23rd Annual Valentine’s Dinner Dance

On February 11, 2012, the Thalassemia Foundation of Canada held its 23rd Annual Valentine’s Dinner Dance. The gala event, held this year at The Royalton Banquet Hall in Woodbridge, Ontario, is the Foundation’s largest fundraiser to support thalassemia patients and their families, and to assist in funding research on treatments for the disease.

Shortly after arriving at the hall, guests indulged in a deluxe antipasto bar as they mingled with their friends. They were then formally welcomed to the event by the evening’s masters of ceremonies, Angela Marra-Sudano and Gabe Lollino. During the four-course dinner, Rachel Cleland and Jason Lamont wowed the crowd with their amazing voices as they performed a number of well-known classical pieces. Also during dinner, Dr. Isaac Odame, co-director and staff physician of the Hemoglobinopathy Program at The Hospital for Sick Children, presented his heart-felt talk as the evening’s esteemed guest speaker.

The Thalassemia Foundation of Canada uses the dinner dance as an opportunity to bestow awards on deserving individuals. This year, three awards were presented: the Appreciation Award was given to Lisa D’Annunzio; the Chris Bennedson President’s Award (Continued on page 14)

Second Annual Walk-for-Thalassemia

By Enza Salituro

On May 6, 2012, the second annual Walk-for-Thalassemia took place, and was another great success! The event, benefitting the Thalassemia Foundation of Canada, was held at Ester Lorrie Park in Etobicoke (Toronto). The funds raised are completely dedicated to education, research, and providing necessary support for patients in Canada who have thalassemia.

With the sun shining and spirits high, participants embarked on either the five kilometre or nearly 10 kilometre route. Some people chose to do a leisurely stroll, using the opportunity to catch up with friends as they walked, while others opted to get their daily exercise in and run the course. Everyone involved was easy to spot, seeing as each participant received a vibrant red t-shirt courtesy of sponsor LiUNA – Local 506.

Following their return, participants were welcomed back with fresh popcorn, made on site at the popcorn stand, also donated by LiUNA. Guests were also offered cold water, fresh fruit, and (Continued on page 11)
President’s Message

Positive news is always welcome! This is especially true regarding improving patient access to new treatments. Early in October 2012, Health Minister Leona Aglukkaq made an announcement that provides new hope to the estimated 2.8 million Canadians living with rare disorders. Health Canada is moving forward on creating a framework for “orphan drugs” with the goal of providing information and timelier access to the appropriate medication for those diagnosed with a rare disease. Along with potentially opening the doors to new and better treatments, the government has launched a comprehensive database called Orphanet – to provide information and services for rare diseases.

I congratulate Canadian Organization for Rare Disorders (CORD), its president Dr. Durhane Wong-Reiger, and all those who worked hard and contributed efforts towards this achievement.

I am hopeful that this will pave the way for access to better treatments and new inventions for thalassemia patients across Canada. It is a sad reality that Canada lags behind many other countries on access to iron chelation therapies and comprehensive care programs. The bigger challenge facing thalassemia patients today is not adherence to treatments, but rather, access to optimal care and management of life changes – such as transitioning from pediatric to adult care.

The Thalassemia Foundation of Canada’s collaboration with CORD, Network of Rare Blood Disorders, and the Sickle Cell community reinforces the joint advocacy efforts towards improving care for thalassemia patients and other patient groups fighting for the same goals – such as timelier access to new treatments, comprehensive care programs, and improving overall patient care.

Our participation on the various committees of Canadian Blood Services for dialogue and discussions on blood safety and supply issues ensures that concerns of thalassemia patients are heard. Also, our participation in consultation meetings on health care reforms hosted by the Canadian Medical Association provides a voice for thalassemia patients on the future of health care.

Last spring, the Foundation introduced the Thalassemia Secondary Student Excellence Award to motivate and encourage thalassemia patients to continue to work through life’s challenges, contribute to their community, and share their talents and gifts with others. The purpose of this award is to recognize thalassemia patients who demonstrate determination, commitment, and enthusiasm. This award program will also enhance the Foundation’s focus on engaging younger patients and new volunteers to lead the future of our organization.

