



THAL-A-VISION

Published Periodically by Thalassaemia Foundation of Canada

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FROM THE DESK OF THE PRESIDENT.

Dear Friends,

I am honoured to have been elected as president of the Thalassaemia Foundation of Canada—to lead and serve the thalassaemia community, following in the footsteps of the great individuals who served in this role over the past years. A small charity, yet a strong organization, the Foundation draws its strength from dedicated volunteers and loyal supporters. I am very pleased to be working with the talented individuals who form our current Board of Directors.

We have recently created various committees, consisting of Board members and other motivated volunteers, to focus our efforts on many important issues. Over the last year we have collectively met great goals, which you will learn about through the articles in this newsletter.

It is patients and parents who inspire, guide and motivate us in the fight against thalassaemia. In recent months, the Foundation surveyed adult thalassaemia patients—who receive care at the University Hospital Network in Toronto—for their input and feedback on the work of the Foundation. The results are encouraging and will drive the Board members and volunteers to build on their strengths and to improve in some areas as required. We welcome all suggestions and value everyone's opinions.

Part of our mandate is to fund scientific research on thalassaemia, because it is through brilliant research and the tireless efforts of our expert scientists that a cure would be found. In addition to funding two research fellowship grants this year, we are sponsoring the funding of a third research grant—to run over three years—in partnership with the Canadian Institute of Health Research (CIHR) through the Small Health Organizations Partnership Program (SHOPP).

Another important initiative is patient support, and in this context the Foundation, along with the help of private donors, has purchased new furniture for the adult thalassaemia clinic at the Toronto General Hospital. Also this year, we initiated a scholarship award in honour of our late president and dear friend, Corrado Falcitelli. A cheque for \$4000 was presented to the recipient, Joanna Choi, at our recent Valentine's Day Gala. I congratulate Joanna on receiving the award and I wish her the best of success in her academic pursuits. I also extend my appreciation to the Falcitelli family for their generous donation in matching the \$2000 awarded by the Foundation in Corrado's memory.

The Foundation continues to advocate for equal access to new medical advancements and to essential care for the treatment of thalassaemia; equal access to optimal treatment for all thalassaemia patients in Canada is our top priority. Collaboration with other rare disorder-focused organizations, such as sickle cell associations, the Anemia Institute for Research and Education and member groups of the Network of Rare Blood Disorders Organizations, is an integral part of our advocacy campaign. We all believe that access to optimal treatment can only be achieved through comprehensive care programs for thalassaemia patients (both children and adults).

And so it is with excitement that I announce that we are only weeks away from printing the first edition of "The Standards of Care for Children and Adult Thalassaemia Patients in Canada." The Standards document brings together leading expertise on prevention, diagnosis, and treatment for thalassaemia to formulate national practice guidelines and to identify resource requirements. The Standards will also be an instrumental tool in setting benchmarks for the evaluation of program delivery and outcomes. Because the proposed document will provide national standards of care, it will help to ensure consistency and continuity of care across provinces and institutions.

I dedicate this issue of our newsletter to two of our remarkable heroes who fought thalassaemia against all odds and led their lives with courage and determination. Sadly, last year, we lost two of our brave heroes: Corrado Falcitelli and Howard Leung. Many of us know Corrado as the previous president of the Foundation, who dedicated much of his time to raising funds for the Foundation and was champion of the toy drive for the hemoglobinopathies patients at the Hospital for Sick Children. Howard was a very strong supporter of the Thalassaemia Foundation of Canada and served as Vice President in 1999. He was a great friend to many, an advocate for thalassaemia, and generous and kind to those in need. To carry on the work done by Corrado and Howard, and to keep their memories alive, the first step is to persist in the fight against thalassaemia.

I am most pleased with the continuous success of our fundraising committee—specifically the great work of Ms. Christina Marra, treasurer of the Foundation and chair of the fundraising committee. Every year, generous supporters help us raise a substantial amount of our budget through the Valentine's Day Gala, the Roma Fence Golf Tournament, the Guelph Chapter Dinner and Dance and many other events and fundraising activities. I take this opportunity, on behalf of the thalassaemia patients and the Board of Directors of the Thalassaemia Foundation of Canada, to thank our supporters and donors for their generous contributions to our cause.

