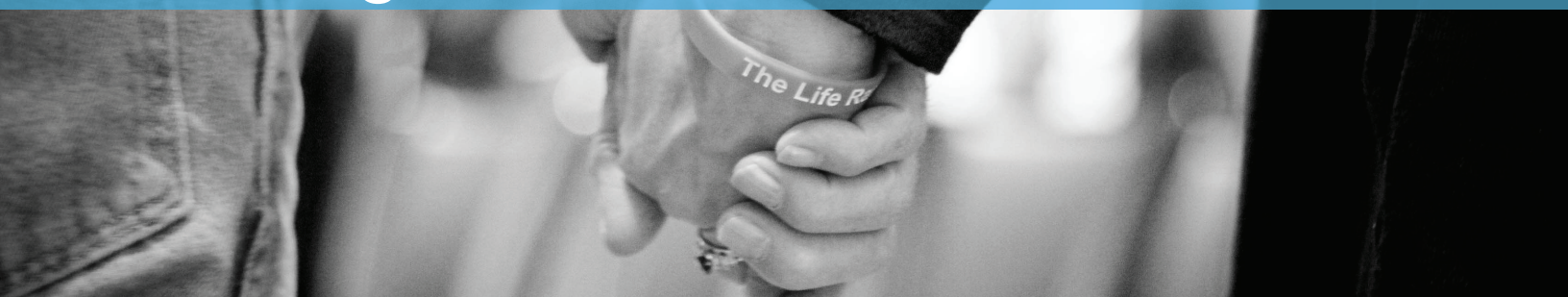


Ensuring no one has to face GIST alone



In Loving Memory: Janet Mendoza, Gerald Perkus, George Dunn, Godsent Odero, Katherine Somervell, Cynthia Folie, Herb Puryear, Kie (KK) Go, Vicki Dotson, Nellie Dunn, Eleanor T. Svedi, Dana Hice Pearson

In honor of our H.E.R.O. campaign, we are profiling our GIST Superheroes **GIST Superhero Profile: Cindy Farr**

By **Belinda Gist**, Guest Contributor

Romans 12:12 “Rejoicing in hope; patient in tribulation; continuing instant in prayer...”

Let me introduce you to Cindy Farr.

Cindy’s super power is her faith. Having become a Christian in her teenage years, Cindy has always sought God’s guidance and received comfort in her faith. She is a wife and mom, a community volunteer, and a powerhouse woodcarver. Now in the

sixth decade of her life, Cindy lives a life of generosity, joy, and challenge.

She is a mom to two grown children. She homeschooled them from preschool through 12th grade back in the 1980’s, in the pioneer days of homeschooling when it was mostly unheard of. Homeschooling takes great investment, dedication, and commitment; there is no schedule to

See **HERO** on page 5

Understanding Kidney Disease

By **Michelle Durborow**, Scientific Operations Senior Director
and **Kathrena Aljallad**, Patient Registry Director

Injury to the kidneys can occur for a variety of reasons in patients with Gastrointestinal Stromal Tumors (GIST). In some cancers, such occurrence may be associated with the cancer treatment, radiation, or the disease itself. To some extent, comorbidities and



concomitant treatment as well as lifestyle-associated risk factors have also been linked to kidney disease.

In GIST, imatinib shifted the treatment paradigm in cancer. Those patients who are responsive to the drug have a longer life expectancy. Along with this are a set of challenges that patients

See **KIDNEY** on page 6

Advocating for Rare Diseases Law in Chile

By **Piga Fernandez**, LRG Global Consultant



Fundacion GIST Chile was invited by the Federation of Rare Diseases in Chile (FECHER) to participate in a meeting where the main topic was the need of a Rare Diseases Law in Chile.

The meeting took place in Santiago, in a building that for many years was the Congress venue, and still hosts main parliamentary activities.

Speakers at the meeting included Karol Cariola, President of the Congress Health Commission; Robinson Cristi, President of the Federation of Rare Diseases; Hugo Dolmesch, President of the

See **CHILE** on page 13

15 Years – 15 Major Accomplishments (out of many!)

The Life Raft Group became a formal non-profit on June 10, 2002.

Due to the success of the breakthrough targeted treatment, STI-571 (imatinib), we began as a grass roots effort by a group of men and women with a deadly cancer in 2000. By the year 2002, we were ready to take on the mission of helping GIST patients to survive and thrive, while continuing to find a cure.

Now, 15 years later, we have accomplished unprecedented achievements in our journey. They would not have been possible without the generous help of you, our donors.

We need you more than ever to continue. Although we have achieved much, there is a great deal of work to be done. There is still no “cure” for GIST, and although we

have learned a great deal about the biology of the disease, there are still mutations for which there are no targeted treatments.

Many patients still become resistant to what was once a successful treatment for them.

Can we rely on you to help us by donating now, so that we can continue the work we began 15 years ago?

From 15 dollars to 15 million, any and all donations are welcome.