As we carry on with our activities in the coming years, moving towards a better future for thalassemia patients, the outlook is very optimistic from a medical aspect – more so since the recent strides in gene therapy research. The Foundation’s fundraising campaigns and educational events have been very successful in achieving their desired outcomes. We are forever indebted to our many volunteers who have dedicated their time and tireless efforts over the years, and to the donors who continue to support our cause so generously.
UPDATE – Thalassaemia International Federation

Thalassaemia International Federation: 25 Years of Contribution

By Riyad Elbard, Treasurer, Thalassaemia International Federation

Thalassaemia International Federation (TIF) marked a major milestone in 2012 as it celebrated its 25th anniversary. The organization was created in 1987 at a meeting in Milan, Italy, by a small group of dedicated individuals from Cyprus, Italy, Greece, Pakistan, the United Kingdom, and the United States, who chose to commit their time and collaborate efforts on fighting thalassemia, a rare blood disorder that was thought of as a fatal childhood disease at the time.

It is a great achievement that, today, TIF is recognized worldwide as a patient-driven organization, works in official relations with the World Health Organization (WHO), and contributes in many European and International patient forums. The numerous publications TIF has distributed over the years have been read by patients, parents, doctors, allied health teams, and health authorities around the globe; these publications are instrumental educational tools that are referenced for treatment guidelines and clinical management of thalassemia and related complications.

Mr. Panos Englezos, President of TIF, has been the solid foundation of the organization for the past 25 years and has contributed tremendously to it – from his charismatic and influential leadership to TIF’s successes in achieving its remarkable goals. Mr. George Constantinou (UK) and Mr. Robert Ficarra (USA) are two founding members of TIF along with Mr. Englezos (Cyprus), and they have been active and contributing members of the organization’s Board since its inception 25 years ago. Recognition must also be given to all of the current and past TIF Board members who have worked diligently as a united team over the years for the benefit of TIF, and thus, the benefit of thalassemia patients worldwide. Their tremendous efforts, dedication, and commitment deserve the highest respect and appreciation.

A celebration of the 25-year anniversary was held during the course of the 3rd Pan-European Conference on Haemoglobinopathies and Rare Anaemias held in Limassol, Cyprus, from October 24 to 26, 2012. Held under the auspices of the Cyprus Presidency of the Council of the European Union, and with the support and close collaboration of the Cyprus Ministry of Health, the conference was a gathering of stakeholders from the 27 Member States of the European Union, as well as from other countries that are Member States of the Council of Europe, and from neighboring countries, to discuss avenues of action to tackle the growing public health burden of chronic and rare diseases in the European region of the World Health Organization (WHO).

Considerable focus has been given to the events that took place in the context of the conference in Cyprus. Important resolutions and messages were launched at the event that would promote significant control policies in Europe. Participants agreed that both the scientific and patient programmes were well constructed and balanced, and the great involvement of patients in the whole process was very much appreciated by everyone involved.

TIF’s regional and international conferences have always been among its major activities to promote awareness on thalassemia and to educate both the patient and medical communities. From February 8 to 10, 2012, TIF held its first Pan-Asian Conference on Haemoglobinopathies at the Royal Orchid Sheraton Hotel & Towers in Bangkok, Thailand. The conference gathered 32 prominent speakers from Asia and other parts of the globe, and over 280 other participants from 25 countries (mostly from South East Asia and the Western Pacific regions). Participants included Ministry of Health officials, WHO country representatives, medical specialists, scientists, various health professionals, and many patients and parents. It was the first time that such a large scientific gathering was held for the cause of hemoglobinopathies in the South East Asian/West Pacific region, and it was a huge success.

The conference was held during a time of genuine international commitment towards a better future for patients with the many different forms of thalassemia and other hemoglobin disorders, based on advances in medical research, but also on adopted resolutions by the World Health Organization.

TIF’s next major event will be the 13th International Conference on Thalassaemia and Hemoglobinopathies and the 15th TIF International Conference for Patients and Parents, which will be held at the Abu Dhabi National Exhibition Centre in Abu Dhabi, in the United Arab Emirates, from October 19 to 23, 2013, under the auspices of Her Highness Sheikha Sheikha Bint Saif Al Nahyan. The event promises to have a great impact on educating both the medical and patient communities to enforce equal access and excellence in the treatment of thalassemia and other hemoglobinopathies in the Middle-East region and worldwide.

(Continued on page 4)
The conference will include the presentation of the first Sultan Bin Khalifa International Thalassemia Award to individuals, researchers, centres, and patients who have excelled in their work and contributions in the field of thalassemia.

All conference publications – including programs, presentations, abstracts, resolutions, and press releases – and other relevant information can be found on TIF’s website dedicated to conferences, which can be accessed at www.tif-conference.com.

