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FROM THE DESK OF THE PRESIDENT

THE FOUNDATION ESTABLISHES IMPROVED COMMUNICATION AND DIALOGUE WITH HOSPITAL ADMINISTRATION, DEPARTMENT DIRECTORS AND PHYSICIANS

Following a low point and an impending crises situation facing the Thalassemia Program at University Heath Network's Toronto General Hospital last April and May of this year, top Administration officials at the hospital listened to the Foundations urgent concerns and took immediate temporary corrective measures to ensure continuing quality care for the young adult patients at the hospital's Thalassemia Program.

Further meetings and correspondence with directors and physicians at the University Health Network, Hospital for Sick Children and joining forces with the Anemia Institute for research and education and Sickle Cell Association of Ontario has now cleared a path for us to meet with the District Heath Council of Greater Toronto to discuss developing a long term plan for quality care of adult Thalassemia patients at Toronto area hospitals.

How do we attract more physicians in the field of blood disorders related to Thalassemia, how do we convince provincial and federal Heath officials that funding for long-term care for adult Thalassemia patients is imperative in order for them to lead a reasonable normal life. Those are some of the challenges facing the foundation in the coming year, but we are confident with the full support and backing of top officials from University Heath



Network, Hospital for Sick Children and Anemia Institute and Sickle Cell Association, we have a powerful voice that must and will be heard.

Our Thanks and appreciation to all our supporters, fundraisers and dedicated volunteers, without you we are nothing.

We extend our best wishes for a safe and happy New Year.

God Bless,
Chris Bennedsen, President

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CONSENSUS CONFERENCE

November 7-9, 2001, Ottawa

Canadian Blood Services and Héma-Québec hosted a consensus conference entitled "Blood-Borne HIV and Hepatitis: Optimizing the Donor Selection Process" in Ottawa on November 7 - 9, 2001 to solicit input on the donor selection process.

Over the last 20 years, blood services have gone from welcoming into the blood program, any willing, apparently healthy individual without known hepatitis and malaria exposure, to detailed scrutiny of background, lifestyle, sexual practices and travel of any prospective donor. The donor health assessment has evolved from 8 questions in the past, to over 30 questions today. While these measures have undoubtedly improved safety, they also make the donation process more complicated and less convenient for the volunteer blood donors, and have excluded many people from donating. Currently, we know that laboratory test sensitivity is high and the window period, that is the time between infection and the test's ability to detect infection is significantly shortened. In parallel, the criteria for blood donor eligibility and exclusion have increased.

This conference addressed issues of blood donor eligibility as they relate to the risk of transmission of HIV and Hepatitis and provided a forum for input and discussion from leading Canadian and international authorities in the field. Independent scientists and stakeholder groups addressed public health, scientific, legal, cultural, and ethical principles around blood donor selection in Canada. The consensus panel used this information to develop a consensus draft statement aimed at guiding future developments in blood donor screening.

The shared objective was to develop a set of defining principles which can form a framework for determining maximally discerning donor selection criteria thus ensuring a safe and sufficient blood supply for Canada. This conference was a unique opportunity to develop a consensus with recommendations on how to maximize the gift of the willing donor and the safety of the recipient.

The consensus panel was charged with answering the five following questions:

- (1) What message is communicated to the public about the current donor eligibility and screening process?
- (2) What are the current perceptions and expectations of donors, recipients and members of the public regarding the donor selection, screening and testing programs established to ensure blood safety?
- (3) How effective is the current donor selection, screening and testing program in excluding units with risk while permitting inclusion of donors without potential risk to recipients?
- (4) What are the public health, societal, cultural, ethical and legal principles that should guide the donor selection and screening process?
- (5) What further information and systematic research is necessary to evaluate and improve the current donor screening process?

The consensus panel's draft recommendations were based on the premise that the primary goal of the donor selection process is safety of the blood supply. The panel's recommendations will be finalized by the spring 2002.

