



GIST the News

Hello!

We are very happy to present the first official Newsletter of Life Raft Group, Canada!

Like everyone else in our group, I had never heard of a cancer called "GIST", but then, in 2000, it struck my sister-in-law Elsie.

Shortly after her surgery, an oncologist friend told me about a remarkable new drug that had become available for GIST. Our search for gleevec (still known as "STI-571" in those early days) clinical trial sites led us to Norman Scherzer, in the New York City area.

Norman, whose wife Anita has GIST, was starting to organize the Life Raft Group. With help and advice from Norman and others, Elsie soon managed to get into a clinical trial at a hospital in New York City.

Over the next few years, a few Canadian GISTers began to meet informally for support and information sharing; but it was not until 2008 that we were in a position to develop a national Canadian not-for-profit organization that works in concert with the U.S. Life Raft Group.

My professional background (as a biochemist at the University of Guelph, with experience in cancer research) has given me an unusual opportunity to participate both in GIST support and in GIST science. (Unusual, but not unique - in fact, around the world, there are several scientists and doctors who have a personal connection to GIST. A number of us have contributed, at least in a small way, to GIST research.)

Life Raft Group, Canada has been growing rapidly! I want to salute our Board - a tireless, dedicated, and creative group of GIST patients and caregivers. In forthcoming Newsletters, they will be introducing themselves to you. Another big step forward has been our hiring, earlier this year, of our part-time administrative assistant, Kristin Austman. Her hard work and imagination have brought this Newsletter to fruition.

Please enjoy this first number of the Newsletter. We welcome your comments and suggestions!

**David Josephy, President
Life Raft Group, Canada**

Dr. Jean-Yves Blay Speaks in Toronto

On Friday June 10, Toronto-area members gathered to hear 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 has

been the lead investigator on several important GIST clinical trials. He is also the current president of the European Organisation for the Research and Treatment of Cancer (EORTC), an indication of the high esteem in which he is held by the medical community.

In a recent cover story in the on-line magazine "Cancer World" (www.cancerworld.org/), Dr. Blay is characterized as "a human dynamo, constantly on the move – colleagues speak of phenomenal drive and unlimited energy, despite him seemingly never eating lunch, which is very unusual in France."

"Dr. Blay is one of the top European clinical specialists in GIST treatment."

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Dr. Blay was on his way home to France after attending the annual

meeting of the American Society of Clinical Oncology (ASCO) in Chicago, one of the largest cancer clinical meetings in the world. He presented some of his own work at that meeting.

Our group met at the downtown Toronto "Gilda's Club". We are very grateful to them for allowing us to use their space once again.

Dr. Blay discussed several new findings in GIST research that were presented at the ASCO meeting.

Here are a few of the highlights.

"Dr. Blay discussed several new findings in GIST research ..."

Remarkable effectiveness of adjuvant imatinib (gleevec)

The latest results of the international clinical trial headed by Dr. Heikki Joensuu, University Central Hospital, Helsinki, Finland (the first doctor to treat a GIST patient with imatinib) have been very exciting. The presentation titled **"Twelve versus 36 months of adjuvant imatinib (IM) as treatment of operable GIST with a high risk of recurrence: Final results of a randomized trial"** showed, for the first time, that three years of treatment with imatinib, following surgery for localized GIST, greatly improves both recurrence-free survival and overall survival in high-risk patients. Put simply, this means that adjuvant gleevec is highly effective in keeping most patients from having progression of their disease, and it keeps people living longer. Our group and others around the world will be relying on these results in continuing to advocate for patient access to adjuvant therapy.

Regorafenib: the third line drug for GIST?

The *first-line* treatment for metastatic or recurrent GIST is imatinib (gleevec), and the *second-line* treatment, if progression occurs during gleevec treatment, is sunitinib (sutent); but there is as yet no approved third-line drug. Unfortunately, despite high hopes, the drug nilotinib (Novartis) did not succeed in trials as a possible third-line drug.

However, the prospects look much better for regorafenib (Bayer). Dr. Susan George and colleagues at Dana-Farber Cancer Center in Boston presented *"A multi-center phase II study of regorafenib in patients with advanced GIST, after therapy with imatinib and sunitinib."*

They concluded that "Regorafenib has significant activity" in these patients. An international phase III trial is currently underway, and there seems to be general optimism that regorafenib will take up the **third-line** position. However, Dr. Blay noted that the drug is *"not easy to take"*. The ASCO abstract states that 19 of the 33 patients in the trial required dose reduction, due to toxicity.

