



Dear Members,

October 2013

Life Raft Group Canada has had a busy and productive year with, as usual, some successes and many challenges. I want to thank all of the Board members for their continuing hard work and valuable contributions. Kristin Austman is working for the organization on an approximately half-time basis and her administrative support and coordination of our efforts has been very greatly appreciated. The Board has been meeting monthly, using Skype teleconferencing, and our agendas have always been full. Our financial position remains healthy, although further diversification of our revenue sources remains an important priority.

Our first Day of Learning, held in North York last year in conjunction with our 2012 Annual General Meeting, was a very successful event. There was good attendance and the Day was ranked highly by the participants. As soon as it was over, we resolved to do another one, and began planning for the October 2013 Day of Learning. I'm happy to say this that this second event seems to have come together very well.

The Board recognizes that we need to broaden our outreach across Canada, and that means that we cannot hold every major event in Toronto. However, the concentration of members in the Greater Toronto Area means that, at the present time, there's nowhere else in the country where we can convene such a large group for a GIST-focused event.

I will highlight a few of the issues that we have been working on during the past year.

The federal government has promulgated the new "Canada Not-for-Profit Corporations Act" to replace the previous Canada Corporations Act (CCA). The new Act changes the governance rules and regulations by which a group such as ours must abide. The deadline for organizations to transition to the new Act is October 17, 2014. Since changes to the Bylaws need to be approved by the membership at a general meeting, this timeline meant that we needed to have our new bylaws ready to present to you at this 2013 AGM.

Therefore, we have worked diligently with our legal counsel, Jane Armstrong of Vorvis, Anderson, Gray, Armstrong LLP, Guelph, to prepare the new set of bylaws and our Articles of Continuance, which must be presented to Industry Canada. By and large, these changes are of a technical nature. I will go over some of the specific changes at the appropriate place in today's agenda.

We have implemented a major upgrade to our website, a task in which Kristin played the lead role. We are continuing to improve the website and it is a priority to make it fully bilingual.

With regard to our efforts to improve access to GIST therapy in Canada, our major campaigns again related to drug access. We continue to work for the extension of timelines for the public funding of gleevec for adjuvant therapy of localized GIST following surgery. It appears that in most jurisdictions in Canada, funding is now available for three years, for medium- and high-risk patients. However, we anticipate that evidence for the benefit of longer periods of treatment will continue to accrue from the ongoing international clinical trials and we will need to continue pressing for funding to be extended further.

This year, the period of Novartis exclusivity (or patent protection) on Gleevec in Canada ended. However, the story is a lot more complicated than that. Novartis is defending more than one patent, and appears to be trying to continue to maintain exclusivity on the use of gleevec in GIST (vs. its use in leukemia). The legal and

administrative situation remains very confusing. Generic versions of Gleevec (imatinib) are now approved for sale in Canada. Two products are available, one from Apotex and one from Teva. However, neither product has been approved by Health Canada for use in GIST. We believe that, in this situation, public and private insurance plans should continue to provide access only to Novartis Gleevec for GIST patients. As of the time of writing, this principle appears to be established in Ontario, at least as has been stated by Ontario Public Drug Plans. Despite the province's stated position, the actual rollout of generic imatinib across the province has been confused, and we already know of situations where GIST patients have been given generic imatinib rather than Novartis Gleevec by their pharmacists, apparently in error. We're continuing to be very vigilant about this issue.

The situation in several other provinces appears to be unsatisfactory. In New Brunswick, British Columbia, and some other provinces, the provincial drug plans are apparently requiring GIST patients to switch to generic imatinib, despite the fact that the generic drug is not approved by Health Canada for use in GIST. We consider this to be a completely unacceptable situation and we are campaigning hard to get all provinces and territories to follow Ontario's lead in maintaining access only to brand-name Gleevec.

Another important drug access issue is regorafenib (brand name Stivarga). This drug has been approved as the third-line treatment for GIST in the USA, on the basis of encouraging clinical trial data, and Health Canada has recently (October 2013) also approved its use. The struggle now will be to get private and public insurance plans to provide funding for the drug. At present, Canadian GIST patients requiring access to Stivarga are in a difficult position, because the pCODR consideration process is still in progress and no decision has yet been made.

Life Raft Group Canada continues to coordinate its efforts and outreach with the much larger Life Raft Group USA. We also continue to partner with the world-wide New Horizons GIST organization, and I am continuing to sit on its steering committee. We held a successful New Horizons meeting in Miami, Florida in June, with participation from GIST support groups around the world, including strong new participation from Brazil, India, and China. The 38 participants included 22 patient representatives, 10 speakers, 4 pharmaceutical representatives, and 2 onsite logistics staff. The focus of this year's meeting was on clinical trials for GIST and the role of patient participation in clinical trial planning. Also, we received updates on GIST treatment, from Dr. Peter Reichardt (HELIOS Klinikum Berlin) and Dr. Jonathan Trent of the University of Miami Sylvester Comprehensive Cancer Center; as well as a research update from Dr. Anette Duensing of the LRG Research Team. The detailed report on this meeting has been prepared and I would be happy to forward it to anyone who is interested. We're hoping that the next New Horizons meeting will take place in 2014 in Switzerland.

Recognizing the pressing need for our group to expand its activities both in breadth across Canada and in-depth, the Board decided to hold its second Strategic Planning session (the first was held in Montreal in 2010), which will take place on the day following this AGM. We have again engaged Susan Turner (Turner & Associates Inc.), who led our first successful session in Montreal. I hope that this meeting will allow us to plan effectively for the next stage of expansion of our efforts, remaining focused as always on our mission to improve the quality of life of GIST patients in Canada.

Respectfully submitted,

David Josephy,  
President,  
Life Raft Group Canada