TIF’s efforts in its goal to spread knowledge are not limited to hosting educational events. The organization recently announced the launch and imminent distribution of five important publications:

- **Guidelines for the Management of Thalassaemia Intermedia**
- **Guidelines for Non Transfusion Dependent Thalassaemias**
- **Thalassaemia Guidelines for Acute Complications**
- **White Book on the Criteria for Reference Centres and Networks for Hb Disorders and Rare Anaemias**
- **Nurses Guidelines**

To learn more about TIF and to register as a member, or for frequent updates on TIF activities and/or to receive copies of TIF’s news magazine, you are encouraged to visit the organization’s website at www.thalassaemia.org.cy.

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**By Tony Falcitelli and Hafsa Hafsa**

There were many strong candidates who applied for the 2012 Corrado Falcitelli Memorial Scholarship Award. Daniel Maiorano was chosen as the award recipient and received $2,000 towards his university tuition. He is currently registered in the Bachelor of Applied Technology program at George Brown College.

**2012 Secondary Student Excellence Award**

This year, a new award was introduced for secondary students. The purpose of this award is to recognize thalassemia patients who demonstrate determination, commitment, and enthusiasm. These qualities can be revealed through the candidates’ academic achievements, extracurricular activities, and volunteer work. The 2012 Secondary Student Excellence Award recipient was Hafsa Hafsa, and she was granted $500. Hafsa completed her high school diploma and is currently registered in the Bachelor of Commerce program at Ryerson University.

The Thalassemia Foundation of Canada and the Falcitelli family congratulate both winners and wish them success in their education and future goals.

Secondary and post-secondary students are encouraged to apply for their respective award for 2013. (Application forms can be found at www.thalassaemia.ca.) The application due date for both awards is January 31, 2013. Best of luck to all candidates!

Hafsa Hafsa shares with ThalaVision her thoughts on winning the 2012 Secondary Student Excellence Award, living with thalassemia, and the importance of inspiring younger generations:

Having thalassemia does not stop me from doing what I want or wish to do. I have never let my disease interfere with my education; in fact, I have found myself to be even more dedicated. I have always aspired to become a chartered accountant, and my first year at Ryerson is the first step towards achieving my goal. Moreover, the reason why I applied for the scholarship was because I wanted to feel the sense of accomplishment. The money does not matter to me so much; what matters is to be recognized as a winner. Since this is not the only scholarship that I have received – I also got a scholarship for maintaining a high average throughout high school – I am planning on contributing the entire amount towards my tuition fee. Therefore, I feel much relieved!

I think that the younger generation should recognize its potential, as everyone is capable of achieving something. Just remember that thalassemia cannot stop us from achieving what we desire; let’s not even consider it an illness! All you need to do is set a goal and begin your journey towards it. Also, we all need to set an example for the coming generations, so that no one is left behind. And our first step could be to get involved with the Thalassemia Foundation of Canada in any way possible; for example, we can create a blog with inspirational writings, or use the Foundation’s Twitter account to answer any career/education-related questions.
The relationship between markers of iron load, iron-associated oxidative damage, and metabolite profiles in iron overloaded thalassemia patients.

By Dr. Farzana Sayani

Thalassemia is associated with transfusion related iron overload. The iron accumulates in organs including the liver, heart, pancreas and other endocrine organs and leads to various complications. In iron-overload, the free non-transferrin bound iron (NTBI) is toxic and leads to formation of free radicals that contribute to oxidative stress and damage to lipids, proteins and DNA. The oxidative damage eventually leads to cell death, and subsequent organ dysfunction. Current management of iron overload involves identifying the amount of iron in various organs including the liver and heart. This information is subsequently used to adjust chelation therapy to reduce iron levels and thus reduce damage to organs.

Current methods to measure iron load include serum ferritin, liver MRI to measure the liver iron content, and cardiac MRI to measure cardiac iron load. These tools are very helpful and have allowed clinicians to tailor chelation treatment and have resulted in improvement in patient care and survival. However, these methods of detecting iron load have limitations. By the time significant iron load is seen on MRI, cell damage from toxic iron is already long underway. New methods that allow us to identify earlier signs of iron damage may enable clinicians to start chelation sooner, or make changes in treatment before significant changes are seen on the MRI. These methods may have the potential to improve organ function and patient survival.

These methods may have the potential to improve organ function and patient survival.