A possible drug therapy for GISTs carrying the PDGFRA D842V mutation

Although most GISTs are associated with a mutation in the KIT gene, some GISTs are "KIT wild-type", but have a mutation in a different (although related) gene, PDGFRA, which encodes a protein with the cumbersome name *"Platelet-Derived Growth Factor Receptor Alpha"*. The most common mutation in these GISTs is "PDGFRA D842V". Unfortunately, the usual tyrosine kinase inhibitor drugs for GIST, such as gleevec and sutent, don't work against this target. Dr. Michael Heinrich (Oregon Health & Science University) presented basic research showing that a new drug, crenolanib (CP-868596; AROG Pharmaceuticals), is an effective inhibitor of PDGFRA D842V. A phase II clinical study in GIST patients with this mutation is being initiated.

Everyone who participated was greatly impressed by Dr. Blay's knowledge, compassion, and commitment. After his formal presentation, he graciously took time to answer questions and chat informally.

Gilda's Club, Toronto

June 2011



From left to right: John Lundon (LRG Member), David Josephy (LRG President), Alice Lundon (LRG Member), Dr. Jean-Yves Blay, Doris McCormick (LRG Member), Elizabeth Burrows (LRG Member), Morty Wagman (LRG Member) & Judi Wagman (LRG Treasurer)



Mullet May-hem: Mullets for GIST Cancer

Raising Awareness & Funds

The first annual Mullet May-hem was held in Kamloops, B.C. from March 1 to May 29, 2011.

The purpose of this event was to raise awareness about GIST, and to raise funds to support the mission and vision of GIST Sarcoma Life Raft Group, Canada.

Some of you may be wondering, at this point, "what the heck is a mullet and how can it raise awareness and money for LRG Canada?" A mullet is a hair style (some say a life style) with no real known origin but has been around for decades — worn by men, women and children. Simply described, the hair is short in front and on top, but long in the back. There are many different styles of mullets (see www.gistmulletts.ca), but you get the idea.

This event was the result of the creative energy of Tyler and Kiefer Burrows, sons of a GIST patient. It included designing t-shirts and posters, as well as recruiting sponsors. In February 2011 they decided to put their plan in place. The challenge went out to people (in this city of 90,000) to grow mullets from March 1 to May 29. While doing so, participants collected pledges to continue growing their mullets.

"This morning I'd never heard about GIST or how drugs are accessed in each province, but now I do. Its amazing how much you can learn in a short conversation!"

For this first year the focus was mostly on raising awareness about this rare sarcoma, and the inequitable access, from province to province, to the necessary drugs in Canada.

The following sponsors donated prizes, venues, money, publicity and time:

- | | |
|--------------------------|-------------------------------|
| Manhattan Grill | Underwraps Design |
| Starbucks | Opia Apparel |
| Rivers Night Club | Cliffside Climbing Gym |

NL Radio, in Kamloops, interviewed Lynn Burrows (Tyler and Kieffer's mom) about the event, which allowed her to share information about GIST, LRG Canada and the "geographic lottery" Canada has regarding public funding of cancer drugs.

"Total funds raised to date — \$3700!"

At the May 29th wind-up event 3 prizes were awarded for: (1) best overall mullet, (2) person who most suits their mullet, and (3) creepiest mullet (Tyler and Kieffer's father won this one!).

Total funds raised to date — \$3700. Measuring how much awareness was raised is much more difficult, but clearly Kamloops knows more about GIST now than they did four months ago. The radio interviewer, from NL Radio, put it aptly when he said, "This morning I'd never heard about GIST or how drugs are accessed in each province, but now I do. Its amazing how much you can learn is a short conversation!"



The Mullet Winners



Your Challenge for 2012!

The Burrows family and LRG Canada challenge other cities, towns, and communities in Canada to have their own Mullet May-hem in 2012. For more information please contact: info@liferaftgroup.ca



Life Raft Group Canada?
Life Raft Group U.S.A.?
Are you folks related??



When a small group of GIST patients and caregivers got together in 2008 to start a Canadian support group, we decided to adopt a name and logo patterned on the Life Raft Group U.S.A., a much bigger and longer-established organization.

