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FROM THE DESK OF THE PRESIDENT

UNIVERSITY HEALTH NETWORK'S STRATEGIC PLANNING DOES NOT INCLUDE IMPROVING OR EXPANDING THE THALASSEMIA AND SICKLE CELL PROGRAM AT THEIR "CENTRE OF EXCELLENCE" AT THE TORONTO GENERAL HOSPITAL, ACCORDING TO TOP ADMINISTRATIVE OFFICIALS FROM THE HEALTH NETWORK.

The program deemed an "Academic Jewel" a few years ago, a program UHN would preserve and protect apparently proved to be too costly for the administration due to the highly specialized care, regular transfusions, monitoring, and counseling that Thalassemia and Sickle Cell patients require to sustain life. Their request to the Ministry of Health for additional funding for the program was denied.

After five exhaustive meetings at the Toronto District Health Council over the past seven months, the UHN's position as described above has changed slightly to a commitment to recruit in order to return to the same service level as it was a few years ago, i.e. to having a full-time hematologist as opposed to a part-time one as it is currently. Other many positive aspects of specialized and quality care for adult Thalassemia and Sickle Cell patients were also discussed. As it stands urgent and immediate action is required to improve the condition at the clinic at Toronto General Hospital. Since a cap of 98 patients were imposed two years ago by the CEO, COO, and UHN's Board, the conditions at the clinic have gradually deteriorated to the point where patients dread the thought of going there for their monthly transfusions and monitoring. If it were not for the dedicated efforts of the Nurse Co-ordinator and the Social Worker at the clinic, it would appear to be a place waiting for a disaster to happen.

It bears ill for the forty Thalassemia and thirty-five Sickle Cell patients over the age of 18 years old, that are at the present time practically standing in the doorway at Sick Children's Hospital waiting to be transferred to an adult facility that has the space and know-how, to



provide them with the specialized treatment and care they require throughout their adult life. In three years that number will swell to sixty for Thalassemia patients and ninety-one for Sickle Cell patients.

At the present time, the Toronto District Health Council is preparing a final report of the findings and recommendations of the working

group, which will then be presented to the Ontario Ministry of Health, hopefully within the next three weeks. Following immediately with an urgent request from the Thalassemia Foundation of Canada and the Sickle Cell Association of Ontario, that the report be dealt with as a high priority item.

We sincerely hope that the time and effort of the many people involved in these proceedings will not have been in vain, and that positive results will start to surface in the New Year.

Our best wishes for a safe and happy holiday season.

God Bless,
Chris Bennedsen, President

IN THIS ISSUE

- From the Desk of the President
- A Social Worker's Message
- Sons Of Italy Dinner Dance
- MINI Cooper Car Raffle Update
- Basilicata Social Club Di Toronto
- First International Thalassemia Associations Workshop
- Guelph Dinner and Dance
- Vancouver Thalassemia Society Walkathon

A SOCIAL WORKER'S MESSAGE



Greetings from the Hospital for Sick Children! I have been given the opportunity to introduce myself and talk a little bit about what Social Work services in the Thalassemia clinic are all about. For those of you who regularly come to the Hospital for Sick Children I am the

new face on the team – having joined at the beginning of June and replacing the previous Social Worker, Kathy Netten who has moved to another program at the Hospital. Although new to the Hospital I bring with me seven years of experience working with children and families in a variety of settings, and I look forward to the challenges and opportunities at the Hospital.

I have already had the opportunity to meet many children, teens and their families and I am struck by some of the common things that patients and families at the clinic cope with:

- For some families, learning the diagnosis of their child and making emotional and family adjustments can be a very difficult time.
- For other children and families difficulties come when Desferal treatment and blood transfusions become part of the routine.
- Children may need support from parents and school to accommodate lower levels of energy and school absences.
- Several teens have talked to me about what it is like to try to juggle a growing social life with Desferal needles, and how it may take a lot of support to stick with the treatment.

