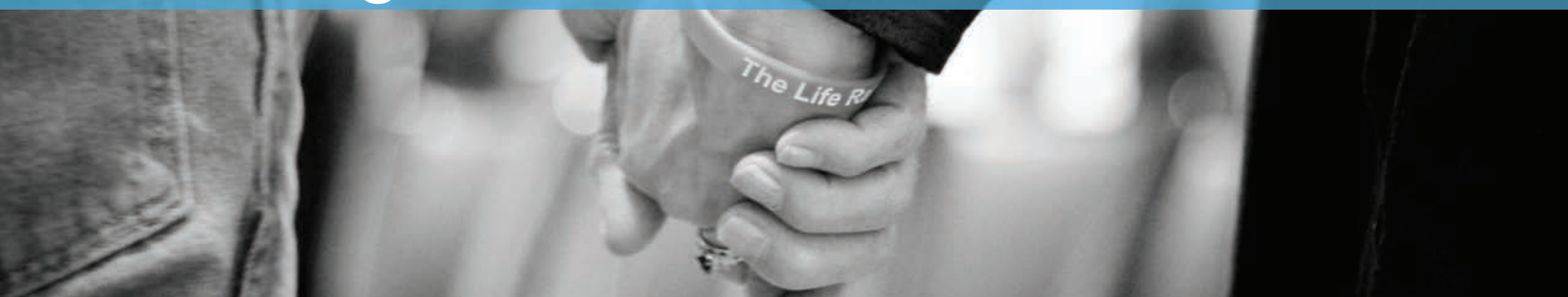


# Ensuring no one has to face GIST alone

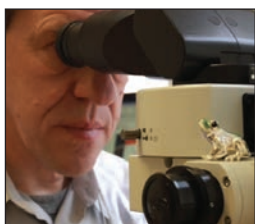


In Loving Memory: David Kors, Henk Boomsma, Marije Govers-Moria, Gary Somers, Art Watts

## GIST Collaborative Tissue Bank: A researcher's perspective

By **Dr. Matthew van de Rijn**, Stanford University Medical Center

**T**he Life Raft Group GIST Collaborative Tissue Bank consists of a collection of tumor specimens from a large number of patients, stored at Stanford University. The advantages of having a tissue bank for a rare disease such as GIST are many. First, it provides a centralized location from which specimens can be sent for mutational analysis to Oregon Health & Science



van de Rijn

University, a very practical option for GIST patients. In addition, the collection of these samples can be used in a wide range of research studies— all with the goal of improving the survival of GIST patients in the future. One of the approaches we use at the tissue bank is to generate “tissue microarrays” from the samples, a procedure that will be

See **TISSUE** on page 5

## How to S.T.O.P. caregiver burnout

By **Mary Garland**, Communications Director

**A**ccording to a 2015 report by the National Alliance of Caregivers, approximately 43.5 million adults in the United States provided unpaid care to an adult or child in 2015. Caregivers come from diverse demographic backgrounds, but a majority of them provide care for a relative, with one in ten taking care of a spouse.

Nearly one in ten caregivers is 75

years or older, mostly caregiving for a spouse at a time in their lives when their income may be fixed. They shoulder not only the emotional burden, but also the financial strain of managing household expenses for themselves and their spouses. The Mayo Clinic reports that 80 percent of longterm care in the U.S. is provided by

See **CAREGIVER** on page 4

## Generic imatinib approved in the US for CML: What does it mean for GIST patients?

**LRG Research Program to track efficacy**

By **Michelle Durborow**, Patient Registry Director



**O**n February 1, 2016, the commercial launch of the generic version of imatinib mesylate (Gleevec), for CML (Chronic Myeloid Leukemia) was approved by the FDA after the Novartis patent expiration, and will become available for the first time in the United States through Sun Pharmaceuticals. The patent expiration date for the imatinib indication for GIST is not until 2020.

