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FROM THE DESK OF THE PRESIDENT

AND NOW THEY ARE NO MORE

In the beginning of the New Millennium year 2001, our foundation was filled with hope and expectation that life would improve for our Thalassemia patients, instead it turned out to be five months of sadness. Sorrow and uncertainty in that one by one five of our young adult patients lost their fight against the dreaded disease including our dear friend and long time editor of the newsletter, Gino Fortunato, age 35.



tals caring for young adult patients are inadequate and grossly under funded. A concentrated effort on our part must be made to convince the Health Authorities that an increase in funding for Thalassemia Programs are urgently needed in order for our patients to receive adequate care and counselling.

With your help we can make a difference.

God Bless,
Chris Bennedsen, President

It has now become increasingly clear to us that Thalassemia programs at hospi-

1ST CANADIAN CONFERENCE ON HEPATITIS C

Thalassemia Foundation of Canada has a team of volunteers working on a two year project called Hepatitis C Education In Thalassemia which is funded by Health Canada. The project, which will conclude on March 31, 2002, is designed to promote understanding and awareness of hepatitis C in the thalassemia community. The project goals are to provide support within the thalassemia community to thalassemia patients infected with hepatitis C, and to improve the knowledge base of such patients in terms of treatment options and prevention practices.

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1ST CANADIAN CONFERENCE ON HEPATITIS C cont'd

In an effort to achieve the objectives of the project a representation from the thalassemia community attended the 1st Canadian Conference on Hepatitis C. The conference was held on May 1st to May 4th, 2001 at the Montreal Hilton Bonaventure. A brief summary on some of the knowledge learned from the conference is provided below.

Health Canada, Ontario Ministry of Health and Long Term Care, Quebec Ministry of Health and Social Services, and Schering Canada Inc.'s Biotechnology Oncology Unit sponsored the conference. The Canadian Hemophilia Society and a steering committee of community and professional organizations led the organization of this huge conference. Approximately 750 people attended this very informative conference. Amongst the 750 present were researchers, scientists, care and treatment providers such as doctors, nurses, lab technologists and social workers. Many people who have hepatitis C or have family members with hepatitis C also attended.

The topics of discussion were on the natural history of the hepatitis C virus, how the infection occurs, hepatitis C diagnosis, along with testing and transmission of Hepatitis C. Also covered were risk and prevention, the quality of life for hepatitis C infected patients, living with hepatitis C, which involved the social perspective as well as legal, ethical, and human rights issues. The last of the topics covered included future therapy, vaccine development, complications that can occur in Hepatitis C, and liver transplantation.

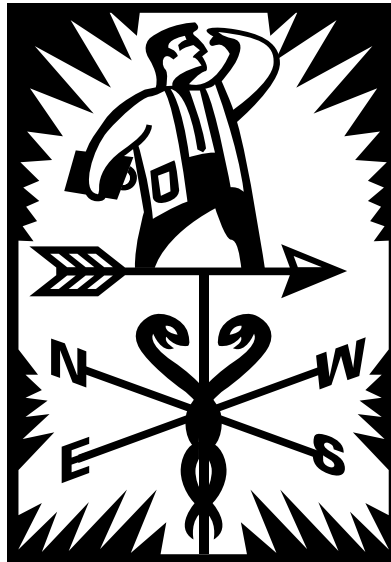
Nearly 300,000 people in Canada are infected with the hepatitis C virus, only 30% of these people are aware that they have the hepatitis C virus. Hepatitis C affects everyone differently. Depending on a patient's individual situation, hepatitis C can be considered a mild, chronic, severe or fatal disease – it is not the same for all people. Hepatitis C can progress very slowly and some people can live with hepatitis C for many years without ever feeling unwell. Or hepatitis C can progress very quickly, in which it can become a serious threat to your health in as little as

ten years. There are 2 types of hepatitis C – acute hepatitis (short term infection) and chronic hepatitis (long term, progressive infection). Iron and alcohol will advance the damage caused by hepatitis C. Cirrhosis is a predictor of liver cancer; experts believe that if there is no cirrhosis, then there is no problem.