Our team – consisting of me, Niloufar Abdolmohammadi (summer research student), Maggy Zhang (lab technician), and Dr. Aalim Weljie (metabolomics studies) – sought to use metabolomics technologies to determine if it can identify unique metabolite profiles in iron-overloaded thalassemia patients. We also sought to determine if these metabolite profiles could predict for iron load, serum ferritin, liver iron, cardiac iron load, and oxidative damage.

In this pilot study, 12 thalassemia patients and 12 control individuals were enrolled. Blood and urine samples were collected at baseline (Continued on page 6)
and every six months for one year. Thalassemia patients also underwent routine investigations for iron monitoring including serum ferritin, and liver and cardiac MRI, as per standard practice. The samples were analyzed using gas-chromatography/mass spectrometry and metabolomics technologies.

Using metabolomics technologies, we were able to show that iron overloaded thalassemia patients have different changes in their metabolites and metabolism compared to normal individuals. Unique metabolite profiles were seen in the different thalassemia forms (thalassemia major, thalassemia intermedia, and Hemoglobin H disease). The different chelators also gave unique metabolite patterns. More interestingly, the results also suggested that different metabolite profiles may allow us to predict iron load. Different metabolite profiles were seen for high ferritin, high liver iron, and high cardiac iron. Different metabolite profiles may also have the potential to predict for iron-related oxidative damage of lipids and DNA as measured by malondialdehyde (MDA) and 8-hydroxy-2′-deoxyguanosine (8-OHdG) levels.

These preliminary results are very interesting and exciting, and are the first report of the use of metabolomics technologies to further study iron overload and thalassemia. These metabolite profiles may have the potential to serve as biomarkers of iron load and iron-related damage in thalassemia patients. In addition, this may potentially allow for earlier treatment intervention. Further data analysis to assess for changes in metabolite profiles over a one year period is underway. These preliminary results are encouraging. Future goals are to expand this project to enroll more patients in a multicenter study.

I would like to thank the Thalassemia Foundation of Canada for its support in funding this research project. A big thank you also goes to the patients and staff at the Southern Alberta Rare Blood and Bleeding Disorders Comprehensive Care Program at the Foothills Medical Centre in Calgary for their enthusiasm, participation, and support for this project.

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THE MISSION OF THE THALASSEMIA FOUNDATION OF CANADA

To support and fund thalassemia scientific research, treatment, patient services, public awareness and education.

OUR GOALS

- To provide patients and caregivers with accurate and up-to-date information on thalassemia research and treatment.
- To help patients navigate through the health care system, while providing beneficial resources and support services to the thalassemia community.
- To further research and innovation in thalassemia treatment and care.

A CURE REMAINS TO BE FOUND

Thalassemia is a lifelong condition that presents many unique challenges. The physical demands of the disease and the ongoing medical treatment needed for it can take a toll on patients and families, causing emotional distress and impacting the overall effectiveness of treatment, survival and quality of life.

A cure needs to be found. Please do your part. Donate today.

THALASSEMIA FOUNDATION OF CANADA

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Winter 2012-13

What is Thalassemia?

Thalassemia (derived from *thalassa* and *anaemia*, Greek for “sea” and “lack of blood,” respectively) is a genetic blood disease, also known as Cooley’s anemia, or Mediterranean anemia. People born with this disorder cannot make normal hemoglobin, which is needed to produce healthy red blood cells.

WHO CARRIES THALASSEMIA?

Thalassemia is most often found in people of Chinese, South Asian, Mediterranean, Middle Eastern, or African origin.

WHAT IS THALASSEMIA MAJOR?

In thalassemia major, red blood cells are destroyed almost as soon as they are produced, and the bone marrow cannot produce a sufficient number to replace them. Children born with thalassemia major usually develop the symptoms of severe anemia within the first year of life. Lacking the ability to produce normal adult hemoglobin, those with thalassemia major experience chronic fatigue, paleness, jaundice and slower growth development. Prolonged anemia will cause bone deformities and eventually lead to death within the first decade of life. The only treatment to combat severe anemia is regular blood transfusions and iron chelation.

WHAT IS THALASSEMIA INTERMEDIA?

Thalassemia intermedia is caused by one of the more severe thalassemic genes combined with a milder thalassemic gene. Children and adults living with thalassemia intermedia are moderately anemic but many patients survive without regular blood transfusions.

WHAT IS THALASSEMIA MINOR?

