

Social Media Helps Rescue Croatian Patient

By Mary Garland
Communications Director

Danijel Romic, a 34-year old GIST patient from Crikvenica in Croatia, was faced with a challenge. Diagnosed with GIST in 2014, he did not have access to a potential life-saving treatment, Nexavar, which in Croatia is not registered for the treatment of GIST.

He reached out on Facebook, including to the Life Raft Group page,

Romic Continued on Page 10



Danijel with his 2 children

NIH Clinic Combines Research, Knowledge, and Hope

By Sara Rothschild
Program Operations Senior Director

I had the pleasure of attending the 15th Pediatric and Wildtype Clinic along with Becky Owens from GIST Support International as patient advocates. The Clinic was held at the National Institute of Health in Bethesda, MD on July 5-7, 2017. The Clinic is a collaboration between clinicians and researchers to collect data, investigate and develop treatments for GIST patients who do not have either c-KIT or PDGFR mutations. This includes patients with Carney's Triad, Carney-Stratakis Dyad and what has been referred to as wildtype GIST, or Pediatric-like

NIH Continued on Page 9

In the beginning...Patient-reported outcomes

By Jerry Call
Data Analyst

Patient-reported outcomes is a buzz-phase that we hear a lot these days. At the Life Raft Group, I was recently in a meeting where we were discussing patient-reported outcomes, the LRG registry and patient-powered science. I'm still not quite sure what the definition of patient-reported outcomes is, but I can tell you exactly when I understood how important, no, how life-changing they could be. I will concede that it's probably not going to be life-changing for everyone, but it can be a really, really big deal.

For me, the revelation began in July 2000. My wife,

Stephanie, had been diagnosed with metastatic GIST nine months earlier. At that time, almost everyone thought GIST was another cancer called leiomyosarcoma (LMS). At best, some thought that GIST was just a variant of LMS.

At that time, I belonged to a listserv for LMS patients ran by Gilles Frydman of the American Cancer On-line Resources (ACOR). Treatment for LMS (and GIST) was what today we call cytotoxic chemotherapy. Back then we just called it chemotherapy because almost all cancer-directed drug therapy was cytotoxic chemotherapy. Doxorubicin and Adriamycin were the two most common chemos and they were often given in a very difficult mixture called MAID (Mesna, Adriamycin, Ifosfomide and Decarbazine). Common knowledge at the time was "that

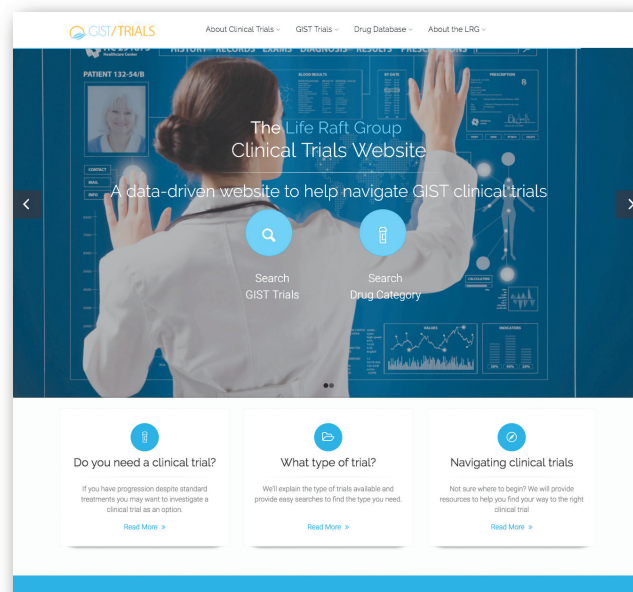
Outcomes Continued on Page 8

A data-driven website to help patients navigate GIST clinical trials

Clinical trials play a key role in testing new ways to detect, treat, and prevent diseases. When patients are faced with the challenge of searching for treatment options that can only be accessed through a clinical trial, the process can be overwhelming and confusing. Patients will have to sift through many clinical trial options, while also trying to decipher complex scientific information.

