



## **GIST Sarcoma Life Raft Group Canada -- President's Report -- November 2011**

Dear Members,

I am happy to report to you concerning the Life Raft Group's activities over the past year. This has been a successful year of accomplishments, in which we launched several important initiatives.

Before describing these activities, I want to pause to recognize the people we have lost in the past year, and to whose memory we rededicate our efforts. Linda Hampson of Toronto was a founding Board member of our Group. Linda was one of the first GIST patients I met in Canada; she attended an informal gathering of GIST patients and caregivers at my house, in the fall of 2002, and we often met subsequently, including an unforgettable road trip to the LifeFest meeting in Chicago in Sept. 2008. Rain poured down all weekend, while we were in the O'Hare Hyatt attending LifeFest, and the Des Plaines River spilled over its banks. Coming home, we had to drive through one of the worst midwest floods in many years. The interstate was closed, and I remember Linda searching the map for likely side-road escape routes, as we headed further and further south across the corn fields of central Indiana. But neither floods nor her own declining health deterred her. We were all deeply saddened when we learned that Linda had lost her long struggle with GIST. We also mourn the loss of Mr. Rod Scaife and of parents of two of our members - Mr. Serge Banyongen's mother, Suzanne, and Mr. Dinesh Patel's father, Vallababhai.

Our Montreal AGM, and the Strategic Planning session held immediately after the AGM, have helped us to establish an ambitious agenda for the development of our Group, and we have already taken steps to accomplishing several of the goals we agreed upon at that session, as I will describe below. We have continued to intensify our efforts, and we held ten Board meetings during the year - almost one every month - mainly by Skype internet conferencing technology.

Our membership continues to grow, with more than 20 new members added this year. We now have more than 100 members, located in all provinces except Saskatchewan and P.E.I. Our largest concentration of members is in southern Ontario, and we are hoping to start up a "Toronto chapter", with regular (perhaps monthly) meetings soon.

Recognizing that the task of running our Group has grown beyond what can be accomplished by volunteers alone, we decided to seek a part-time contract Administrative Assistant. We struck a three-person search committee consisting of myself, Judi Wagman, and Deb Maskens of the Kidney Cancer Canada Board. We placed an advertisement on the Charity Village web-site and received more than 200 applications. From this pool, we interviewed several candidates and chose Ms. Kristin Austman. Kristin has been working on our behalf since March, and her efforts have greatly enhanced our operations and scope. Member outreach is an important priority, and with much help from Kristin, we produced and distributed our first Newsletter in the summer. We have also implemented a toll-free phone number 1-855-LRG-GIST (574-4478) and FAX line (FAX 1-866-888-7787).

Again this year, we contributed to the annual "Report Card on Cancer in Canada" of the Cancer Advocacy Coalition of Canada, with an update on GIST drug funding issues, and I attended the media release event for the Report in Toronto, in April.

Another goal that we set, at our Strategic Planning session, was to establish a Medical Advisory Council of medical professionals, who can provide us with guidance and consultation on medical issues and also help us to get our own messages out to Canadian doctors treating GIST patients. I am happy to report that several doctors have already agreed to join our MAC, and we are now well on the way to operational status.

In June, we hosted a talk by Dr Jean-Yves Blay, Professor of Medical Oncology at Université Lyon and head of the Medical Oncology department at Centre Léon Bérard. Dr. Blay is one of the top European clinical specialists in GIST treatment. He stopped in Toronto on his way home after the American Society of Clinical Oncology (ASCO) meeting in Chicago, and he kindly spoke to our group at a gathering at Gilda's Club, as we reported on in the Newsletter.

Another important event for GISTers in 2011 was the release, at ASCO, of the very encouraging results of the three-year adjuvant gleevec clinical trial in Europe. This has prompted us to step up our advocacy efforts to achieve public funding for adjuvant gleevec, with a focus on Ontario, which is often the "key opinion leader" among the provinces. This campaign has included letters and meetings with MPPs and Ministry of Health staff. I am cautiously optimistic about the outcome of our work in this regard.

We recognize that achieving federal charitable status will help us to establish a long-term sustainable financial structure for the organization. To this end, our Treasurer Judi Wagman has started working with Mr. Joel Sector, LL.B., at the firm of Drache Aptowitzer in Ottawa, to begin the formal application process.

I attended the international "New Horizons" meeting of GIST advocacy group leaders, in Amsterdam, in June, and I was appointed to the Steering Committee that is overseeing the transition to a new format for this annual meeting. The "new New Horizons" will be run directly by the GIST advocacy groups and will be a smaller and more focused event aimed at enhancing the capabilities of national organizations around the world.

I have also continued to work as a member of the Life Raft USA "Science Team".

In the Fall 2010 and Winter 2011 academic semesters, I was on a sabbatical research leave at Harvard Medical School, Boston, where I was doing GIST research in the lab of Dr. Jonathan Fletcher. I also had the opportunity to participate in several GIST group events, such as the "Walk for the Cure" fundraiser, held near New York City and a patient gathering hosted by Susan Farmer in Providence, Rhode Island.

The generous support of Novartis Oncology Canada, Pfizer Oncology Canada, and Jacobson and Associates continues to be an important ingredient to our success and is gratefully acknowledged.

In closing, I wish to recognize the contributions made by all of the members of the Board. Silvia Steinhilber is stepping down as Vice-President, a Board position that she has held since we established the group in 2008. Silvia's contribution has been very important to our development and we are indeed grateful for her participation. We have also welcomed onto the Board two new members, Doris McCormick (Toronto) and Katherine Grandy (St. John's), who are bringing wonderful new energy and ideas to our organization.

David Josephy,  
President  
Guelph, Ontario