At the Hospital for Sick Children, Social Workers are attached to the various programs to provide professional therapeutic support to children and families that is based in an understanding of the child's disease. This may be different from speaking to a Social Worker in another setting who may not be as

informed about what it is like to live with Thalassemia. There are a number of ways that I can provide support to patients and families. I am able to offer individual counseling for children and teens and counseling for parents, couples or families. I may be able to assist in linking families to community resources if there is a need for financial help or home support. In addition some families have found it helpful to have an advocate working with them in the hospital or in the community or school for various concerns.

I would invite children, teens and parents to speak with me about:

- A child or family's adjustment to Thalassemia and treatment
- A child's difficulties at school or with other children that arise because of Thalassemia
- Times when you experience stress and how you can cope
- Parenting issues and concerns about your other children
- Family conflict which may affect your ability to cope
- Financial difficulties created by your child's illness or treatment
- Concerns that you or your child may be at risk of emotional, physical or sexual abuse
- Concerns about communication with the health care team

In my conversations with patients and families in the last few months I have been struck by the challenges that Thalassemia presents, but I have also been struck by the strengths of parents and children. In particular I have observed that some children have become very involved in their own treatment and have become very sensitive to the situations of others as a result of their own experiences. I hope to be able to work with families along this journey of living with Thalassemia and would encourage you to contact me at the hospital or through the clinic nurses during appointment times.

Wendy Bulthuis MSW, RSW
Clinical Social Worker
Sickle Cell/Thalassemia Program and
Clinical Genetics/Metabolics Program
The Hospital for Sick Children

BASILICATA SOCIAL CLUB DI TORONTO

On Saturday, November 16, 2002 the Basilicata Club of Toronto celebrated their first anniversary at La Perla Banquet Hall. Close to 700 people attended the dinner/ dance that also honoured the memory of Johnny Lombardi (CHIN International). The evening was broadcast and televised by CFMT and CHIN International. Andrea, Thalassemia patient of HSC,

and Dr. Kirby briefly spoke to the guests and thanked them for their support. The Thalassemia MINI Cooper was put in the entrance of the hall and raffle tickets were sold on site. All proceeds of the evening will be kindly donated to The Thalassemia Foundation of Canada on behalf of Tony Ottorino, President of Basilicata Social Club.



Andrea (patient at HSC) and Dr. Melanie Kirby (hematologist at HSC)



*Corrado Falcitelli (left) Vice-President of Thalassemia Foundation of Canada
Tony Ottorino (right) President of Basilicata Social Club Di Toronto*

MINI COOPER CAR RAFFLE UPDATE

We are well into the MINI Cooper raffle with just over 2 months left before the lucky winner is announced. Over half of the tickets have been sold and the car has done its rounds of the GTA. The car is situated at The Swimming Pool and tickets are available at the MINI's

headquarters located at 3200 Dufferin St (416) 782-SWIM. Other locations that have graciously sold tickets and held the MINI on site for the Foundation include: Acceso Restaurant & Bar, Andrews Restaurant, Apotex Inc, Novex, Norwest Precision Ltd., Poolside Café, Tazza Espresso Bar & Café, The Man Show at the Toronto Congress Centre, TorPharm, Williams Coffee Pub in Etobicoke.



*MINI Cooper Car Committee (l to r Mike, Corrado, and Joe)
Pictured in front of the MINI Headquarters at The Swimming Pool-3200 Dufferin St (416) 782-SWIM*

Let us make an extra effort to sell all 5000 tickets this year, the more tickets that are sold, the more money will be raised for the Foundation. If there are any questions do not hesitate to contact me via email: Corrado Falcitelli cfalce@yahoo.com