Riyad Elbard
President
Thalassaemia Foundation of Canada



REMEMBERING CORRADO FALCITELLI

The Falcitelli Family

Corrado Falcitelli meant so much to those who knew him. Not only was he a devoted fiancé, son, brother, uncle and friend, but he was also an inspiration and role model for so many people. On February 7, 2007, we said goodbye to our hero with heavy hearts. Although we mourn the loss of such a remarkable person, we are also proud and grateful for being blessed with having him in our lives.



Corrado will always be remembered for a life well-lived. One of his greatest accomplishments was serving as President of the Thalassemia Foundation of Canada. Together with the dedicated Board, he raised funds for research and patient care and also sought to improve the quality of life for those who suffered from Thalassemia. He actively participated in conferences around the world and rallied for political support. Corrado spent countless hours advocating for patient care with respect, dignity and most of all, integrity. His tremendous devotion to the cause of Thalassemia was never for praise or glory but because he genuinely cared.

Despite the overwhelming challenges he faced throughout his life, he chose to focus on what he could do rather than on what he couldn't or shouldn't have been able to do. Instead of being filled with despair at the journey he faced, he was always filled with hope. Those who had the privilege of knowing him were constantly amazed at what he was able to accomplish in so little time. Corrado knew no boundaries

nor did he accept any limitations—he was truly larger than life. He will always be remembered for his beautiful smile, infectious laugh, his fun-loving nature and warm-hearted compassion.

Even in life, Corrado was an angel among us, always putting the needs of others ahead of his own. Perhaps the most fitting way to honour Corrado is for each of us to live a full and meaningful life in the time we are given. Embrace each

day for the wonderful blessing that it is and focus only on the positive. We should always make a conscious effort to love freely, care deeply and fight passionately for those we love and the causes that are dear to us.

By ensuring Corrado's legacy of hope, courage and service to others lives on, we can carry a little piece of heaven in our hearts and always keep his memory alive. Corrado has been granted the rest he so nobly earned; it is now our chance to make him proud.

Let us continue his mission of supporting the Thalassemia Foundation of Canada by volunteering our time and providing financial support to find a cure for the disease. This will allow Corrado's dream to come true: "After finding a cure, we will be able to celebrate the history of Thalassemia."

"Carpe Diem" (Seize the Day) & "Audacia" (Courage)

SPECIAL ANNOUNCEMENTS

In the past year, the following patients and their partners welcomed babies into their families:

Kathie Francis - Mike Livia

Gino Turano - Sylvia Kolitsopoulos - Angie Costa - Joe Costa

The Thalassemia Foundation of Canada would like to congratulate these people and wish all the best to them and their bundles of joy!

2008-2009 RESEARCH GRANT COMPETITION RESULTS

Winnie Leung and Angela Covato

CONGRATULATIONS TO DR. VOLKER BLANK AND DR. DOUGLAS TEMPLETON!

Dr. Volker Blank and Dr. Douglas Templeton are the 2008-2009 recipients of grants awarded by the Thalassemia Foundation of Canada's Research Grant Competition.

Dr. Blank's research study, titled "Novel regulators of red blood cell differentiation," 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 was also at the Department of Hematology at Harvard University for several years. Since 1999, he has been at the Lady Davis Institute at McGill University in Montreal, where he holds positions as Assistant Professor of Medicine and Project Director.

Dr. Templeton's research study, titled "Renal Tubular Transport of Iron Chelates," is also being funded for 2 years.

Dr. Templeton is a Professor of Medicine at the University of Toronto and an established international expert in the field of trace element biochemistry. He received his PhD from Carleton University, his MD from the University of Western Ontario, and completed post-doctoral training at the Hospital for Sick Children in biochemistry. He has been on faculty at the University of Toronto since 1985.

The Thalassemia Foundation of Canada would like to congratulate both Dr. Blank and Dr. Templeton and wish them continued success in their research endeavours.

In partnership with the Small Health Organizations Partnership Program (SHOPP), the Thalassemia Foundation of Canada fosters partnership opportunities with small health charities and not-for-profit organizations with modest health research funding capacity by co-funding training and salary awards. The benefit of this program is that the Canadian Institute for Health Research (CIHR) offers partnership opportunities for small health organizations to increase their health research capacity while becoming more in line with the strategic directions of the Institutes. This program also meets CIHR's strategic objective of outstanding research through effective partnerships in specific areas of research. These funding opportunities will be launched in June; please check the CIHR Web site (www.cihr-irsc.gc.ca) for more details.