Many of us have participated in the activities of the U.S. group — attending meetings and contributing to their listserv (chat-room).

We continue to cooperate informally with Life Raft Group U.S.A. and other GIST support organizations around the world. However, there are no financial or institutional connections between the Canadian and U.S. groups.

Our Member Survey Continues ...

As many of you know, Life Raft Group, Canada is in the process of conducting a nation-wide survey of our members in order to learn more about Canadian GIST patients' access to GIST specialists, treatment, drugs, information and support.

If you haven't received a phone call yet, not to worry, the survey is still in process. I have been able to speak with many of you on the phone, and I have received a number of completed surveys in the mail.

With summer being here, and my hours of work with LRG Canada being part-time, I will continue to call members for some time yet.

A written version of this survey can be found linked on our website on the Patient Support Page, www.liferaftgroup.ca/support.html. The link is named **May 2011 Survey**.

Participation in this survey is entirely voluntary.

Thank you!

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AGM—Hold the Date!

LRG Canada will be holding its AGM the weekend of **November 5th & 6th** in Vancouver.

Our guest speaker will be Dr. Lee, a pathologist who will present a talk related to GIST.

Details on venue and agenda are still pending. More information to come ...





The Campaign for Public Funding of Gleevec (imatinib) for Adjuvant Therapy of GIST

Can you help?

As also mentioned in the article on Dr. Blay speaking in Toronto, the results of the European clinical trial of three-year gleevec adjuvant therapy of GIST were one of the highlights of the recent ASCO 2011 meeting in Chicago.

For the first time, we have clear evidence that prolonged therapy (for more than one year) with gleevec, following surgery, delays disease progression and prolongs the lives of GIST patients.

Commenting on the new data, in the Newsletter of "Sarcoma Patients Euronet", Dr. Axel Le Cesne (Institut Gustave Roussy, France) said "This trial will undeniably change a therapeutic standard, as it is now established that high risk GISTs need to receive 400 mg/day of imatinib as adjuvant treatment for a minimal duration of three years".

Will this vital treatment be accessible to Canadian GIST patients? Novartis Pharmaceuticals closed down its *compassionate use* program to new patients, as of February 2011. This leaves patients with only three options for access to the drug: (1) pay cash, (2) rely on private insurance (if you have it), or (3) wait for public funding.

For more than two years, LRG Canada has been trying to convince provincial governments across the country to add adjuvant therapy of GIST to their *formularies* — providing at least some assurance that patients will not be denied treatment because of a lack of private insurance coverage or personal means.

It has been a difficult and, at times, discouraging struggle, but we will not quit. **Please note that this discussion is focused on gleevec for adjuvant therapy of GIST – that is, drug treatment following successful surgery of a localized GIST tumor.**

Gleevec for recurrent, inoperable or metastatic GIST (GIST that has spread) is already covered by the public formularies.

We see Ontario as a key province, because many other jurisdictions are likely to follow suit once Ontario decides to provide access through public funding. For now, the 'patchwork quilt' of public drug programs across Canada is still full of holes.

The most hopeful situations are in B.C., Quebec, and Nova Scotia. New Brunswick gave a negative decision in January. In most other provinces, the wheels of bureaucracy are still slowly grinding towards a decision.

What does this mean for our members? Even if your oncologist prescribes adjuvant gleevec (even for one year of treatment, let alone for the three-year course that is now clearly indicated, at least in higher risk cases) your access to the drug is far from certain or secure. Whether you get the drug may depend on your private insurance (if you have it); or how hard your doctor is willing to fight "the system" on your behalf; or the capricious decision of a health ministry bureaucrat reviewing a *special access* request; and, probably most of all, on which province you happen to be living in. Canadians have a right to expect better results from our Medicare system!

Armed with the data presented at ASCO 2011, Life Raft Group Canada is planning to step up its efforts to push provincial governments to make positive funding decisions.

Please let us know if you would like to help by calling 1-855-LRG-GIST (574-4478) or emailing info@liferaftgroup.ca

We need folks who will call their MPPs, write letters, speak to their local newspapers, etc. We are especially interested in hearing from patients who are residents of Ontario and are currently taking adjuvant gleevec, or who need access to the treatment but have not been able to get it.

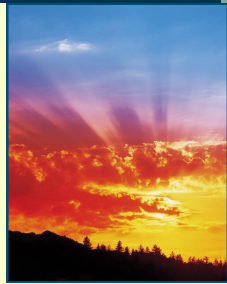
THANK YOU!