The Life Raft Group (LRG) and its volunteers have developed GIST/Trials, a free, easy-to-use clinical trial database designed to provide patients, caregivers, and members of the public current information about clinical research studies relevant to GIST. It contains information about clinical studies being conducted throughout the United States and in many countries throughout the world.

The data and information provided on this site are sourced from ClinicalTrials.gov, abstracts, publications from scientific forums, FDA drug product information, and other reliable public information sites about the drug or trial. The GIST/Trials database is organized in a way that easily allows GIST patients to get the most vital information



needed to facilitate the process of navigation and decision-making, while also educating and advocating for patients to take an active role in their treatment.

For patients, making a timely decision to participate in the right trial is a crucial step in managing their disease. Clinical trials share the same goal of recruiting participants in a timely manner, as well as maintaining patients' participation. Not meeting these goals is the greatest obstacle in developing the next treatment.

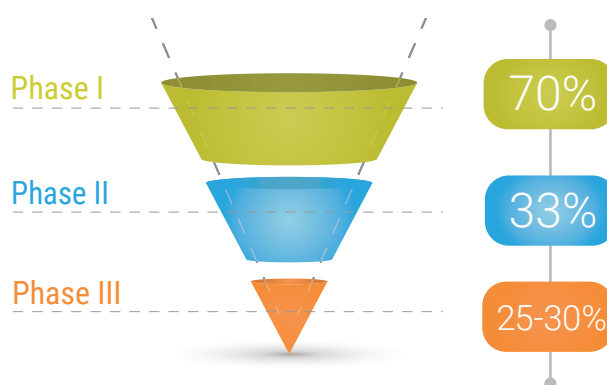
Facts and Figures

Average # of people joining a clinical trial



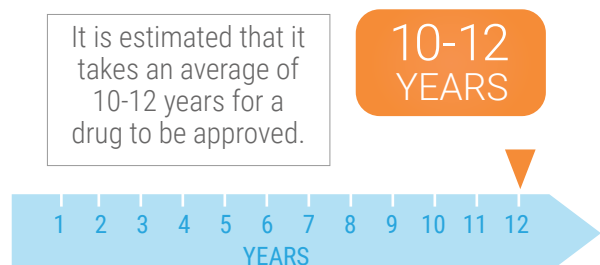
Source from: Institute of Medicine (US) Forum on Drug Discovery, Development, and Translation. Transforming Clinical Research in the United States: Challenges and Opportunities: Workshop Summary. Washington (DC): National Academies Press (US); 2010. 6. Clinical Trials in Cancer. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK50895/>

Percentage of trials moving to the next phase?



Source from: <https://www.fda.gov/forpatients/approvals/drugs/ucm405622.htm>

Length of Drug Approval



Source from: <https://www.hiv.va.gov/patient/clinical-trials/drug-approval-process.asp>
<https://www.drugs.com/fda-approval-process.html>

Visit www.gisttrials.org

to help you and your healthcare team navigate GIST-related clinical trials





– Collaboration in Action

By Pete Knox
Acting Project Management Director

The LRG launched SideEQ (www.mysideeq.org) several months ago, and has had a number of patients sign up – both those with GIST and with other diseases. If you are one of them, thank you! You may already know the numerous benefits the site can provide. If you haven't signed up yet, you may be wondering what's in it for you. After reading this article, you will not only know how you will personally benefit, but also why SideEQ is a tool with the power to help patients in general.

At its heart, SideEQ is based on collaboration:

Collaboration between the LRG and patients, between patients themselves (both within and across diseases), and between patients and researchers. All of these groups have one thing in common – the desire to improve the quality of life of patients. SideEQ does this in two ways – by allowing patients to have a place to track their medications and side effects, and by giving them access to information (both from healthcare professionals and other patients) that allows them to manage these side effects. When patients are able to manage their side effects, they can take control of their disease, stay on their medication, and have improved outcomes. **An important core function of SideEQ is its ability to measure the impact of side effects on patient adherence.**

Why do patients need SideEQ?