Sun Pharmaceuticals was the first to file an ANDA (Abbreviated New Drug Application) for generic imatinib for CML, and is eligible for 180 days

See **GENERIC** on page 8

# The heart of the matter: Cardiac health for GIST patients

By **Kathrena Aljallad**, Patient Registry Associate

**T**he heart is at the center of the cardiovascular system, the main function of which is to pump blood throughout the body, providing tissue and organs with the oxygen and nutrients they need. To ensure that the body has all the nutrients to stay healthy, the heart has to function properly and efficiently. Cardiovascular disease

generally refers to conditions where narrowed or blocked blood vessels can lead to chest pain (angina), heart attack or stroke. There are other types of heart conditions that affect the heart's valves, rhythm

or muscle. The most common types of heart disease are hypertension (high blood pressure), stroke and coronary artery disease. According to the American Heart Association, heart disease is the leading cause of death in the world, accounting for 17.3 million deaths a year. There are many risk factors for developing heart disease, including high blood cholesterol, diabetes, obesity, family history

of heart disease, smoking and being over the age of 65. Additional risk factors are specific to GIST patients.

GIST patients should keep in mind the risks that are associated with the medications they are on. The most common drugs for GIST patients, Gleevec, Sutent and Stivarga, are all

Tyrosine Kinase Inhibitors (TKIs). Tyrosine kinase plays a critical role in activating signaling pathways that regulate cell growth, differentiation, metabolism, migration and programmed cell death. In cancers, there is a dysregulation of this signaling pathway, leading to proliferation of cancerous cells and/or preventing the cells

from undergoing programmed cell death. TKIs inhibit several of these tyrosine kinases, which target the cancer cells and prevent them from dividing, but sometimes they may also target healthy cells.

## Gleevec

Imatinib mesylate (Gleevec) targets several tyrosine kinases, such as Abl, KIT, and PDGFRs. It was found that

inhibition of Abl appeared to have contributed to cardiotoxicity. Although uncommon, cardiac issues have been reported in patients taking Gleevec. Examples include congestive heart failure and left ventricular dysfunction. Although they were reported in only 0.7% of patients, it is something to be aware of especially for people already with heart disease or risk factors. (Source: Novartis Oncology: Gleevec Prescribing Information)

## Sutent

Sutent is a potent inhibitor of VEGF, which is a protein that stimulates the growth of new blood vessels. Inhibiting the VEGF pathway is promising in cancer treatment. However, it has been linked to a rapid onset of hypertension and other cardiac issues. Patients should monitor their blood pressure while on Sutent and should be treated as needed. Other cardiac issues that have been reported are heart failure, cardiomyopathy and heart attack. It is recommended that patients who have a history of these issues should take Sutent with caution and discuss treatment with their oncologist and cardiologist. (Source: Pfizer: Sutent Prescribing Information)



**Monitoring heart health is vital for GIST patients**

## The Life Raft Group

### Who are we, what do we do?

The LRG has a simple focus: to cure a form of cancer — gastrointestinal stromal tumors (GIST) — and to help those living with it until then. To do this, the Life Raft Group focuses on three key areas: research, patient support & education, and advocacy.

### How to help

Donations to The Life Raft Group, a 501(c)(3) nonprofit organization, are tax deductible in the United States. You can donate by credit card at [www.liferaftgroup.org/donate.html](http://www.liferaftgroup.org/donate.html) or by sending a check to: The Life Raft Group 155 US Highway 46, Suite 202, Wayne, NJ 07470.

### Disclaimer

We are patients and caregivers, not doctors. Information shared is not a substitute for discussion with your doctor. Please advise Mary Garland, Communication Director, at [mgarland@liferaftgroup.org](mailto:mgarland@liferaftgroup.org) of any errors.

See **HEART** on page 11

# On the road with the LRG: NCATS presentation

By **Mildred Menos**, Strategic Alliances Director

On Tuesday, January 12, a small delegation of LRG staff journeyed to Washington, DC, to make a presentation to the executive leadership of the National Center for Advancing Translational Science (NCATS). The team from LRG included Deputy Executive Director Marisa Bolognese, Patient Registry Director Michelle Durborow, and Director of Strategic Alliances Mildred Menos.



National Center  
for Advancing  
Translational Sciences

practical policy, procedures and innovations that improve the daily lives and overall health of patients and the public.

Although NCATS does not focus on specific diseases, one of many goals that they and the LRG have in

common is the importance of addressing the bottlenecks inherent in the

current research and drug development space that are creating time-consuming delays and inefficiencies in the way data is shared. This is an especially crucial issue for a rare cancer such as GIST, which has a small and scattered patient population globally and no advanced screening techniques to date.