People with a thalassemia mutation in one gene only are known as carriers or are said to have thalassemia minor. Thalassemia minor results in no anemia or very slight anemia. People who are carriers do not require blood transfusions or iron therapy, unless proven to be iron deficient.

HOW CAN THALASSEMIA BE TREATED?

Regular blood transfusions allow patients with thalassemia to grow normally and be active. Unfortunately, transfusions result in excess iron in the body. Excess iron in vital organs increases the risk for liver disease, heart, endocrine and spleen complications, diabetes, osteoarthritis and osteoporosis – to name just a few. In some cases, it can also lead to premature death.

Today, iron chelators (drugs designed to remove excess iron) have significantly changed the prognosis of thalassemia. Patients can grow and develop normally, with relatively normal heart and liver functions. Patients are living longer and having families of their own. Medical advances continue to improve the life expectancy and quality of life for those living with thalassemia. Treatments that are especially promising for the future include gene therapy, bone marrow transplants (in which donor bone marrow is inserted into the patient’s bones and begins producing normal, healthy blood cells) and cord blood transplants (in which stem cells rather than bone marrow cells are used in the procedure).

DO YOU CARRY THALASSEMIA?

Many people from the areas of the world where thalassemia is common have thalassemia minor. Checking for thalassemia requires a special blood test, called HEMOGLOBIN ELECTROPHORESIS, which you must request from your doctor. This test can identify a carrier of thalassemia. If you, your parents or ancestors are from an area of the world where thalassemia is common, PLEASE REQUEST a hemoglobin electrophoresis blood test from your doctor. It is important to identify yourself as a possible carrier of thalassemia. Carriers have a one in four (25%) chance with every pregnancy of having a baby with thalassemia major if his/her mate also has thalassemia minor.

HOW DO YOU INHERIT THALASSEMIA?

Thalassemia is an inherited genetic disease. It is not transmitted through blood, air or water. It cannot be caused by poor nutrition or medical conditions. If both parents carry thalassemia minor their children may have thalassemia minor, they may have completely normal blood or they may have thalassemia major. In each pregnancy there is a one in four (25%) chance that their child will have thalassemia major, a two in four (50%) chance that the child will have thalassemia minor and a one in four (25%) chance that the child will have normal blood (see Diagram).
My name is Anita Aimola.

I’m 41 years old and I have thalassemia major. I was born and raised in Guelph, the eldest of two siblings: my younger brother also has thalassemia. Both my parents were born in Italy, so we inherited the “wonderful” thalassemia trait. Growing up in an Italian home was very special, because we were always surrounded by family and friends. Not only did these people pass on their stories and traditions, but there was also always a lot of good food on offer. (This is probably why I love Italy so much, too.)

Thalassemia affected my life from the beginning. I remember being a young girl and going to the hospital in Guelph for my transfusions. This stopped when I was about eight years old because I developed antibodies in my blood. I just remember feeling very tired – probably because the antibodies lowered my hemoglobin so drastically. Doctors told my parents that I would no longer be transfused because my body wouldn’t accept anyone else’s blood. Since this happened in 1979, and at that time there was no other treatment available, the doctors didn’t think I would make it past the age of 10. Well, I guess they were wrong. I managed to live my teenage years with a lower hemoglobin. I graduated from high school, and was working towards becoming a floral designer.

Unfortunately, around 1991, my hemoglobin levels lowered even more, affecting my bone marrow and my optic canal. (The bone marrow pressed on the optic nerve, causing me to lose a good part of my sight.) The doctors declared me legally blind. Let’s just say, that was the worst day of my life! I not only lost my sight, but I also lost the little confidence and independence that I had. Then I met Dr. Olivieri, from Toronto, who basically brought me back to life. She was doing a study with a new treatment called Butyrate and thought I was the perfect candidate for it. Long story short, both I and my brother are successful participants of the Butyrate study, and my hemoglobin is finally at a healthy level.

When I was asked what inspired me to start fundraising for the Thalassemia Foundation of Canada, I didn’t know what to say, other than that it just happened. A few of my friends were planning a fashion show and decided to donate the proceeds to the TFC. It was a big success and other friends said they wanted to help, so it snowballed into a great fundraising dinner dance. Even though a lot of work goes into planning it (for which I have to give credit to the girls on the event committee) it’s definitely worth it. It’s been amazing to see how much support we’ve been given through the years from donors and families attending our event. March 2013 will mark the 19th year we’ve held the event, and every year it just keeps getting better.

