

Ensuring no one has to face GIST alone

In Loving Memory: Wang Shan Po, Elizabeth Gilbert, Doris Dallow, Bill Addis, Christopher Carley, Ross Gallagher, Queenie Hastings, Joe Temperley, Lucy Madsen

Chris Carley: Goodbye to a Hero

By **John Claybron Poss**, LRG Board Member

A few weeks ago, Chris Carley lost his battle with GIST and the Life Raft Group lost one of its heroes. He was 73 and had been fighting his battle with GIST since 1995. He is survived by his beloved and devoted wife, Nancy; two sons; two daughters; eight grandchildren and hundreds of friends. I was blessed to be one of



CARLEY

those friends — and like all his other friends, I can tell you two things for sure about Chris: He loved life and he loved to tell a good story.

For many years, Chris was a prominent developer in Chicago, where he built thousands of condominium and apartment units. Perhaps he is best known for his efforts to build the tallest building in the western hemisphere, the Fordham Spire, aka the Chicago Spire, aka the Calatrava

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Water of Life: A Night to Remember

By **Jessica Nowak**, LRG Development Manager

The second annual Water of Life whisky fundraiser was a night to remember! This year's event, hosted by Dr. Matt Lurin to benefit the Life Raft Group, was held at Midtown Loft & Terrace in New York City. More than 200 people attended, including whisky brand ambassadors and participants.



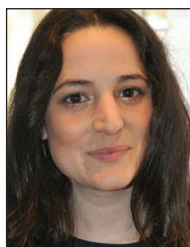
The idea of Whisky Speed Dating may have initially seemed unorthodox to some, but the concept was quickly adopted. Guests were able to sample up to 16 different brands of whisky, paired with fine cuisine from Abigail Kirsch catering. Throughout the evening, guests chatted with brand ambassadors to learn about the origins of their brands and how different types of whisky are made. They also had the

The LRG Stresses Management of Side Effects

By **Erin Kristoff**, LRG Director of Marketing

Published on www.curetoday.com March 22, 2016

We are in the midst of one of the most exciting times in history to be involved in cancer research. Over 60 anti-cancer drugs have gained FDA-approval in the last 10 years, and that number is only growing with more treatment



KRISTOFF

indication approvals in 2015 and the early months of 2016 than in 2013 and 2014 combined.

New treatments are on the rise. Initiatives like the one billion dollar "Cancer Moonshot" program and immunotherapy projects are emerging. While these far-reaching efforts are designed to accelerate cures and make massive impact on the

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LRG Advocates Making a Difference: OVAC Lobby Day

By **Teena Petersohn**, LRG Board Member

WOW!!! What a great experience, to make your presence known in Washington DC!

Each year, One Voice Against Cancer (OVAC) organizes a lobby day to urge Congress to support funding for cancer research, prevention and education through the National Institutes of Health (NIH), National Cancer Institute (NCI) and Centers for Disease Control (CDC). OVAC is a coalition of some 46 cancer-related organizations, of which the Life Raft Group is a member.

I headed to Crystal City, where the OVAC meeting was being held on Sunday, May 8, 2016. This was my second year attending. On Monday morning, I met up with Marisa Bolognese, Deputy Executive Director

of LRG; fellow GISTer Jeannie Dennis and her daughter, Kristen Dennis. It was great to be able to sit down and visit with them again and catch up on



Left to right: Jeannie Dennis, Kristen Dennis, Teena Petersohn, and Marisa Bolognese.

what has been happening with each of us since I last saw them. Jeannie and Kristen were back for the second time too.

We spent Monday afternoon in training — hearing about the “ask” we were to make and a little about the atmosphere on the Hill. In the late afternoon, we met up with others from the state we represented. Iowa had three other people, although we just represented two congressional districts.

Early Tuesday morning, we were taken to the Hill. As Iowa had no morning appointments, we were able to do some sightseeing and visited the offices of the two representatives who weren’t from our districts. We left them a packet with the information we wanted them to consider. The more people that hear about this, the better the chance of support of our ask.

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Thank you to our Major Donors for March and April for helping support “The Gift of Time”

- Carlos Baldor
- BST Consultants
- Brennan and Claire Carley
- Dublins Pub
- Dolores Hawkins
- Dr. Josh Kugler
- Novartis Pharmaceuticals Corporation
- Pfizer Global Pharmaceuticals
- Brian Rabin
- Jess Ravich
- Michael Schorah
- Pat and Bob Stichweh
- The Hektoen Institute for Medical Research, LLC.
- The Orthodox Rabbinical Association
- Leon Wyant

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 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 of any errors.

Nutritional Series Part 3: What Is Angiogenesis?

By **Kathryn Troy**, LRG Patient Registry Health Educator

Angiogenesis is a natural biological process that promotes the body's growth of new blood vessels used for healing and cell reproduction. As described by the Angiogenesis Foundation, it is controlled by the body's production of a highly delicate balance of stimulators and inhibitors in healthy tissue. Too much or too little can result in abnormal blood vessel growth and lead to chronic conditions, including cancer, diabetes, cardiovascular disease, stroke and more.