The LRG team presented selections from its cutting-edge Patient Regis-

try platform, Tissue Bank, Virtual Tumor Board, ongoing research and innovation projects and various other educational and programmatic services. The full house included notable names from leadership such as NCATS Executive Director Chris Austin and Deputy Director Pamela McInnes. Also present were representatives from the Sarcoma Learning Collaborative, a research consortium headquartered at the University of Kansas devoted to discovering and developing new treatments for sarcomas affecting children, adolescents and adults, that the Life Raft Group has also been in dialogue with.

The LRG is proud to contribute to the power and impact collaboration can have on the rare disease landscape and looks forward to keeping you up to date on the outputs of these partnerships in the months ahead. ■



## CALENDAR OF EVENTS

**MARCH 30, 2016**

**GIST "Knight" of Learning at OHSU**

Center for Health and Healing  
Portland, OR  
7:00 PM - 8:30 PM  
[bit.ly/gdolportland2016](http://bit.ly/gdolportland2016)

**MAY 12, 2016**

**Water of Life 2016**

Midtown Loft  
New York, NY  
5:00 PM - 11:30 PM  
[www.lrgwateroflife.org](http://www.lrgwateroflife.org)

**JULY 15-17, 2016**

**Life Fest 2016**

Torrance Marriott Redondo Beach  
3635 Fashion Way  
Torrance, CA 90503  
**REGISTRATION NOW OPEN**

**APRIL 3, 2016**

**GIST Day of Learning Miami**

University of Miami  
Miami, FL  
8:00 AM - 2:15 PM  
[bit.ly/GDOLMiami2016](http://bit.ly/GDOLMiami2016)



**LIFE FEST 2016**

[www.liferaftgroup.org/lifest](http://www.liferaftgroup.org/lifest)



## CAREGIVER from page 1

informal (unpaid) caregivers.

Most caregivers help with arranging doctor and hospital visits, dealing with insurance and payment issues, the activities of daily living and medical/nursing tasks.

For GIST caregivers, this also means monitoring treatment that is life long, including dealing with regular scans and the “scanxiety” which accompanies them. It means constant vigilance for medication compliance, helping with side effects and dealing with the challenges the patient faces.

It often means acting as an advocate for the patient, assuring that if and when they are admitted to the hospital, there is a collaborative effort on the part of the medical team and all of the patient’s medical history is taken into consideration.

Many caregivers report a decline in their own health due to their role. This may be a result of the stress involved in caretaking, but may also be due to age-related factors.

Caregiver stress is a recognized diagnosis in the world of mental health. It is important to recognize that many of the tasks of caregiving can be the catalyst for a host of emotions that are perfectly normal:

- Resentment
- Anger
- Frustration
- Anxiety
- Fear

- Depression
- Social isolation

Many of the feelings that arise for caregivers come from a physical source. Being mentally and physically exhausted can result in symptoms such as feeling tired all the time, sleeping too much or too little, overeating or not eating regularly, not exercising, coming down with frequent illnesses due to a weakened immune system, or abusing alcohol or drugs to cope with painful emotions.



**Caregivers are a vital part of the patient’s treatment team.**

Too much stress can have catastrophic consequences. It can result in “burnout” or as Norman Scherzer, LRG Executive Director, describes it, “battle

fatigue.” This is a very valid description, as each and every day GIST patients and their caregivers battle the dragon that is cancer.

### Signs of battle fatigue include:

- Having less energy than usual
- Feeling constantly anxious
- Being exhausted in spite of adequate rest
- Feeling like you are on an emotional roller coaster
- Neglecting your own needs
- Spending a majority of your time with caregiving-related tasks
- Having little or no time or interest in things that used to give you pleasure

It is time to put the brakes on caregiver burnout. It is time to S.T.O.P.

**S: Seek help.** Ask others to pick up some of the daily tasks that you perform. Share your feelings with friends, family, clergy or in a support group. Say “yes” when someone offers to help.

**T: Take time for yourself.** Find someone to spend time with your loved one so you can go to the gym, walk around the block, read a good book or have coffee with a friend. Tell someone when you feel overwhelmed. Take a class in meditation or yoga.

**O: Overcome your desire to be “superman” or “superwoman.”** Admit when you are in need of rest. Take advantage of opportunities for pleasurable social occasions.

**P: Pamper yourself.** Get a manicure. Schedule a massage. Promise you will not let yourself become exhausted, frightened or overwhelmed. Plan regular doctor’s visits for yourself, including an annual physical. Seek psychological support if you are overly anxious or severely depressed.

