tremendously over the last 10 years, however more needs to be done, specialty in areas of screening and prevention programmes, awareness, patient's education on the disease and patient integration into society.

TIF has evolved from a small group of nation members from western countries to an organization with members and representatives from various

countries across the globe. During the course of the Dubai TIF 2006 Conference, TIF will hold its bi-annual General Members Meeting followed by elections of the new Board of Directors. Every four years TIF Voting Member Nations will choose 14 nominees to become the next TIF Board of Directors, which must consist of 7 thalassemia patients and 7 non-patients. This democratic exercise has become a competitive challenge as many Voting Member Nations are enthusiastic to become part of TIF's Board of Directors to share ideas and provide leadership on improving health care for thalassemia patient's world wide.

The rapid expansion in TIF's membership and representation brought major increase in expectations and demands on TIF by its member countries and its affiliated national thalassemia associations. As a global organization TIF has become a world recognized authority on Thalassemia and has developed official relation with WHOM and regional collaboration networks with many thalassemia associations and other international health care organizations →

SIX-YEAR-OLD RAISES MONEY FOR THALASSEMIA RESEARCH

On Sunday Oct 2, 2005, six-year-old Cassandra Malandrino held a fundraiser at Papp's Restaurant in Pickering to raise money for thalassemia research. Family and friends gathered to participate in the event, which included a dinner buffet, music, and door prizes. The children had the most fun with their own piñata and chocolate fountain.

All proceeds from the event were donated to the Thalassemia Foundation of Canada. Cassandra presented Corrado Falcitelli, President of the Thalassemia Foundation of Canada, with a cheque for \$1555.00. Cassandra wishes to thank all those who attended and Papp's Restaurant for making this event such a big success.



in the world. TIF has recently joined with other blood user groups to form the Pan-European Blood Safety Alliance. The Alliance's mission is to increase safety of blood and blood products for all users and consumer. TIF participation and contributions to various conferences on Thalassemia and events related to thalassemia world wide is an ongoing part of TIF's main activities.

TIF continues to provide very helpful publications and educational material on thalassemia and its complications. These publications are translated to various languages and are directed to patients, parents, health care providers, and health authorities. TIF educational centre in Nicosia, Cyprus organizes two workshops every year, the first on laboratory aspects held in May of every year. The second workshop is usually held in November with focus on the Clinical Management of Thalassemia. The workshops are designed to share the knowledge of world renowned experts on thalassemia and its complications with haematologists and physicians treating thalassemia patients from developing nations.

Delegation visits organized by TIF remain to be most effective in bringing better treatments to Thalassemia patients in countries where treatment is minimal or little is known about thalassemia. TIF collaboration with local associations, WHO, and health authorities in various countries has realized success in maintaining steady progress in the improvement of treatment of thalassemia patients in the developing world.

Medical advancements and developments in the treatment of thalassemia are the main factors in

increasing the survival rate of Thalassemia patients. The success of TIF in leading the promotion of optimal treatment for thalassemia patients, and promoting awareness of the disease, and educating parents and patients on better treatment has contributed to the survival of many patients across the world. With the success new challenges has emerged and has become more evident. The challenges today facing doctors, patients, and institutions are to determine how to deliver the same quality of care for adult thalassemia patients in an adult setting with the same standards of care as it has been delivered to children with thalassemia over the years while maintaining the same success rate of patient's survival.

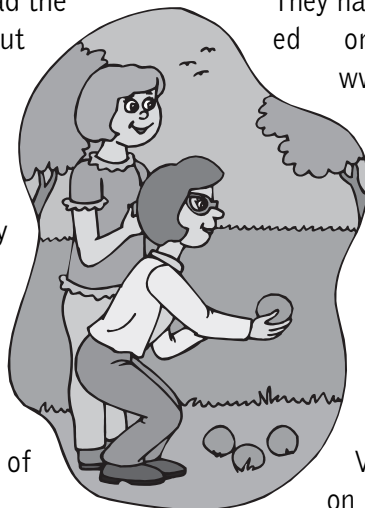
Extensive research by pharmaceutical companies interested in bringing better care to thalassemia patients and improvement to quality of life of the patients brings us to a new era, the era of oral iron chelation. The approval of Exjade (ICL 670) in the United States, Europe and many other countries to follow, and Deferiprone (L1) being licensed in Europe and various parts of the world provides a better outlook at a more promising future for thalassemia patients. These new options raise new challenges. The first challenge is to make all options readily available to all patients across the world. The second challenge is to educate patients on treatment options available and to insure that an informed decision is made by the patient or parent.