Josie Sirna, on behalf of the Thalassemia Foundation of Canada, presented the following paper:

The Thalassemia Foundation of Canada is thankful to donors for the life that they give to thalassemia patients and other blood recipients. Without the generosity of blood donors, members of the thalassemia community would have died in childhood. That said, there are patients who have died from or are living with the infectious diseases transfused to us in the past.

Testing of donated blood for infectious diseases is mandatory in Canada and the countries of the developed world, yet testing for HIV and hepatitis is still considered a luxury for many of our peers in some countries. The choice given to blood recipients in the developing world is die now (of anemia) or die later (of HIV or hepatitis). In Canada basic blood supply safety has been mastered but it is not perfect.

Remember that no matter how sensitive tests for hepatitis & HIV have become, they are not perfect.

There is still a window early in the infection where viral transmission can occur and it is this window that makes selecting out individuals who have engaged in risky behaviors imperative. Until the day when this window can be shut we recipients are completely dependent on the memory of donors and their honesty.

The questions asked of donors are intrusive and we blood recipients are immeasurably grateful to those who endure the process. It is the vigilance and scrutiny of current donors that allows thalassemia patients some reassurance each and every month when 1 or 3 or 4 units of donated blood are transfused into us. To some, selecting out individuals at risk may be considered discriminatory, but to blood recipients it may be the choice between health and sickness.

To the collectors of blood in Canada, don't allow accusations of discrimination stop you from selecting donors who have not participated in risk activities recently.

Apart from the infectious disease risk of the Canadian blood supply, thalassemia patients are constantly concerned about the abundance of Canada's blood supply – do not turn away potential blood donors for “behaviors” which are part of their very distant past. Scrutiny of blood donors is necessary but base the selection criteria on what is known today of risks, of technology, and of Canadians' behaviors. Consider updating the donor selection process so that it reflects current risk behaviors, but err on the side of safety to the blood supply because at the end of the day there are recipients at the other end of that blood unit.

ROMA FENCE GOLF TOURNAMENT

Christina Marra

Roma Fence Ltd. and Frost Fence & Wire Products once again hosted their fifth annual golf tournament. It was a tremendous success! With over 90 golfers, and 120 people for dinner, approximately \$15,000.00 was raised for the Thalassemia Foundation of Canada.



They would like again to thank their many sponsors and volunteers who continue to contribute each year to help make the tournament a success.

We hope to see you again next year!

NATIONAL LIASON COMMITTEE

October 22 & 23, 2001, Ottawa

Canadian Blood Services (CBS) hosted the inaugural meeting in Ottawa on October 22 & 23, 2001 of the National Liaison Committee (NLC). Howard Leung accepted an invitation by CBS to sit on the NLC and represent the Thalassemia Foundation of Canada (TFC).

The impetus for the establishment of the NLC was a desire to engage stakeholders in active and meaningful ways to ensure the ability to cope with future difficulties by working together. The NLC will ensure that Canadians, particularly those who have a direct interest in the blood system, contribute to decision making on issues affecting the blood system. The NLC is intended to identify issues, and

offer ideas, opinions and concerns from across Canada.

The NLC members discussed the key topics of building a better blood system for Canadians on day one and developed a presentation to be given to the CBS Board of Directors on day two.

At press time, the distribution of the NLC 'draft' meeting report was deemed 'confidential' thus it could not be circulated to our respective organizations until it has been approved by all the NLC members. The details of the NLC meeting report will be available on the next TFC newsletter or on the CBS web site at www.blood-services.ca once it's approved.

TIF REPORT - CONFERENCE 2001

October 17-19, Athens, Greece - Riyad Elbard

Scientific Conference

The 8th International Conference on Thalassemia and Hemoglobinopathies was held on October 17-19 at the Astir Palace resort over-looking the beautiful coast of the Mediterranean Sea in Athens, Greece. The conference was well-attended considering the unstable world situation that is overshadowing all of us. The conference was well organized; it was definitely a successful event. Scientific lectures were held concerning the latest developments in Thalassemia, and complications of the disorder.