Go to:liferaftgroup.org/donate

15 Major Accomplishments of the Life Raft Group

1. Forming a global community to work together to find a cure for GIST
2. Establishing the largest GIST Patient Registry, now with state-of-the-art functionality
3. Creating the GIST Collaborative Tissue Bank
4. Implementing a model for a collaborative Research Team
5. Becoming the largest funder of GIST research over the last ten years
6. Collaborating with major academic institutions in the Columbia Research Project
7. Placing patients in the forefront of the decision-making process for research
8. Establishing the reputation of the LRG through the publication of peer-reviewed journal articles and the GIST and Sarcoma Journal
9. Forming the Virtual Tumor Board to offset cutbacks for the NIH in-person clinic
10. Advocating for patients and funding on a local, national and international level
11. Presenting GIST Days of Learning (GDOLs) across the country
12. Expanding programs globally, especially through the establishment of Alianza GIST
13. Holding a biennial gathering (Life Fest) of GIST patients, caregivers and medical professionals to share the latest in GIST research and to network
14. Implementing an Expert Patient Training Course to empower patients with knowledge

And most importantly,

15. Granting the gift of time to a grandfather to walk his granddaughter down the aisle; two lovers to watch another sunset together on a deserted beach or a child to be able to celebrate another Mother's Day.



We help save lives.

2017 GDOLs Kick Off in Miami and New York City

By **Laura Occhiuzzi**, Outreach & Engagement Senior Director

On Saturday, March 25th, The Life Raft Group held the first 2017 GIST Day of Learning, also known as “GDOL,” in Miami, Florida. GDOLs are free, one-day programs that provide both education and support to the GIST community. Top GIST specialists present the latest updates on research and treatment options as well as provide a comprehensive review of the science behind GIST. GDOLs provide an opportunity to not only meet and interact with local expert practitioners in an intimate setting, but also for patients to connect with one another in a supportive environment.

Jonathan Trent, MD from Sylvester Comprehensive Cancer Center began the morning with a presentation on “GIST 101.” Later in the day, he discussed the topic of “Accelerating a Cure.” Breelyn Wilky, MD, also



Attendees in the spirit of the H.E.R.O. campaign at the Miami GDOL.

from Sylvester, spoke about “The Role of the Immune System in GIST and Implications for Future Therapies.”

We were fortunate to have a surgical panel that included Alan Livingstone, MD from Sylvester Comprehensive Cancer Center and Ricardo Gonzalez, MD from Moffit Cancer Center.

Lisa Marie Merheb then provided direction and information about support as she spoke about “Psychological implications in GIST.”

Sosipatros Boikos, MD from Massey Cancer Center closed out

See **GDOLs** on page 10

This is not the End – A Survivor’s Story

By **Jerry Call**, Data Analyst

A story about a cancer survivor recently appeared in the *Washington Post*: “This is not the end; Using immunotherapy and a genetic glitch to give cancer patients hope.” The story is about a young woman, Stefanie Joho, at the end of her treatment options. With one last attempt at an experimental therapy, she had an amazing response to a recently approved immunotherapy, Keytruda.

The article about the treatment is an interesting read; the story of an already approved drug being used for a colon cancer patient, a condition for which it’s not approved. It is about an underlying genetic defect

that predisposes a patient to have more genetic damage than the typical cancer patient. Keytruda, and other drugs in this class (PD1 inhibitors), have already been suspected to work in cancers that have more genetic damage. It’s thought that it’s easier for the immune system to recognize a cancer with more genetic damage as something foreign and attack it than a cancer with less genetic damage.

The story itself is a great read, but I’m not going to retell it here. You can read the entire story at the link: wapo.st/2s3DIq9

Equally fascinating, and perhaps more useful to GIST patients, is the story

of what it took for this young woman to find and participate in the trial that saved her life.

To save her life, Stefanie Joho had to step outside the normal path of cancer patients. She had to rely, not on what she was told was possible, but what she herself, with indispensable help from her family, discovered to be possible. Stefanie had been told by her oncologist that he was out of options; but, he mentioned that some interesting work was going on in immunotherapy. However, her first attempt at following up in this lead led to a dead-end when

See **SURVIVOR** on page 12

BE A H.E.R.O. FOR CANCER

Become a #Hero4cancer and Help Expedite Research Outcomes

By **Diana Nieves**, Outreach & Engagement Director

Characters like Batman and Superman can be fun and inspiring in their fictional world, but the fight against cancer is very real. On March 6th, 2017, the Life raft Group officially launched its Help Expedite Research Outcomes (H.E.R.O.) Campaign because cancer research is in trouble. There isn't enough data, tissue or dollars to save lives fast enough. Cancer research needs heroes who can help save lives. LRG's goal is to increase donations in data, tissue and funding of \$5 million dollars towards collaborative research projects. You can be the hero of your own story, for someone you love or pay it forward to someone in need of your help. Become a #Hero4cancer and earn your superpowers by donating:



Tissue:

Tissue is vital for cancer research. Unless in a major institution, all tissue is destroyed after a certain period of time. Initiatives like the LRG GIST Collaborative Tissue Bank work with researchers to expand the amount and reach of tissue and drastically accelerate scientific exploration. By donating to a tissue bank, patients are preserving that vital data and ensuring

it can be used to help them and others in the future. Visit liferaftgroup.org/join-our-tissue-bank/ to learn more about LRG's tissue bank and donating tissue.

Data:

Patient-powered science is crucial to understanding cancer management and expediting research. The ability to compile and share clinical histories, especially those tied to tissue analysis, provides valuable data for your medical team, as well as to researchers evaluating drug efficacy and epidemiological factors. Having the data stored in one central location, like the LRG's GIST Patient Registry and our patient portal GIST/PRIME, can help you better manage your own or your loved one's GIST care. Go to liferaftgroup.org/patient-registry/ to join LRG's Patient Registry.