Riyad Elbard
Treasurer, Thalassemia International Federation
Vice-president, Thalassemia Foundation of Canada

LOCAL 506 BOCCE BALL TOURNAMENT

On August 26, 2005 I had the pleasure to be invited out to Ambercroft Labourers' 506 Training Centre located at 1600 Major Mackenzie Drive East in Richmond Hill for their annual Charity Bocce Tournament.

I was introduced by one of the organizers, Isabella Costanzo, who dedicated this year's proceeds to the Thalassemia Foundation of Canada.



They have over 300 photos posted on our website at www.506tc.org click on the picture and again on the very last line which reads "Pictures of the bocce ball tournament click here."

In total \$10,000.00 was raised on that day and the cheque presentation will occur at the Valentine's Dinner/ Dance on February 11, 2006.



Mercedes SMART Raffle 2006



The draw will be held at our 17th Annual Valentine's Dinner/ Dance on Saturday, February 11, 2006. The Valentine's event will be held at The Renaissance Parque Banquet & Convention Centre located at 2800 Hwy #7 West, Concord. (East of Jane). The cost of the full dinner and deluxe open bar is \$100 per person with a partial tax receipt issued. The winner of the SMART car will be announced at the Valentine's Dinner/ Dance. If the winner is not in attendance, they will be contacted by our Foundation.

The time is fast approaching for our Annual Car Raffle. Our 2006 Mercedes SMART has just been delivered. The details are similar to last year. Only 7500 numbered tickets will be sold at \$10 each. The Grand Prize winner will receive a Brand New 2006 Mercedes SMART.

For further information or to order tickets for the Mercedes SMART car raffle or the 17th Annual Valentine's Dinner/ Dance contact:

Corrado: corrado@thalassemia.ca
Raffle Tickets will be available and the car can be viewed at *The Swimming Pool*, 3200 Dufferin St. 416- 782- SWIM (7946)



Frank Riggio Ticket #6709. Winner of the 2005 MINI Cooper Raffle next to Board members of the *Thalassemia Foundation of Canada*.

SURVEY RESULTS

In June, I approached the Thalassemia Foundation Board with an idea to survey the transfused thalassemia patients at TGH. The intention of the survey would be to find out what patients' views on the Foundation are and what would encourage them to get involved. The Board fully supported this idea, and the survey was carried out over the summer.

In November, I presented to results of the survey to the Board. While patients recognise and appreciate the work the Foundation does in fundraising and patient advocacy, there were some clear themes in terms of concerns for patients.

The first is a lack of information shared with the patients about what the Foundation does, what it can offer patients, and its events. The second was a feeling that it is a closed group with a set agenda and a set way of doing things, and new people and ideas are not welcome. Patients also felt that the ethnic diversity of the patient population is not reflected in the Board members and the Foundation activities.

Patients voiced that they would like to hear more about what the Foundation is doing and how they can be involved. They would like more outreach and com-

munication from the members of the Foundation. They suggested that they would like to have small and casual social events, as a chance to connect with other patients and families.

The Thalassemia Foundation Board listened to and heard the concerns reflected in the survey. They will consider how they can better work with the patients and meet their needs. They intend to plan a small social event for early in the New Year. Also, anyone who provided his or her mailing address as part of the survey will receive the newsletter in the mail. If you did not provide your address and wish to receive the newsletter, please contact Silvia Livia at 416-242-THAL (8425) or Silvia@thalassemia.ca.

This is an opportunity for both the Thalassemia Foundation and thalassemia patients to connect with and work with each other. The Foundation wants patients to know that it is open to suggestions and new ideas. Its members hope patients will take this opportunity to become more involved, as its potential to work in the interests of all thalassemia patients can only be realised with increased patient input and involvement.