Mr. Costas Papageorgiou, President of TIF and chairman of the conference Organizing Committee, welcomed all the attendants at the Opening Ceremonies held on Thursday evening. Delegates enjoyed a memorable night of great food, dancing to excellent music and fun at the Gala Dinner on Saturday October 20.

The presentations covered all aspects of Thalassemia. Dr Bernadette Modell's presentation on delivering genetic screening to the community was one of the most interesting lectures. She discussed the need and benefits of such screening programs that are designed to minimize Thalassemia incidents in the community. Lectures on iron chelation dominated the program agenda on Saturday, October 20, 2001.

In his lecture, Dr. Hans Peter Nick spoke about the latest oral iron chelator (ICL670) being developed by Novartis. The tridentate compound is designed to excrete iron in the feces. The goal of the researchers is a safe and user-friendly oral chelator to be given in a single dose once or twice daily. The half-life of the drug is 11-19 hours. It metabolizes quickly and has rapid effectiveness. The drug is in its early progress stage. It is at Phase II and will be at Phase III sometime in the next three years. Two studies on the drug are presently taking place. Study 104, in Boston,

examines the efficacy of the compound and involves a 19-day stay in hospital. Study 105, which focuses on safety of the compound, is being conducted in Milan, Turin, and Cagliari in Italy. It is a longer and more involved study; it runs for about three to nine months and requires the participation of 60-75 patients. The drug seems to be very promising, but it is still too early to make predictions. Studies like these can take years to accomplish.

Other compounds of oral iron chelators were discussed during the presentations. Deferiprone (L1) and Kefler (the latter which is used mostly in India) are the only two available on the market. The two drugs are being used in extreme cases where patients cannot tolerate the use of Desferal. Combination therapy of L1 and Desferal offered to patients in Europe is still experimental. Without a doubt, oral chelation



Mr. Tony Genova, Mr. Corrado Falcitelli, VP Thalassemia Foundation of Canada, Mr. Riyad Elbard, TIF Treasurer, and Mr. George Constantinou, long time TIF Board Member.



Mr. Costas Papageorgiou, TIF President, Mr. Corrado Falcitelli, VP Thalassemia Foundation of Canada, Mr. Riyad Elbard, TIF Treasurer, and Mr. Tony Genova at the Athens Conference.

will be available in the near future for the treatment of iron over load in Thalassemia; however at present, Desferal is still the best option.

Patients and Parents Conference

The tragic events of September 11 put a damper on the TIF 2001 Conference. During this period of uncertainty, the TIF Office received many phone calls, faxes, and e-mails from individuals and Thalassemia associations concerning travel to Greece to attend the conference. Security concerns and travel restrictions led to a large number of last minute cancellations. The TIF Office had to act on the decision of TIF Board Members and send notices announcing the cancellation of all TIF activities at the conference. TIF Board Members confirmed a unanimous decision on October 13, 2001 to postpone all TIF activities, including the General Members Meeting and the election of a new TIF Board, to a later date.

The organizing committee and TIF Board Members exerted a great effort in last-minute planning to set up meetings for the patients and parents that attended the conference. A meeting for parents and patients was held in the afternoon on both Friday and Saturday. A TIF medical session was held on Sunday morning followed by an open discussion for parents and patients.

The highlight of the conference was a presentation of a film showing the adventurous trip of 5 Thalassemia patients from Pakistan. Imran, Mariam, Batool, Abeera, and Rehman are all Thalassemia



Mr. Riyad Elbard, TIF Treasurer, presenting to Mrs. Merula Steagall, President of ABRASTA, 12 Desferal infusion pumps donated by TIF to Thalassemics in Brazil. Also shown in picture (far left) Mr. Corrado Falcitelli, VP Thalassemia Foundation of Canada, and Mr. Tony Genova (far right).

patients between the ages of 9 and 15. They climbed to the base camp of K2, the second highest mountain in the world. The Thalassemia Society of Pakistan organized the activity to promote awareness on Thalassemia and to raise funds. Parents, patients, doctors, and Board Members of the Thalassemia Society of Pakistan participated in the walk. Mr. Stavros Melides, who was the official representative of TIF on a delegation visit to Pakistan at the time of the trip, also participated in the walk.