Through the years, coping with thalassemia has been very difficult, as other patients would know: everyone has their own circumstances to deal with. For me, it’s been a definite struggle – especially losing my sight. On the other hand, it’s made me stronger and filled me with hope. And I’m also extremely grateful for the blessings of many special
At its annual Patient and Family Conference in June 2012, the Cooley’s Anemia Foundation (a US-wide organization) honoured individuals with thalassemia who had reached a very special benchmark: they had passed their 50th birthday. Sixty-four individuals were honoured.

The genetic blood disorder thalassemia was originally considered a pediatric disorder; however, with tremendous advances in care in the past decades, more and more patients have lived into adulthood, with many starting families of their own – a situation which was undreamed of before the advent of iron chelation therapy in the 1970s.

Patients living into their 50s and beyond is just the latest sign that advances in care are having a profound impact on the lives of all with thalassemia, proving that with proper care, people with thalassemia can live fuller, healthier and longer lives.

My Experience Living With Thalassemia

By John Principato

Interviewer: What is it like living with thalassemia in your 40s?

John: I haven’t really noticed many things that are different than in my 30s, 20s, etc. I have slowed down a bit but I think that comes to all of us as we age. I am happy that I have my health still and not too many complications to manage.

Interviewer: How do you cope with challenges?

John: Staying positive ALL THE TIME. Compliance of treatments and living a healthy lifestyle. I try to set one goal for each year then work to achieve it (e.g. to eat healthier or start exercising regularly, etc.).

Interviewer: What are your accomplishments?

John: I’ve been married 18 years, and have a beautiful wife, four great kids, and two dogs. I just completed my degree in nursing (BScN). I’ve had my diploma in nursing since 1986, and have worked as a nurse since then (so 25+ years now). I’m currently a Nurse Educator. I’m also a hockey trainer for my two boys’ hockey teams. I own a 1967 Camaro convertible. In seven years I will reach retirement age – who would have thought thalassemia patients would come this far?!

Interviewer: Do you have any suggestions to offer to other thalassemia patients?

John: Stay positive all the time – it’s not worth being miserable. Regardless of illness, life really is too short. Be compliant with your treatment(s); it will determine how well you do health-wise. No matter what, family always comes first, which means that if you want to be around for them, you really have to put your health right up there with family. Have no regrets.

friends that I’ve met through the years. Many of these friendships have been with other patients and their families, since they better understand what I’m going through. It’s important to be there for others and to also have that support.

Take care and keep well,
Anita
Over the last little while, the adult thalassemia clinic at Toronto General Hospital (TGH) has seen a number of staff changes. ThalaVision would like to introduce its readers to the newest members of the TGH family. For this issue, ThalaVision sits down for a chat with Colleen Johnson, one of the two new Nurse Practitioners who have been working in the Red Blood Cell Disorders Clinic since March 2012.

Colleen, what does your position entail, exactly?

Nurse Practitioners in the clinic are responsible for the 400-500 thalassemia, sickle cell and various other red blood cell disorders patients. On a day-to-day basis, we review patients receiving blood or other treatment in the medical day unit, as well as see patients up in the clinic on the 12th floor. We also have to return telephone calls and emails from patients. The other part of our job is to look at ways to improve the Red Blood Cell Disorders Program.

Tell us a bit about yourself and how you came to be working in the thalassemia clinic.

I came to work at the Red Blood Cell Disorders Program after 20 years of experience in oncology and palliative care. My last job was at Trillium Health Centre in Mississauga. Before that I worked for many years at Princess Margaret Hospital. I was looking for a “shake-up” in my career and decided to make the leap into a new specialty area. It has really been a challenge in many ways but I am happy to be at a downtown teaching hospital again.

What were your thoughts on the clinic and the patients when you first started working there?

When I first started working at the clinic I was very overwhelmed by the change. I was an expert in cancer treatments and guiding patients through the cancer journey, but brand new to thalassemia and sickle cell patients. It was hard to be a novice nurse again in a clinical area in which I had never worked. At first, I found the thalassemia patients welcoming but sceptical about another change in staff. As the months have passed, I feel like I am starting to develop good relationships with patients.

What are some good/unique aspects to the clinic and what do you think could be improved upon?

I really enjoy seeing the relationships that some patients have developed with each other as well as with the day unit nursing and clerical staff. I always need to remind myself that I am the newcomer and that I need to “learn the ropes” from the patients and staff: textbook learning cannot replace hands-on clinical work.