For 2008-2009, the Thalassemia Foundation of Canada has awarded approximately \$110,000 in research grant monies towards efforts in treating and curing the debilitating disease thalassemia.

The Thalassemia Foundation of Canada will be calling for more research grant proposals this fall for 2009-2010. Check the Foundation's Web site, www.thalassemia.ca, for updates.

UPCOMING EVENTS IN THE THALASSEMIA COMMUNITY

22ND ANNUAL TAG PATIENT/FAMILY CONFERENCE - (ALREADY OCCURRED)

o May 9 to 11, 2008, Washington, D.C., USA

1ST PAN-AMERICAN THALASSEMIA CONFERENCE - (ALREADY OCCURRED)

o May 30 to June 1, 2008, Rio de Janeiro, Brazil

o For more information, visit http://www.abrale.org.br/docs/pan_ingles.html

THALASSEMIA: A CHILDHOOD CONDITION COMES OF AGE

(A conference presented by the UK Thalassaemia Society, in association with the Royal Society of Medicine)

o June 10, 2008

RETIREMENT PARTY FOR NURSE MANAGER BEVERLY TYLER

o June 12, 2008, from 5:00 pm to 7:30 pm in the DeGasperis Atrium, on the 4th floor of the Toronto General Hospital

o Please RSVP by June 1st to Sylvia Olalia at 416-340-4882. (Sylvia has a card which everyone is welcome to sign and will also be collecting donations in order to purchase a gift.)

ANNUAL ROMA FENCE GOLF TOURNAMENT

o September 2008

o More information to come

TIF 2008 INTERNATIONAL CONFERENCE

o October 8 to 11, 2008, in Singapore

o For more information, visit <http://www.thalassaemia2008singapore.org>

THALASSEMIA INTERNATIONAL FEDERATION UPDATE

By Riyadh Elbard, Treasurer, Thalassemia International Federation

The Thalassemia International Federation (TIF) celebrated its 20th anniversary on May 25, 2007, in Nicosia, Cyprus. The celebration was honoured with the presence of the President of Cyprus, as well as ambassadors of TIF member countries and prominent members of the Cyprus community. For twenty years, TIF and its member countries have dedicated tireless efforts in the fight against thalassemia. Great progress has been achieved in promoting and implementing prevention programs in many countries and securing medical care for many thalassemia patients worldwide. Today, TIF is stronger than ever, with members and collaborators around the world. This milestone anniversary marks the success of TIF and its longstanding commitment to the fight against thalassemia.

Education and awareness of thalassemia are high on the priority list for TIF. Every year, a course in clinical management and a workshop on laboratory aspects are held in Cyprus, which lead experts on thalassemia and related fields to provide educational programs for practitioners in the field. Similarly, the biannual association's workshop offers a unique opportunity to network, learn and share from experiences to build a stronger collaboration among thalassemia associations. In addition, TIF provides support and sponsorship to many educational workshops and conferences—held at the local and regional level—in numerous countries.

As a lead resource on thalassemia education, TIF distributes over 13 publications and booklets to provide essential education about thalassemia for patients and parents, and to provide treatment guidelines for health care teams all over the globe. A book on patients' rights and another entitled "Guide to Establishing a Non-Profit Patients Support Organization" are TIF's latest publications. Also, "TIF Guidelines for the Clinical Treatment of Thalassemia" has been updated to include recent medical developments and advancements in the treatment of thalassemia. The report has been printed and will be available for distribution shortly.

This September, University College of London—with substantial funding from TIF—will launch a course in the Hemoglobinopathies. This unique course offers an e-learning MSc in Hemoglobinopathies, accessible to interested health professionals around the globe. The MSc in Hemoglobinopathies is the first degree of its kind.

Today, TIF is faced with the challenge of fulfilling the increasing and varying demands of thalassemia patients and thalassemia associations around the world. Hemoglobinopathies are prevalent in Europe due to increased migration of populations from highly affected countries of the developing world. It has become apparent that there is a great need for spreading awareness and to educate patients, parents and health professionals in every European

country. Even though health infrastructures and quality services are available and in place in most European countries, there is still a need to improve awareness about thalassemia in order to provide specialized services to patients who are heterogeneously spread, often in small population pockets, across most European countries.