Mr. Panos Englezos, Chairman of TIF, presented certificates of recognition to each of the five young Thalassemic heroes in the presence of the Pakistani ambassador to Greece. Six Desferal infusion pumps were donated by TIF to the Thalassemia Society of Pakistan. The Pakistani ambassador to Greece presented a picture to Mr. Papageorgiou of the Thalassemic heroes at the Base camp of K2. With the film, the children want to send a message to the world: "IF LOOKED AFTER PROPERLY, THALASSEMIA PATIENTS CAN DO ANYTHING IN THE WORLD". The film and the recognition ceremony were an inspiration and a motivation to all.

In his closing remarks, Mr. Panos Englezos assured Thalassemia associations and all general members of TIF that a general meeting would be arranged soon for early next year. He thanked all the delegates for attending the conference and for their dedication to the fight against Thalassemia. He also reminded everyone that unity is our strength.



Mr. Stavros Melides and Mr. Panos Englezos, TIF Chairman, presenting certificates of recognition to the five Thalassemia patients from Pakistan who walked to the Base camp of K2.



REPORT FROM THE MEDICAL ADVISORY BOARD

November, 2001

In September 2000, Mr. Chris Bennedsen and the Board of Directors invited me to assume the chairmanship of the Medical Advisory Board (MAB). Shortly thereafter, four other distinguished physicians agreed to serve on the MAB with me, and we are grateful for their willingness to do so in spite of their many clinical, teaching, research, and administrative responsibilities. They are:

Dr. Victor Blanchette, whom many of you know well. He is Professor of Pediatrics and Head of Hematology/Oncology at the Hospital for Sick Children in Toronto.

Dr. George Sweeney, Professor of Medicine Emeritus at McMaster University, a well respected pharmacologist, and editor-in-chief of the medical journal, *Clinical and Investigative Medicine*.

Dr. Brian Leber, Associate Professor of Medicine at McMaster University, a clinical hematologist and a physician-scientist in molecular medicine.

To broaden our liaison with our sister organization in the US, we are delighted that Dr. Alan R. Cohen agreed to serve as a full member of our MAB. Dr. Cohen is Chair of the Medical Advisory Board, Cooley's Anemia Foundation in the US. He is Professor and Chair, Department of Pediatrics at the University of Pennsylvania, and Physician-in-Chief, Children's Hospital in Philadelphia.

Mr. Howard Leung became the coordinator of the MAB, and his untiring effort on our behalf is indispensable and greatly appreciated.

The primary responsibility of the MAB is the assessment of the scientific merits of research grant applications submitted annually to the Foundation. To that end, copies of all applications are forwarded to each MAB member, who evaluates the applicant(s),

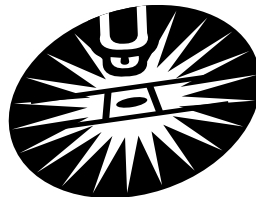
research plan, budget, and relevance for thalassemia. These evaluations are then collated, and discussed among MAB members. The final MAB recommendations are forwarded to the Foundation's Board of Directors for their final funding decision.

In November 2000, one renewal application and two new applications were reviewed. Dr. Ying Liu's fellowship, working in Prof. Doug Templeton's laboratory at the University of Toronto, was renewed. She worked on heart cell problem as a result of iron overload. The application from a new investigator, Dr. Volker Blank, Assistant Professor of Medicine at McGill University, and Lady Davis Institute for Medical Research, Jewish General Hospital in Montreal, was also approved. Dr. Blank works on the genetic basis of the inter-relationship between heme and globin production.