Funds:

Cancer research is expensive, and research funds are limited, especially for rare diseases. Supporting promising new research efforts at major academic institutions such as our recent collaboration with Columbia



University Medical Center, analyzing research data, testing tissue, performing next generation genomic sequencing, identifying new treatments and supporting patient education are all costly. To save lives, we need to invest in promising new targeted therapies and leverage all the clinical know-

how we have today until these new treatments are available. There are all kinds of heroes. All donations over \$50 will be acknowledged with a certificate of HEROship and listed in our Hall of Heroes online.

Donate online:
liferaftgroup.org/donate/

\$50 and become an Everyday Hero

\$100 and become a Classic Hero

\$250 and become a Super Hero

\$500 and become a Mythical Hero

\$1000 and become a Legendary Hero

\$5000 and become an Epic Hero

To learn more about our H.E.R.O. campaign and download educational infographics to share with others, please visit:

liferaftgroup.org/hero/



HERO from page 1

guide you, no field trips to give you a break, and no PTA to support you. Cindy is now a grandmother who enjoys special time with her three granddaughters, teaching them to craft and cook and enjoy their time spent playing together.

Cindy has spent much of her life as a community servant and volunteer. She has offered 20 years as a volunteer at a local Crisis Pregnancy Center. She volunteered at her local hospital for close to a decade, both at the reception desk and making crafts as a fundraiser for those unable to pay for their own hospital care. She has also invested 11 years working as a hospice volunteer, providing grace and solace to families in their most trying hours.

Her healthcare journey began in 2006 with a diagnosis of thyroid cancer. Although there had been some thyroid issues in her family, the diagnosis of cancer was unexpected and unwelcome. A short two years later, she was diagnosed with diabetes. After a respite, cancer once again returned in the form of an abdominal GIST tumor, an ovarian cancer tumor, then closely followed by an area of breast cancer. Cindy had a partial mastectomy to remove the area of lobular carcinoma in situ (LCIS) and another surgery to remove both a cantaloupe-sized GIST tumor in her abdomen and a grapefruit-sized ovarian tumor in her pelvis.

Cindy began taking Gleevec; she felt good and felt that her treatment was successful. In the autumn of 2015, she learned that she had a fast-growing mutating GIST tumor that merited attention. Her omentum was surgically removed in July 2016, along with all three known GIST tumors.

Later in 2016, a routine mammogram revealed that she now had breast

cancer in her other breast: Ductal carcinoma in situ (DCIS). Cindy is a powerhouse, but enough insult to her body was enough! She decided to have a right breast mastectomy and begin the first steps of immediate breast reconstruction. Her breast would be fully reconstructed nearly six months later, and the remaining



GIST Superhero Cindy Farr

breast would also be operated on to ultimately match the other. Since these surgeries, Cindy has struggled through ten months of pain, and adverse effects from being given incorrect medicine that led to gall bladder surgery and further hospitalizations.

To quote Cindy, "Only the Lord kept me together through all these difficult things. When I felt I was empty, and had no hope, I could always pray to Him, knowing He heard and that His heart was hurting for me. He gave me the strength to go on."

In her personal time, Cindy is a woodcarver. This is a hobby that she shares with her husband, Gene. Three years ago, she went to a woodcarving

conference with some friends and serendipitously, found herself in the company of a woodcarver who also excels in chainsaw carving... a skill Cindy has always wanted to acquire. The gentleman offered to teach Cindy to carve anything she wanted with a chainsaw. She chose a peacock, her symbol of hope.

She was first visited by a peacock when her mother was nearing the end of her life, and Cindy needed a sign from the Lord that He was going to help her through everything that was going on. A full-grown male peacock appeared on their property and stayed for two whole weeks, perching nightly in a large pine tree at the edge of their property, close to the house, trumpeting to let her know he was there. Since this glorious bird appeared in her life when she was in such distress and gave wings to her hope, Cindy has found that peacocks in many forms appear when she needs hope, confirmation, and peace. She rejoices in this symbol of her hope for the future.

Cindy has a bucket list. When she fell ill, she looked hard at what she wanted to embrace and experience in her life. Her husband of 41 years was her strongest supporter and encouraged her to go for it! Cindy is now "officially" a zip-liner, cardmaker/scrapbooker, Habitat for Humanity home-builder, cruise-taker, target-shooter, a Cleveland Museum of Art-aficionado, and a hero. She wants to be found living her life to the fullest as she slides into Home Plate! Godspeed, Miss Cindy! ■

Learn more at
bit.ly/Hero4Cancer

#HERO4Cancer

KIDNEY from page 1

face in improving quality of life. Preventing kidney disease is one of them. It is important to learn about kidney disease, causes, risk factors, treatments and proactive measures that patients can apply across the continuum of GIST care.

What are the Kidneys and Their Functions?

Kidneys are a pair of bean-shaped organs that are located towards the back of the abdominal cavity on either side of the spine. Each kidney is composed of about a million nephrons, serving as the functional unit, headed by a glomerulus, responsible for filtering the blood and turning filtrates into what will become urine. Their main function is to help maintain water and electrolyte balance within the body. They also have an important role in producing several hormones and enzymes such as erythropoietin (for production of red blood cells) and renin (plays a role in maintaining blood pressure), and to help convert Vitamin D into its active form which is essential for healthy bones. In addition, they aid in the excretion of wastes and foreign compounds, such as medications.