### Radical self-care

It is vital for caregivers to care for themselves first. Without this “radical self-care,” the ability to care for someone else is not only difficult, but often impossible. The analogy of oxygen masks on an airplane is a valid one: You must put on your own oxygen mask first in order to be able to extend aid to others.

In 12-step programs such as Alcoholics Anonymous and Alanon, there are very helpful tools for both

See **CAREGIVER** on page 10

## TISSUE from page 1

explained in further detail below. At the moment, the tissue bank consists predominantly of so-called “paraffin blocks.” These paraffin blocks are much easier to manage and store than frozen tissue specimens. Many of the technologies that researchers now use to study disease can be applied to material obtained from paraffin-embedded specimens. Thus, for practical reasons, the tissue bank has focused predominantly on paraffin block material.

### What are paraffin blocks?

Whenever a patient undergoes surgery to remove a tumor, the material removed from the patient will be fixed in formalin, after which parts of the specimen will be submitted for microscopic analysis. Before the tissue can be analyzed by the pathologist, the fragments of tissue are impregnated with paraffin and a “paraffin block” is formed.

The fragments of tissue that are thus processed generally measure 1cm x 1cm x 0.3 cm. Very thin slices (0.5 micrometers) of these paraffin blocks will subsequently be examined under the microscope. The majority of the tissue actually remains in the paraffin block. The paraffin blocks are stored for many years in the archives of surgical pathology departments in the hospital where the tumor was removed.

When a tumor such as GIST is removed from a patient, the pathologist will submit one paraffin block per centimeter of tumor size. For example, if a patient has a tumor with a diameter of eight centimeters, eight separate blocks will be obtained and eight separate areas of the tumor will be examined under the microscope.

The reason for this is that tumors can vary in appearance from area to area and pathologists want to have a good overall sample size for each tumor. The goal of The Life Raft Group is to obtain at least one paraffin block from each patient surgery to populate the tissue bank and ensure sufficient

**“...the collection of these samples can be used in a wide range of research studies—all with the goal of improving the survival of GIST patients in the future.”**

material is retained in the pathology archives of the hospitals where the surgery occurred. Therefore, samples will be available for researchers to perform studies that hopefully will benefit patients suffering from GIST.

### Why concentrate paraffin blocks from multiple patients in a tissue bank?

The presence of a tissue bank has many advantages. Imagine, for example, a researcher who might have a hypothesis about why certain GIST tumors behave more aggressively than others. He or she will need an idea of how many samples might be available to study. In the absence of a centralized national tissue bank, the researcher will mostly look at the archives at his or her institute and perhaps the institutes of a few collaborators. This in itself is a very laborious process and often will take months to accomplish. Quite often, there are not enough specimens available. The importance of a tissue bank for a disease that is rare, such as GIST, lies in the fact that a single phone call will suffice to ensure whether sufficient specimens are

available and the project can progress, allowing the research process to move faster. Researchers often have a large number of hypotheses and information about the availability of specimens is extremely important.

In addition, the physical tissue bank containing the paraffin blocks is coupled with very high quality clinical information about patients from which these samples were obtained. This database, the “LRG Patient Registry,” has been organized through the efforts of the Life Raft Group and very quickly allows researchers to obtain (in a completely de-identified manner) the important features of the patient’s clinical history. The advantages of this are immense.

See **TISSUE** on page 10

## Latest GIST Cancer Journal has arrived!



The GIST Cancer Journal is the first journal specifically focused on Gastrointestinal Stromal Tumors (GIST).

### ALL INQUIRIES:

Pete Knox  
Director of Strategic Planning  
973-837-9092 x123  
pknox@liferaftgroup.org





Norman and Anita Scherzer  
Love is the foundation of the LRG.

# ALL WE NEED IS LOVE



"Having Katelyn, I have felt love in a new and wonderful way!"  
- Kim Trout



"I love my siblings because they motivate me to be myself."  
- Helena Mattioli

Dear LRG Community,

Thanks to our:

- Caregivers, the unsung heroes who care for and give to our patients every day
- Research team, who tirelessly reach for our mission to find a cure
- Donors, who support our research efforts to educate the world about GIST
- Volunteers, who give unconditionally
- Physicians, who treat our patients
- LRG staff, who keep the raft afloat and give our community the gifts of time and hope
- And finally, our patients, who keep rowing despite it all and support our patient registry and tissue bank

"And whoever saves a life, it is considered as if he saved an entire world."