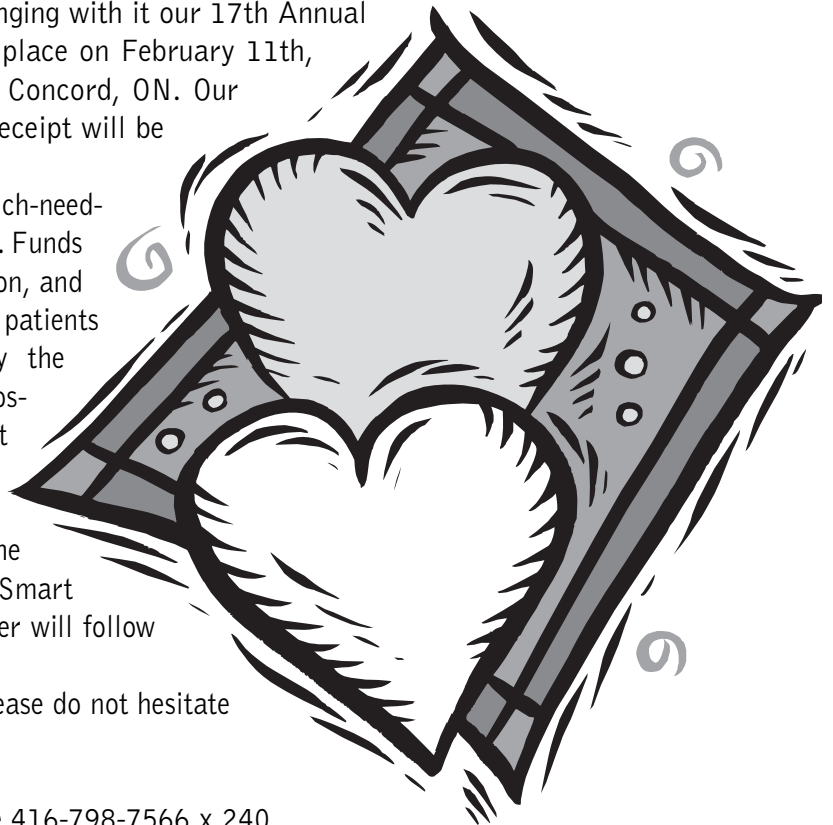
VALENTINE'S 2006

Valentine's Day is just around the corner, bringing with it our 17th Annual Valentine's Dinner/Dance; this year taking place on February 11th, 2006 at Renaissance Parque Banquet Hall, in Concord, ON. Our 2006 ticket price is \$100.00 and a partial tax receipt will be issued to you.

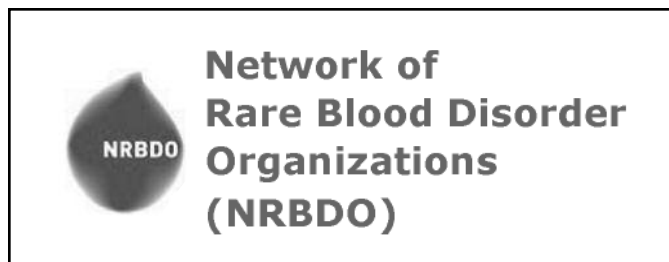
Our annual Valentine's Dance assists in raising much-needed funds for the Thalassemia Foundation Of Canada. Funds that are completely dedicated to research, education, and the providing of necessary medical equipment for patients suffering from Thalassemia. Funds collected by the Thalassemia Foundation of Canada have made it possible to bestow \$100,000.00 in Research Grants last year in the fields of Hemoglobinopathies and the eventual eradication of Thalassemia.

This year's venue includes a silent auction and the announcement of the winner of the 2006 Mercedes Smart Car. Cocktails will be served at 6:30 p.m. and dinner will follow at 7:30 p.m.

If you have any questions regarding this event, please do not hesitate to contact me.



Christina Marra: cmarra@romafence.com / Office 416-798-7566 x 240



The Network was established in April 2004, under the leadership and guidance of the Canadian Hemophilia Society and is funded by a Sector Development Grant from Health Canada's National Voluntary Health Organizations to create and coordinate a network of rare blood disorder organizations.

The purpose of the project is to create an active network of key volunteers and staff from within the following blood disorder groups: the Canadian Hemophilia Society, the Canadian Hereditary Angioedema Society (CHAES), the Canadian Immunodeficiencies Patient Organization (CIPO), the Thalassemia Foundation of Canada, the Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC), the Neutropenia Support Association Inc. and the Canadian Organization for Rare Disorders (CORD).

The goal is to raise the level of awareness and knowledge of the patient groups' roles in the following key issues: the importance of patient registries, the advantages of specialized care centres for complex, rare disorders, the tracking of blood and blood products to permit inventory management and effective recall and notification procedures, the need for active adverse reaction reporting and post-marketing surveillance of therapies used to treat these disorders and others, as determined by the needs of the groups.