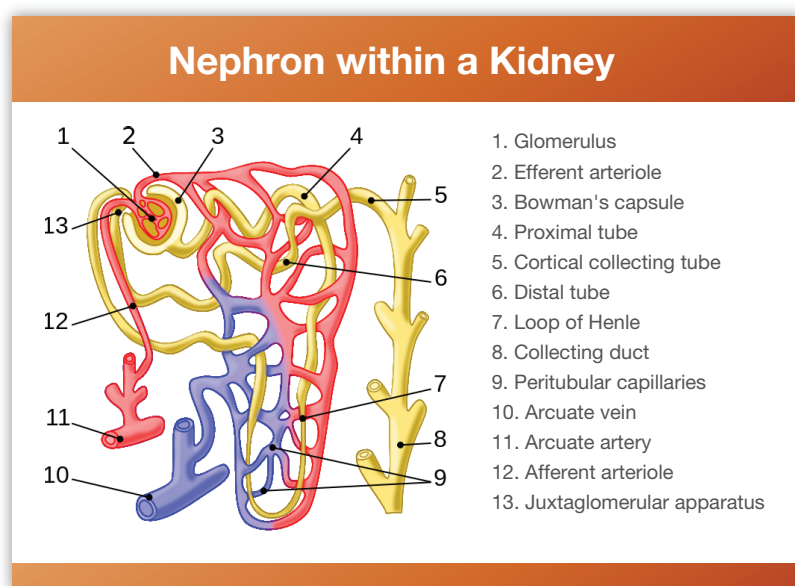
How Common is Kidney Disease?

Kidney disease is referred to as the inability of the kidneys to remove wastes and excess water from

the blood due to damage or injury. According to the National Center for Chronic Disease Prevention and Health Promotion at the CDC, 1 in 7 adults in the United States, aged 18 years and older may have chronic kidney disease (CKD) at varying stages. And, about 96% of people with kidney damage are not aware they have CKD.¹

Types of Kidney Disease

Kidney disease can be classified into two distinct categories: acute renal failure and chronic kidney disease.



ACUTE RENAL FAILURE

Acute Renal Failure (ARF) occurs when kidney function declines rapidly (onset is within just a few days) and the kidneys cannot perform their normal function. One of the biggest signs of ARF is decreased urine output.

There are three types of ARF, each brought on by a different cause:

1. **Pre-Renal** – inadequate blood circulation to the kidneys, causing them to not be able to clean blood properly. Dehydration, blood loss, chronic liver disease and atherosclerosis are the most common causes.

2. **Intrinsic** – involves damage or injury within both kidneys (approximately 40% of ARF cases). This can be due to low RBC/platelets, fever, reduced urination, hypercalcemia, toxins, and ischemia (inadequate blood supply).
3. **Post-Renal** – also known as acute renal obstruction. This is often caused by something blocking the elimination of urine produced by the kidneys such as kidney/bladder stones, direct injury and enlarged prostate.

Treatment for ARF is focused on targeting the underlying component. Doctors sometimes prescribe angiotensin-converting enzyme (ACE) inhibitors or recommend renal replacement therapy (RRT) depending on the extent of the kidney injury.

CHRONIC KIDNEY DISEASE

Chronic Kidney Disease (CKD) is a condition where there is a slow loss of kidney function over time and cannot be reversed. There are five stages to kidney disease, with each stage indicating progressively

worse filtration as indicated by the Glomerular filtration rate (GFR). The final stage of CKD is called end-stage renal disease (ESRD). This is the point where the kidneys are no longer able to perform their function efficiently and patients will need dialysis or a kidney transplant.

What are the Risk Factors?

According to the American Kidney Fund, some of the main risk factors for chronic kidney disease are:

- Diabetes

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- High Blood Pressure and cardiovascular disease
- Age over 60
- Family history of kidney failure
- Race (Hispanics, African American, Native Americans)

Other factors include:

- Autoimmune disorders
- Nephrotoxic chemicals (such as radiologic contrast)
- Kidney stones and infection
- Problems with the arteries feeding the kidneys
- Some medicines, such as pain and cancer drugs

How is Kidney Disease Tested?

- **Serum Creatinine** – most common clinical test used to measure if the kidney is functioning well. This is usually included in a regular laboratory blood draw that GIST patients have. A rise in the serum creatinine indicates that the kidney is not working as well as it should. In a normal kidney creatinine is excreted efficiently. Therefore, a buildup of which may be a sign that the kidney is not filtering creatinine, and everything else that it needs to.
- **Urinalysis** – also a common clinical test that manifests kidney function. Abnormal presence of protein or blood cells in the urine may indicate a potential kidney issue. Other reasons such as urinary tract infection, or a kidney stone may also be the reason for abnormal levels.

- **Glomerular filtration rate (GFR)** – most important test to measure the level of kidney function. A normal GFR is over 90mls/min/1.73m². It varies according to age, sex, and body size, and declines with age. This is usually a calculation based on serum creatinine and a few other factors. A GFR under 60 for three or more months indicates chronic kidney disease.

What are the Ways to Prevent Kidney Disease?

- ▶ Follow the DASH (Dietary Approaches to Stop Hypertension) Diet – rich in fruits, vegetables, low-fat dairy products, whole grains, fish, poultry, beans, seeds, and nuts. It is low in sodium, added sugars and sweets, fat and red meat
- ▶ Stay hydrated
- ▶ Monitor and treat blood pressure and cholesterol levels
- ▶ Limit your alcohol intake
- ▶ Limit use of non-steroidal anti-inflammatory drugs (NSAIDs)
- ▶ Quit smoking
- ▶ Exercise regularly
- ▶ Control weight
- ▶ Get an annual physical

The leading risk factors that cause kidney disease are among the leading health risks in the United States: diabetes and hypertension. Given the prevalence of kidney disease and the common symptoms and side effects (i.e. dehydration, hypertension, etc.)

that GIST patients experience, the GIST population needs to be mindful of protecting their kidneys and overall health.