In this era of “personalized” or “precision” medicine, doctors want the ability to target treatments specifically to the needs of the patient to improve outcomes. This often means tailoring treatments to a specific mutation, but in reality, it's much more than that. True “personalized” medicine involves listening to the patient and trying whenever possible to match their treatment regimen to their lives. This includes addressing any specific side effects they may have and giving them strategies to overcome or minimize them in order for them to go about their daily routine.

Unfortunately, this is difficult to accomplish when physicians see a multitude of patients per day. Often, they have only a few minutes to talk to the patient and many questions to answer, and don't have time to address issues like side effects. Thus, the burden of side effects management is shifted to patients and their caregivers. SideEQ helps to shoulder this burden in three ways: first, by giving access to best practices for specific side effects; second, by allowing patients and caregivers to post their tips (as well as read previous posted tips) on how they control their side effects; and finally, by allowing patients and caregivers to enter not only the side effects they are currently experiencing, but also their disease and any

medications they may be taking for it. This allows them to see statistics for each side effect specific to their disease and medication, letting them know how rare it may or may not be.

SideEQ was designed for patients who suffer from different diseases including, but not limited to, GIST so as to help as many people as possible. The LRG has been reaching out to various patient groups to help them introduce SideEQ to their patients and has already been successful in collaborating with the National Leiomyosarcoma Foundation. We are happy to collaborate with new organizations and will continue to do so.

Why do researchers need SideEQ?

Understanding the impact of disease and treatment on the quality of life of patients has always been important, but has been difficult to measure. Patients rarely get to discuss their side effects with physicians, and if they are part of a study, this information often gets left out. Because of this, researchers get an incomplete picture of what the treatment journey is really like. When side effect and quality of life information can be collected from a wide variety and large number of patients, this helps sharpen that picture. SideEQ was designed to do just that. Data on side effects and treatments is de-identified and then aggregated, giving it the ability to be shared with researchers so they can better understand how patients treat their side effects, and ultimately the effect those behaviors can have on patient outcomes. The research industry is just now learning what patients have known instinctively for a very long time – that information provided by patients can in fact be very useful, and in some cases, as with side effects, can complement clinical data. This is often termed “real world evidence” and is a big focus in research and regulatory circles right now, as it is seen by many as the “missing piece” that will ultimately lead to better drugs and improved outcomes. Simply put, SideEQ helps supply that missing piece, and we're very happy to collaborate with researchers to help make that happen.

What's next?

While SideEQ has already been quite successful with a few hundred users and over 20 diseases represented, our intention is to grow and improve even further. We will continue to reach out to patient groups in an effort to introduce it to as many patients as possible. We have also spoken with researchers, regulators, and industry leaders to help ensure that we are able to provide the type of data that is most needed. We are also continuously improving the product itself, with new enhancements already in development, and will continue to provide updates. To learn more go to www.mysideeq.org. After a quick and easy registration, go ahead and fill out your profile and take a look around!

La Jolla Provided a Beautiful Backdrop for Our Three-Day July Event

By Laura Occhiuzzi
Outreach and Engagement Senior Director

The Life Raft Group and UCSD hosted a three-day event at University of California, San Diego UCSD-Moores Cancer Center from July 13th through July 15th.

A GIST Awareness Day (GAD) event took place on July 13th. The event was held on the campus of UCSD at Jacobs Medical Center. We celebrate this day worldwide to increase awareness, distribute educational materials and enlighten others as to the complexities of this rare disease. A huge thank you to Dina Wiley, Debra Melikian and John and Claudia Link for their assistance. We truly appreciate all the volunteers who help us along the way.

On July 14th, in addition to a clinic held by Dr. Jason Sicklick and Dr Paul Fanta, we toured Dr. Sicklick's research lab. We had over 20 people on the tour as Dr. Sicklick took us through a day in the life of a researcher. Research starts with a passionate clinician. It takes passionate patients to donate tissue and provide clinical data. Both the tissue and data are shared with the researcher.

How do we get closer to finding a cure? Follow these steps: join the Life Raft Group, donate your tissue and join the patient registry! Help us get one step closer to finding a cure!