Infection is by blood of an infected person with blood of another. Shared saliva isn't a cause of infection. The risk of spreading hepatitis C through normal household contact, breast-feeding, or kissing your family or friends, is very low. Sexual transmission is very low in monogamous, long term couples; however, menstrual blood is known to carry HCV and women should take precautions or avoid any sexual activities during that time. Although there isn't complete agreement from experts, transmission from mother to a newborn child (vertical transmission) is less than 10%. Blood etiquette should be practiced by all: infected or not – do not use razors, toothbrushes or anything that has contacted another person's blood.

Medical research has also linked the relationship between toxins, free radicals and the promotion of disease. Healthy detoxification and reduction of free radicals in the body promotes health and can prevent disease. In the case of thalassemia, the major cause of free radical production is free iron; so once again, the importance of decreasing iron load by using Desferal is recommended. Studies have also shown that quality nutritional supplementation may prevent and treat degenerative disease states. Hepatitis C patients will benefit from optimum liver health and for healthy living.

Treatment can slow the damage to the liver and even prevent the development of cirrhosis. Some of the early therapy for hepatitis C was interferon. This therapy did not prove to be too successful; the response rate on this therapy was below 15%. The next therapy was interferon + ribavirin and the response rate to this was 16-69% depending on the genotype, and the degree of liver damage. Patients



with cirrhosis responded a lot less to this treatment than patients who had less advanced liver damage. Some of the side effects include anemia, depression, insomnia, weight loss, loss of appetite, fatigue and flu-like symptoms.

Future therapy, which is under a clinical study phase, is pegylated interferon alone. The success rate on this is between 13-59%. The success rate for pegylated interferon + ribavirin is 33-88%. This looks like a very promising study and its side effects is less. Additionally, pegylated interferon is long-lasting which means injection would be required only once a week instead of 2-3 times a week. The estimated cost for this treatment is approximately \$15,000 US per person for one year. This treatment brings down hemoglobin levels drastically. This means that patients with thalassemia major would require blood transfusions much more often. This would result in an extremely high iron content within the body. Other future therapies are interferon with enzymes, chemotherapy (medications) that fight the processing of the virus (for example:

inhibitors of polymerases, helicases, or proteases). Vaccine development for hepatitis C is very difficult because of the virus' very unique ability to evade the body's immune system. Overall, there is much hope for the future of hepatitis C, many experts are enthusiastic that some treatments may be able to cure people of the virus in the future.

Thalassemia Foundation of Canada is committed to promote awareness and education on hepatitis C in thalassemia. Information packages on hepatitis C, including details from the conference, will be mailed by the end of June to individuals on the Hepatitis C Update List and posted to the www.thalassemia.ca web site. I encourage those who don't have hepatitis C but would like to receive information on hepatitis C to contact me at **416 968-0720** or e-mail riyad@thalassemia.ca

Special thanks to Naushy Mullani for her assistance in providing the report on the conference.

Riyad Elbard

THE 11TH INTERNATIONAL CONFERENCE ON ORAL CHELATION CATANIA, SICILY

The 11th International Conference on Oral Chelation in the Treatment of Thalassemia and Other Diseases was held March 22-25 in Catania, Sicily. Angela Polsinelli, a TFC board member, attended the conference as a representative for the Foundation. There were many participants, especially doctors from all over the world.

Some of the doctors involved were:

- Dr. B. Wonke from London
- Dr. C. Politis from Athens
- Dr. A. Piga from Torino
- Dr. D. Pennell from London
- Dr. L. Korkina from Moscow
- Dr. G. Kontoghiorghes from Cyprus
- Dr. R. Grady from New York
- Dr. V. Eybl from Czech Republic
- Dr. A. Cohen from Philadelphia
- Dr. A. Cao from Cagliari
- Dr. M. Agarwal from Bombay
- Dr. M. Spino from Toronto
- Dr. F. Tricta from Toronto
- Dr. C. Vullo from Ferrara

The thrust of the conference was the treatment of iron overload. Although Desferal is still the chelator of choice, many doctors are looking at the possibility of treating patients with a combination of Desferal and oral chelators such as L1. Doctors around the globe are starting to realize that not every patient can be treated in the same manner; there is not only one protocol suitable for all people. A more individualized approach is necessary due to the many differences in patients. For example, for patients with reactions to Desferal, alternating the drug with L1 would allow these patients a "breather" and hopefully help them deal with their reactions.