There are proactive measures that can be taken to either prevent or detect kidney disease:

1. Modify some of the risk factors that are within your control like drinking more water, eating healthy and being physically active.
2. Talk to your physicians about requesting that the test/s be included in regular laboratory blood draw. Request to have the tests prior to starting TKI treatment to get a baseline of the kidney function, and have them repeated continuously while on treatment to monitor levels. Detecting changes early can help you and your physician decide on appropriate ways to treat kidney disease while managing GIST.
3. Work with your doctor to factor in any familial dispositions in assessing risk for kidney disease, and discuss treating comorbidities you may have like hypertension and diabetes as well as working out a plan to lessen exposure to radiologic (CT scans, PET scans, etc..) contrasts.

Contrast Media and Kidney Disease

Computed Tomography (CT) is a standard imaging method for monitoring and evaluating treatment response in cancer patients and is typically administered with contrast media to help the radiologist see images more clearly. This may sometimes lead to what is known as Contrast-Induced Nephropathy (CIN). Contrast-Induced Nephropathy

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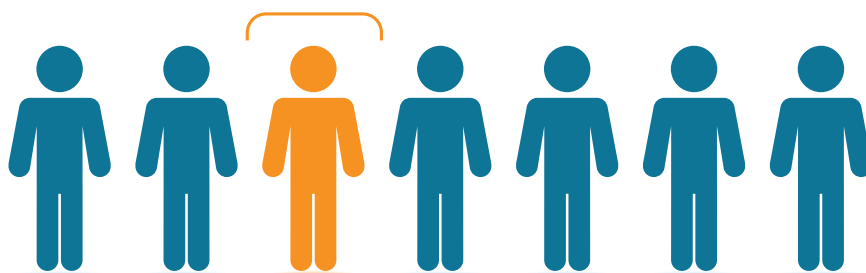
(CIN) refers to an iatrogenic acute kidney injury after administration of contrast media (CM) and can be defined as an increase in serum creatinine of at least 25% within three days after CM administration in the absence of another etiology². The incidence is highly dependent on renal function prior to CM administration and additional risk factors, of which diabetes mellitus is the most important one. Cancer patients are more prone to have renal insufficiency due to nephrotoxic chemotherapy, but more importantly there is a high percentage of cancer patients who are elderly and predisposed to dehydration. Stating that the increase in creatinine is solely due to the intravenous contrast in cancer patients is difficult to conclude due to the possibility of other etiologies besides contrast exposure that could play a role in the development of nephropathy. The main way to help prevent the onset of CIN is through hydration, which can decrease CM concentrations in the kidneys.

TKIs and Kidney Disease

Tyrosine kinase inhibitors (TKIs), such as imatinib (Gleevec) is a class of chemotherapy medications that block the enzyme, tyrosine kinase and are used as a targeted treatment for cancers such as GIST. Imatinib is an example of one TKI that is used to treat GIST and CML. A study by Marcolino, et.al, looked at 105 CML patients undergoing imatinib treatment and the incidence

of acute renal failure and chronic kidney disease in this population. The median time on imatinib was 4.5 years and at the end of treatment, 7% of patients developed acute renal failure and 12% developed chronic kidney disease.³ The study suggested that imatinib therapy in CML patients is associated with acute renal failure and that long-term treatment is related to a clinically relevant decrease in the estimated GFR that may lead to chronic kidney disease.³

1 in 7 adults in the United States* may have chronic kidney disease (CKD) at varying stages



*Age 18 years and older

In another study, Yilmaz, et.al. reviewed the records of 468 newly diagnosed CML patients who were treated with imatinib (253 patients), dasatinib (99 patients), or nilotinib (116 patients). The median duration of TKI treatment was 52 months. Acute Kidney Injury was observed in 19 patients, (16 received imatinib, 1 received dasatinib and 2 received nilotinib).⁶ The median time from the start of TKI therapy to the onset of this injury was nine days.⁶ Forty-eight (48) patients had a history of chronic kidney disease (CKD) at the start of TKI treatment and of which 60% had history of diabetes, hypertension and coronary artery disease.⁶ Another 58 patients developed CKD while on therapy. Among those with CKD, Eight-four patients, (84%) were treated with imatinib.⁶ Most (95%) of these cases were classified as stage

III kidney disease, and 5% were stage IV⁶. The median time from the start of TKI therapy to onset of CKD was 12 months⁶. The study found that treatment with imatinib was found to have the strongest association with the development of CKD (Multivariate analysis; Odds ratio of 8.3, 95% CI, 3.5–19.4; $P < .001$) as indicated by a decline in GFR.⁶

Both studies lead to the suggestion that renal function should be periodically monitored in patients undergoing treatment with imatinib. Yilmaz's study stressed the importance to monitor renal function at an earlier time as most ARF cases occur during the first three months of therapy. Marcolino's study further recommended avoiding concomitant administration

of potential nephrotoxic agents (i.e. radiocontrast agents, aminoglycosides, NSAIDs) to avoid cumulative impairment in renal function.