14TH ANNUAL VALENTINE'S DINNER/DANCE

The time is fast approaching for our 14th Annual Valentine's Dinner/Dance. As in previous years we are doing a car raffle. This year the grand prize is a 2003 MINI Cooper. The draw will be held at our 14th Annual Valentine's Dinner/Dance on Saturday, February 8, 2003. The Valentine's event will be held at The Regency Banquet & Convention Centre located at 8400 Jane St. (North of Hwy. 7). The cost of the full dinner and deluxe open bar is \$90 per person. The tickets for the car raffle are \$10. Proceeds of this event and raffle go to assisting the Thalassaemia Foundation of Canada in funding Thalassaemia research and purchase medical equipment for The Hospital for Sick Children. The winner of the MINI Cooper will be announced at the Valentine's Dinner/ Dance. If the winner is not in attendance, they will be contacted by our Foundation. For further information or to order

tickets for the MINI Cooper Raffle or the 14th Annual Valentine's Dinner/ Dance contact:

Connie Bennedsen: (416) 424-2578

Corrado Falcitelli: cfalce@yahoo.com

Raffle Tickets will be available and the car can be viewed at The Swimming Pool, 3200 Dufferin St. 416-782- SWIM (7946)



*Chris Bennedsen, President
of Thalassaemia Foundation
of Canada with the 2003
MINI Cooper*

FIRST INTERNATIONAL THALASSEMIA ASSOCIATIONS WORKSHOP September 26-27, 2002 Nicosia, Cyprus

TIF Office with the help of Cyprus Thalassaemia Association and the support of the Government of Cyprus held a very organized and very successful International Thalassaemia Associations workshop. Over seventy Thalassaemia associations from 35 countries around the globe attended the workshop. Representatives came to the workshop from Taiwan, China, The Pacific Rim, South East Asia, India, New Zealand, Australia, Europe, North Africa, The Middle East, Argentina, Brazil, Trinidad, and North America. A good number of Thalassaemia Patients were among the delegates, many of them are long time members of their local associations. The two days event was focused on presentations and discussions.

Opening ceremonies were marked by the welcome speeches presented by Mr. Frixos Savvides, Minister of Health of Cyprus, and Dr. Victor Boulyjenkov, Director of Human Genetics and Non-Communicable Disease of WHO. Mr Panos Englezos presented awards recognizing the great efforts of the dedicated individuals who contributed their support to the

Cyprus Thalassaemia Association and TIF Awards recipients were Religious dignitaries, Local politicians, ambassadors and founding members and volunteers of the Cyprus Thalassaemia Associations. The mayor of the city of Nicosia invited the participants to a welcome reception, and entertaining evening of folklore dancing at Famagusta Gate in the old city of Nicosia.

The morning session included presentations on WHO activities on the global fight of Thalassaemia, Blood Safety and the needs for Establishing National associations. Mr Panos Englezos, Chairman of TIF, discussed in his presentation details on activities of TIF on its fight against Thalassaemia. The afternoon topics focused on the main activities and functions of a National Thalassaemia association. Presentations delivered by representatives of long standing national Thalassaemia associations sharing their experiences and success stories.

Later in the day and the following day 10 minutes presentations were made by representatives of the participating associations on the activities of their respec-

tive associations and the conditions of Thalassemia and its treatment in their countries. Also time was allotted for open discussions at the end of each session. This allowed an opportunity for the participants to exchange their views and get objective answers to their questions on the topics of discussions.

Dr Antonio Piga, Director of Thalassemia Medical Centre of Torino, Italy, talked about policies of clinical care on the first day, and on the second day he talked about Thalassemia Reference Centre and the future of Thalassemia. His presentations were most interesting and very informative. He explained the guidelines currently used for clinical care and the requirement and establishment for a Thalassemia reference centre.

Ms. Dawn Adler delivered an excellent presentation on the activities of Thalassemia Action Group (TAG) USA. Also presentations by the delegates from Taiwan and Brazil captured attention of the participants.