The conference left the participants with a positive outlook. What became obvious from the meetings is that there are many scientists out there looking for other oral chelators that might be able to solve the problems being faced by patients.

Stefanie Polsinelli
ciro@poassport.ca

TIF REPORT

This year is a TIF International Conference year. TIF 10th International Conference for Parents and Thalassemics in conjunction with the 8th International Conference on Thalassemia and the Haemoglobinopathies, will be held October 18-21, 2001 at Asitir Palace Resort, Athens, Greece. Scientific discussions on all aspects of Clinical Management of Thalassemia, and Scientific sessions addressed to parents and thalassemics in simpler language will be presented and translated from English to Greek and Italian. Parents and Thalassemics enter free to all scientific presentations. The conference seems to be interesting and very educational.

This year is also a general election year. Eleven countries that are general members will be eligible to become voting members at the next General Meeting in Athens. This transition will give them the right to vote for or be voted as Board Members. To exercise these democratic rights and to encourage more participation by all members, TIF has been increasing

its efforts in promoting and supporting the formation of stronger associations in all countries.

TIF Office has been busy on planning and organizing workshops and supporting various educational and scientific events. TIF Workshops were directed on Blood Safety, Clinical Management of Thalassemia, and Compliance. The project on Epidemiology of Thalassemia has been completed. This has provided interesting and useful information on Clinical Management Patterns and Burden of Illness.

Publication on Prevention of Thalassemia is one of the major projects for TIF this year. This project is an important part of TIF's goal to establish and strengthen prevention policies in countries of high Thalassemia incidences. The publication, which is in its final stages, will be in two parts and will provide the best information possible on prevention policies to National Public Health Authorities where needed.

cont'd on next page

PAST EVENTS

UPDATE ON THE WINNIPEG CHAPTER OF THE TFC

On November 4, 2000 the Winnipeg chapter held a Bingo Bowling fundraiser with the support of its community and proud sponsors, such as Calabria Market and Deli- who donated the late snack.

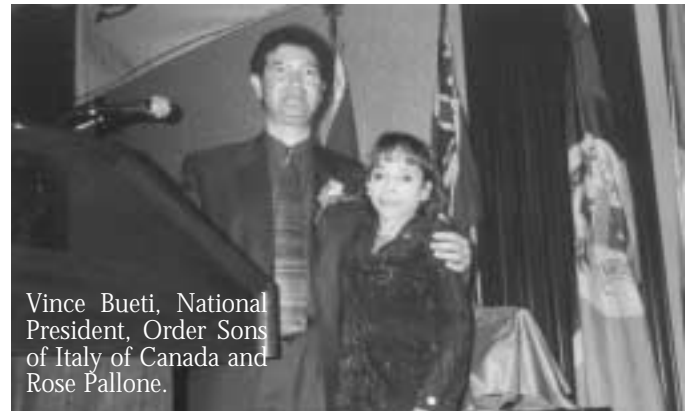
The fundraiser brought in nine hundred dollars, which the Winnipeg chapter will use for research and patient support services.

On this occasion, the Winnipeg chapter also presented Calabria Market and Deli with a plaque of appreciation.

On March 17, 2001, President Rose Pallone and Treasurer Gena Beco of the Winnipeg chapter attended the Sons of Italy Dinner and Dance. Rose, who spoke on behalf of her chapter, received a donation cheque from the Sons of Italy.



Rose Pallone, President of Thalassemia Foundation of Canada, Winnipeg Chapter with Derek Nonzy, Owner of Calabria Market and Deli.



Vince Bueti, National President, Order Sons of Italy of Canada and Rose Pallone.