The Angiogenesis Foundation describes the control of angiogenesis in comparison to “on” and “off” switches. “On” switches stimulate

angiogenesis, or blood vessel growth. “Off” switches inhibit it. The National Institutes of Health (NIH) reports that

“stimulation of angiogenesis can be therapeutic” in regard to heart disease, wound healing and more; while “decreasing or inhibiting angiogenesis can be therapeutic in cancer, rheumatoid arthritis and other diseases.”



Blackberries contain anthocyanins which inhibit tumor growth.

The most common treatments for GIST patients — Imatinib (Gleevec), sunitinib (Sutent), regorafenib (Stivarga) and sorafenib (Nexavar) — inhibit angiogenesis by reducing vascular endothelial growth factor

(VEGF) production in GIST tumors. VEGF is a signal protein produced by cells that stimulates angiogenesis, vasculogenesis, inflammation and vascular permeability.

Foods that inhibit angiogenesis

Foods that have high concentrations of VEGF inhibitors may also inhibit angiogenesis. Therefore, research has shown that eating these foods may help shrink tumors by restricting VEGF and, ultimately, inhibiting new blood vessel growth.

The following list was sourced on the Eat to Beat Cancer™ database at www.eattobeat.org/evidence:

Anthocyanins: Researchers at the Ohio State Comprehensive Cancer Center found that anthocyanins, a

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How to be a GIST Hero: Donating Tissue for GIST Research

By **Michelle Durborow**, LRG Patient Registry Director

For patients who have recently been diagnosed with cancer, donating a tissue sample is probably the last thing on their minds. But it's an important consideration. Researchers often rely on donated tissue to advance research that will ultimately lead to an increased number of treatment options, and most likely, increased survival for patients with cancer. This is a simple way for you to become a “GIST hero.”

Why should you donate tissue?

Donating tissue for scientific causes is a personal decision, but can also be an altruistic one, especially for rare cancer research. There are several valid reasons why you should

consider it. Donated tumor samples have allowed GIST researchers over the years to learn what drives certain cancer cells and to:

- Find new ways to diagnose, prevent and treat them.
- Develop and test new drugs.
- Determine which treatments work for particular tumor mutations or groups of patients.
- Discover new cancer biomarkers.
- Find better ways of controlling side effects and symptoms.

But, in a rare cancer like GIST, no one sample can provide answers. A collective effort is needed.

Today, many cancer patients are asked to donate both their tissue sample and the medical information that pertains to it. The Life Raft Group's Patient Registry and GIST Collaborative Tissue Bank have taught us that the more patient information that accompanies the sample, the more valuable the sample is to the research community. Knowing details about the sample and the patient (who remains anonymous) can help researchers understand how individual factors affect the behavior of GIST.

Tissue samples taken to diagnose GIST either at biopsy or after surgery, or from any metastatic GIST tumors removed, are saved in paraffin wax

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GIST Day of Learning: Education and Support for Area GISTers

By **Michelle Durborow**, LRG Patient Registry Director; **Sara Rothschild**, LRG Program Director and **Laura Occhiuzzi**, LRG Assistant Program Director



The Life Raft Group kicked off its 2016 GIST Day of Learning (GDOL) series this spring with events from coast to coast. GDOLs are free, one-day programs that provide both education and support for the GIST community. Top GIST specialists present the latest on research and treatment options and provide a comprehensive review of the science behind GIST. GDOLs provide an opportunity not only to meet and interact with local expert practitioners in an intimate setting, but also for patients to connect with one another in a supportive environment.

Portland

The first GDOL was held in Portland, Oregon on Wednesday, March 30 at the Oregon Health & Science University (OHSU) Center for Health & Healing. The event was initiated by Mark Heinrich, son of Dr. Michael Heinrich, as a school service project for his senior year. Mark, who introduced the event, said that he has been inspired by the work that his

father does for the GIST community as both a doctor and a scientist.

Topics included treatment updates for GIST, understanding the importance of GIST pathology and mutational testing, and information and resources for participating in clinical trials.

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10 Things That Happen When You're Diagnosed With Cancer

By **Josalin Dunn**, LRG Member

Cancer. We all know someone who has it or we know someone who knows someone who has it. Either way, it's a subject that is kind of taboo. Firstly, the majority of the population think when they first hear the big C-word is that you're going to be bald, you only get cancer when you're old and you probably (hopefully not) will die.



DUNN

Well, I'm telling you right now that not all of that applies to every single person with cancer. Everyone's story is different. So from the perspective of a 19-year-old girl who has been battling cancer for 11 years, here are ten things that happen when you are diagnosed with cancer.

1 People are going to ask if you are OK over and over and over.

I mean, can you blame them? What else do you say to someone who just told you they have a mass of mutating cells in their body? That sucks? Sorry? There's really no good response. So be patient with this recurring question because it is going to happen a lot.

2 You're not going to want to tell people about your diagnosis.

For the sake of wanting to be normal, I don't always express to people about my disease. As soon as the C-word comes out of your mouth, their jaws drop and their eyes get big. If you're in a room full of people, all

heads turn and they just stare at you with these pitiful, puppy dog eyes. From that point on, people treat you a little differently. They try helping you with simple tasks as if you're incapable. The almost give you special treatment which can be a little annoying sometimes, but on the other hand, can have its benefits, which brings me to my next example.