What do you hope to see in the future – in the clinic, with patients, etc.?

I really feel like I am too new to this clinic to have aspirations for future changes to the clinic. I am still trying to become clinically strong. Ask me this question again in one year!

What do you personally hope to bring to the clinic?

Working with oncology patients has taught me to listen and try to understand the patient experience. I really hope I can bring those skills to working with this population of patients with red blood cell disorders. This will take time and I hope others will continue to have patience with me.

You have the patients’ attention now with this interview: what is one thing you really want to impart to them?

I want patients to understand that the volume of patients we deal with is very high. When I don’t remember something that was discussed last month please don’t get offended or think I do not care. I ask that patients bear with me as I am trying to learn the journey of patients with all red blood cell disorders so that I can better do my job to support them.
other healthy snacks, all donated by Surve Construction. Powerline’s deejay made the day even more memorable, as children and teens enjoyed the latest Top40 tunes while mingling with family and friends within the community. Passersby stopped by the meeting area to inquire about our cause: local student volunteers welcomed everyone and passed out informational brochures and pins promoting the Thalassemia Foundation of Canada. The walk-a-thon not only acts as a fundraiser for the Foundation, but also helps raise awareness of thalassemia and the Foundation in the broader community.

Participants in the walk showed incredible determination to raise as much money as possible, soliciting friends and relatives to support their cause. The Thalassemia Foundation of Canada is extremely grateful to everyone who participated in the walk and who donated funds. Big thanks also go out to the organizers of the event, as well as all of the companies and individuals who donated goods and services to the event. The event cannot take place without your generosity.

We’re aiming to make the walk-a-thon a yearly event. We hope you will be able to join us May 5, 2013, for the third annual Walk-for-Thalassemia! Stay tuned to www.thalassemia.ca for full details on the upcoming event.
The Roma Fence Group of Companies 16th Annual Golf Invitational, in support of the Thalassemia Foundation of Canada (TFC), took place on August 29, 2012, at the Board of Trade Country Club in Woodbridge, Ontario.

At the event, golfers enjoy a fun-filled day of 18 holes of golf, a pre-game lunch, a post-game deluxe dinner, and the chance to win incredible prizes.

This year’s event saw 128 golfers enjoy the pre-game porchetta lunch and play the course; approximately 150 guests attended the post-game dinner, which took place at Montecassino Place Woodbridge. Thanks to everyone involved, the event raised over $13,000 for the TFC, which provides support to thalassemia patients and their families, and helps fund research on treatments – and ultimately, a cure – for the disease.

We look forward to the 2013 golf invitational on August 28, and hope to see you there! For further details on the event, visit www.thalassemia.ca.

Roma Fence and the TFC wish to thank everyone who took part in this year’s golf tournament, especially the generous sponsors and contributors of the event.

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- Roma Fence Ltd.
- Sid Isenberg
- Steelguard Fence Ltd.
- The Falcitelli Family
- The Fence People
- TLN Telelatino
- Tony Marra
- Woodbridge International Golf (& Social Club)
**BOWLING FOR THALASSEMIA**

*By Fame Risorto and Lisa D’Annunzio*

On June 22, 2012, we held our third annual Bowling for Thalassemia fundraiser. We are pleased to report that through the support and efforts of our relatives and friends who came out in record numbers, we raised $12,600.

Inspired by thalassemia patient Marco Risorto, the bowling events have raised over $33,000 to date for the Thalassemia Foundation of Canada. We would like to thank everyone who attended this year’s event, which was held in support of a great cause. This fun event is making a difference in our mission to find a cure for thalassemia.

The bowling fundraiser was held at NEBs Funworld in Oshawa. There is something for everyone at NEBs – the world’s largest 5-pin bowling centre – and it helped make the bowling event a great outing for the entire family. As in previous years, the “Rock ‘n Bowl” was a major attraction, and kept the energy pumping for everyone. Aside from bowling, the night’s activities also included a silent auction, numerous raffle draws with great prizes, and a snack table full of delicious homemade food.

We will continue our efforts to promote and expand Bowling for Thalassemia; with the interest the event has garnered thus far, we’re sure to succeed! We look forward to seeing you in June 2013 for our next event – stay tuned to www.thalassemia.ca for further details.