In the Life Raft Group Patient Registry

Turning to our own Patient Registry with 1673 GIST patient records at the time of observation to attempt to determine the prevalence of kidney disease within the database, it was observed that there were 45 patients who had reported kidney disease or suspected kidney disease. This included self-reported symptoms of increased creatinine levels, decreased kidney function, and hydronephrosis. The average

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age of this group is 63 years. Prior to receiving symptom reports, their average time on imatinib treatment was 54 months and the patients have received an average of 13 radiologic scans (not specified if with contrast). The preliminary data does not prove a direct relationship between the development of kidney disease and scans or medication. This is an observation that needs further investigation.

Currently, the Registry data on kidney disease in GIST patients is limited. It is biased to the United States GIST population and is based on patient self-reported information, where either not many patients report kidney disease or are not aware that they may have it. The accompanying side effects and symptoms from both

the disease, treatment and scans need to be taken into consideration in understanding the development of this disease among GIST patients. As this topic develops, the LRG Patient Registry will continue to attempt to collect more information regarding kidney disease and keep its members informed. ■

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CANCERVERSARY: Angela Howell – Celebrating 12 years!

I was diagnosed with a Kit positive GIST cancer on June 10, 2005 at the age of 44. At the time of my diagnosis, I was told that this cancer was a rare and aggressive sarcoma that showed no response to traditional cancer treatment and my prognosis was not good. Life certainly didn't feel very fair.

I had married my high school sweetheart and this wasn't what we had mapped out for our life journey. I

remember thinking I didn't have time to be sick. I was the mother of four children ranging from middle school to grad school. I felt helpless and alone.

The only hope that I had to hold onto was an option to participate in a

clinical trial of Gleevec. I wasn't even guaranteed that I would be receiving the medication. It had not been

approved by the FDA for treatment yet and this trial was a blind study. I remember thinking I had nothing to lose and everything to gain. So I decided to do it. That was only the beginning of my journey back to the land of the living.

In 2010, I was fortunate to travel to New

Jersey and CELEBRATE 10 years of research with the Life Raft Group. Wow, what an amazing trip. We celebrated dinner, fireworks and friendship on the Hudson. I no longer felt alone. I met so many beautiful people and that gave me the hope that we can beat this!

All the hard work and long hours dedicated by all the doctors, researchers, and all the important members of the team have given me back

my life. Since my diagnosis, I have had opportunity to travel to England, France, Ireland, Spain, Italy, New York and New Jersey. I have been here to welcome all of my children's' life partners to our family. I am enjoying being a Nana to four precious grandchildren and counting. My most recent addition was just last month. I am 56 and I will celebrate my 36th wedding anniversary and my 12th Cancerversary in June. I never thought I was going to be here for this. I think it is easy to take life for granted until you come close to losing it, so I celebrate life DAILY! Thank you, thank you, thank you!



GDOL from page 3

the afternoon with a presentation on “Advances and Challenges in KIT/PDGFRA Wildtype GIST and Implications for Treatment.” A question and answer session followed.

The sessions were informative and welcomed by all participants.

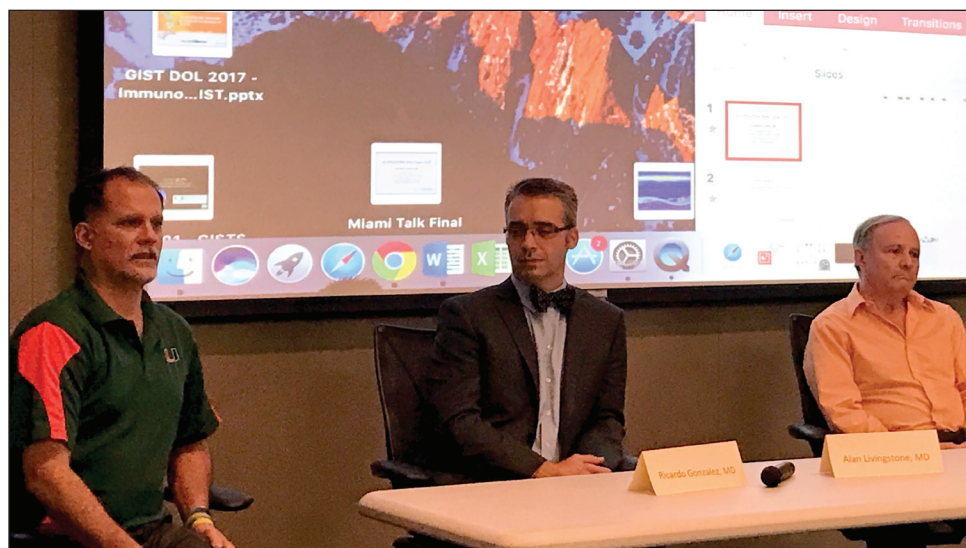
As part of our H.E.R.O. Campaign, participants had the opportunity to decorate superhero masks to highlight the fact that you can be a **#Hero4Cancer** by donating your tissue, data or funds to help accelerate cancer research.

A special thank you goes out to Alyssa Occhiuzzi, Marian and Dale Ritter and Van Russell for volunteering their time.

Our next GDOL was held on May 24th at the American Cancer Society in New York City. Norman Scherzer, Executive Director of the Life Raft Group, opened the evening by presenting a historical perspective of the LRG and his story of hope and survival.

Gary K. Schwartz, MD, Chief of Hematology/Oncology and Deputy Director for Clinical Research at NewYork/Presbyterian, Columbia University Medical Center presented “The Impact of Clinical Research on Patient Care.” An informative session by Ping Chi, MD, Medical Oncologist from Memorial Sloan-Kettering Cancer Center on “New Advances in Research and Clinical Insights” was well received. The final speaker was Beth Schroepe, MD, Ph.D, Associate Professor of Clinical Surgery at Columbia University College of Physicians and Surgeons, who discussed “Surgical Management of G.I. Tumors,” which provided information about what a patient needs to know before and after surgery.