Mr. Loizos Pericleous, Secretary of TIF, led the delegation visit to Morocco on February 23rd to 27th. The outcome of the visit was very positive in providing TIF the grounds to build a close and fruitful collaboration with all interested parties in Morocco. Future delegation visits are on the agenda. Also, educational events are planned in Libya, Morocco, Tunisia, Algeria, Egypt, Jordan, and UK.

The last TIF Board Meeting was held at TIF Headquarters in Cyprus on March 10th and 11th. A discussion on the financial status of TIF and ways of securing its long-term survival was a major item on the agenda. This has been a concern in the last few years as TIF activities expanded in participating and planning events and in providing more services.

I would like to conclude this note by thanking everyone for his or her continuous support to TIF. Also, I hope that I would see many of you at TIF International Conference in Athens. It would be a great opportunity to learn the latest on Thalassaemia, share a good time and enjoy meeting new friends.

I remind everyone that I could be reached at tel: 416-968-0720 E-mail: riyad@thalassemia.ca for any further information on TIF or the conference, or any other related matter.

Riyad Elbard,
Treasurer, Thalassaemia International Federation
Trustee, Thalassaemia Foundation of Canada

PAST EVENTS

CORRADO FALCITELLI'S CHARITY BIRTHDAY PARTY 2001

On Saturday, March 17, 2001, the third annual Birthday/ Fundraiser was held at Acrobat Restaurant Lounge. Friends and family attended the annual event to catch up with old friends, meet new friends and raise money for the Thalassaemia Foundation of Canada. I hope to see more friends attend next year's Fourth Annual Fundraiser. Special gratitude to Acrobat for providing the guests with various hot and cold Hors d'oeuvres.

Corrado Falcitelli Email: cfalce@yahoo.com



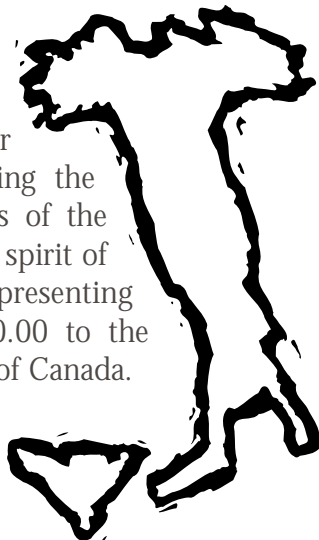
Corrado Falcitelli, Vice-President Thalassaemia Foundation of Canada (right) with brothers Tony (left) and Gino (middle) and sister-in-laws at Annual Birthday Fundraiser, Acrobat Restaurant Lounge.

SONS OF ITALY CONVENTION

May 18-21, 2001
Hamilton, Ontario

At the orders Gala-Dinner Awards Night held during the convention, many lodges of the order showed their usual spirit of caring and giving by presenting cheques totalling \$7,300.00 to the Thalassaemia Foundation of Canada.

Our thanks always,
Chris Bennedsen.



L.I.U.N.A LOCAL 506

Labour International Union Local 506 held their annual Nick Barbieri Charity Bocce Tournament August 11th 2000. A total of \$14,000.00 was raised at this event.

At a ceremony held at the Ambercroft Training Centre, Richmond Hill on February 13th 2001. A cheque for \$7000.00 to the Thalassaemia Foundation and a cheque for \$7,000.00 to the Juvenile Diabetes Foundation was presented to representatives of the foundation.

Our thanks and appreciation to the Local 506 for their generous donation.

Chris Bennedsen

THE 12TH ANNUAL VALENTINE'S DINNER DANCE

A night you shouldn't have missed and you should not miss in years to come. A glamorous evening with exquisite food, an amazing live band and a stunning hall. Not to mention, the women in gowns and the men in classy suits and for a reasonable price of \$90 a ticket. You can win door prizes, there are silent auctions and the grand prize of a Volkswagen Beetle car all for a good cause, the Thalassemia Foundation of Canada.