In 2001, the grant application process is amended and streamlined. In September, seven Letters of Intent were submitted to the Foundation, from applicants as far away as Montreal and Vancouver. After MAB review, four applicants were invited to submit full applications. The review process is now in full swing, to evaluate one final progress report from Dr. Y. Liu, one progress report/renewal application from Dr. V. Blank, and three other new applications.

It is our goal to ensure that the research grant program of the Foundation, initiated and sustained admirably by many members and friends of this organization, meets a high standard. Lastly, I want to express my personal thanks for the opportunity to serve the Foundation as Chair of the MAB.

David H.K. Chui, MD, FRCPC
Professor of Pathology and Molecular Medicine
McMaster University Medical Center
Hamilton, ON



THE FIRST “ANEMIA” COALITION

On Thursday, November 22, 2001, a historical event took place: the first meeting of the Anemia Joint Working Group. The purpose of the meeting was to discuss common issues and concerns with the goal of identifying actions that can be collective towards improving diagnosis, treatment and care for persons affected by all types of anemia. This was the first such coalition in Canada and perhaps, in North America and the world.

The Anemia Institute for Research and Education was proud to host the gathering, which included representatives from Thalassemia Foundation of Canada, Aplastic Anemia and Myelodysplasia Association of Canada, Sickle Cell Association of Canada, Fanconi Canada, Lupus Canada and Celiac Association of Canada. In addition, healthcare professionals were present from Toronto General Hospital, McMaster University and the Hospital for Sick Children.

Perhaps the most important things that we learned from the blood tragedies of the 1980's is that the patients needs to be informed and to take and role in managing their own healthcare. More importantly, we learned that consumers need to be knowledgeable about issues affecting the healthcare system and to be an advocate, not just for their own healthcare, but for the improvement in the system.

What we learned in the 1990's from our advocacy to achieve compensation for the blood tragedies of 1980's was the importance of working together. Consumers united across disease categories to fight for compensation. The public united with those affected to offer their support and to pressure the governments for change. And we were successful because we worked together for a common cause.

There are many commons challenges for those affected by the different types of anemia, not the least of which is getting our needs heard in a healthcare system that is already stretched to its limits to provide adequate care and support. We hope that by working together we can not only raise the profile of anemia but also create, among ourselves, solutions that are self-directed and mutually beneficial. By helping each other, we help our own communities. By helping out own communities, we help all Canadians.

For more information about the Anemia Joint Working Group, please contact the Anemia institute for Research and Education, (416) 969-7435, 1-877- 99AMEMIA, www.anemiainstitute.org.

Durhane Wong-Rieger, PhD
President & CEO, Anemia Institute

Yesterday was my anniversary. It was one year ago, on Hallowe'en, that I became the Social Worker for the Sickle Cell/Thalassemia Program. I came with minimal knowledge. In fact, prior to my interview I frantically looked through the medical dictionary to see what Thalassemia even was. My knowledge of Thalassemia (or lack there of) was graciously excused, trusting that I could learn, and I was given the job.

I spent my first few months trailing Bev and Dr. Brill-Edwards around the clinic in hopes of getting to know my transfused and non-transfused patients. Slowly I moved from names and diagnoses to names of family members, partners, studies and occupations. The year brought with it struggles and growth for myself, my co-workers and patients



alike. We have experienced the deaths of cherished community members, program changes and losses of staff-members; however, we have also experienced new clinic team members, births, weddings and lots of engagements!

I am truly honoured to provide support to individuals in the Thalassemia and Sickle Cell community and look forward to continued chats, resource requests, chances to advocate for you and counseling opportunities. Thank you staff for including me as part of this team, and thank you patients for accepting me in my role.

Kelly Flannigan, M.S.W.
Social Worker for the Sickle Cell/ Thalassemia Clinic.