TIF is thus increasing its focus on assisting thalassemia patients and thalassemia associations in European countries. Delegation visits to Albania and Bulgaria in recent years were successful in establishing closer collaboration with the national associations and achieved great results on projects focused on blood safety and increasing blood donations. Also, recent delegation visits to Germany and the Netherlands will strengthen the national thalassemia associations in those countries to advocate for improving patient care.

The first Pan-European Workshop on Thalassemia was held in Lisbon, Spain, on November 26, 2007, prior to the Fourth International EURORDIS Conference entitled "Patients and EU for Promoting Health for Patients with Rare Diseases." TIF has collaborated with thalassemia organisations throughout Europe; 150 patients and doctors from 15 countries attended the Pan-European workshop, surpassing all expectations.

The highlight of the workshop was the patients' discussion session, which provided them with an open forum in which they could share their challenges of aging with thalassemia, as well as to discuss how they cope with their treatments and how their treatments impact their lives. The workshop was very successful in reaching out to European patients, motivating them to enjoy life to its fullest as well as educating them on recent medical advancements in the treatment of the disease.

TIF's next big event takes place this fall. The 11th International Conference on Thalassemia and the Hemoglobinopathies and the 13th International Conference for Thalassemia Patients and Parents, hosted by the Thalassemia Society of Singapore, will take place from October 7th to the 11th in Singapore. The conference promises to be another wonderful event that will provide a great opportunity for reaching out to thalassemia patients worldwide and for creating stronger collaborations with thalassemia associations in Southeast Asia.

I invite you all to join the world thalassemia community at TIF's conference in Singapore to learn about the latest state-of-the-art treatments for thalassemia and its related complications. To register and for more information on the conference—and on TIF and its activities in general—please visit www.thalassaemia.org.

FIRST ANNUAL INTERNATIONAL RARE DISEASE DAY

By Angela Covato

FEBRUARY 29TH: A RARE DAY FOR VERY SPECIAL PEOPLE

Marking the occasion of the 1st International Rare Disease Day on February 29, 2008, the Canadian Organization for Rare Disorders (CORD) organized a rally day on Parliament Hill. Winnie Leung and Angela Covato, representatives of the Thalassemia Foundation of Canada, were in attendance. Along with other patient group delegates, family members and supporters of Canadians with rare disorders, the two representatives met with more than 60 individual Members of Parliament (MP) and Senate on Parliament Hill in Ottawa.

This momentous occasion was spearheaded by CORD to raise awareness of the inequities in healthcare available to Canadians who suffer from diseases that afflict small numbers of people only, as well as to ask for support for a national “Chance for Life Fund” for treatments for these rare disorders.

The day began with a Newsmakers breakfast at the National Press Club attended by MPs and patient advocates. Don Bell, MP from North Vancouver who lost a grandson to a rare disorder this past July, unveiled his motion to call upon the Canadian government to recognize rare disorders and consider an action plan to provide treatment and support to Canadians with rare disorders. “Canada remains one of the few developed countries without an orphan drug policy that supports development of treatments for rare disorders,” said Mr. Bell. “We believe that all Canadians, regardless of whether they have a rare or common disorder, should have access to the same standard of care.”

Also in attendance was MP Rob Merrifield, former chair of the House Standing Committee of Health. His report, released last December, recognized the inequities of the process used by the Common Drug Review (CDR), the national agency that recommends which drugs should be included in public drug plans. The report urged that a distinct and appropriate process be established for rare disorders.

Patients Deb Maskens with Kidney Cancer Canada and Simon Ibell with the Canadian “MPS” Society presented powerful testimonies of their struggles to gain access to life-saving therapy. “My private drug plan picks up 100% of my drug cost but I am in this fight because it is unfair that my neighbor, with the same disease, is dying because the Ontario Drug Plan won’t pay for his treatment,” reported Deb Maskens.

Similarly, Simon Ibell raised the concern of moving from British Columbia (where his drug is being covered by the hospitals) to Ontario (where the drug has been denied coverage). “Because I was on a clinical trial, Shire [the drug company] has extended compassionate access; otherwise, I wouldn’t be able to be here. There are other patients still not getting access.”