Sam Ciccolini was the master of ceremonies to approximately 500 people Saturday night. People enjoyed a wonderful dinner, deluxe bar and luxurious accommodations provided by Le Pare Banquet Hall. I was eyeing all the exquisite collections in the silent auction. My personal favourites were the jewellery donated by Ashely Jewellery and the paintings such as "Northen Barns" and "The Earthly Paradise" (Salvador Dali). Oh yeah, I definitely needed that 19" T.V. in my bedroom (donated by Joe Gallo Bros. Paving). And if you were a big Raptors fan you could have bid for tickets during the live auction (donated by Masters Insurance Ltd.).



Valentine Dinner Dance, Cheque presentation

Congratulations to all those who won prizes and those who participated in the auctions. A lucky lady in Montreal, Helene Roulston, won the Volkswagen Beetle car. To all volunteers, sponsors who donated gifts, corporate sponsors, ticket and dance committee, executive directors, trustees, board members, clubs and community groups, and all those who made this evening a night to remember and all for a good cause - WE THANK YOU!

During dinner there were speeches being made and special awards handed out. Dr. Peter Liu, Director, Heart & Stroke, was the guest speaker for the evening. Chris Bennedsen was granted the Appreciation award. Guiseppe Decicco, a corporate sponsor from the Swimming Pool Restaurant Bar & Lounge (Dufferin south of 401) won the Heart award. And finally Riyadh Elbard won the President award.

After dinner, the night was still young, and young it made you feel. The band Masquerade brought you back far enough to the good old days and make you feel like dancing. Even if you forgot your dancing shoes at home there was no way that your feet would let you sit still. Masquerade did an outstanding performance - and who would have thought that the blond guitar player/singer was Italian?!!! The extravaganza ended at 1:00 am. I was sad to leave a night of continuous excitement but my feet needed to rest.

See you next year!
Good health and God bless.
Carmelina Salituro

THALASSEMIA FOUNDATION LAUNCHES WEB SITE

The Thalassemia Foundation of Canada is proud to announce the launch of its Web Site at www.thalassemia.ca. Ten years ago, the Foundation held its first meeting. Since then, we've spent endless hours discussing, planning, and working together to educate ourselves - and the public about Thalassemia. Through its newsletters and meetings, we're proud of the work that's being done. As we look towards the future, we recognized one very important means of disseminating this information that we've been missing - the Internet. By posting this information on our Web site, we look forward to reaching more people than we could have imagined before.

Looking to the future: As the Foundation starts to grow, we'd like to hear your comments. To submit an article, to sign up for our bimonthly newsletter with the latest Web site information, or to just give us your comments, please fill out the feedback form on our site or send an e-mail to info@thalassemia.ca. Let's work together to get this information out there. After all, it's your foundation too!

Angela Malandrino - blueseptember73@yahoo.com

EUGENIO (GINO) FORTUNATO 1965 - 2001

As I meet all the people in my brother's life, the same words left their mouth, "He was a nice guy. He always had a smile. He never complained. He was strong." I knew that, I'm his youngest brother. But what sitting there in that funeral home allowed me to do, is to understand how truly difficult it must be to walk in my brother's shoes. That I didn't know. I didn't think about how much strength it must take to go through every day with as many challenges as Gino faced.

Gino would start his day by pricking his finger to monitor his blood sugar level, one of many times in an average day. If sugar levels are high, an insulin shot is taken, no problem. The breakfast, along with cocktail of many pills, which requires a medical team to keep in check. In between helping out friends with PC problems, tinkering on the web and crusading for that Thalassaemia Association, more pills and needles. Throughout it all, Gino very rarely complained or answered negatively when asked, "how are you?".

Every few weeks, Gino would visit the hospital for biopsy, blood transfusion, foot checkup or whatever else came along in his medically full life. Many of us take for granted that we can get up, eat and go somewhere without having to monitor our health, taking a host of pills or making our routine trip 'the hospital'. Many of us grumble and are the first to tell other in detail how awful we feel when we have the inconvenience of a cold or flu. After witnessing my brother stick himself with butterfly needles on a daily basis, I soon stopped to ask people how they were. I now ask, "how it goes?". One of the many lessons my brother taught me.