THE HEMOGLOBINOPATHY PROGRAM AT THE TORONTO GENERAL HOSPITAL

From the Office of Dr. Ian Quirt, Interim Director

Old Faces-New Faces

Dr. Michele Brill-Edwards has returned to Ottawa to resume a full-time practice in pediatrics. Dr. Brill-Edwards has been coming to Toronto to follow patients in the Hemoglobinopathy Clinic on Tuesday, Wednesday and Thursday; however, this proved to be extremely taxing physically and she decided that one medical practice in one city was a much more sensible approach. Dr. Nancy Olivieri is currently taking a one-year sabbatical in England. During Dr. Olivieri's absence, Dr. Alan Tinmouth and Dr. Ian Quirt have become directly involved with the patient care component of the program.

Dr. Alan Tinmouth is an expert in transfusion medicine. He is currently co-ordinator and research scientist at the Canadian Blood Services Toronto Regional Centre and in conjunction with Dr. David Sutton, is carrying out important programs focused on blood component therapy through the blood transfusion laboratory of the University Health Network.

Dr. Ian Quirt is a hematologist from the University Health Network who has become the interim Director of the clinical program during Dr. Olivieri's absence.

Together with the changes in personnel, several new components are being added to the clinical hemoglobinopathy program.

Medical Records

Until recently, the medical notes from the individuals who were followed through the Hemoglobinopathy Clinic were handwritten and kept in files that were stored exclusively in the clinic. While this provided an excellent medical record at the clinic, it led to these files not being available to physicians in the emergency department of the Toronto General or Toronto Western Hospitals in the evenings or on weekends and if the physicians called in from other hospitals to obtain medical details on a patient's care, no records were available.

A new system of record keeping has been implemented as of August. The notes are now dictated on

a hospital based system so that all of the medical notes are not available by the computer to all the medical areas within the Toronto General Hospital and Toronto Western Hospital. If a physician calls in a middle of the night from another hospital, the medical records department can view the recent clinical notes; photocopy them and fax them to the physician at the other hospital. We hope that this new system will allow much better communication between the doctors at other hospitals in the Toronto area and lead to an improvement in the care of people with Thalassemia and Sickle Cell disease.

The Iron Chelation Program

Until recently, the number of individuals that could be on iron chelation to prevent tissue damage from iron overload was limited by budget constraints. Dr. Erik Yeo, Dr. Armad Keating, Dr. Michael Baker, and Mr. Tom Closson have been extremely supportive of the hemoglobinopathy program and have been meeting with representatives from Thalassemia Foundation and the Ministry of Health to remove these limitations so that all individuals with thalassemia who could benefit from iron chelation therapy will receive it. We are extremely grateful for the support that administration of the University Health Network has given the program.

A Comprehensive Program in the Treatment of Patients with Sickle Cell Disease

Most Patients with thalassemia that reach 18 or 19 years of age leave the clinic at the Hospital for Sick Children and start to be followed through the clinic at the Toronto General Hospital; however, the majority of the patients with sickle cell disease start being followed by specialists in internal medicine and hematologists in the community hospitals in greater Toronto area. We are very anxious that advances in the management of patients with sickle cell disease such as aggressive pain management, the use of hydroxyurea to elevate hemoglobin F levels, and the use of magnesium to prevent dehydration of red blood cells be made available to all patients with sickle cell disease. Dr. Quirt has already contacted several hematologists throughout the greater Toronto area, and they are enthusiastic to become

part of the overall program that will try to standardize and update the care of patients with sickle cell disease. Ultimately, it is hoped that a website can be created that will update all the advances in treatment that should be offered to these individuals.

Obstetrics Program

Special monitoring and special precautions must be carried out when individuals with thalassemia and sickle cell disease become pregnant. Last year, the high risk obstetrics program for the centre of Toronto moved from the Toronto General Hospital to Mount Sinai Hospital. This caused a physical separation of the physicians who specialize in the management of patients with thalassemia and sickle cell disease from the obstetricians who manage patients with high risk pregnancies. Dr. Anne McLeod now provides a valuable service to individuals with thalassemia and sickle cell disease who become pregnant. Dr. McLeod is a member of the Division of Medical Oncology and Hematology at the University Health Network and Mount Sinai Hospital. Her Office is at Mount Sinai Hospital. She will see all individuals with hemoglobinopathies who become pregnant and follow them at the time of their delivery. We also encourage any young lady who is planning to become pregnant to meet with Dr. McLeod in advance for counselling.