I received compliments on my presentation. It was a brief summary on the mission of Thalassemia Foundation of Canada its history, founding members, major achievements, its main activities and fundraising functions. I detailed our active participation and collaboration as volunteer organization on the national, regional and local levels, and the current challenges facing Thalassemia Foundation of Canada. I also talked about the excellent health of Thalassemia patients in Canada and their normal lives as active members of society. I mentioned the great research programs at Canadian institutions and our support and contributions to research. Later that day I was

approached with many questions of interest and inquiries on the treatment of Thalassemia in Canada and the overall well being of Canadian patients.

Pharmaceuticals companies were strongly present at the workshop. Participants visited the display booths showing the latest medical products at the workshop. An hour session of products presentations was included in the program.

In his concluding remarks Mr Panos Englezos announced the donation of 160 Desferal infusion pumps to be distributed among the associations from developing countries. The pumps were handed on the same day to association representatives to take back with them.

The workshop was very successful in achieving its goals in bringing together the National Thalassemia Associations to work collectively on the fight against Thalassemia across the world. The participation was much larger than expected and the event was well organized. This will initiate new collaborations of associations with TIF and among associations. The hard work of TIF Office Staff and the efforts of TIF Chairman, TIF Board Members and the Cyprus Thalassemia Association were recognized and applauded for the success of the workshop. TIF Board is seriously considering the International Associations Workshop become a bi-annual event.

Riyad Elbard
Treasurer, TIF Trustee
Thalassemia Foundation of Canada

VANCOUVER THALASSEMIA SOCIETY WALKATHON

The Vancouver Thalassemia Society Walkathon was held on August 10, 2002. This was the 6th annual walkathon fund raising event the Society has hosted. It was held at Confederation Park in Burnaby from 11:00 am to 3:00 pm. It was a beautiful day, sunny with a cool breeze. It was very comfortable and a great day for a walk. We had about 35 to 40 members, friends and families that participated. The board of directors supplied soft drinks, chips and other snacks. The Society bought lunch that included KFC chicken and Pizza Hut pizza. Everyone enjoyed the picnic lunch very much. Shortly after the lunch, the walk

started around the field. Confederation Park has a lot of facilities including a large public swimming pool, children's playground, skateboard area, a tennis court, and a barbecue area.

After the walk, members had a good time for catching up and comparing notes on treatment of Desferal, blood transfusion, and other new things on the horizon. Kids were keeping themselves very busy enjoying the playground while the adults were talking. Later on some children and members ended the event with a swim.

Ken Lui

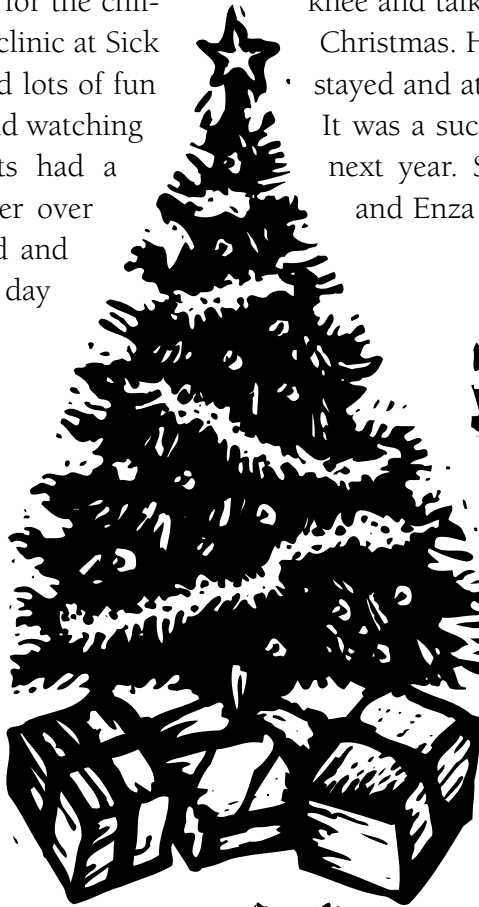
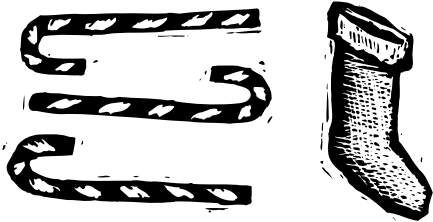
2ND ANNUAL CHILDREN'S CHRISTMAS PARTY