The support that the patients and caregivers give one another at GDOLs



From left to right: Dr. Jonathan Trent, Dr. Ricardo Gonzalez, Dr. Alan Livingstone at the Miami GDOL. View video presentations from the Miami GDOL at lifteraftgroup.org/videos/

is incredible. If you have the opportunity to attend one of our GDOLs this year, don't miss it. You will be glad you took advantage of this opportunity to both learn and network with other GISTers.

Moore's Cancer Center in San Diego/La Jolla will be our next GDOL stop on July 15, 2017. More information

about this and other LRG events will continue to be updated on the LRG website. Interested in having the LRG come to your city for our next GDOL? Email your ideas to Laura Occhiuzzi at locchiuzzi@lifteraftgroup.org.

We would like to thank our sponsors, Novartis and Pfizer for supporting our GDOL series. ■



From left to right: Dr. Beth Schroepe, Dr. Ping Chi and Dr. Gary Schwartz at the New York GDOL.



New York GDOL participants support our HERO campaign.

A special thank you to our GDOL sponsors



Networking with the experts at ASCO

◀ From left to right: William D. Tap, MD - Memorial Sloan Kettering Cancer Center, George D. Demetri, MD - Dana-Farber Cancer Institute, Norman J. Scherzer - The Life Raft Group, Sebastian Bauer, MD - West German Cancer Center

SUVIVOR from page 3

the hospital immunologist told her that no suitable trials were available.

It was Stefanie's sister, Jess, that did the initial homework, searched for and found the clinical trial that resulted in the amazing response. As detailed in the *Washington Post* article, "For Joho, now 27 and living in suburban Philadelphia, the hard lesson from the past few years is clear: The cancer field is changing so rapidly that patients can't rely on their doctors to find them the best treatments." "Oncologists can barely keep up, My sister found a trial I was a perfect candidate for, and my doctors didn't even know it existed... I got chills all over my body, to think that I was at the end of the road, with no options, and then to be part of such a change."

I have long known that being a proactive educated patient could improve a patient's survival. A few people might challenge such a strong description as "known." I will concede that it doesn't help every patient. There are examples of patients doing nothing except what they were told doing well, as well as cases of where very proactive patients did not benefit from their activism, and even cases where they made their situation worse. However, I have seen or heard of countless cases where their knowledge, drive and activism made a huge difference.

Lessons Learned

Let's take a closer look at a few of the lessons one can learn from Stefanie Joho.

- When your oncologist says that he or she is out of options, it doesn't necessarily mean that you are.

- When your local hospital says they don't have a trial for you, it doesn't mean that no trial for you exists elsewhere.
- Help from family or, less frequently, friends, can have a huge impact. It may be a case of someone that is more tech-savvy than you are. It's also difficult for many cancer patients to focus on research when they are often sick, depressed and trying to come to grips with their own mortality. In many cases, a spouse or significant other, brother, sister, son, daughter, or mother or father can help with research, calls, appointments and all sorts of things. Take help if offered; ask



for it if you need it, just remember that in the end, you control final decisions. Sometimes you will have to "weed out" potentially bad advice from the good.

- Don't be afraid to participate in clinical trials; but do your homework. How did you find out about the trial? Did you find it; or was it recommended to you? Understand that some trials may be offered to you, not because they are your best option, but because they are in the best interest of those offering you the trial, such as to "fill" a slot in a local trial. That's not to say all local trials are bad, but you should understand that the trial

that is the most rational in terms of your chances of response, may not be offered locally.

- (okay; so this one wasn't in the article, but. . .) Being an effective proactive cancer patient requires you to become informed about your cancer. One of the best ways to do this is to join a support group for the same type of cancer that you have. By being in touch with many people (often hundreds) with the same cancer, you can tap into their shared knowledge. Find out about new drugs, new trials, expert doctors, the best hospitals, side effect management and countless other subjects.
- Learn how to evaluate evidence and information. This is not an easy or a quick task, but it's an important one.

In addition to the lessons that can be learned from the article, there are some lessons, both positive and negative, that can be learned by reading the comments from readers at the bottom of the article. Look for common threads about survival tactics from the readers. It's fair that some commenters point out that not everyone is eligible for a clinical trial, trials don't help everyone, medical care is too expensive, etc., but there are still a lot of common threads in the comments. ■

McGinley, J. (May 28, 2017). This is not the end: Using immunotherapy and a genetic glitch to give cancer patients hope. *The Washington Post*. (Online article - wapo.st/2s3DIq9)

If you have an example of how being an educated proactive patient made a difference (hopefully good, but bad as well), I hope you will share it with others in our email community, or send them to Mary Garland, mgarland@liferaftgroup.org.

CHILE from page 1

Supreme Court of Justice; Jaime Burrows, Health Sub Secretary who represented the Health Minister who could not attend the meeting; Migdalia Denis, Member of the Rare Diseases International Committee; Angela Vivanco, Professor of Constitutional Rights for the Catholic University of Chile and Camila Quirland from the School of Public Health of the University of Chile.

Also in attendance were representatives from Patient Organizations and their deputies including Karla Rubilar, Javier Macay and Victor Torres.