Norman Scherzer, Executive Director



We love when doctors collaborate—especially in the same room at the same time. Pictured from left: Dr. Brian Scully, Chief of Infectious Disease and Dr. Joshua R. Sonett, Chief of Thoracic Surgery at New York Presbyterian, collaborating on Anita Scherzer's care.



"I love my little girl so much already and can't wait to meet her this spring!" - Milly Menos



Jerry Cudzil,  
President

## WE LOVE OUR BOARD

"We have made significant strides in helping patients and caregivers navigate this mental, emotional and physical roller coaster that we call GIST. But the strides are woefully inadequate, as we continue to lose too many people we care about to this disease. I am awestruck and inspired by the focus and tireless effort our staff puts forward every day. There is an old saying that goes: It is easy to focus. But the hardest thing to do is to refocus, every single day. The only way to win this GIST battle, or any battle for that matter, is to have the ability to refocus every single day. *Dum spiro spero.*" - Jerry Cudzil



"I am thankful for all the great years with my dad (Lawrence Glasser) and his outstanding caretaker, my mom and current LRG volunteer, Eileen Glasser." - Gary Glasser





Noha Hussein and her husband Ayman and daughter Kenzy. "They are the two that keep me going!"



"Celebrating our wedding anniversary!" - Su DJ



Congratulations Maria Mastretta!  
We love weddings!



"The most precious jewels you will ever have around your neck are the arms of your children."  
- Sara Rothschild



"Love of family." - Dr. Brian Rubin



"I love how my son tries to keep me tech savvy. That may not work, but he definitely keeps me smiling!" - Kathleen Gronet



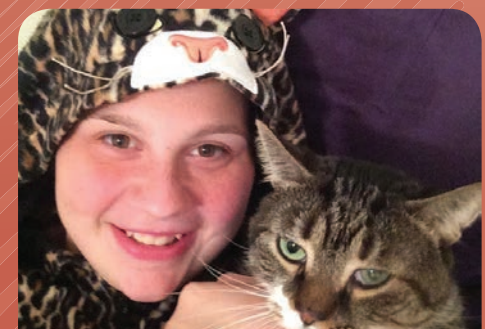
My favorite support group, my FAMILY! - Teena Petersohn



Liz Aguar and Caregiver



"Sharing Christmas Joy with my beautiful daughters and precious little granddaughters! Happy times!" - Anita Getler



"I love spending time with my cat because his love is unconditional." - Angela Edson



"Celebrating my 10-year cancer anniversary, beating cancer and my fear of heights by zip lining!" - Carolina Ponce

## GENERIC from page 1

of marketing exclusivity. Generic versions of Gleevec have already been approved in other countries.

Gleevec is one of the first successful oral targeted chemotherapeutic drugs, and over the years the LRG has monitored patients and gathered data that indicates the efficacy of Gleevec and its ability to prolong survival with tolerable side effects. Generic imatinib has yet to prove equal results. To assess the efficacy and tolerability of the generic imatinib, the LRG is launching a research program to gather comparable data beyond the FDA requirement of bioequivalence.

Generic drugs must undergo the same rigorous quality control as the innovator (brand name) drug. To gain

FDA approval, a generic drug must:

- Contain the same active ingredients as the innovator drug (inactive ingredients may vary)
- Be identical in strength, dosage, form and route of administration
- Have the same use indications
- Meet bioequivalency criteria of 80 to 125 test reference ratio
- Meet the same batch requirements for identity, strength, purity and quality
- Be manufactured under the same strict standards of FDA's Good Manufacturing Practice regulations as the innovator drug

What must be taken into consideration, however, is that some variability occurs in the manufacturing of both brand and generic drugs. The FDA limits the amount of variability, outlining acceptable standards.

Generic drugs are not required to contain the same inactive ingredi-

ents of the innovator drug. These can include flavorings, fillers and preservatives. Patients may react differently to the inactive ingredients in the generic medication. It is important to check for any inactive ingredients that you may have an allergy or sensitivity to before taking any medication.

The generic medication may also differ in size, shape, scoring, color and packaging.