Education

An in-depth understanding of their medical condition is extremely important for patients with thalassemia and sickle cell disease. The need to treat infections early and to prevent long-term complications of transfusion therapy is extremely important information. Currently, numerous pamphlets exist; however, not all

individuals learn best by reading pamphlets. Dr. Christine Chen is a hematologist in the Department of Medical Oncology and Hematology at the University Health Network and Mount Sinai Hospital. Dr. Chen has special interest in patient education. Ms. Kelly Flannigan is a social worker attached to the hemoglobinopathy program who has become a valuable resource to patients not only to meet their social needs but to meet their educational needs. Dr. Chen and Ms. Flannigan will start working together to create educational tools for individuals and then will evaluate how effective these tools are.

Newer Transfusion Technologies

Transfusion is an extremely important supportive care for patients with thalassemia and sickle cell disease. Unfortunately, repeated transfusions frequently lead to iron overload that can cause severe damage to the heart, liver, pancreas and the immune system. Newer technologies are becoming available to harvest young red blood cells from donors. These red blood cells will survive for a much longer period of time after being transfused to an individual but contain the same amount of iron. It is hoped that programs of transfusing new red blood cells to patients may lead to reduction in iron overload. It is also possible that programs that involve removal of a small quantity of patient's own blood and replacement of that quantity by donor blood will lead to improvement levels without any net gain in iron.

Because of his link with the Canadian Blood Services, Dr. Alan Tinmouth is going to coordinate studies evaluating whether these newer transfusion technologies will provide improved outcomes for patients with hemoglobinopathies.

ORDER SONS OF ITALY COLUMBUS DAY DANCE

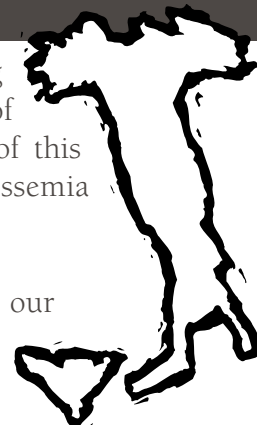
Connie Bennedsen

On October 27th, 2001 the Fiorente-Patronato Lodge held their annual Columbus Day Dinner Dance at Villa Monaco in Concord, Ontario. A gathering of friends and guests enjoyed the evening of excellent food, great music and good fun.

This event marked the 52nd consecutive Columbus Day Dinner Dance held by the Fiorente-Patronato Lodge. Through the years, the Lodge has been involved with many charitable projects.

The order has been supporting the Thalassemia Foundation of Canada since 1985. Proceeds of this Dance will go to the Thalassemia Foundation of Canada.

We would like to thank all of our donors and to everyone who came out to enjoy the evening.



MORE PAST EVENTS AND FUNDRAISERS

CIBPA FASHION SHOW

Stefanie Polsinelli

On Tuesday October 23rd, the Ladies' Auxiliary of the Canadian Italian Business and Professional Association (CIBPA) held their annual fundraising fashion show. Luckily for us, this year the Thalassaemia Foundation of Canada was chosen as its pet charity.

The event was held at the Royalton Banquet Hall, a fairly recent addition to the city of Vaughan.

The evening started with a few quick welcoming speeches, followed by a thank-you voiced by Corrado Falcitelli, the Foundation's spokesperson for the event. Corrado's talk was witty and informative; unfortunately, with the noise the audience was making at the time, not a word of it was heard by people sitting further away from him than the front row. This matter was addressed when one of the senior members of the Ladies' Auxiliary later publicly apologized to Corrado on behalf of everyone present.

The evening progressed smoothly after that. The dinner was delicious and everyone seemed to enjoy this chance to have a "ladies night out". Although

the event was planned to start at 5:30 p.m., dinner was not served until about 8 p.m., which in turn made the fashion show start about two hours after that.