The Canadian Organization for Rare Disorders, which serves as an umbrella group for rare disease groups throughout Canada, has



(L-R): Durhane Wong-Rieger, Winnie Leung, Angela Covato



Don Bell, MP for North Vancouver

called upon the governments to create the Chance for Life Fund to give patients with rare disorders an equal chance to life-saving or life-enhancing therapies. They are also calling for a rare disorders research program, enhanced newborn screening to identify infants with rare disorders, centers of reference to diagnose and treat patients and an Orphan Drug Policy, to stimulate development of new treatments.

International Rare Disease Day provided a “rare” opportunity to get the message out to policy makers and the public. Hopefully, it will also have created the moment for genuine progress in assuring that Canadians with rare disorders have equal access to healthcare.

IN MEMORY OF HOWARD SUM HO LEUNG

The Leung Family



“Would you were here to lend wings to my voice and turn my mutterings into songs. Yet I shall read knowing that among the ‘Strangers’ an invisible ‘Friend’ is listening and smiling sweetly and tenderly.”

Kahlil Gibran

With saddened hearts, on Monday April 30, 2007, we said good-bye to Howard, our beloved son, loving brother, best friend and most cherished uncle, cousin and nephew. Passing too soon in his 45th year, Howard will be greatly missed by his many relatives and friends who loved him dearly.

Although we mourn the loss of one so precious to us, we feel blessed to have had his special soul touch our lives. We are bewildered and inspired by the courage Howard displayed as he walked his challenging life journey with a strong will, fighting spirit and wicked sense of humour. Despite the many obstacles to his health that he faced from so early on in life, Howard had a huge capacity for extreme kindness and generosity to others. He was a strong supporter of the Thalassemia Foundation of Canada, a true sage to his friends and loved ones and an advocate for—and gentle spirit to—those in need; Howard’s absence truly impacts us all.

As he joins his many much-loved friends who have gone before him, Howard’s premature demise tragically echoes the continued need for improved quality patient care that focuses on respect, dignity and integrity.

Let us pay homage to our hero by lending our voices to the cause and turning the tragic echoes into a universal song. By supporting the Thalassemia Foundation of Canada and advocating quality patient care as a mandate, we may carry on Howard’s legacy of hope—quality care for all patients and at last, a cure for thalassemia.

After a long-fought battle, Howard may rest now with those he loves who have gone before him. Howard, our best and only son and brother...until we meet again.

THE CORRADO FALCITELLI MEMORIAL SCHOLARSHIP

Tony Falcitelli

In memory of our past President, Corrado Falcitelli, the Falcitelli Family and the Thalassemia Foundation of Canada have created a scholarship award. This \$4000 scholarship will be awarded to a Canadian patient with Thalassemia Major who is registered in a full-time post secondary education program. The purpose of this award is to provide an incentive to patients contemplating the continuation of their education. We hope this scholarship will inspire and motivate patients to reach their education and career goals.



The 2008 Corrado Falcitelli Memorial Scholarship winner is Joanna Choi. Joanna is a 2nd year student in the Life Sciences program at the University of Toronto. Congratulations, Joanna, and we wish you the best in your future endeavors.

For more information about the Corrado Falcitelli Memorial Scholarship, please visit www.thalassemia.ca.

THALASSEMIA FOUNDATION GUELPH CHAPTER BENEFIT DINNER AND DANCE

Winnie Leung

On Saturday March 1, 2008, the Thalassemia Foundation's Guelph Chapter hosted its annual Benefit Dinner and Dance at the Guelph Place Banquet Hall.

It was an evening filled with fun, food, and friends and family coming together to fundraise to support thalassemia patients and to help find a cure for the disease through prevention, clinical management and research.

Hosted by Anita Aimola, the Guelph Chapter's committee lead as well as a thalassemia patient, the evening began with ticket sales for the silent auction and raffle prizes, the latter of which were donated by many generous supporters and financial contributors. Guests at the event enjoyed an open bar and a tantalizing four-course Italian feast, followed by decadent desserts, coffees and cappuccinos.

The Guelph Chapter paid tribute to Howard Leung, a patient and former vice-president of the Thalassemia Foundation of Canada. Howard was a long time supporter of this annual fundraising event and a good friend to many of the guests in attendance.

The evening concluded with everyone hitting the dance floor, showing off their moves to contemporary rock/pop ballads and old-time favourites provided by Sound Samsation D.J. Sam Lucchesse.