On Dec 8th, we held our second annual children's Christmas party. It was a great event for the children and parents of the Thalassemia clinic at Sick Children's Hospital. The children had lots of fun making reindeer antlers, colouring and watching Rusty the Clown while the parents had a chance to catch up with one another over coffee and goodies. Pizza was served and then Santa showed up to make the day

complete. All the children had a chance to sit on his knee and talk about all the things they wanted for Christmas. He gave all the children gifts and even stayed and ate some pizza!

It was a successful event and we hope to see you next year. Special thanks go to Connie, Sandy and Enza for organizing the event for the kids.

Angela Covato



THANK YOU DR. DAVID CHUI

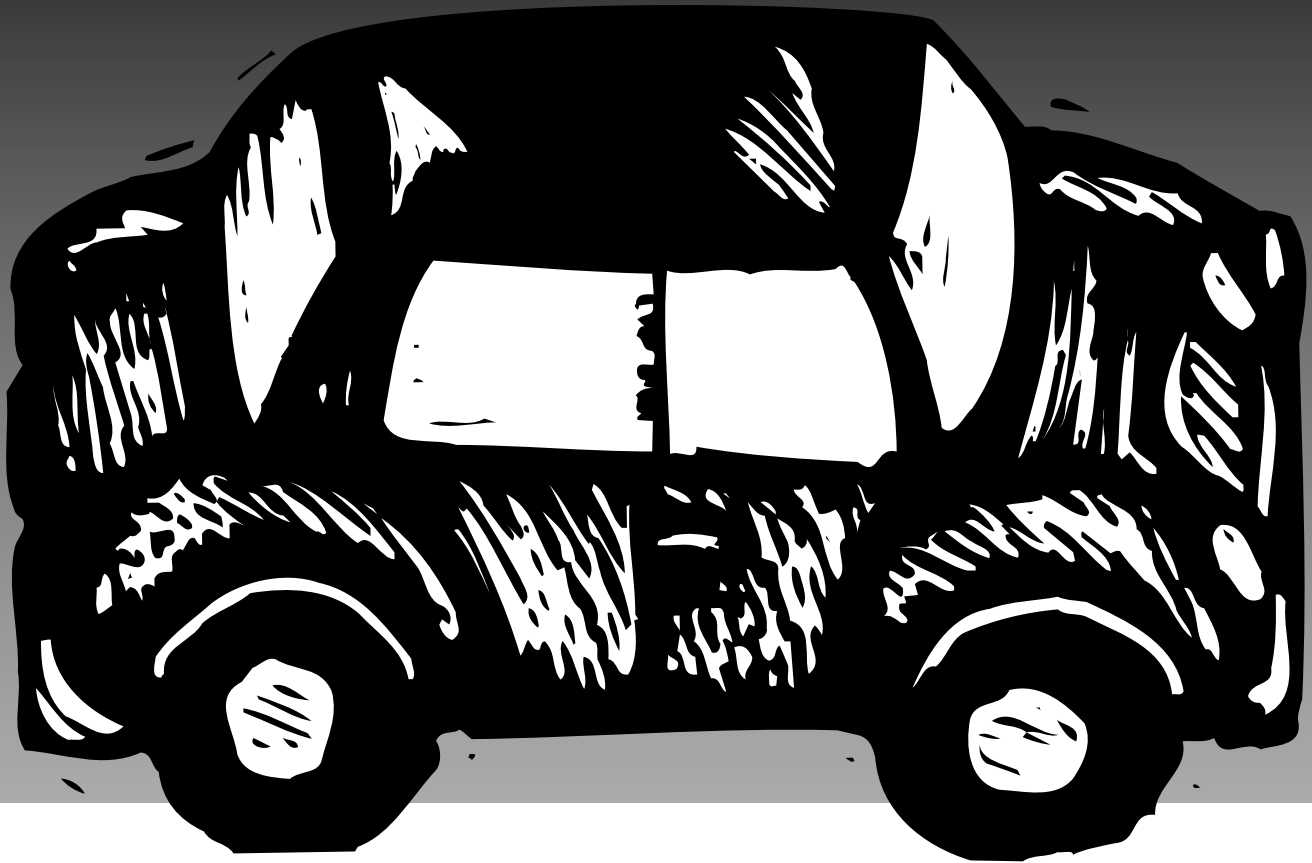
Dr. David Chui has been involved with the Thalassemia Foundation of Canada for over 10 years. He will be leaving his post at McMaster University in Hamilton and has accepted a position at Boston University in the United States.