We have met or seen people who have terrible terminal illness or just in 'rough shape'. Many people find this to be a perfect excuse to adopt a huge chip on their shoulder and drain the happiness from the people whom they know. Some people barricade themselves in their room, or within themselves and refuse to come out. How does someone know that their days are numbered far shorter than others get up and look forward to helping anyone? Why would someone with these circumstances choose to even bother learning something new; like the web or



PC's? We know many able bodied people who choose not to learn or help on a daily basis. Not only that, but Gino also traveled to Italy, Australia, purchased a new car and regularly bought lottery tickets. His actions proved that Gino had no plans to pack it soon.

It seemed that every day Gino woke up, he felt that this might be his last day so he better make it count. Many of Gino's friends who appreciated this simple fact, loved his courageous spirit.

Even as children, Gino, Vince and I were typical brothers. We played hockey, rode our bikes and got into mischief. You would never think that Gino was any different than the rest of us. Even his crazy inventions, home made fireworks and ability to test even our parent's patience, gave the impression that all was normal. To my surprise even many of these childhood friends came to the funeral home. Afterwards, we exchanged childhood stories and realized that this was the essence of Gino, a general good time with friends.

Now that my brother has passed on, what can I say? My brother never said too much (other than the occasional joke), he was a man of action, a courageous soul who prided himself on his gift of compassion.

I hope that we learn from Gino's example and become generous and grateful with whatever hand God has dealt us.

Tony Fortunato

TORONTO MINI-CONFERENCE

The TFC is planning a small conference in Toronto for an upcoming weekend in the fall. This will give patients, parents and doctors an opportunity to gather in one place from all over Canada and the United States to share new developments and information. Keep your ears and eyes open for more details. If you have any topics in mind that you would like to discuss, we would appreciate any suggestions. Fax us at (416) 242-8425. Don't forget to check our Web site for further details.

FUTURE EVENTS

INTERNATIONAL CONFERENCE IN GREECE

From October 18-21, 2001, Greece is going to be buzzing with activity. The 8th International Conference on Thalassemia and haemoglobinopathies in conjunction with Thalassaemia International Federation (TIF) 10th International Conference for Thalassemia Parents and Thalasseemics. Both events will be held at the Astir Palace Resort in Vouliagmeni, Athens. Parents and Thalasseemics enter free to all Scientific Sessions. Translation from English to Greek and Italian is provided during all sessions.

Friday, October 19th and
Saturday October 20th, 2001

Two days of scientific discussions on all aspects of the Clinical Management of Thalassemia.

Sunday 21st October, 2001
Morning Sessions:

Scientific sessions addressed to parents and thalasseemics in simpler language. Besides from the medical conference and meetings, there will be gala dinners and an evening tour of Athens. It appears that both conferences are going to be very interesting. Details will follow in the next few months - keep an eye on our Web site. For more information, prices, and new developments, call Riyadh Elbard, our TIF representative, at (416) 968-0720 or e-mail: riyad@thalassemia.ca.



Roma Fence Golf Tournament at the Kleinburg Golf and Country Club, followed by dinner at Villa Monaco - July 25, 2001

The Sons of Italy Columbus Day Dance at the Villa Monaco - October 27, 2001

TFC Children's Christmas Party at the Hospital for Sick Children - December 9, 2001

CHANGE OF ADDRESS

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| |
|----------------------------------|
| Name _____ |
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| _____ |
| City _____ |
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Guelph Dinner/Dance

The Guelph chapter of the Thalassemia Foundation of Canada will be holding its annual fundraiser on Friday, November 9, 2001. It will be held at the Guelph Place Banquet Hall, with cocktails being served at 6:30 P.M. The price for tickets for the event is still to be determined. As in the past, there will be a raffle and door prizes. Any donation of prizes is greatly appreciated. Money raised will go to the Thalassemia Foundation.

The Guelph chapter extends this invitation to everyone, and hopes that many Toronto patients, and the families and friends will be able to make it.

The chairperson for this event is Anita Aimola.
Email: guelph_chapter@yahoo.ca

Write Us

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