3 Cancer perks.

Need to get out of a date? Cancer. Miss an important deadline. Cancer. Want to eat an ungodly amount of calories without feeling guilty about it? Cancer. The possibilities are endless! Never again do you have to use the "My dog ate my homework" or "Wow, that traffic was awful"

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10 THINGS from page 4

excuse because you have just been gifted with the number one excuse of all excuses. Once you throw it out there is nothing anyone can say about it.

4 You're going to spend hours upon hours inside of scans.

Or for me, it was a bed away from my bed. Pop some headphones in my ears to drown out the loud noise and I was asleep within minutes (my technicians are always amazed at this feat). It's going to be loud. It's going to be uncomfortable staying absolutely still for two hours straight. But hey, it needs to be done, so make the best of it. Wear some fuzzy socks to your appointment, ask for a warm blanket and take a little siesta while the doctors do their thing.

5 Needles are a daily occurrence.

Have a fear of needles? Yeah, you should get over that real quick. You're going to be poked and prodded so many times your arms will look like they belong to a heroin addict. Some nurses get id one with one poke. If you're like me and have veins that roll, nurses will poke you three or four times while they are digging in your arm trying to "fish" for your vein. Gross, right It's never a comfortable event. So find one of those cheese paintings in the room to stare at, squeeze your friend's hand, take deep breaths and it will be over before you know it.

6 Cranberry juice will be your best friend.

Chemo makes the best of foods your puke bucket's next victim. There are still some foods to this day that I can't even smell or I will

get nauseous with the memory of seeing it after it was half digested. Cranberry juice was the only thing I could ingest during chemo without getting sick. That and chicken fingers from Applebee's. I'm telling you, cranberry juice works wonders!

7 You're going to have the most stylish head ever!

Look in my closed and I have some pretty hefty boxes full of all things related to head accessories. Hats, bandanas and wigs, you name it! This is a great opportunity to experiment with that hair style or color that you never had the nerve to do with your real hair, but now you have endless options of wigs to suit your fancy. You can totally rock that hot pink pixie cut and no one can judge you because you have cancer and you do what you want.

8 You'll joke about cancer more than you're serious about it.

I can't even begin to tell you how many times my brothers would do something like punching me in the arm in public and I would say loudly, "Ow! That's my cancer!" They would then look around the room with red faces and say to me, "Be quiet, Jos! That's not even where your cancer is!" Makes me laugh every time.

9 You're going to have the best support system.

When you have cancer, you get tons of things, and I mean tons. Balloons, teddy bears, cads, etc. Oh my gosh, the cards. They're never ending. Being a typical seven-year-old, I was ecstatic when I got things in the mail. When I was able to go home, I would diligently watch the clock until it hit one p.m., and I would race down the driveway and wait for the mail-

man to come and give me the mail that contained at least three cards for me. From that kid you talked to once in second grade, to a family member you never knew existed, they've all got your back. Even though most of your friends and family don't know what you're going through, a lot of people do. Go venture the halls of the hospital. Find some support groups or forums online. There you can find some people who are going through exactly what you're going through, and what do ya know? You just made a new friend!

10 You're going to have some pretty awful days.

There's going to be days that you don't even want to get out of bed because you feel so awful. There's going to be days you look in the mirror at your bald head and wonder how anyone could ever think you're beautiful. There's going to be days you're lying there hooked up to all these machines while you see your friends on social media hanging out with each other and living life. It's OK to have those days, because you know what? Cancer sucks. It really sucks. Take your rainy day once in a while, but wake up the next day, look at yourself in the mirror in your bald-headed glory and tell yourself how awesome you are. You're battling cancer and still look this fierce? Dang girl. You're pretty freaking awesome.

Josalin Dunn is currently a student at Brigham Young University, studying Special Education with a goal in mind to attend Graduate School to become an Occupational Therapist.

She discovered her love of helping those with special needs while volunteering in a facility in Provo. She believes in living life to its fullest.

This piece originally appeared in an online magazine called Odyssey Beta. ■

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Spire. It was a grand vision, which was very typical of Chris. If you are curious about the project, you can easily find many articles about it at bit.ly/SpireChicago

According to Chris, his financing for the project fell through when he went head to head with Donald Trump and some rumored nefarious dealings by Trump, who was building a competing building in Chicago at that time, had a very chilling effect on Chris's ability to raise money.

Santiago Calatrava, arguably one of the greatest architects of our time, designed the building. After the project failed, Calatrava said something very insightful about Chris: "He's not just a rational developer. He's driven by his heart."

And so he was. Chris led with his heart in all things, and his passion for life and for helping people was an irresistible force.

He became a hero to GISTers in 2000, when he thought he was near the end of the road in his fight. In March of that year, he and Nancy went to see Dr. George Demetri at Dana Farber. He tried a couple of unsuccessful clinical trials — but by June, his fight was close to over. However, Dr. Demetri gave him this news: "There is a drug that we think would be very effective, but we just can't get any of it." Chris wanted to know more and Dr. Demetri shared the details.