### Bioequivalence

Manufacturers of generics need to prove that their drug is bioequivalent to the brand name drug - showing comparable or no clinically significant difference in their bioavailability and similar times to achieve peak blood concentrations. Bioavailability is a measurement of the extent and rate of the therapeutically active medicine that reaches the systemic circulation and

**“Bioequivalence does not necessarily mean therapeutic equivalence. To be therapeutically equivalent, a drug should have the same clinical effect and safety profile. These are not demonstrated in a bioequivalence test.”**

is therefore available for absorption at the site of action. Scientists perform pharmacokinetic tests to measure the difference between the way the brand and generic drugs are absorbed into the body. For a generic drug to be considered bioequivalent, it should meet 90 percent confidence intervals of 80 to 125 percent test reference ratio. Significant difference is 20% ( $\alpha = 0.05$  significance level). This simply means that the generic's bioavailability is not significantly less than the brand name and vice versa. Bioequivalence does not necessarily mean therapeutic equivalence. To be therapeutically equivalent, a drug should have the same clinical effect and safety profile. These are not demonstrated in a bioequivalence test.

The FDA reviews the bioequivalence, and all generic drugs must have their manufacturing processes and packaging and testing sites held to the same standards as for name brand drugs. (Source: FDA)

### Cost Factor

Most generic drugs carry a lower price than the brand name equivalent. This does not mean lower quality, but consumers should monitor information about the generic form of their medication with their physician and medical teams.

Although the patent has expired only for CML and not for GIST, there are factors that will contribute to GIST patients being switched to generic imatinib. Factors will include the patient's personal decision in concert with consultation with their medical team, what the insurance company will cover, and the cost.

Although pricing for generics are typically significantly lower, based on preliminary information, the difference in cost for generic imatinib is within a 2.5 to 3 percent range at this time.

If your decision is to remain on the brand (Gleevec), there are several things you can do. Your physician can write the prescription as “Dispense as Written.” Inform your pharmacist that the generic indication currently is for CML, and does not include GIST. Call your insurance company to assure that they will continue to cover the name brand.

Check for updates on the Generics section of the LRG website: [www.liferaftgroup.org/generics/](http://www.liferaftgroup.org/generics/)

Also on our website are FAQ's and resources to help you better understand what this transition will mean for patients, including information on financial assistance and insurance.

### The LRG Launches Research Program

See **GENERIC** on page 9



## GENERIC from page 8

As US patients begin taking the generic form of imatinib, the LRG will launch a research program to evaluate the impact on treatment.

A key factor in monitoring treatment effectiveness our patient registry. Joining the LRG Patient Registry enables us to collect collaborative data that may lead to more effective treatments, and eventually a cure. If you are not a member, support our efforts by signing up today at: [www.liferaftgroup.org/life-raft-groupmembership-application-form/](http://www.liferaftgroup.org/life-raft-groupmembership-application-form/).

Members who choose to transition to generic imatinib are encouraged to participate in the LRG Generics Research Program. In collaboration with TDM Pharmaceutical Research, the study will monitor both CML and GIST patients who are on branded Gleevec and who plan to transition to generic imatinib. Learning if there is variation in drug levels for an individual who switches between brand and generic will prove to be a beneficial tool. Such monitoring can help the treating physician to provide personalized management and care in monitoring the disease and side effects. Blood

level testing is a crucial tool to developing individual treatment plans. If significant differences are discovered between the brand and generic drug levels, the physician will have options that may include switching the patient back to the brand drug.

The study will involve imatinib Blood Level Testing (BLT), a method of determining the trough level, or lowest level, of the drug in the blood. Research suggests there may be a relationship between the trough levels of imatinib and clinical benefits in GIST. Numerous factors can affect this level, including body metabolism, prescribed dosage, and drug-drug interactions. Research has suggested that a level of 1100 ng/ml may be the therapeutic level, or optimal threshold for drug efficacy.<sup>1</sup> Further research is devoted to investigating the relationship between imatinib exposure and efficacy to develop guidelines for the potential of BLT use in clinical practice.<sup>2,3</sup>

In order to qualify for the study:

- Patients must reside in the United States.
- Patients must allow their insurance to be billed for the testing twice (once while on brand and once while on generic).

- Patients must enroll in the LRG Patient Registry if they have not already done so.
- Please be advised that other inclusion criteria may apply.

To learn more about the research program or to enroll, please contact Michelle Durborow at [mdurborow@liferaftgroup.org](mailto:mdurborow@liferaftgroup.org). You may read more on our website: [www.liferaftgroup.org/generics-research-program/](http://www.liferaftgroup.org/generics-research-program/)

For more information about this testing procedure, please contact TDM at 302-832-1008 or [support@TDMRxResearch.com](mailto:support@TDMRxResearch.com).

