

October 2020

A word from the head office

Dear members,

I hope with all my heart that you are doing well and are keeping absolutely safe.

But what a year 2020!!! With all the twists and turns due to the Covid-19... I know that it hasn't been easy for anyone!... Let us keep hope, because in a certain future, all of this will already be behind us.



Here are a few news from our head office.

At the beginning of 2020, Gloria and we the board had the wind in our sails. We were well advanced in the organization of our meeting and general assembly for June 2020 (in person and virtually) because for the first time, we were in the process of organizing everything to offer you a virtual General Assembly for those who could not travel...but the Covid-19 arrived...

When we realized that the pandemic was growing, we had to take the decision to put everything on hold, because we were in an uncertain future regarding this virus. The head office had to quickly adapt to this new reality.

Because our activities were put on hold, during the months of confinement, we started scanning many documents on thalidomide with the goal of putting them on our website and making them accessible to all of you. I worked from home because travel between regions was forbidden while Gloria was able to stay at the office. We did regular Zoom reunions to always keep in contact.

In July, our lovely Gloria had to suddenly step away from the office for medical reasons. As I had no communication with her because her health did not allow it, I advised the members and partners that the office was closed. During her absence, to the best of my knowledge, I held onto the fort, doing call backs. I responded to emergencies while awaiting Gloria's return.

Finally, I would like to thank you for your kind words of encouragement and thanks that we receive at the office. It always warms our hearts to read you. Rest assured that my greatest desire is to make sure that we remain united no matter what, because we are one big and beautiful family. Soon, as soon as the situation allows, we will organize another gathering where we will be able to hug each other again and it was surely be a great pleasure for all of us, I am sure!

Until then, please stay safe, take care of yourselves and do not forget that the head office is always there for you, dear friends, members of the big and beautiful TVAC family.

See you soon, and happy reading.

Your devoted president,

Myriam Bouffard

Survey Results

As mentioned in our last Interaction bulletin, Lucie Tremblay has been mandated to launch a survey for you in order to establish the current state of our association, to develop possible evolution scenarios, and understand and identify the needs of our members.

We obtained a response rate of 45%. In this regard, we want to thank you for taking some of your time to answer us.

Please know that your answers and comments have allowed Lucie to make a clearer interpretation on the following topics:

- The future of our association;
- The satisfaction rate with the TVAC (which, according to your answers, is quite high);
- The needs of our members (e.g.: organizing activities to socialize more with our peers);
- The Interaction bulletin (important for the majority)
- The web site

To this day, we are working to establish new challenges and organizing a strategic planning to look at the evolution of our organization on the longer term.

Virtual meeting with Celgene

On June 26th, 2020, Gloria and I had a meeting via Zoom with Celgene. The objective of the meeting was to introduce us to the new work team and inform us that Celgene has now become Bristol Myers Squibb. They also spoke to us about the update to the RevAid program.

If you wish to have more information on the RevAid program, you can do so at the following resources:

By telephone: 1-888-738-2431

By fax: 1-877-585-2382

By email: revaaid@assistprogram.com

Special to the Globe And Mail

Sir Harold Evans

Here is the Globe and Mail interview with Stephen Raynes following the tragic loss of giant Sir Harold Evans, advocate for thalidomide survivors.

STEPHEN RAYNES

Published October 13, 2020

How Sir Harold Evans helped the cause of Canadian thalidomide survivors from behind the scenes



For decades, he was a champion of justice for Britons left with painful disabilities and shortened lives by a dangerous drug. His death last month was a tragic loss. Now, it's time to honour his less well-known work for thalidomide survivors.

On Sept. 23, 2020, the world lost a giant. Sir Harold Evans was a brilliant and acclaimed journalist, writer and editor. To me, however, Sir Harold, or Harry, as he insisted on being called, was a comrade in arms – a relentless and courageous advocate and an ally in the 50-plus-year war fighting for the survivors of the drug thalidomide. Sir Harold's sword was the power of the pen. In the 1970s, as the editor of The Sunday Times, he led a journalistic crusade chronicling the heinous criminal conduct of Chemie Gruenthal (the German chemical company that invented thalidomide), the callousness

and negligence of Distillers (the British distributor of thalidomide) and the utter incompetence of the British government regulatory officials who permitted thalidomide onto the market.

Equally as important, Sir Harold and his Times team brought the personal stories of the British thalidomide survivors and their private suffering to the public. His groundbreaking coverage exposed the thalidomide scandal in Britain, led directly to a change in British law and laid the groundwork for the subsequent campaign almost 40 years later in which the British government finally funded a trust for the 466 thalidomide survivors. In exposing the thalidomide tragedy in Britain, Sir Harold was out in front. What just a few people know, however, is the critical behind-the-scenes role he played on behalf of the Canadian thalidomide survivors.