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**2nd Annual PIG ROAST to Support Thalassemia**

*By Fame Risorto*

On August 11, 2012, Roger and Susan Simoes hosted their 2nd Annual Pig Roast to Support Thalassemia. The Simoes once again extended their beautiful home and hearts to help prepare this wonderful event.

The day in Bradford, Ontario, started off with grey skies, but cleared up just in time to hold the event. Approximately 100 people braved the uncertain weather to attend the event, and with everyone’s generosity, over $3,300 was raised in support of the Thalassemia Foundation of Canada and the search to find a cure for thalassemia! The day was filled with great food, great fun, and dear friends – what more can anyone ask for?

Warm thanks are extended to the many residents and local businesses of Bradford who donated food and supplies to ensure the success of the event. Special mention must be made for John and Linda Hodgson, Portugalia Bakery, Sargeant’s Rentals, and IAGO Construction.

Fame, John, Jonathan and Marco Risorto extend heartfelt thanks to treasured friends Roger and Susan Simoes, and Jose and Alvaro Da Silva. Here’s to many more pig roasts!
(Continued from front cover) was given to John and Fame Risorto; and a second Appreciation Award was given to Sergio and Adelina Ceccarelli. The Foundation is grateful to all of the recipients for their hard work and dedication to its cause. The 2012 Corrado Falcitelli Memorial Scholarship Award was also handed out that evening, to proud recipient Daniel Maiorano. Thanks to the efforts of all donors, sponsors and other supporters of the Valentine’s gala and the Thalassemia Foundation of Canada, the Foundation was able to donate $110,000 towards thalassemia research in 2012. The cheque for this donation was presented by the Board members at the Valentine’s dance.

During dinner, numerous door and raffle prizes were given out, and guests were able to tour the incredible silent auction display in the lobby and bid on their favourite items. Another big-ticket event of the evening was the 50/50 draw. Once the meal was over, Veriation DJ Services had all the guests on their feet, dancing to a mix of classic oldies and the latest Top40 tunes.

The Foundation would like to thank everyone involved in the event, especially the volunteers who gave so freely of their time, and the donors and sponsors who continue to amaze with their endless generosity. Without your help and support, this event – and the success of the Thalassemia Foundation of Canada – would not be possible.

Contributors

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Universal Electric Motors
Angelo & Rita Viola
Claudio Viola
Woodbridge International Golf (& Social Club)
Nick & Helen Zlavras
The Roma Fence Group of Companies 17th Annual Golf Invitational is coming soon! August 28, 2013

Shot-Gun start 1:00 p.m. Dinner to follow Montecassino Place Woodbridge
Cardinal Golf Club 2740 Davis Drive West Kettleby, ON

For more information on this event, contact Christina Marra at cmarra@romafence.com or 416.735.1180.

ThalaVision is now accepting ads!
Reach thousands of readers and promote your business while supporting a great cause. All proceeds from submitted ads go to the Thalassemia Foundation of Canada and its quest to fund thalassemia patient care and scientific research.

For ad rates, specs and deadlines, contact Stefanie Polsinelli at stefanie.polsinelli@thalassemia.ca
Dear Friend,

We are extending an invitation to you, your family members, friends and work colleagues to become a member of our organization, Thalassemia Foundation of Canada.

For years, Thalassemia Foundation of Canada has successfully achieved its goals through the tremendous dedication of its Board members and other volunteer members, and the support of generous donations from the public. Our team of volunteers consists of patients and non-patients who either serve on our Board or as general members; members donate their valuable time and effort toward the Foundation’s numerous activities and projects.

By becoming a member, you will assist Thalassemia Foundation of Canada in continuing to support and fund thalassemia-based scientific research, treatment, patient services, public awareness and education.

The benefits of becoming a member, just to name a few, include: a subscription to the Foundation’s ThalaVision newsletter; voting rights at our Annual General Meeting held in April 2013; access to books, brochures and information on thalassemia; and detailed information on upcoming events and fundraisers.

In order to become a member for 2013-2014, please complete the membership information on the form below and mail it, along with a $10 membership payment, to the address noted below.

Donations along with your membership fee would be greatly appreciated. Your donations will bring us closer to reaching our ultimate goal of finding a cure for thalassemia.

Thank you for your support.

Alfonso Sinaguglia
Chair, Membership Committee

MEMBERSHIP FORM

Name: ________________________________

Address: ________________________________

Phone: ________________________________

Email: ________________________________

Additional donations can be submitted along with your $10 membership payment. Thank you.

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