

NEW HORIZONS GIST

SEPTEMBER 5 – 7, 2018 – VIENNA, AUSTRIA

Welcome! We face great challenges.

Insufficient research capacity.

Doctors and oncologists who still have not heard of GIST.

Misdiagnosis; faulty pathology; lack of mutational testing.

Patients unable to access diagnosis, treatment.

Many countries that still have no support group.

Uncertain funding for patient support groups

... and for New Horizons GIST.

Most of all, GIST patients face the challenge of survival!

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But we have *overcome* many challenges!

We have pioneered the rare disease support group concept.

We have kept New Horizons going - and thriving - for more than a decade; even without assured funding or any designated organizational “home” ... because of our collective spirit of cooperation and mutual support.

We have helped many countries’ GIST support groups to get established and to learn from the longer-established groups.

We have encouraged and inspired doctors and researchers to engage with patient groups on a basis of mutual respect.

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And we are excited by recent advances: reasons for hope.

Remarkable new drugs under development/ in clinical trials.

Improved surgical and diagnostic techniques.

Ever-better mutual support and engagement among the GIST support organizations world-wide.

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We remember loved ones we have lost.



Ferdinand Mwangura



Eve Bressington



Elsie Hernandez

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We are resolutely committed to our mission.

to ensure the survival of GIST patients;

to assist patients and caregivers in maximizing the quality of their lives;

to support activities resulting in a cure for GIST.

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GIST 1: Challenges and open questions in GIST treatment from the patient perspective (10 min each)

2. Metastatic disease

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GIST Busters T-Shirt (Men's Blue)

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1



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Welcome to our T-Shirt Fundraiser! Make a \$35 donation to GIST Sarcoma Life Raft Group Canada and receive a GIST Busters T-Shirt as a gift from us. A \$25 tax receipt will also be provided with each donation (\$10 subtracted from the total donation amount to cover the cost of the t-shirt).

Have questions about the fundraiser or the T-shirts? Please [contact us](#).



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\$35.00

Select options



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\$35.00

Select options



GIST Busters T-Shirt (Men's Yellow)

\$35.00

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\$35.00

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GIST Busters T-Shirt (Women's Yellow)

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Can we (finally) push the need for mutational testing of all new GISTs ... If necessary, by a test-case malpractice lawsuit on behalf of a wild-type patient who suffers bad side effects - with no benefit - from imatinib therapy?

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**Will one of the new drugs (Avapritinib(BLU-285), Deciphera, Plexxikon ...) - if and when approved - be better than imatininb in first-line treatment?
Could this be tested by “off-label” use in first line?**

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When imatinib resistance develops, would it be better to continue imatinib and add a new drug (avapritinib? or ...?), instead of stopping imatinib and switching to another drug?

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The long-term side effects of TKIs, including imatinib:

What can we learn from other diseases (esp. CML) that are treated with TKIs?

Can a useful animal model of side effects be developed?

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Many patients - despite months/ years of successful treatment with TKIs, eventually develop progressive disease that is very hard to treat.

(Dr. Tap: “GIST patients do well, until they don’t do well ... and then they don’t do well.”)

Is a more aggressive approach to residual stable lesions (RFA? Surgery? Chemo-embolism?) appropriate, given that so few options are available for effective control of progressive GIST?

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