Record numbers attended our GIST Day of Learning

on July 15th. Over 100 people gathered to support one another and learn from the experts. The day started with a patient support group led by our Southern California state leader, Dina Wiley. Against the setting of a beautiful atrium, Dina's expertise as a group facilitator came shining through. Patients, caregivers and friends truly benefitted from the support. A huge thank you to Dina for her passion and dedication to our LRG community.

Norman Scherzer, Executive Director of The Life Raft Group, opened the afternoon session with an LRG update. He talked about our new initiatives and our vision moving forward. Norman presented Dr. Sicklick with a \$10,000 check to support his research efforts at UCSD.



PICTURED: Dr. Jason Sicklick, Deb Melikian, Norman Scherzer, & Malcolm Aste

"Beyond the Big Picture of GIST- No Subtype Left Behind" was presented by Dr. Sicklick, followed by Paul Fanta, MD (both from UCSD) who discussed "Personalized Medicine for Treating GIST." Dr. Michael Heinrich came from Portland (OSHU) to

present "A Treatment of GIST: The Next Generation." Dr. Sandip Patel from UCSD discussed Immunotherapy. Debra Melikian spoke from the heart as she concluded the program with her personal GIST Journey. Thank you, Deb, for sharing your very touching and emotional story of life, love and hope.

We thank Pfizer, Bayer, Blueprint and Novartis for supporting our GIST Days of Learning. We thank the staff of UCSD for their time and effort planning and organizing the event along with us. Thanks to our presenters for always being there for our GIST community. We appreciate all you do!



Upcoming Events

**Night to Fight Cancer
NYC**
October 19th, 2017

GDOL Toronto
October 21st, 2017

Interested in having us come to your city for a GDOL?
Email your ideas to Laura at
locchiuzzi@liferaftgroup.org.

Dana Pearson - "Until We Meet Again"

We lost a great light in the Life Raft Group with the passing of Dana Pearson back in June. Dana touched the lives of others in a profound way, always smiling, always reaching for life-affirming experiences in the midst of her own struggles.

Her last Facebook post summarizes her abiding faith and love of family:

" At 1:23pm today I asked our lord and savior to give me a lift to heaven. I asked this without reservation as I have lived my life as he had asked of me. I leave behind a loving family that is not yet ready for my departure. Please limit the tears, as I prefer to be remembered for all the fun times we shared. I loved life and certainly wish I had more time to make more memories with each of you. There is no need to be concerned for me as I am with my loved ones in heaven where I will await the rest of my family and friends when it is their time.



To honor my presence here on earth, I ask that you hold your loved one tight and let them know you love them and reach out to that person in need to help them rise above their current situation. I am very thankful for all the amazing

friendships I have enjoyed. I feel so blessed to have had so many and look forward to the day when we will be reunited. Until then, I ask that you live a full life, one you can look back on with the pride I feel right now. Life is so much shorter than you can imagine, but it is well worth the ride. Make those memories now while you have the time. I love "All Ya'll" very much. Until we meet again..."

If you didn't have the privilege of meeting Dana, or have not yet seen the videos from our last Life Fest meeting, you can hear her talk about how side effects impacted her life here:

<https://youtu.be/gvtABSnpWGI>

She will be greatly missed.

LRG attends Partnering for Cures in Boston

By Kathrena Aljallad
Patient Registry Director

I recently traveled to Boston, Massachusetts to attend Partnering for Cures. This is a meeting sponsored by Faster Cures that brings together patient advocates, scientists, policy-makers, and other leading members in the industry who are working towards fostering valuable collaboration in order to help provide patients what they really need, a cure.

The key topic for this conference was "patient-centricity", the concept that patients are the experts in their own disease and should be the ones propelling changes within the health care industry.