In 2012, I along with Mercedes Benegbi, the executive director of the Thalidomide Victims Association of Canada (TVAC); Joseph Fiorante, a Vancouver lawyer; and Christopher Holz and Natalie Dash, Canadian political strategists, led a task force committed to seeking to secure from the federal government a fund for the Canadian thalidomide survivors to ensure they could live the remainder of their lives with independence, financial security and dignity.

The government had never previously provided any meaningful support for Canadian thalidomide survivors. Sadly, it had failed to do so despite the fact that the Canadian Food and Drug Directorate was culpable in permitting thalidomide to be sold in Canada starting in the late 1950s and failing to withdraw the sinister drug from the market until 1962, after thalidomide babies had been born in Canada and around the world. My personal connection to the thalidomide community runs deep.

My late father, Arthur Raynes, a trial lawyer like me, tried the first U.S. thalidomide case in 1969. In the 1970s and early 80s, my father successfully represented 36 Canadian thalidomide children in the American courts. His work on behalf of Canadian and American thalidomide children and their families for more than 15 years was the professional passion of his life.

It was during those cases that he came to know and become an ally of Sir Harold and Phillip Knightley of The Times. They shared with each other the evidence they had accumulated in their respective investigations, as well as their strategies to take on the distributors of thalidomide. Sir Harold and Mr. Knightley were particularly interested in the successes in the American courts, in stark contrast to the inadequacies the British justice system had afforded the thalidomide families.

With that backdrop from 40 years earlier, permit me to outline how Sir Harold's achievements and hand touched the Canadian thalidomide campaign and the Canadian survivors. Early in 2014, the task force approached key members of Stephen Harper's Conservative federal government after assembling evidence for more than a year and a half.

The initial response to our approach was chilly, to say the least. The task force was completely ignored for the next nine months after confronting the government with overwhelming evidence of its moral responsibility because of the conduct of the Canadian Food and Drug Directorate, and with heartbreaking video-taped testimonials from many courageous thalidomide survivors who had suffered in silence for more than 50 years. At that point, our task force decided to go around the government and put pressure on members of Parliament through the media. As trained trial lawyers and strategists, we know that if we cannot persuade the opposing party to do the right thing and resolve disputes, we go to trial – we go to the jury (as American lawyers say).

My partner, Mr. Fiorante, and I travelled to London to meet with the leaders of the British thalidomide campaign. In London, we spent time with one of its fearless leaders, Guy Tweedy. Mr. Tweedy and his thalidomide colleagues had successfully waged a seven-year campaign against the British government and Diageo (the successor to Distillers), which led to the government providing a significant financial contribution for the first time to the previously formed British Thalidomide Trust in 2009, and for Diageo to increase its contributions significantly.

The newly funded Thalidomide Trust was an important, successful model providing financial independence and security to British thalidomide survivors. It would not have been possible were it not for Sir Harold having laid the foundation 40-plus years earlier. While in London, Mr. Tweedy, in assisting us in strategizing the task force's Canadian campaign, told Mr. Fiorante and me, "You must speak with Sir Harold Evans. He will help." That was an understatement.

Upon my return to the United States, I called Sir Harold. He immediately remembered my father, was excited about the prospect of helping Canadian thalidomide survivors and told me to come right over to his home. I brought with me our videotape of the heartbreaking interviews we had taken of thalidomide survivors

throughout Canada, as well as the presentation we had submitted to the federal government. I also brought with me a copy of his 1979 book, *Suffer the Children: The Story of Thalidomide* by the Insight Team of The Times of London.

In the book, there were two successive chapters juxtaposing the success of the American cases with the inadequacies of compensation for the thalidomide survivors in the British courts. The irony was not lost on either of us that decades later I was coming to him on behalf of the task force and the Canadian survivors to build on the British model of a government fund.

Sir Harold spent countless hours with me watching the video interviews of thalidomide survivors and learning about the evidence we had accumulated and the strategy of our campaign. He was moved to tears by the survivors' sharing of their suffering and energized and excited to assist. He provided important advice on the editing and framing of our presentation and our strategy, and concluded our meeting by saying, "Stephen, I must put you in touch with my friend, David Walmsley, the editor in chief of The Globe and Mail."