Also it is the networks objective to facilitate the development of policies on the four key issues within each of the blood disorder groups. This objective will address the priority of building capacity within organizations in this sector to develop policies on the key issues identified.

Three meetings and monthly teleconferences since June 2004 have focused on the need for the creation of comprehensive care centres for these rare blood disorders on the model of the 24 hemophilia comprehensive care centres across Canada. Another issue that has emerged is the need for orphan drug legislation to facilitate access to treatments for rare disorders in Canada. Currently, pharmaceutical companies hesitate to go through the onerous drug approval process for drugs if the market is considered too small.

The first meeting allowed the Network to create a grid to measure where each group stands in relation to these key issues: the state of comprehensive care centres for each condition, the existence of treatment guidelines, the organizations' links to a Medical and Scientific Committee and the existence of a national patient registry.

The network is well into its second year and has been successful on receiving a second funding grant for 2005-2006. Members of the group intend to maintain the links created after the end of the initial project in March 2005.

The current focus of the network groups is sharing successful models that have been developed to deal with the above issues from a patient group perspective. This need will be discussed during the upcoming conference on Comprehensive Care for Rare Blood Disorders to be held in Toronto, at Bank of Montreal Institute for Learning on Feb 3-5, 2006.

For more info on The Network of Rare Blood Disorder Organizations please visit Thalassemia Foundation website or Canadian Hemophilia Society website or the following link:

<http://www.hemophilia.ca/nrbdo/en/index.php>

Comprehensive Care for Rare Blood Disorders
Toronto, February 3-5, 2006.
Bank of Montreal Institute for Learning

The Network of Rare Blood Disorder Organizations, in collaboration with the Canadian Hemophilia Society, will be holding a conference on Comprehensive Care for Rare Blood Disorders in Toronto, at Bank of Montreal Institute for Learning on Feb 3-5, 2006.

The conference goals are 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 currently planned are:

- * 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

ANNUAL MEETING

The annual general meeting of the Thalassemia Foundation of Canada will be held on Monday, April 24th, 2006 at 7:30 pm. We are located in Suite 204 at 338 Falstaff Ave. just off highway 401 at Keele Street. If you are a member, you will receive a mail out before the meeting. If you are not a member, you are welcome to join us as a guest in order to receive information about the Foundation's fundraising efforts, education efforts, actions and successes over the past year. For more information, please visit our website at www.thalassemia.ca.



* Proposed models of comprehensive care

The conference is expected to attract more than 100 people, including leaders of the participating patient groups, physicians concerned about comprehensive care for these disease groups, allied health care professionals, and representatives from Canada's blood system operators as well as from provincial governments which are responsible for health care delivery in Canada.

For more info please visit the following link <http://www.hemophilia.ca/nrbdo/en/index.php>

BASSETT DIRECT BBQ

During the summer of 2005, the employees of Bassett Direct had a barbecue lunch to raise funds for the Thalassemia Foundation of Canada. The Board of Directors would like to thank Bassett for all of their efforts and generosity.



Donna Shelley and Rich of Basset Direct, presenting a cheque to Board Member, Silvia.

12TH ANNUAL GUELPH CHAPTER BENEFIT DINNER-DANCE

The 12th Annual Fundraising Dinner was held on Saturday October 22, 2005. It was an evening of great fun and friendly hospitality was enjoyed by over 300 people. The event was a great success once again. There were many door and raffle prizes. Funds raised at the event will be donated to the Thalassemia Foundation of Canada towards medical research on Thalassemia.

The Thalassemia Foundation of Canada presented Anita with an Appreciation Award for her great efforts over the past twelve years. Also, special thanks to every member of the organizing committee and to the people of Guelph for their generous support. We are looking forward to next years event!

Angela Costa



UPCOMING EVENTS, FUNDRAISERS & CONFERENCES



WIN ME



2006 Mercedes 

\$10 raffle tickets

Proceeds to assist

Thalassemia Foundation of Canada

Fund Research and Purchase Medical Equipment

Draw to be held on February 11th, 2006

www.thalassemia.ca

Corrado: corrado@thalassemia.ca

Car displayed at Swimming Pool 416-782-SWIM

Lottery License #M278766, Only 7500 Tickets Printed.

CHANGE OF ADDRESS

Please send change of address to:
Thalassemia Foundation of Canada
338 Falstaff Ave. #204, North York, ON M6L 3E7

Name _____
New Address _____

City _____
Province _____ Postal Code _____

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