The Thalassemia Foundation's Guelph Chapter would like to thank committee members Tilda Aimola, Adriana Carlino, Marisa Finoro, Lucy Mattucci, Sharon Mazziotti and Diane Wagar for their dedicated efforts. Also, accolades must be paid to the Guelph Place Banquet Hall for the beautiful venue provided for the evening, Andy Palubeski for leading ticket sales and Mark Moretti, the charming master of ceremonies. A generous thank you goes out to the Guelph community and all those who helped with the event; your continuous support and your help in preparing for this special evening is greatly appreciated.

In the past 14 years, the Guelph Chapter has raised over \$120,000 for thalassemia research and patient care.



VALENTINE'S DINNER DANCE

Christina Marra



On February 16th, 2008, the Thalassemia Foundation of Canada hosted its 19th annual Valentine's Dinner Dance. This year, the festivities were held at the Venetian Banquet Hall & Convention Centre in Concord, Ontario. Guests enjoyed a fabulous four-course meal followed by a special porchetta station later in the evening.

The musical group DeLa Funk performed for guests while they enjoyed their cocktails and perused the goods on offer from Fifth Avenue Jewellers. New Image provided the main stage entertainment for the remainder of the evening.

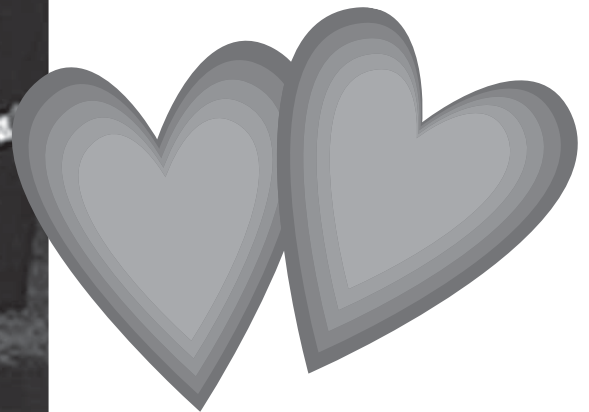
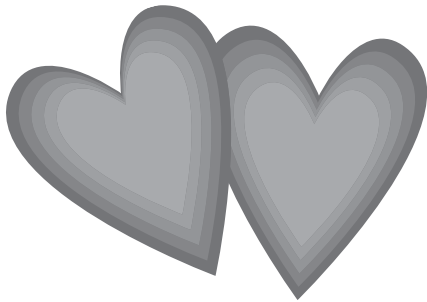
A silent auction and raffle draws were held throughout the evening. The big draw of the evening was the chance to win a brand new Vespa motor scooter. Congratulations go out to lucky winner Bill Parmar, of Thornhill, Ontario.

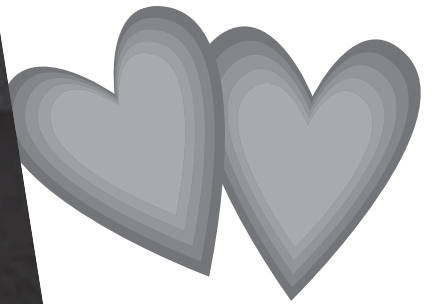
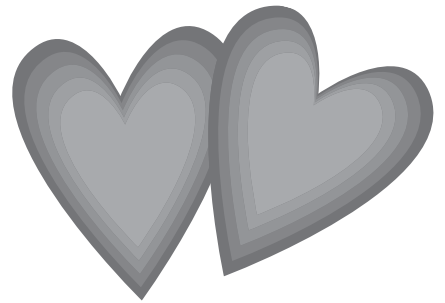
The Foundation was pleased to be able to present a cheque for \$110,000 for Thalassemia research and patient care.

Much gratitude is extended to our evening's masters of ceremony, Michael Ciccolini and Angela Marra-Sudano. A heartfelt thank you also goes out to Dr. Melanie Kirby-Allen for her attendance and special presentation on Thalassemia.

We appreciate the hard work of our ticket and dance committees and of course, the tremendous displays of generosity from our 550 guests in attendance as well as from all those who so kindly donated prizes for our raffle.

We hope to see you again next year!