New Horizons 2011

By Lynn Burrows, LRG
Canada Board Secretary

On 13-15 May 2011, David Josephy, LRG Canada Board President, and I attended the 9th annual **"New Horizons in treating cancer"** conference held in Amsterdam, Netherlands. Sponsored by Novartis, the conference provided patient advocate leaders (representing CML and GIST) with an opportunity for 3 days of learning, companionship, and the chance to share experiences across borders. The conference welcomed 137 patient representatives (96 CML; 41 GIST) from 48 countries across Europe, North America, Asia, Australia, Africa, the Middle East, and Latin America.



The conference began with an opening welcome from Paul Dijkstra, on behalf of the Dutch CML patient community, and Tom Jansen, on behalf of the Dutch GIST patient community. The afternoon lectures focused on the global discrepancies in cancer outcomes, and the power and potential of patient advocacy for both the CML and GIST groups.

On Day 2 the conference broke out into GIST and CML tracks to hear disease-specific talks. In the GIST track we heard from four experts, followed by questions from participants, and then panel discussions. This format allowed advocacy participants and experts to openly share concerns and information.

Each GIST expert spoke on a different topic:

- ◆ **Dr. Paolo Casali** (Italy) compared the guidelines of the ESMO (European Society for Medical Oncology) with those of the NCCN (National Comprehensive Cancer Network);
- ◆ **Dr. Jean-Yves Blay** (France) discussed the prevention of resistance;
- ◆ **Dr. Jonathan Fletcher** (USA) reviewed advances in GIST research; and
- ◆ **Dr. Peter Reichardt** (Germany) outlined procedures for treating resistant GIST.



See the SPEAN website for more information (<http://www.sarcoma-patients.eu/> — scroll down to "9th New Horizons in Treating Cancer: Conference Report").

This amazing day of information exchange and expert discussions ended with the participants riding a bus to **'De Hoop op de Swarte'** restaurant (which was on the waterfront & surrounded by traditional old windmills). Sharing a meal and an evening together gave us a chance to make new and re-new friendships, and to learn more about each other.

The last day of the conference was devoted to *'marketplace'* sessions, in which small groups of people had an opportunity to gather around a poster, or a short presentation, to discuss a chosen advocacy topic. We began with **"Sharing Best Practice Advocacy Marketplace"** which was a poster session on a selection of best practices in CML and GIST.

With David as my assistant, we held a poster session on our latest fundraiser, **"Raising Awareness about GIST: Mullet May-hem Fund and Awareness Raiser"** (www.gistmulletts.ca).

This was followed by six **"Expert Advocacy Marketplace"** sessions. Each was a highly interactive short presentation and discussion. Participants were able to choose three out of the six sessions, which were of interest to them.

Topics included: **long term survivorship; educational needs of patients; medicine adherence; TKIs and pregnancy; the role of patient advocates in promoting patient safety; and assessing the value of innovative treatments.**

The conference was closed by Jan Geissler on behalf of the CML community, and Estelle Lecointe on behalf of the GIST community. They thanked Novartis for their unstinting support and hosting of the conference over the last 9 years.

This year marks the end of the combined CML and GIST conference, but Novartis promises to be one of the sponsors as we stand on the **"threshold of a promising new phase of global initiatives to further the ambitions of the GIST patient community"**.

The steering committee, of which David is a member, will be working on the new guise of future New Horizons meetings for the GIST community.



A Special THANK YOU

Life Raft Group, Canada is acknowledging and expressing our appreciation to two of our stakeholders:



and



These pharmaceutical companies, and their representatives, have been very generous with their financial support, and their acts of encouragement as our organization moves from startup towards maturity.

Since our inception in 2008, members of the Board of Directors have interacted with several representatives of each company. We wish to particularly recognize David Tremblay of Novartis, and Michael Braun of Pfizer.

GIST Sarcoma Life Raft Group, Canada

Our Mission

To ensure the survival of GIST patients, and to assist patients and caregivers in maximizing the quality of their lives.

Our Vision

To support activities resulting in a cure for GIST, bringing every Canadian affected by this rare cancer onto our Life Raft until we achieve that goal.

Our Values

Hope, Responsiveness, Respect, Responsibility, Accountability & Collaboration.



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