



Dear Members,

October 2012

Once again, I have the pleasure of reporting to you, our members, about some of the accomplishments of the Life Raft Group over the past year. There is plenty to tell you about. As you will see, we can take pride in the successful completion of a large number of efforts which were just starting, at the time of my 2011 report.

I would first like to express my gratitude to two members of the board whose service will conclude this year. Doris McCormick has served as a Member-at-Large. In my President's report last year, I mentioned that we were hoping to establish a regular GTA/ Toronto-area get-together. We did that. The GTA group has now met several times and is clearly set to continue as a valuable and enjoyable venue for mutual support and learning. Doris has been the driving force behind this positive development, and her commitment, friendly demeanor, and quiet charm have ensured that everyone looks forward to the next opportunity to meet.

Judi Wagman is stepping down as Treasurer, a position that she has held almost from the time of establishment of the group in 2008. Treasurer is, as I'm sure you appreciate, an indispensable position in any not-for-profit organization. Keeping track of the money is essential, and Judi has done that impeccably. But she has gone far beyond that mandate in supporting the growth and operation of the group. She has spearheaded our funding applications and our successful application for charitable status. She has helped to organize and update our bylaws. She and Morty hosted our first Toronto-area get together. We owe her a profound debt of gratitude and we wish her and Morty the very best.

Losing Judi's service as Treasurer could have been traumatic, but, to our great good fortune, Malcolm Sutherland has stepped into this role, and Judi and Malcolm have coordinated closely to make the transition seamless. Malcolm has a degree in mathematics, so we can be confident that the numbers are going to add up correctly!

Special thanks go out to Tania McLaughlin, a GISTer from New Brunswick (which, as all good Canadians should be aware, is the only officially bilingual province in the country!) for her much appreciated contribution in helping us to get our web page operating in both English and French.

Kristin Austman has continued to serve as our part-time contract Administrative Assistant. Kristin is now such an important member of the Life Raft Canada team that I find it hard to recall how we ever got anything done without her. We have continued to hold Board meetings throughout the year, on a monthly basis, using Skype conferencing, and Kristin coordinates the agenda, records the minutes, and handles the technology for our meetings. Kristin coordinated the publication of our in May 2012 Newsletter, which grew and grew until it reached a length of 16 pages.

In my 2011 report, I noted that we were well on the way to achieve operational status for our Medical Advisory Council of medical professionals. We got there in 2012 and the MAC has already met once by teleconference. We are deeply indebted to the doctors who have generously agreed to help in this effort. Dr. Charles Blanke in Vancouver, a member of our Council, has been a tremendous advocate for GIST patients in Canada. Dr. Blanke will soon be returning to Oregon Health Sciences University. This is a loss for Canada but we know that Dr. Blanke will continue making major contributions to GIST research and clinical care.

I am happy to report the successful completion of another endeavor that was mentioned in last year's President's report. This was our advocacy effort to achieve public funding for adjuvant gleevec in Ontario. This goal was achieved with the announcement by Ontario public drug programs in February 2012. However, funding is limited to one year of adjuvant treatment, even though there is already clear medical evidence justifying at least three years of treatment. So, we are not resting in our efforts, and will continue to advocate for the extension of funding to three years. We are also monitoring the status of public funding in other provinces and are determined to keep working to achieve best practices across Canada.

In terms of the administration of the group, one of our major goals was to achieve approval of charitable status by Canada Revenue Agency. This goal was accomplished this past summer. The opportunity for individuals to make tax-deductible contributions to our group is already greatly enhancing our fundraising ability. It also imposes substantially greater reporting requirements on the board. In September, I attended an information session, "Non-profit Organizations and Advocacy" presented by the Government Relations Institute of Canada in Toronto. This was a very informative and useful morning of seminars providing insight into the legal requirements stemming from the recent enactment of new federal legislation governing all charities and not-for-profit corporations in Canada. Even though we have only had our charitable status for a very short time, what these statutory changes mean is that we need to begin working very soon to meet the requirements for obtaining our "Certificate of Continuance".

Judging from the preregistration figures, our October 2012 day of learning and annual general meeting looks set to be much the biggest and strongest event that we have ever mounted. I'm confident that it will provide additional impetus for us to enter 2013 in great shape for another year of strengthening our capacity to do the tasks that are absolutely central to our mission: providing support to our members and doing everything in our power to improve the standard of care for GIST patients across Canada.

Yours sincerely,

David Josephy,
President