The conference opened with a plenary titled "Patient-centricity: What's the return on Engagement?", where members of different organizations discussed how their patients help drive their organization. A common theme within this discussion was patient registries and engaging the patient's voice in different areas of healthcare including clinical trial design, drug marketing, and helping pharmaceutical companies understand the true burden of a disease. Theresa Mullin from the U.S. Food and Drug Administration can be quoted for saying that "Patients are experts," and they should be listened to and learned from. This is not news for the Life Raft Group since we have always known the importance of a patient's voice. The LRG Patient Registry is a perfect example of this. For over fifteen years, we have collected medical information from patients themselves regarding their GIST diagnosis

and throughout their entire treatment. Today, our Patient Registry is the largest GIST registry with robust data that is provided by the patient experts themselves.

The conference went to breakout sessions, where topics such as sharing data and clinical trials were discussed. Data sharing is crucial in helping researchers draw conclusions and better understand diseases, yet there are still barriers that prevent the ease of sharing data. Some suggestions that arose to breaking these barriers include more accessible electronic health records and patients advocating for their cause to Congress. Although there have been advances in the data sharing world with new technology being developed such as data mining and data sharing databases, there is still a long way to go.



The Life Raft Group shares in the belief that collaboration will help drive us closer to the cure. Our recent joint research project with Columbia University Medical Center, NewYork Presbyterian is an example of collaboration meant to help keep patients alive and find new treatments.

GIST AWARENESS DAY

Argentina • Chile • Colombia • Dominican Republic • Guatemala • Honduras • Kenya



We celebrate GIST Awareness Day on July 13th every year. July is Sarcoma Awareness Month, and since GIST is a sarcoma, it is an opportunity to draw attention to this rare disease. We chose the 13th, as 13 people are diagnosed with GIST each day in the U.S.

GAD was celebrated around the globe this year, with gatherings, celebrations and a three-day event in La Jolla that included a GIST Day of Learning attended by over 100 participants, and a tour of Dr. Jason Sicklick's lab at Moores Cancer Center.

To view videos and photos from around the world, visit the GAD gallery on our website:
www.liferaftgroup.org/gist-awareness-day-2017-gallery/

NUESTROS SUPER HÉROES Y HÉROINAS

ANDREA TORRES

"La actitud solo es una pequeña cosa que hace gran diferencia"

Tegucigalpa - Honduras

Eres mucho mas fuerte de lo que crees

Alizaria GIST 2017

"DÍA DE LA CONCIENCIACIÓN DEL GIST"

13 DE JULIO

#HERO4CANCER

La Jolla, CA • Mexico • Mumbai • Peru • Philadelphia • Venezuela • Washington, D.C.

Our theme for GIST Awareness Day was [#Hero4Cancer](#). Participants enjoyed making capes and masks, posing as “superheroes” and interacting with Tommy Tissue and Dina Data. Tommy and Dina were reminders at our events that we all can be a hero for cancer by donating our data through our Patient Registry, tissue to our GIST Collaborative Tissue Bank, and funds to help us continue research to help patients increase survival.

To learn more about how to help:
www.liferaftgroup.org/hero



Outcomes Continued from Page 1

abdominal LMS (GIST) did not seem to respond as well as LMS from other locations (LMS).

Look hard enough and you could find really bleak information (much of which was inaccurate); such as one blog (not sure it was called a blog back then), that claimed LMS as one of the deadliest of all cancers.

By July of 2000, Stephanie had exhausted the normal treatment route; trying two rounds of MAID with her local oncologist, followed by surgical consults at an academic hospital, a second opinion at Dana-Farber, one of the top sarcoma referral hospitals, a tissue-sensitivity test followed by more chemo and even some interferon mixed with an alternative treatment. But finally reading thousands of emails written by patients in the listserv was about to pay off big-time.

In addition to the listserv, I had started the long journey of learning about cancer. Somewhere between “thank god for the internet” and “be careful, it’s the internet,” I learned how to learn. This meant finding out about new things like PubMed, the library repository where nearly every medical paper is indexed. Here I could find abstracts and start learning. With a little bit of a jump-start from PubMed coupled with the visit to Dana-Farber, I had already figured out that GIST and LMS were different. After the Dana-Farber visit, where Stephanie was told that she probably had GIST and not LMS, I started to focus much more on GIST when doing research.