Chris responded with typical passion, "Well, that won't do. I'm calling my big brother who works at the Wall Street Journal. He'll do something!"

In fact, Chris's brother, William Carley, was a senior reporter at the paper.

I talked to Bill and he recounted the story, "Chris called me and told me that Novartis had a drug that would save his life but that no one could get any of the drug for GIST."

Bill said that he called Dr. Demetri to confirm Chris's story, who shared with

end of the road. He asked about the likelihood of a trial for GIST in the near future. "We're looking at it," the researcher replied.

Less than a week later, George Demetri got a call from Novartis. "We have a limited amount of drug available to start a Phase II trial for GIST."

Bill refuses to take any credit for the drug's sudden availability.

All of that is why, in June of 2000, Chris Carley became Patient Number Two and arguably accelerated the delivery of STI-571 to all the other patients in the Phase II trial, myself included. Most of us who participated in the Phase II trial were at death's door, with only weeks or months left to live. So, getting STI-571 a few

weeks or months earlier than it might have otherwise been available saved many lives.

Chris tells the story a little more dramatically. His version is on the LIVESTRONG Foundation website (<https://www.livestrong.org/we-can-help/survivor-stories/chris-c>). He also shares the story of his ongoing battle with cancer-related depression. It's worth a read and a listen (there's a video of Chris).

STI-571/Gleevec bought Chris and Nancy almost 16 years of high-quality survival. During those years, he didn't sit around. He built two more downtown condominium projects; took a swing at building the Spire; and worked tirelessly for many non-profits, including the LIVESTRONG Foundation, Gilda's Club, the YMCA and, of course, the Life Raft Group. And he told good stories — lots and lots of good stories.



10 year survivors at Life Fest 2010. Chris Carley, top left. John Poss, front row second from left.

him that the drug, STI-571, had been very successful in treating Chronic Myeloid Leukemia, but was still in clinical trials and hadn't been approved by the FDA. Apparently, Novartis simply didn't have sufficient supplies to support a clinical trial for GIST. Dr. Demetri also shared that he had been successful in getting the drug for one patient from Finland (the famed "Patient Number One") and the results had been spectacular.

It just so happened that Novartis, the drugmaker of STI-571, was in the middle of a public offering of its shares in the United States. So, about a week or so after his calls with Chris and Dr. Demetri, Bill showed up at a presentation that Novartis was making to a gaggle of financial analysts.

After the presentation, Bill made his way to the head of research and introduced himself as a reporter from the Wall Street Journal. Bill asked about progress in the trials and shared that his brother had GIST and was at the

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HERO from page 6

For all his life, Chris was a handful. It took a special woman to keep him on course. I've always said that cancer is harder on the caregivers than it is on the patient. Nancy fought tenaciously for Chris every step of the way. Toward the end, I spent many hours listening to her work through what options might be available, where she could help Chris find another miracle that might buy more years. She was, and is, amazing.

My last conversation with Chris was a few days before he passed. He was weak and had trouble talking — but was haranguing me to get off my sorry behind and help him find another clinical trial. When he

was done with that, he solicited my support to start a new non-profit to help people navigate their way to the right doctors, the best care, and through the maze of tedious insurance-claim filing. The man didn't have any quit in him at all.

God bless you my friend, Chris Carley. I'm quite sure that Heaven can always use a good story. ■



LRG to Participate in Moonshot Project

On June 29th, LRG Executive Director, Norman Scherzer, will be attending Vice President Joe Biden's "National Moonshot Summit," at Howard University.

A "by invitation only" event, the summit is designed to bring together scientists, oncologists, donors and patients for a national conference on cancer research. The one-day conference is intended to ramp up Biden's push to double the pace of cancer research.

The conference will be the first of its kind to focus on more than 100 types of cancer. It is also the first cancer summit sponsored by the government, and backed by the federal task force that President Obama established in January, 2016.

Greg Simon, the head of the initiative, views it as an opportunity to prioritize strategies for prevention, early detection, access to treatment and collaborative research.

Simon said that as a result of Biden's initiative the National Cancer Institute is working closely with pharmaceutical companies to make more drugs available in clinical trials that test combination treatments. The FDA will open a new center to review combination treatments more efficiently, and Biden's team is working to design the website that lists clinical trials so patients can more easily identify options.

It is our intention to bring the Life Raft Group members' ideas and concerns to the summit. Have an idea? Email: Mary Garland mgarland@liferaftgroup.org ■



CALENDAR OF EVENTS

SPRING 2016

Team J Ride Across America

<https://www.gofundme.com/hydrocephalus-awareness>

JUNE 29, 2016

GIST Day of Learning New York

American Cancer Society
132 West 32nd Street - New York
5:00 PM - 7:45 PM
bit.ly/GDOLNewYork2016

JULY 9, 2016

Zumbathon for GAD

Cleveland Estabrook Recreation
4125 Fulton Road
Cleveland Ohio 44144
1:00-3:00PM

JULY 13, 2016

GIST Awareness Day 2016

Torrance Marriott Redondo Beach,
Torrance CA
All Day

JULY 15-17, 2016

Life Fest 2016

Torrance Marriott Redondo Beach,
Torrance CA



www.liferaftgroup.org/lifest



Our theme for Life Fest and GIST Awareness Day 2016 is the Gift of Time.