The fashions featured came from well-known stores like Laura II, Roma Furs, Melanie Lyne, Tuxedo Royale, and Zero 20 Bambini. The styles shown were the latest Fall fashions from the stores located in the Greater Toronto Area and surrounding cities. The show included clothing styles for women, men and children. The clothing ranged from casual everyday-wear to formal dresses and suits appropriate for the upcoming holidays.

The models used in the show were great, but the kids stole the show. They sashayed down the catwalk like pros even though it was hours past their bedtime.

The total monies raised for the event have yet to be announced. A cheque will be presented to Foundation member Angela Polsinelli at the next Ladies' Auxiliary function.

CAMBRIDGE DINNER DANCE

Connie Bennedsen

On November 10, 2001 the Aurora Lodge, Order Sons of Italy of Canada held a fundraising Dinner for the Thalassaemia Foundation of Canada.

All who attended had a great time. Good food, great music and lots of prizes to be won.

We would like to thank Josie Cumbo National Charity Chairperson, Order Sons of Italy of Canada, for all her time and effort into making this event a huge success. Way to go Josie!

Thank you all for attending and hope to see you all next year.

From left to right: Connie, John Anna, Angela, Joe, Amadeo, Enza.



Second Annual VW Beetle Raffle



The time is fast approaching for our Second Annual VW Beetle Raffle. Our 2002 VW Beetle is presently being built and will soon be delivered to VW Canada Headquarters. The details are similar to last year. Only 5000 numbered tickets will be sold at of \$10 per ticket. The Grand Prize is a 2002 VW Beetle.

The draw will be held at our 13th Annual Valentine's Dinner/ Dance on Saturday, February 16, 2002. The Valentine's Dinner/ Dance will be held at La Perla Banquet Hall located at 8083 Jane St.

Toronto. The cost of the full dinner and deluxe open bar is \$90 per person with a partial tax receipt issued. The winner of the Beetle will be announced at the Valentine's Dance. If the winner is not in attendance, they will be contacted by our Foundation.

For information or to order tickets for the VW Beetle Raffle tickets or our Valentine's Dinner/ Dance contact:
Thalassemia Line: (416) 242-THAL (8425)
Angela Polsinelli:(416) 244- 5211
Corrado Falcitelli: cfalce@yahoo.com



2001 Winner: Helène Koulston from Montreal. Raffle Ticket #03577

GUELPH CHAPTER'S 8TH ANNUAL FUNDRAISER

On Friday, November 9, 2001 a dozen TFC members from Toronto headed west along the 401 to Guelph. We arrived at the Guelph Place Banquet Hall to a warm welcome for their TFC – Guelph Chapter's 8th Annual Dinner/Dance Fundraiser.

We remembered friends...lost and celebrated their life and the evening with great food, music, and conversation. The highlight of the evening was when a whole roasted pig was brought out and portioned

out to all until only its head remained. Then, that little piggy went on the auctioning block. A frenzied bidding session followed with the winning bid coming in at \$250!

Thanks to all that contributed door and raffle prizes, Guelph Place staff, and all the attendees.

Kudos to Anita Aimola and her entire organizing committee and for once again producing a fabulous event!

ORDER FORM (cut off date for mail order: Jan 15, 2002)

I WOULD LIKE TO PURCHASE THE FOLLOWING TICKETS:	
_____ 13TH ANNUAL VALENTINES DINNER/DANCE @ \$90.00 EA _____	
_____ TICKETS FOR WIN A VOLKSWAGEN BEETLE @ 10.00 EACH _____	
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POSTAL CODE: _____	
PLEASE CHARGE MY VISA CARD THE ABOVE AMOUNT:	
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PLEASE MAIL IN YOUR ORDER TO THE ADDRESS BELOW - Make cheque payable to: Thalassemia Foundation of Canada

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Special Thanks to everyone who submitted in articles and pictures for this newsletter.