After the Dana-Farber visit, I read about little-publicized research that found c-kit mutations in a very small number of patients. However, at that time, there hadn’t really been the big connection. The ah-ha moment would come when a drug proved so effectively matched to a mutate gene that it changed everything. Well, there had been, but it was recent and obscure enough that my fledgling research skills hadn’t uncovered it. The ah-ha connection between drug and mutation came in a leukemia, chronic myelogenous leukemia (CML).

In July 2000, Norman Scherzer posted about an amazing

response that his wife, Anita, had after one month on a new drug, STI-571. Anita was participating in a very limited (30 patients were intended) phase II trial of the drug at Fox Chase Cancer Center in Philadelphia. Gary Golnick, another caregiver to his wife, Mary, quickly followed with a post about the trial, including several other patients that were responding at Dana-Farber. He also had a few other details, like the name of all three trial sites in the U.S.A..

Armed with these facts, I did some quick research. I found that this new drug, STI-571, had been developed for CML and had already undergone a phase I trial in CML (thus they could move directly into phase II in GIST). In CML,

it inhibited a different protein, Bcr-Abl. Bcr-Abl mutations and the resulting defective protein were basically the cause of CML. It turns out that this drug was incredibly effective in CML. In the phase I trial, something like 55 of 56 patients had responded to the drug. In the world of cancer, that wasn’t just effective, it was unheard of.

With details about the trial, I called each of the three research nurses running the GIST phase II trial (B2222) in the US. From them, I first learned about patient 0 and her response to the drug. Patient 0 was the first GIST patient to take STI-571 before

the trial. I learned that it was a c-kit inhibitor and that this was probably why it was working for GIST. But there was something different in their voices. When Stephanie was at Dana-Farber, we talked about clinical trials with her doctors (but not the STI-571 trial, since it wasn’t open yet and wasn’t being talked about). The prevailing attitude about trials at that time (everywhere, not just Dana-Farber) seemed to be “we have a trial; we don’t know if it’s going to work, it might help patients in the future”. There was little talk, or at least little optimism, that trials could help patients, and that certainly didn’t come across as their intent. That attitude was completely absent in those three research nurses. To the contrary, they could hardly conceal their excitement and I’m not sure they were trying to. It was early, but the drug was working...and working very well.

After talking to the research nurses, it was time to put two and two together. I wrote a long post to the LMS listserv

The ah-ha moment would come when a drug proved so effectively matched to a mutate gene that it changed everything.

Outcomes Continued from Page 8

about abdominal LMS. Long story shortened; if you have abdominal LMS, make sure it gets stained for c-kit. If it stains positive, you probably have GIST and need to get into this trial. I filled in some of the background about GIST's having c-kit mutations (now days we call these KIT instead of c-kit) and CML, phase I results etc.

The phase II trial that was supposed to recruit 30 patients now had a problem-many, many more applications. To their credit, they ended up opening more slots and ended with 147 patients, including Stephanie, Anita and Mary Golnick and many others. Still, the word of a miracle drug for a cancer that was notorious for not responding to treatment, spread quickly and every advanced GIST

patient in the world with access to the internet and/or GIST/sarcoma specialists wanted and needed access to STI-571. Again, GIST doctors and centers rose to the challenge. Two large phase III trials were quickly organized and began recruiting patients in less than two months.

You might have guessed by now; STI-571 is now known as imatinib, or Gleevec in the US and Glivec in the rest of the world. And many patients knew about this drug long before it became a superstar at the 2001 ASCO meeting and long before it was approved for GIST in 2002. They know about it because patients reported outcomes...to themselves.

So, you tell me: can patient-reported outcomes make a difference?

NIH Continued from Page 1

GIST. These tumors frequently stain negatively for a protein called Succinate Dehydrogenase, a condition referred to as being Succinate Dehydrogenase Deficient (SDH Deficient).

Inspired by the vision of Norman Scherzer, Dr. Lee Helman and others, the clinic brings patients together from around the country to have their case reviewed by an expert. While attending the clinic, they undergo a round of appointments including blood work, pathology, meeting with a social worker and have a review of their case by the consulting NIH physicians on hand.