### REFERENCES

1. Demetri GD, Wang Y, Wehrle E, Blanke C, Joensuu H, von Mehren M. Correlation of imatinib plasma levels with clinical benefit in patients (Pts) with unresectable/metastatic gastrointestinal stromal tumors (GIST) (abstract, oral presentation). 2008 Gastrointestinal Cancers Symposium. Orlando, January 25–27, 2008
2. Widmer N, Decosterd LA, Leyvraz S, Duchosal MA, Rosselet A, et al. Relationship of imatinib-free plasma levels and target genotype with efficacy and tolerability. *British Journal of Cancer* 98:1633-1640. 2008
3. Picard S, Titier K, Etienne G, Teilhet E, Ducint D, et al. Trough imatinib plasma levels are associated with both cytogenetic and molecular responses to standard-dose imatinib in chronic myeloid leukemia. *Blood* 109: 3496-3499

## CANCERVERSARIES



### Sara Gould 2 YEARS

“Two years into my GIST journey I am more positive about everything life offers. I want to celebrate each and every day I am alive. I want to see more of the world while spending more time with my family and friends. As I mark my second Cancerversary, I am humbled because I am a survivor and reminded how precious life is.”



### Gerard van Oortmerssen 5 YEARS

“It is a privilege to be alive! Since my diagnosis I am grateful for every single day and I enjoy life immensely. It is great to be part of the global GIST community and I appreciate the endeavors of the Life Raft Group.”



## TISSUE from page 5

### What is a tissue microarray (TMA)?

A tissue microarray is essentially a collection of very small fragments of tumor samples from multiple patients that are arranged in neat rows and columns in a paraffin block. Sections from this array contain a very small part of each tumor of all the patients represented and can be placed on a single glass slide. These slides can then be used for tests such as immunohistochemical staining, a technique in which the presence or absence of a particular protein can be demonstrated.

The advantage of having all tumors combined in a single array is that only one immunostaining experiment needs to be run. This saves an enormous amount of time and money and allows the researcher to test multiple hypotheses at a low cost.

The presence or absence of the proteins in question can then be correlated with the clinical data obtained from the LRG Patient

Registry. In this way, one can very quickly determine whether a set of the proteins correlates with clinical outcome or can be used for diagnostic purposes. For example, we used a GIST TMA to quickly confirm that the novel diagnostic marker, DOG1 protein, was indeed present in the vast majority of GISTs.

It is important to realize that making a TMA does not destroy the original paraffin block in any way. Only a 0.6 mm tissue core is removed and the vast majority of the diagnostic tissue remains intact.

In summary, the tissue bank of GIST specimens, combined with the clinical data obtained by the Life Raft Group, forms an invaluable resource for researchers. TMAs offer an efficient and cost-effective way to study these specimens. In addition, TMAs provide a cost-efficient way to use the material for research. Since approximately 150 sections can be taken from each TMA block, and each original paraffin block has up to 50 tissue cores that can be

used to generate new TMAs, there is a nearly unlimited quantity of specimens available. In my laboratory, we use these TMAs frequently to quickly assess the reliability of protein to serve as prognostic or diagnostic markers. ■

## SECOND ANNUAL WATER OF LIFE CHARITY EVENT



MIDTOWN LOFT - NYC  
MAY 12<sup>th</sup> 6:00PM

The Water of Life event is an annual whisky fundraiser hosted by Dr. Matthew J Lurin (co-founder of the Whisky Nerds) to help raise money towards critical research that is dedicated to finding a cure for GIST.

Over the course of the evening, guests will have the opportunity to try over 25 whiskies out of well over 100 possibilities, accompanied by food pairings at each table, a buffet dinner and desserts.

Learn more about the event at:  
[www.lrgwateroflife.org](http://www.lrgwateroflife.org)

## CAREGIVER from page 4

recovering alcoholics and their family members. These tools can easily be utilized by caregivers. One of the tools is learning the “three Cs: You didn’t cause it, you can’t control it, and you can’t cure it.” This helps to take away the over-responsibility you may feel and the survivor’s guilt you may have for not having the disease.