Our event logo is an hourglass, with each grain of sand representing a cherished moment in time. Help us celebrate the gift of time by sharing your moments with us. Take a photo, make a video, hold a GIST Awareness Day event to call attention to how valuable time is.

One of the best ways to show gratitude for your gifts of time is to grant more quality time to other GIST patients by supporting our mission to promote survival. Your donation to our upcoming Spring Appeal will help achieve this goal. You can also donate at any time via our donation page.

Make a Donation

liferaftgroup.org/donate

I am so grateful that I get to share life with my loving husband, son and grandson.
– Kathleen

I'm thankful for my family and time that we get to spend together.
– Dana

Seeing seven great-great nieces and nephews born to our family.
– Dina



November 2015 I was able to enjoy my trip of a lifetime, a two week tour of Israel.
– Colleen

Being able to spend time with my mom, a GISTer, at family gatherings.
– Meg

Thank you to our sponsors for GIST Awareness Day



get ready to

Celebrate

JULY
13



GIST Awareness Day

Inform others about GIST

GET SOCIAL

Post your Gift of Time Photos with the hashtags
#GiftofTime #GISTAwarenessDay2016

Hold an Event

Create a Fundraising page (Ask us how)

Life Fest: July 15-17

Interact with GIST Specialists

Network with other GISTers

Enjoy beautiful Redondo Beach

Post on our Gift of Time display

Learn about the latest GIST research

Post on our Gift of Time display

Thank you to our sponsors for Life Fest 2016



GDOL from page 4

The featured speakers were medical oncologist Michael Heinrich, pathology expert Christopher Corless and registered nurse Tracy Walker, all from OHSU. LRG Patient Registry Director Michelle Durborow provided an overview of LRG programs, focusing on the LRG Patient Registry and Tissue Bank. She outlined the impact of data from tissue donation and its benefits for LRG members.

A special thank you goes out to the Heinrich family and friends for their assistance in holding this event.

Miami

Miami's fifth annual GDOL was held on Sunday, April 3, with 40 GISTers and their loved ones in attendance. This conference would not be possible without the support and cooperation of our friend and colleague, Dr. Jonathan Trent, Co-Director Musculoskeletal Center, Director of Sarcoma Medical Research Program, and Professor at the University of Miami. His knowledge, commitment, and passion for helping the GIST community have fostered a true collaboration between the LRG and the Sylvester Comprehensive Cancer Center. We are thankful to Sylvester for partnering with us and enabling us to provide these excellent conferences.

Dr. Breelyn Wilky kicked off the event with an "Overview of GIST and its Medical Management." She provided the group with a strong foundation of basic knowledge about GIST, as well as discussing the clinical trials taking

place at Sylvester and side effects management.

Dr. Alan Livingstone followed with "Surgical Management of GIST." He reviewed some complicated cases successfully operated on at Sylvester, impressing the group with the skillfulness of the surgeons.

One GISTer shared a testimonial: He had been suffering from a large tumor that impacted his quality of life. Other institutions told him that they would be unable to remove it with surgery. However, he then moved to Florida, where Dr. Livingstone operated on him (at the persistence of Dr.



Sara Rothschild with the staff of Sylvester Cancer Center.

Trent). His outlook and quality of life improved dramatically.

Another GISTer, who is a national CrossFit competitor, inspired the group with his perseverance, positivity and determination that he wasn't going to let cancer beat him down.

Pathologist Andrew Rosenberg gave a captivating presentation, "Understanding Pathology and the Role of Mutational Testing," on how GIST is diagnosed and the important role of molecular testing. A Q&A panel followed, which allowed participants to ask a range of questions to the doctors in attendance.



GISTers benefit from expert presentations.

Lisa Marie Merheb, MSW, LCMW, shared important resources and support options for navigating care during her talk on the "Psychosocial Implications of GIST."

Dr. Trent finished the day by presenting "How Can We Accelerate a Cure?," in which he focused on some new, innovative approaches being tried at Sylvester, including immunotherapy and a vaccination trial. He also touched upon generics, a topic of interest to many GIST patients.

We would like to thank our volunteer photographer, Don Edgar of DL Photography, for capturing the GDOL, as well as our volunteer videographer, Van Russell, for recording the meeting on video. To view photos and videos, please visit: www.liferaftgroup.org/2016/04/gdol-miami-2016-photos/.



Sharing Gifts of Time at the Miami GDOL.

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Chicago



Informative sessions enhance patient and caregiver knowledge.

On Monday, May 9, The Life Raft Group held the next stop of the GDOL series in Evanston, Illinois, on Chicago's North Shore. NorthShore University Health System/Evanston Hospital campus hosted the evening event, which was dedicated to Chris Carley, an LRG board member and longtime Chicago resident who passed away the weekend before. Jim Hughes, LRG board member and Chicago state leader, spoke about Chris and his accomplishments, vision and support of the LRG.