In addition to meeting with patients, the research experts gather to discuss updates on the clinical and genetic studies at the NIH.

Specialized support services are provided for the patients and their caregivers, with seminars tailored to their needs.

Each year on the first evening, LRG ex-officio board member Ray Montague hosts an annual dinner for all attendees at a local restaurant followed by socializing, which provides time for the patients and families to network, and to realize that they are not alone.

This year, 11 new patients were seen at the clinic, bringing the total tally since the Clinic's inception to 163.

While we were there, we had the opportunity to celebrate GIST Awareness Day with patients and families who attended this pediatric clinic. Everyone had the opportunity to meet Tommy Tissue and Dina Data, the symbols of our

H.E.R.O. campaign that emphasizes the importance of donating data, tissue and funds for research. They know firsthand how important tissue and data are in finding a cure for their rare diseases. If it wasn't for tissue and data, we would never know about a special rare type of GIST that impacts many young people. This Clinic set a precedent for collaboration among patients, NIH and multiple clinicians and researchers across institutions to

identify special mutations in the succinate dehydrogenase gene that were never thought of as associated with a disease called GIST.

Posing in capes and masks brought home the idea that all our patients are "heroes."

Becky Owens of GIST Support International has provided a summary of Dr. Lee Helman's keynote address. The full text can be found on our website:

<https://goo.gl/1uiHpJ>

Dr. Helman summarized the landscape of treatment, and described new areas of research, including investigating a class of drugs called DNA demethyltransferase inhibitors that could possibly demethylate SDH-deficient tumors.

To quote Dr. Helman, "First we have to understand it, then we have to develop treatments. That's what we are working very hard to do and that is our hope. We're very appreciative to see all of the Clinic patients, because the more we see you, the more we understand."

Patients interested in participating in the NIH Pediatric and Wildtype GIST Clinic may contact: Cluadia.Derse-Anthony@fnicr.nih.gov



Romic Continued from Page 1

seeking assistance.

Referred to Patient Registry Director, Kathrena Aljallad, he was provided with information for attaining his medication, as well as with the support to help him remain hopeful.

Within one day, he received enough medication and money for a three month course of therapy.

Romic was overwhelmed by the generosity he encountered. He was quoted in Dnevnik.hr online news, "Thank you very much for all those who donated the pills or paid me. It was enough for three months of therapy."

His Facebook appeal was targeted to the whole of Croatia, but reached beyond those borders. Within one day, it was released to the media. By the evening of that day, his account was about 55 thousand kuna.

In 2014, he was diagnosed with GIST after a surgery to remove a tumor in the stomach. After surgery, however, it metastasized to the lymph nodes.

The challenge also became the long wait he endured to see an oncologist. Danijel finally started on Gleevec. Unfortunately, he progressed, and needed additional surgery, which removed nine metastases in his lymph nodes, leaving one that was not accessible by surgery.

Romic began a second-line treatment with Sunitinib, but unfortunately was allergic to the first dose immediately. Six months without a viable treatment followed, with Danijel becoming an empowered patient, paying from his own

funds for mutational testing, which indicated that his GIST is SDH B wildtype.

Seeking medical help from private doctors in Vienna, he was dismayed to find that many of the suggested treatments were not available in Croatia. Regorafenib was suggested, and he was willing to start this course of treatment, but it was denied with the explanation that it was pretoxic for his tumor. He believes it was really an economic reason for denying the treatment.

Additional surgery was suggested, but as he waited, the tumor spread so much that the Croatian surgeons did not want to operate.

Finally, he transferred his case to KBC Rebro, where Nexavar was suggested. The issue then became that the medication could not be received through the hospital commission since it was not approved for GIST treatment. There was no way for him to obtain this life-saving treatment.

Help through Bayer was also not available, due to the drug not being approved for GIST treatment in Croatia.

Romic was determined to find a way. He sent out his appeal on Facebook, calling for donations of both medication and funds. The medication can be obtained in Austria, at a cost of about 3,000 euros per month.