Other slogans from Alanon that may help caregivers are: “Easy Does It”, “How Important Is It?”, “First Things First”, and “One Day at A Time.” These are reminders that, as care-

givers we need to prioritize and not allow ourselves to be overwhelmed by the big picture that is caring for someone with GIST.

Putting oneself first is not selfish. It is self-focused, which allows one to become strong enough to go to battle each and every day.

At the LRG, we remind caregivers of one of the most important facts: You are not alone. This community will be your life preserver when you are having difficulty keeping your head above water. ■



## HEART from page 2

### Stivarga

Another VEGF inhibitor, Stivarga, is also known to cause an increased incidence of hypertension. The onset of hypertension typically occurs during the first cycle of treatment. Stivarga should not be started unless blood pressure is adequately controlled. It is also advised to monitor blood pressure weekly for the first six weeks of treatment and then during every cycle, unless there is clinical evidence to monitor more frequently. (Source: Bayer: Stivarga Prescribing Information)

No matter which drug you are on, your physician should be notified if cardiac side effects become more severe to determine if the drug should be discontinued until they are controlled and a management plan is in place.

Although GIST medications may put you at an increased risk of heart disease, there are several proactive

ways to prevent heart disease:

- Maintain a normal blood pressure of less than 120/80 mmHg. According to the American Heart Association, prehypertension is blood pressure that is consistently ranging between 120-139/80-89 mmHg. Blood pressure above 140/90 mmHg is considered hypertension.
- Be physically active. To maintain overall cardiovascular health, it is recommended to exercise at a moderate intensity for a total of 150 minutes per week. Moderate-intensity exercise can include walking, riding a bike at a slow pace, or ballroom dancing.
- Eat a heart healthy diet. The DASH (Dietary Approach to Stop Hypertension) Diet is an excellent way to prevent heart disease. This diet focuses on eating more foods that are rich in potassium,

magnesium and calcium, such as fruits, vegetables, and low-fat dairy foods; and cutting back on foods that are high in sodium, saturated fat, cholesterol, and trans fat.

The chances of developing heart disease can be lessened with proper precautions. One of the most important tests to detect heart disease is monitoring blood pressure. Keeping track of any changes and discussing any risks you may have for developing heart disease with your doctor will help in developing a preventative strategy. Other routine tests to monitor heart health include checking blood cholesterol and triglyceride levels.

It is never too early to take preventative measures and make some lifestyle changes. As a GIST patient, it is vital to take active steps to improve your overall health. ■

## In Memoriam

### David Lee Kors avid outdoorsman, passionate volunteer

*Published in the Sacramento Bee, Sacramento, CA*

David Lee Kors was born in Hammond, Indiana on June 18, 1934 and went to be with his Lord and Savior on December 17, 2015 after battling GIST cancer for three years.

Dave received his Bachelor of Science and Masters of Science degrees in Mechanical Engineering from Purdue University and Southern Methodist University, respectively. Over a 37-year career he contributed to historical NASA initiatives that included the Apollo Mission to the Moon and Space Shuttle programs.

He was married to the love of his life, Nancy Jane Ansteatt, for 54 years.

Together they raised three children. He is survived by his wife, as well as his sister, Alice Elleftson. He was preceded in death by parents Ruth and John Kors, and sisters Doris Kors and Eileen Lloyd. His children include Jennifer (Dave) Leighton, Julie Abrams, and Jonathan (Jennifer) Kors, and grandchildren Elizabeth, Nicolas, Cameron, Arielle, emery, Taylor, Ashley, Joshua and Emily.

Dave served as a Deacon and Elder at Fair Oaks Presbyterian Church, where he and Nancy were members for 30 years, after which they attended Faith Episcopal



Church of Cameron Park. He was passionate about supporting Christian missions worldwide and also volunteered locally on the Rescue School District Board and with Habitat for Humanity. Dave's

zest for the outdoors was manifested through his love of skiing, hiking, biking, camping and traveling. He never backed down from a good challenge, and was always planning the next great project. A Celebration of Life service was held on January

15, 2016 at Fair Oaks Presbyterian Church. In lieu of flowers, donations may be made to cancer research or a missionary of your choice in Dave's name. ■

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155 US Highway 46, Suite 202  
Wayne, NJ 07470  
p: 973-837-9092  
f: 973-837-9095  
e: [liferaft@liferaftgroup.org](mailto:liferaft@liferaftgroup.org)  
w: [www.liferaftgroup.org](http://www.liferaftgroup.org)



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