That connection through Sir Harold, without a doubt, was the critical moment to the success of the Canadian campaign. After watching the videotape and reviewing our written materials, and after meeting Ms. Benegbi, a survivor herself and the brave and tireless leader of TVAC, Mr. Walmsley called me. "This is outrageous," he said. "We are in. We are committing two full-time reporters to this injustice; the story must be told." The fire was lit and the baton had been passed. Over the next several months, our task force provided The Globe with the evidence we had developed, and we facilitated access to the survivors for The Globe's staff to hear their stories firsthand.

Saturday, Nov. 22, 2014: I refer to this day as the first day of the public trial. That day, The Globe printed and published its first story: a detailed exposé on the Canadian government's role in permitting thalidomide onto the market, its delay in withdrawing the drug and the fight for survival of 50-plus year old thalidomide adults.

The Globe featured the Canadian campaign with front-page coverage every day for eight straight days. Mr. Walmsley and his Globe writers, including Ingrid Peritz and André Picard, put the spotlight on a national tragedy and a national shame. It was advocacy journalism to right a wrong in its purest, truest form – in the model of Harold Evans.

THE GLOBE AND MAIL

Sir Harold, mentor and role model to Mr. Walmsley and editor at large of Thomson Reuters, gave the Canadian thalidomide campaign the keys to the courthouse – the courtroom of public opinion. The Globe became the courtroom. All the evidence played out directly in front of the Canadian public and provided our task force with the leverage we needed to secure from the Canadian government what the Canadian thalidomide survivors were entitled to and had been denied for more than 50 years.

Under unrelenting public pressure from this next generation of journalistic crusaders, inspired by and counselled by Sir Harold, the previously obstinate Conservative Canadian government capitulated.

On Monday night, Dec. 1, 2014, Parliament unanimously passed a motion to create a fund to ensure that the Canadian thalidomide survivors would live the remainder of their lives with independence and dignity. Sir Harold watched and counselled our campaign from a distance, but with a crucial behind-the-scenes role.

I feel blessed to have known Sir Harold – Harry – and am eternally grateful for his contribution on behalf of the thalidomide survivors. God bless his soul.

NEW FEATURES IN TVAC !!!

Virtual meetings via Zoom!!!



TVAC is happy to announce a new service that will be available to all members starting on November 10th (in French) and/or on November 17th (in English).

Virtual meetings, via zoom, will be offered four times per month, on Tuesday afternoons from 2 pm to 3:30 pm (alternating meetings in French and in English). The goals are to break the isolation, have fun, chat and above all, have fun.

All you have to do now is register!

For all those who are interested, please send us an email at the following address : assistant.tvac-acvt@bellnet.ca, it will be our pleasure to proceed with your registration.

Interaction bulletin!!!



In our next Interaction bulletins, there will be a brand-new section dedicated to our members, named: **NEWS FROM OUR MEMBERS**

COLUMBOS ... We need you!

The head office is proud to announce that our Interaction bulletin will be distributed four times a year starting next year (winter, spring, summer, and fall).

Why not be our stars of the day, our journalists, our Columbo...

Life experiences section...

You want to tell us about yourself, to share a real-life story, a life experience, a trip, etc...

Health-Medical section...

You have a health problem, and you found a way to relieve yourself?

Have you discovered tools or tricks to make your life easier?

Has your region improved accessibility for disabled people lately? This information could be useful for your peers...

Artists section...

Were you a star in a newspaper?
Have you discovered a new passion? Let us discover it...
Are you a painter, do you sculpt, do macrame, etc...?
Show us your masterpieces!!!

Why not share it!

For all those who would be interested, TVAC will send you a consent form to allow us to share your information in the bulletin.

We invite you to send us your material either by mail at the head office or by email.
Looking forward to hearing from you.

TVAC / ACVT

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IMPORTANT REMINDER!

CANADIAN THALIDOMIDE SURVIVORS SUPPORT PROGRAM

EMAF program 2020-2021:

The EMAF form 2020-2021 will be available in the coming months. Épiq is currently working on an update following comments from survivors received during the annual awareness survey launched by this body.

Ongoing support payments:

To change the way in which you receive these payments, you must fill in the ***Ongoing Support Payment Form***. You can request the form by communicating with the director or you can download it on the Forms page from the website : <https://tsspcanada.ca>.

You can choose to have your ongoing support payments sent in a lump sum once a year, or the amount can be paid in monthly installments throughout the year. Monthly payments are usually paid during the last week of each month.

Thalidomide Survivors Contribution Program

Bureau 3-505 133, Weber Street North
Waterloo (Ontario) N2J 3G9
Email: info@tsspcanada.ca
Telephone: 1-877-507-7706 TTY : 1-877-627-7027 Fax : 1-888-842-1332

The Canadian Thalidomide Survivors Support Program team is always there for you!

Thalidomide Victims Association of Canada

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