Consequently he will be resigning his duties as Chair, Medical Advisory Board of our organization. Dr. Chui has been a member of the Medical Advisory

Board since its' inception and the Chair of it for the past three years. We have once again committed to over \$100,000 in research/operational grants to three promising projects for 2003. We wish to thank Dr. Chui for for all the help he has given to our foundation and for his gracious efforts towards Thalassemia research. We wish him great success in the future.

Howard Leung

Mini Cooper Raffle



The time is fast approaching for our Mini Cooper Raffle. Our 2003 Mini Cooper is presently located at its headquarters, The Swimming Pool 3200 Dufferin St.

The details are similar to last year. Only 5000 numbered tickets will be sold at of \$10 per ticket. The Grand Prize is a 2003 Mini Cooper. The draw will be held at our 14th Annual Valentine's Dinner/ Dance on Saturday, February 8, 2003. The Valentine's

Dinner/ Dance will be held at The Regency Banquet and Convention Centre 8400 Jane St (N of Hwy 7).

The cost of the full dinner and deluxe open bar is \$90 per person with a partial tax receipt issued. The winner of the Mini Cooper 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 Mini Cooper Raffle tickets or our Valentine's Dinner/Dance contact:



Alfonso Sinaguglia: fonz0@rogers.com
905.832.3138

Connie Bennedsen: 416.424.2578

Corrado Falcitelli: cfalce@yahoo.com

SONS OF ITALY DINNER AND DANCE

On October 26th, 2002 the Fiorente-Patronato Lodge Order Sons Of Italy held their annual Columbus Day Dinner Dance. It was held at Villa Monaco in Concord. We had a silent auction and raffle, it was a huge success. All who attended had a great time. The proceeds from the dinner will be donated to the Thalassemia Foundation of Canada.

We hope to see you there next year.

Connie Bennedsen

GUELPH DINNER AND DANCE

The 9th Annual Guelph Dinner and Dance was held on November 2, 2002. It was a fun-filled evening with 400 guests in attendance. There was a silent auction, lots of door prizes, and raffle draws. The event raised approximately \$10,000 for the foundation. Thank you to everyone for their generous support. Special thanks to Anita Aimola, President of the Guelph Chapter and to all members of the committee for their great efforts and hard work in making this event a success. We hope that more Thalassemia patients can come out and support our own cause to this annual event. We look forward to seeing you next year!

Angie Costa

UPCOMING EVENTS, FUNDRAISERS AND CONFERENCES

- Valentine's Day Dinner/Dance - February 8th
Regency Banquet Centre
- MINI Cooper Car Raffle Drawing - February
8th Regency Banquet Centre
*For info/tickets for the dance or raffle please
call 905-832-3138
- 2003 TAG Conference - April 5 & 6 2003
Disneyland Resort, California
- Sons Of Italy Gala- April 5th 2003 – Niagara
Falls, Ontario
- TIF 2003 International Conference - October
15-19 2003 Palermo Sicily, Italy

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*On behalf of
the Board of Directors
of the Thalassemia Foundation
of Canada, we would like to
wish everyone a Safe and
Happy Holiday Season.*

Write Us

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and pictures for this newsletter.

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