2007 THALASSEMIA PATIENT SURVEY

Mohamed Hasham, Winnie Leung, Helen Antoniadis

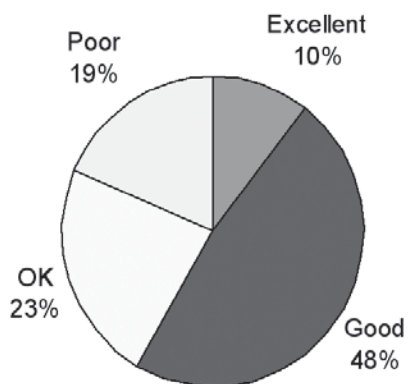
In the fall of 2007, the Board members of the Thalassemia Foundation of Canada (TFC) developed a survey to gauge the interest in—and awareness of—thalassemia patients in the Foundation. The survey was produced with the help and support of Winnie Leung, Mohamed Hasham, and Helen Antoniadis, clinic social worker at the Toronto General Hospital (TGH). Helen not only was involved in preparing the survey, but also was the direct contact with patients at TGH and helped stress the importance of the survey as well as gathered the results. Thanks to Helen’s help, a total of 50 patients responded to the 2007 survey.

The goal of this survey was to build on the results of the TGH clinic survey completed in 2005. Learning from the earlier version, the 2007 survey was developed to be easy for respondents but also to provide valuable information to the Board on the possible direction of future TFC policy.

One question in the 2007 survey specifically asked patients their current opinion of the TFC. The results on the right show 58 per cent have a good to excellent opinion of the TFC. While that is encouraging, nearly the same percentage (57 per cent) only had an “OK” awareness of the TFC’s initiatives.

The 2007 results did indicate that for 70 per cent of those patients that had some interaction with the TFC, the support they received was helpful in addressing their issues and concerns. As the TFC grows and builds awareness among patients, the hope is that 100 per cent of patients can be reached and supported.

2 - What is your current opinion of the Thalassemia Foundation of Canada?



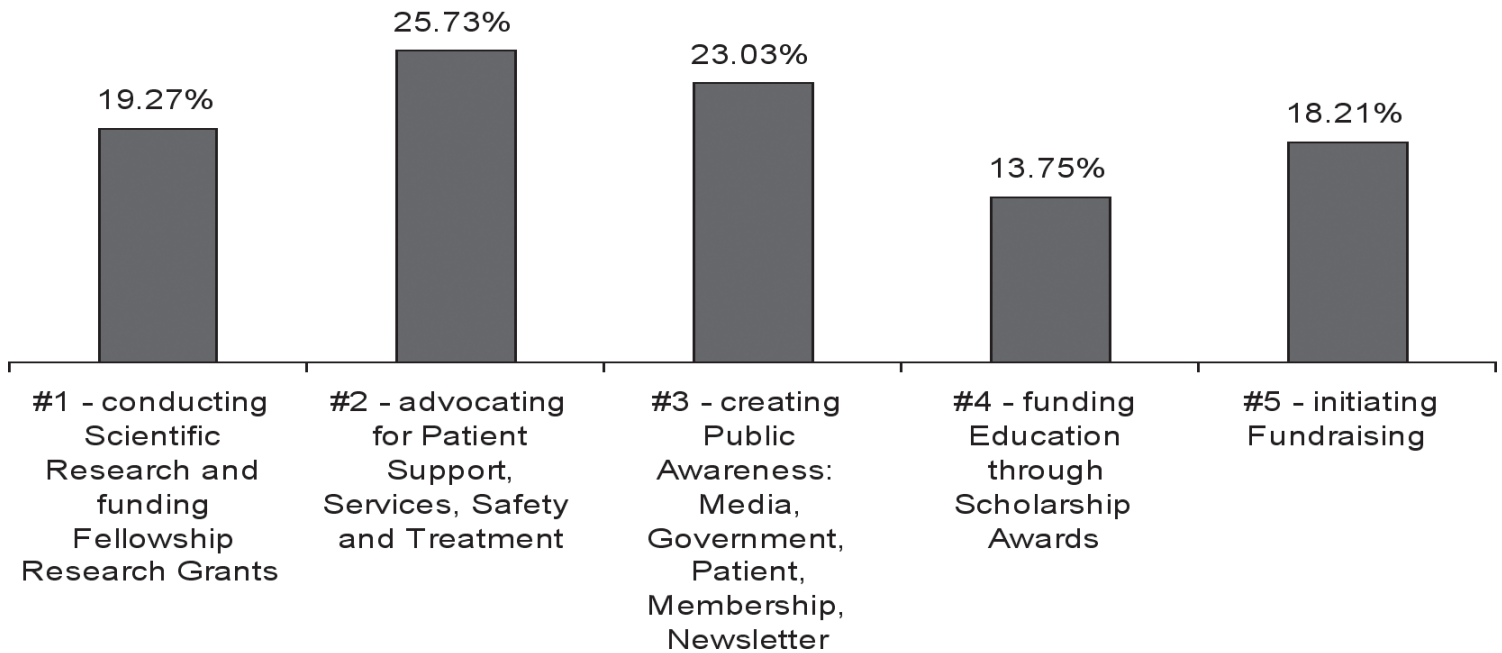
For the Board, this is a call to provide better communication with the patient community regarding the work of the TFC.