Among the presenters were Karl Bilimoria, MD, Director of Surgical Oncology at the Robert H. Lurie

Comprehensive Cancer Center at Northwestern University; Bruce Brockstein, MD, Medical Director at NorthShore University Health System/Kellogg Cancer Center; and a panel of pharmacists from NorthShore, including Ashton Koskosky, Kathryn Schiavo and George Carro, Sr. Director of Oncology Pharmacy Services.

The sessions were very informative. Dr. Bilimoria provided an update on surgical treatment. Dr. Brockstein discussed GIST medical management. Our panel of pharmacists discussed generic vs. brand and other pharmaceutical updates. A Q&A session followed.

Our theme for Life Fest and GIST Awareness Day this year is "The Gift of Time." Our logo is an hourglass, with each grain of sand representing one of our own cherished moments in time. Many of our participants spoke about their "Gift of Time" and placed their memories on our hourglass banner.

We would like to thank our volun-



GDOLs are an opportunity to experience community support.

teer students, Alyssa Occhiuzzi and Michelle Soderlind, for taking photos and videos.

We would like to acknowledge our sponsors who make GDOLs possible: Novartis, Bayer, Pfizer, and Genentech.

New York City will be our next GDOL stop, on June 29, 2016. Please stay tuned to the LRG website and emails for more information on these and other events.

Interested in having the LRG come to your city for our next GDOL? Email your ideas to Laura Occhiuzzi at locchiuzzi@liferaftgroup.org. ■

Advocacy: Patients Shall Be Held Harmless

There has been discussion in the news recently concerning charitable giving patient assistance programs that aid Medicare and Medicaid patients with premium assistance. New federal regulatory guidance seeks to prohibit charitable organizations from helping patients to pay for these essential treatments.

The Life Raft Group is committed to the premise that patients shall be held harmless from the infighting between government, pharmaceutical and

private agencies. We are against any legislation that makes it more difficult for a cancer patient to receive life saving treatment.

To this end, the LRG lends support to the Access to Marketplace Insurance Act, H.R. 3742, legislation that would override the CMS guidance on third-party payments and require health insurance companies to accept payments from non-profit organizations that operate in compliance with the False Claims Act.

The Life Raft Group has joined the Marketplace Access Project, a patient advocacy movement dedicated to protecting non-profit insurance premium assistance for individuals suffering from chronic and life-threatening illnesses.

For more information on H.R. 3742 and how you can support it: www.marketplaceaccess.org/ [#marketplace-access-project](https://twitter.com/marketplace-access-project)

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research landscape, all of these take time and until that time comes, patients need a way to manage their disease.

According to the American Cancer Society, cancer death rates are down 23 percent over the last 21 years. While this number is encouraging, not all cancers fare equally. For many metastatic and rare cancers, survival is measured in months, not years. It is especially vital for these patients that we do better.

The Life Raft Group (LRG) began in 2000, when a handful of patients with gastrointestinal stromal tumors, or GIST, on the early Gleevec trials began sharing their experiences online. It was clear from the beginning that these patients could use their individual experiences and combined knowledge to support and learn from each other. In the last 14 years, the Life Raft Group has grown immensely, meeting the challenges of GIST survivors and caregivers every step of the way.

GIST patients have often stood apart from their fellow cancer survivors for a number of reasons. Although still very much considered a rare cancer with its diagnosis rate of 5,000 new cases per year, GIST predominates a third of all sarcoma diagnoses in a field that includes over 70 known cancers. To put it in perspective, as “common” as GIST may be in sarcoma, sarcoma itself only comprises one percent of all cancers. Also, unlike most rare cancers, GIST benefits from three FDA-approved lines of drug therapy options- most rare cancers don’t even have one. However, there are still many rare GIST mutations that do not respond well to any of the standard treatments. As a result, the GIST community is split into

two camps, those living with what amounts to a chronic illness and those bouncing from treatment to treatment.

As a part of a community that has largely had to care for itself, the LRG has been collecting data in our Patient Registry for the last 15 years. One of the most dominant trends that has surfaced is that over 49 percent of our members took the time out to report experiencing side effects as a result of their drug therapies. Out of a sample group of 1,462, patients reported 827 cases when side

cure®

**“Until cures are found,
drug therapies are a
lifeline to someone
with cancer.”**

effects became so burdensome that they interrupted their drug therapy usage due to them. In light of the fact that they have the ability to influence a patient to either temporarily or permanently discontinue their potentially lifesaving drug, the importance of effectively managing side effects cannot be overstated.

Until cures are found, drug therapies are a lifeline to someone with cancer. Yet, drug therapies are often the cause of industry-termed “adverse events”. Our registry participants have reported many of the same issues as other survivors with common side effects including fatigue, diarrhea, edema, nausea and Hand and Foot Syndrome.

Clinicians are frequently unable to help patients properly address these problems, which affect their quality of life and ability to maintain their drug regimen. Appoint-

ments are often months apart, and patients can be hesitant to speak plainly about side effects, due to a number of factors including the fear of the consequences it may have on treatment recommendations, inadequate consultation time or a self-perceived triviality of the symptom.