The power of social media paid off for this GISTer.

Danijel remains optimistic. The father of two young twins, he was inspired to pursue the gift of time to give them a happy childhood.

We would like to thank our major donors for all of their support



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In loving memory of Beverley Lynn Burrows

Life Raft Group Canada is mourning the loss of our dearly loved Vice-President, Lynn Burrows. Lynn was always a light-hearted and optimistic woman, in spite of her decade of struggle with GIST. Her smile could light up any room... perhaps that is a cliché, but everyone who met Lynn knows how true it is. Lynn was the compassionate heart of our organization. Holding a graduate degree in Counselling from the University of Victoria, British Columbia (2000), Lynn combined professional training with an innate gift for understanding each person's unique situation and needs.

As soon as she joined the LRG Canda Board, she took on a leading role, sparking multiple new initiatives and helping us to address, in particular, the psycho-social needs of our members.

Lynn always connected - providing helpful and practical assistance in a way that was supportive, empathetic, and personal. She was also an impeccably organized, efficient, and committed Board member.

Lynn's first GIST fundraising adventure was "Mullet Madness" in 2011 ... she had to explain to me what a mullet is! Soon, she had much of the town of Kamloops, B.C. growing out their shaggiest long hair to raise funds for Life Raft Group and GIST research. "Mullet Madness" was our first major fundraising event. It was not only a financial success but also a great morale boost to our young organization. Her next merchandising adventure was printing customized tote bags and t-shirts for our 2013 Day of Learning; I remember the laughter we shared, as the Board gathered in her hotel room, on the night before the meeting, to stuff the kits into those bags.

Lynn represented the Canadian group at the GIST New Horizons meeting in Paris (2012). Afterwards, she wrote that "I learned a great deal from this conference on so many levels and do see the need to have them in the future. There is so much we patient advocacy groups do - and sometime struggle to do - on a regional/ local level, but ... we also need the strength of the global group."

Lynn and I attended the New Horizons meeting in Switzerland (2014), where we were treated to a traditional Swiss meal that Martin Wettstein and his wife served in his home by the shore of Lake Lucerne. I'll never forget the long hike that Ginger Sawyer, Lynn, and I took from the meeting hotel to the Lindt chocolate factory store, on a day

that was hot enough to melt our purchases!

Lynn participated in the LifeFest gathering in New Jersey that fall. I remember with chagrin that soon after we left for our "off-site dinner" in Manhattan, we suddenly realized that the charter bus had left Lynn behind, back at the hotel! Lynn wasn't at all perturbed; she just used her phone to access a service I had never heard of - "Uber" - got to Times Square at about the same time that the bus did, and greeted us all with a big grin.

Lynn designed and facilitated an interactive session, "Coping with the Emotional Impact of GIST", and presented it at our Days of Learning in Toronto (2013), Vancouver (2014), and Ottawa (2015). These workshops and the issues that they brought to the fore led directly to our appreciation of the need to re-orient a significant part of our resources to addressing members' needs for psycho-social, not just medical, support.

Lynn's clinical situation was becoming ever more challenging. Several times, she made the long trip across

Canada, from central B.C. to Toronto, to consult with the specialists there. But I never heard her complain about her struggle with GIST. She would just say (in the words of her famous silver bracelet) "Fuck Cancer" (yes, I will say it just as she said it!), laugh, and move on with her busy life.

Lynn, you have left us a legacy of compassion, enthusiasm, positive energy, and above all love. I only wish we could have had more time...

- David Josephy

Lynn leaves behind her husband of 34 years, Will, and their sons; Jason (Denise), Tyler, Kiefe, and Braeden (Danya). Predeceased by her father Allen English of Victoria, she leaves a hole in the hearts of her mother Joan and her brother John (Vicki) as well as her and Will's extended family and friends.

Her family has asked that Lynn be remembered not by flowers, but rather by a donation to www.liferaftgroup.ca or to the Marjorie Willoughby Snowdon Hospice, where Lynn spent the final weeks of life finally relieved of pain with her family by her side.



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29
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61
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