4 - How successful has the Thalassemia Foundation of Canada been in being available to address your needs?



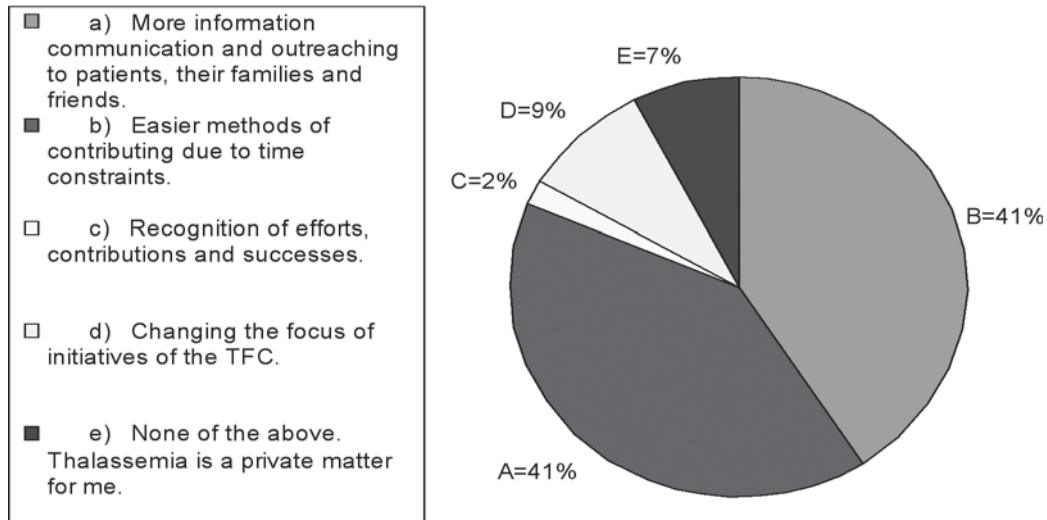
To become more effective among patients, the TFC also asked in what areas the Board should focus in the future. The responses were well distributed, with advocating for patients and public awareness being the two areas that received the majority of responses.

5 - In what areas do you expect the Thalassemia Foundation of Canada to concentrate its efforts in supporting?



The survey closed by asking respondents what would encourage them to become more involved with the TFC, and once again, communication—with 41 per cent of the responses—was key to attracting more volunteers. Equal to communication and outreach was easier methods of contributing. As a result, the Board has been looking into ways to attract more patients to meet with one another and to volunteer.

8 - What would encourage you to become more involved in the Thalassemia Foundation of Canada?



The Board would like to thank all those patients at TGH who took the time to respond to its survey. A special note of appreciation goes out to Helen Antoniadis for all her hard work in ensuring the success of the survey. The Board has reviewed the results and is looking into creative ways to reach out to the patients and support them in their daily life. The success of the 2007 survey results at TGH are encouraging and the Board is looking into surveying patients in clinics across Canada in the hopes of learning more about the national patient community and expanding the Foundation.




Sponsored by
Mackie Harley Davidson

\$ 15.00 for One Ticket
\$ 20.00 for Two Tickets

Draw to be held on
Saturday
February, 7th 2009

Only 8500 tickets printed



Thalassemia Foundation of Canada



WIN THIS HARLEY!

If you are interested in selling tickets at your workplace or would like the Harley motorcycle present at a special event, please contact Mike and Silvia Livia at 416-953-9827 or silvia.livia@thalassemia.ca

Draw to be held on Saturday, February 7th, 2009 at the Annual Valentine's Dance.

CHANGE OF ADDRESS

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

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