Overall, better communication can drastically improve a patient’s ability to manage side effects. Honesty with physicians is key and can provide these clinicians with an opportunity to become more involved with a patient’s care and quality of life issues. From the patient perspective, adding unique specialists to his/her medical team like nutritionists, gastroenterologists and dermatologists, speaking with the nursing staff, as well as seeking out resources that may provide benefit online or through a hospital can make a huge difference when deciding whether to discontinue treatment.

Patient Advocacy Groups can also strive toward better communication. The Life Raft Group’s Patient Registry includes fields for collecting side effects by treatment, which can be tracked over time, crossing institutional boundaries. Additionally, regular correspondence with our registry participants, tied to scan frequency, enables us to stay up-to-date with their pressing concerns. We are also able through these phone and email communications to arm patients with tools and questions to bring to their medical appointments.

Furthermore, our interactions with patients and registry case studies show that most side effects tend to get better over time. An effective side effect management tool could help patients reach this plateau.

In short, better side effect management will lead to improved drug adherence which has a direct impact on patient survival now. ■

WOL from page 1

opportunity to meet plenty of whisky aficionados.

Two special Master classes took place earlier in the evening. Guests who attended “This IS Your Gram-pa’s Whisky Class” sampled whiskies such as Belmont Sour Mash, which was distilled in 1902 and was originally intended for medicinal purposes only! “The Blackadder Experience” featured whiskies aged in a wide range of exclusive oak casks to show how the oak affects each whisky differently.

Ashton Cigars were donated for VIP guests to enjoy during the Cigar Hours. In addition, thirty lucky “Ultra-VIP” guests sampled the finest whiskies on the terrace, which has a breathtaking view of the Empire State Building. Tommy Tardie from the Flatiron Room and Flavien Desbolin from Brandy Library were the pourers for this private tasting, which included whiskies from Dalmore, Exclusive

Malts, Copper and Oak, Anchor Spirits and The Johnnie Walker Road Show. Ultra-VIP guest also received Glencairn VIP and Denver and Liely commemorative glasses to take home.

The Water of Life event is held in memory of Matt Lurin’s stepfather, Joe Temperley, who was a GIST patient. Matt paid special tribute to him with a toast. Mr. Temperley introduced Matt to the world of whisky. “We hope to continue this tradition of introducing others to whisky’s finer aspects with this event, while raising funds for GIST research and education for many years to come,” stated Lurin.

Many thanks to the many brands who donated various whiskies (see them all at bit.ly/WOL2016Brands).



Ultra VIP tasting elevates the whisky experience.

And a special thanks to: Jess Ravich, Kim and Steve Tallau, Raj Sabharwal, Purple Valley Imports, Joe Hyman, Skinner, Anthony Mazzola, Ashton Cigars, Gramercy Wine and Spirits, David Blackmore, Glenmorangie-Ardberg, John Heffernan, Marlon Paltoo, Amanda Schuster, Ellie Tan, The Malt Imposter, Stephen Mathis, Adam Levy, Joshua Gershon Feldman, Stephen Schuler, Chris Corbin and Women Who Whiskey. ■



Dr. Matt Lurin and Dr. Josh Kugler



The perfect venue for Water of Life



Immersed in the whisky experience

TISSUE from page 3

called tissue blocks. These tissue blocks are stored in the pathology department of the hospital where the tissue was removed. Only a small piece of the tissue block is needed for most research projects. The LRG tissue bank protocol applies a thoughtful process to ensure enough of the donation remains for future research.

What do you need to know?

During a medical procedure, such as an operation or biopsy, your doctor will remove the tissue needed for a complete pathology report. Then, with your consent, any leftover tissue can be sent to the LRG's tissue bank and saved for future research.

Your tissue donation may help drive innovation. The LRG tissue bank works with the world's leading GIST researchers in an effort to find a cure — and until then, to find ways to help increase patient survival of GIST. Patients have the option of having their tissue scanned for genetic mutations known to GIST. Part of the tissue will be used to detect the presence or

absence of GIST proteins in question and to quickly determine whether a set of proteins correlates with a clinical outcome or can be used for diagnostic purposes.

For example, we used a GIST tissue

“Donated tumor samples have allowed GIST researchers over the years to learn what drives certain cancer cells.”

microarray (TMA), which is a collection of small fragments of tumor samples from multiple patients, to quickly confirm that the novel diagnostic marker, DOG1 protein, was indeed present in the vast majority of GISTs. This is important as a diagnostic tool, since DOG1 protein is strongly expressed on the cell surface of GISTs and rarely in other soft tissue tumors. All of this information is stored in the LRG Patient Registry, a database that researchers can utilize in studies that seek to improve the effectiveness, safety and precision of future cancer diagnosis, prognosis and treatments.

The other thing you need to know is that as a tissue donor, you are in control. Federal laws and regulations protect the privacy and confidentiality of your medical information, and tissue banks must follow those rules. Your tissue donation and accompanying clinical information are stripped of any personal identification.

Is it that important to donate tissue?