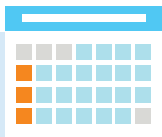
At the conclusion of the meeting, all the participants signed a framework agreement by which we committed ourselves to advocate for a law for Rare Diseases in Chile. ■



▲
Above: From left to right, Camila Quirland, Piga Fernandez, Migdalia Denis and Deputy Karla Rubilar.



◀ **Left:** Piga Fernandez signs the agreement at the Federation of Rare Diseases in Chile (FECHER).



CALENDAR OF GLOBAL EVENTS

July 6th - Patient Gathering Meeting

Location:

Pediatric Clinic in the Mark O. Hatfield Clinical Research Center

National Institutes of Health Clinical Center
10 Center Drive
Bethesda, MD 20814

July 8th - The New York Group Luncheon

Location:

Taste 99 (Carlyle on the Green)
Bethpage State Park
Old Bethpage, New York 11735

To attend, please contact Pat Bonda-Swenson
pbondaswenson@yahoo.com

July 8th - India's Patient Support Group Meeting

Location:

GIST Awareness Day event
Dr. E Borges Road
Parel, Mumbai, Maharashtra
400012, India

July 13th - Mount Sinai Hospital GAD Event

Location:

GIST Awareness Day event on the 3rd floor
Ruttenberg Treatment Center-The Mount Sinai Hospital
1470 Madison Avenue
New York, NY 10029

July 13th - Moores Cancer Center

Location:

GIST Awareness Day event in the Lobby
Jacobs Medical Center at UC San Diego Health
9300 Campus Point Dr.
La Jolla, CA

July 15th - GDOL San Diego

Location:

Jacobs Medical Center at UC San Diego Health
9300 Campus Point Dr.
La Jolla, CA

July 15th - Chile's Patient Support Group Meeting

Location:

GIST Awareness Day event in the Lobby
Avenida Cristóbal Colón, 4198.
Las Condes, Santiago, Chile



THE LIFE RAFT GROUP GIST/PRIME

AN INTERACTIVE PATIENT REGISTRY

GIST Management is Back in Your Hands

The Life Raft Group is proud to announce a new mobile-friendly online tool to help you monitor your GIST history and make a significant contribution to cancer research!

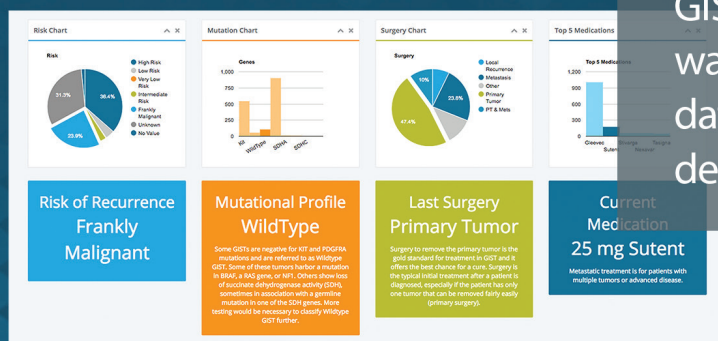


GIST/PRIME can help keep you organized and up-to-date on GIST resources and treatment, as well as give you a chance to compare your experiences to other patients and get individual feedback on your care. Become a part of the global GIST community by contributing your clinical data and joining the largest GIST database in the world.



DITCH THE BINDER!

www.GISTPRIME.org



GIST/PRIME gives you an easy way to track your important data so you can make the best decisions for your own care.

JOINING IS EASY!

- 1 Go to www.GISTPRIME.org and click REGISTER
- 2 Answer a few simple questions to create your account
- 3 Easily fill in diagnosis, treatment and evaluation information
- 4 Come back and update any time to keep your info current

Save the Date: GIST Awareness Day July 13th!

By **Jessica** Nowak, Outreach & Engagement Manager

On July 13th, the Life Raft Group will be celebrating the third annual GIST Awareness Day!

Every year, our goal is to increase awareness about GIST worldwide.

This year, we are celebrating GAD with our H.E.R.O. Campaign, #Hero4Cancer.

We need your support

and assistance to Help

Expedite Research

Outcomes.

Cancer research is in trouble and needs heroes like you.

Batman can save the

day in Gotham City

and Clark Kent can

put on his cape to fight

villains as Superman, but

unfortunately, the fight against

cancer is one they cannot help us

win. That is where you and your

extraordinary powers come in.

The Life Raft Group can help anyone become a patient-powered hero. One can start by donating their tissue, submitting their data, donating funds, spreading the word and advocating for tissue collection and increased funding for research. You can learn more about our new H.E.R.O. campaign and help us save lives by going to liferaftgroup.org/hero/.



Tommy Tissue and Dina Data are excited about GAD!

The Life Raft Group will be holding GIST Awareness Day events at the Moores Cancer Center in San Diego as well as Mount Sinai Hospital in New York City. Both events will be held in the lobby of the institutions on July 13, from 10 AM to 3PM, and will include activities focused on our H.E.R.O. campaign as well as the distribution of educational materials about GIST and the Life Raft Group. There will also be patient meetings held in Michigan and Iowa. Global meetings will be taking place in Mexico and Guatemala. ■

How to Participate

Anyone can hold their own GAD event as well! To find out more about what you can do to help to spread awareness visit...

bit.ly/GAD2017Participate

To learn more about these events, please visit...

bit.ly/GAD2017Events

You may also reach out to Laura Occhiuzzi to learn more. locchiuzzi@liferaftgroup.org

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, Director of Communications, at mgarland@liferaftgroup.org of any errors.

THE LIFE RAFT GROUP GLOBAL COMMUNITY

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