



LIFE RAFT GROUP CANADA
GROUPE SAUVETAGE GIST CANADA

Ensuring that no one has to face GIST alone

www.liferaftgroup.ca

Life Raft Group, Canada Vice-President's Report

October 2012

It has been an honour for me, this year, to step into the role of Vice President. With all the changes in the organization the role of VP is evolving.

This year has been an exciting and challenging year for LRG Canada. The President's Report outlines the progress our organization has achieved this year and this progress opens the door to further growth to fulfill our Mission statement.

In April of this year, I attended the New Horizon's GIST conference, in Paris, as a patient advocate representing LRG Canada. In previous years this conference was a combined meeting for the CML communities and the GIST communities from around the world. This year marked the first GIST focused conference with 18 countries represented from around the world. The focus was *Improving Access to Treatment and the Quality of Care through Global Exchange*. Over the course of four days, researchers, doctors, pharmaceutical companies and representatives from other patient groups around the world, shared their work, their knowledge and their struggles. We were able to see how this rare cancer is impacted by government legislation, pharmaceutical companies and non-profit groups all over the world.

One example of this struck me very deeply. In many of the South American countries, GIST is not considered a specific pathology. In some of these countries, the struggle starts at a very basic level compared to countries such as Canada where GIST is recognized as a specific pathology and certain drugs have been approved for treatment (in some provinces!!). The conference left me with sense of how we, as patient advocates, doctors, researchers, and pharmaceutical companies need to work together world-wide to offer support and knowledge to those countries that are struggling at a more basic level. It also struck me how vital it is that we, as patients, caregivers and patient advocates, must continue to strive to conquer this disease. The phrase, *"ensuring that no one has to face GIST alone"*, was very much present at this conference.

Fundraising, now that LRG Canada is officially a charitable organization (December 2012), will take on a whole new role. We are beginning to explore the many avenues that this can take, from corporate to local events. Signature events and branding are very important in not only raising money, but also for raising awareness of GIST. We are looking into a few ideas that can be translated to each province. To this end, we are in the early stages of putting together a cookbook from the GIST community as an ongoing fundraiser, much like the GIST bracelets are now. We are looking to our members for recipes. We have a lot of work ahead us in the coming year but it is exciting and satisfying knowing that it is all in the name of GIST and the cure!!

Formal policies are mandatory to the success of any organization and LRG continues to update and develop new written policies as the organization grows. One such policy we are working on now is a Privacy Policy. Privacy legislation in Canada explains how organizations and public

bodies are allowed to collect, use and disclose personal information, as well as how individuals can request to access and update this information.

As a national organization, LRG Canada must make such a policy that includes the policies of ten provinces and three territories. At the federal level, Canada has two different privacy acts that are enforced by the Office of the Privacy Commissioner of Canada. The Personal Information Protection and Electronic Documents Act (PIPEDA) and the Privacy Act. PIPEDA applies to organizations that are federally regulated and to the private sectors of each province, unless a province has enacted its own privacy legislation that is “substantially similar” to PIPEDA. British Columbia, Alberta and Quebec have their own private sector privacy policy. Four provinces in Canada have their own health specific privacy legislation, which applies to health information. So you can see that this is a challenging task. We are in the early stages of developing this policy for LRG Canada, but hope to have it completed in the near future.

While it is unfortunate that any of us belong to a patient support and advocate group, I am comforted to know that LRG Canada exists to support and help find a cure for this rare cancer. I am proud to be a part of the Board of Directors working towards this goal!

Thank you,

Lynn Burrows,
Vice President,
LRG Canada