Recently, while visiting the labs of LRG Research Team Member Matthew van de Rijn at Stanford University and Dr. Christopher Corless at Oregon Health & Science University, the need for tissue was driven home. Individual samples are not enough to change the landscape of GIST research, but collectively, each patient's sample can lead to effective treatments and—potentially—a cure. Patients may not directly benefit from donating tissue, but the research on their tissue may benefit patients in the future.

Ready to become a GIST Hero?

Contact the LRG Patient Registry today: mdurborow@liferaftgroup.org. ■

CANCERVERSARY



Ed Cohen 9 YEARS

“My GIST tumor was removed by a skilled surgeon nine years ago this coming Father's Day, giving me the present of continued life. Shortly after the surgery my wife and I found the Life Raft web page, signed up for the listserve and have obtained and shared valuable information. Gleevec, the 21st Century miracle pill, continues to keep my GIST under control. Scans continue to be NED. All this has allowed me to see my grandchildren born and grow, my adult children mature and share life events and good times with my wife of almost 44 years.”



If you have a Cancerversary, let us know. Contact us at info@liferaftgroup.org and we may feature you in a future newsletter!

NUTRITION from page 3

class of flavonoids within food-containing antioxidants, inhibited tumor growth and angiogenesis in experimental rats treated with a potent esophageal carcinogen. Anthocyanins are present in blackberries and red wine.

Lycopene: Lycopene is considered to have a promising amount of cancer-preventing activity and has been evaluated against its effects against prostate cancer in a series of epidemiological studies. It is found in tomatoes, red fruits and vegetables, and inhibits the formation of vascular endothelial cells induced by VEGF.

Evidence supporting the consumption of tomatoes and processed tomato products (tomato sauce) has become available from the Health Professionals Follow-up Study, an epidemiological study. It was found that men whom consumed one serving of tomato sauce a week had a 20% prostate cancer risk reduction, and those whom consumed two servings a week had a risk reduction of one third.

Polyphenols: Sourced from plants,

polyphenols can defend against ultraviolet radiation and aggressive pathogens. Various types are found in olive oil, red wine, berries and pomegranates.

- Olive oil contains the polyphenol DPE, which has been found to have an antitumor effect via anti-inflammatory and antiangiogenic activities.
- Pomegranates contain the polyphenol ellagitannins (EL), which inhibits the growth of tumor blood vessels.
- Grape extracts and seeds contain various polyphenols with anti-cancer and anti-inflammatory activity, including resveratrol and proanthocyanidins.

Eugenol: A natural aromatic substance found in clove oil, cinnamon, basil and nutmeg, eugenol has been shown to inhibit the growth of cancerous tumors by reducing the expression of angiogenic factors (such as VEGF) in mice with gastric cancers.

Gingerol: The main compound found in ginger was found to suppress production of two key angiogene-

sis-stimulating proteins: VEGF and basic fibroblast growth factor (bFGF). Scientists have determined that gingerol blocks the growth of blood vessels in living animals.

Walnuts: A Harvard Medical School study has shown that walnuts inhibit the growth of colon tumors in mice by suppressing angiogenesis. Walnuts were found to significantly decrease the proliferation of blood vessels, as observed in samples of tumor tissue obtained from mice.

Before you eat ...

When evaluating the results of evidence based research, bear in mind that individual results may vary. At this point, it is believed that ingesting more foods that contain VEGF inhibitors could be beneficial. Please consult with your physician before modifying your diet, and continue your research of angiogenesis before making any long-term changes to your diet. While alternative/natural treatments may help reduce the signs and symptoms of cancer, there is no replacement for chemotherapeutic medications that your doctor may prescribe for GIST. ■

For citations visit: bit.ly/NS3ref

ADVOCACY from page 2

Our afternoon was spent meeting with a staffer from District 2, Rep. David Young from my District 3, a staffer from Sen. Joni Ernst's office and with Sen. Chuck Grassley. We each told our own personal stories about why we were there. We discussed the importance of funding the NIH, NCI and CDC so they can do more research, keep their prevention programs going and educate the public on cancer-related topics. We urged them all to support the Cancer Moonshot Initiative.

I felt that each office was concerned about the topics, and three of the four committed to supporting the ASK we

had made. This funding will not be used specifically for GIST research — but Gleevec was not originally manufactured for GIST either, and it works for us! Hopefully, something else will be discovered that will help GIST patients, especially those for whom there is no effective targeted treatment.

I found the OVAC Lobby Day to be a very rewarding adventure. I was able to talk about GIST and the importance of research to this rare cancer. I was able to convey that, even though there is a treatment for some of us, there is not one for all of us, so more needs to be done. Stories like ours,

along with those that involve children, seem to make the biggest impressions on the people we met. I will keep in touch with my representative and both senators throughout the year and I hope to be back in Washington for next year's OVAC Lobby Day. Each of you should consider attending too. If you do, I do not think you will regret your decision.

We all can continue to advocate for GIST throughout the year. For more information on how to do so, please contact Laura Occhuzzi, Assistant Program Director: locchuzzi@liferaftgroup.org. ■

THE LIFE RAFT GROUP

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•Chris Carley passed away on May 3, 2016.
 We hold him in our hearts each and every day.

Life Raft Regional Chapters: Find your reps info at lifteraftgroup.org/find-a-support-group/

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