

Ensuring no one has to face GIST alone



In Loving Memory: Manuel Firgau, Harold Baston, Stephanie Call, Timothy Matsick, Pat Lemeshka, Mark Stanke, William Steele

Piga Fernandez: advocate for change

By **Mary Garland**, Marketing and Communications Associate

Advocacy for GIST patients is a vital part of the work the Life Raft Group undertakes, but there are advocacy “superheroes” out there, going above and beyond to ensure that all GIST patients receive the life-saving treatments they need and deserve. Piga Fernandez, LRG Global Consultant, is one of those exceptional superheroes.

Internationally, treatment for GIST is not as accessible as it is in the United States. Piga

has been a part of the LRG’s efforts to raise awareness about GIST in Latin America through the efforts of Alianza



See **SIGNING** on page 9

Dr. Monica Anderson: inspirational survivor

By **Mary Garland**, Marketing and Communications Associate

Interviewing Dr. Monica “mOe” Anderson is like having a cup of tea with a friend with all the requisite perks: laughter, sharing of life philosophies and sound advice, and mutual respect.



ANDERSON

Dr. Anderson is a survivor. In the introduction to her latest book, *Success is a Side Effect: Leadership, Relationships and Selective Amnesia*, she describes not wanting to label herself as a “survivor,” since GIST was treatable, until she consulted the dictionary. “Survivor means to continue to live; a person alive after an event in which others have died; to exist. It does not mean you are healed, rescued, or no longer facing challenges, nor that you won’t die eventually. It means - right now - I’m alive. And I will make the best of *this* day and *this* place and *this* oppor-

National Cancer Institute team identifies a key molecular defect in SDH patients

By **Pete Knox**, LRG Strategic Planning Director and **Jim Hughes** LRG Clinical Trials Coordinator and Board Member

National Cancer Institute team led by Paul Meltzer recently published a paper in *Science and Translational Medicine* entitled, “Recurrent epimutation of SDHC in gastrointestinal stromal tumors.” The findings have some potential implications



HUGHES

for GIST patients, particularly those who are SDH-deficient.

The study looked at SDH-deficient tumors from 59 patients, ranging in age from seven to 57 years at diagnosis. They identified a known SDH mutation in either SDHA, SDHB, SDHC or SDHD (called SDHX Mutant GIST) in 43 and no SDH mutation (wild type) in 16. The researchers found that the 16 wild type patients (27%) had an

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See **SURVIVOR** on page 10

Developing GISTKids.org

By **Erin MacBean**, LRG Member

During the Life Raft Group Life Fest 2014, a panel of young GIST patients and family members gathered around a table to discuss ideas for advocating for SDH-deficient and wild type GIST. The group agreed that representation of SDH-deficient and wild type GIST was lacking and thus research and treatment options suffered. To help to resolve this, GISTKids.org was started. Declaring the start of a branch-off organization powered by the Life Raft Group was just the tip of the iceberg. Questions began to form. How would we reach the younger patients and families? How would we educate and advocate to such a dynamic group of people? How would we draw attention to something that is very rare? Finally, how would we find funding for our ideas and research goals?

I have to admit, I didn't know what to expect from a handful of young adults and children. I am happy to share that their ideas were phenomenal and inspiring. We first addressed the advocacy issues, and all of us agreed that we needed a website devoted to SDH-deficient and wild type GIST. However, with a younger population of members, it could not be a website filled with text spouting statistics of GIST. To help the younger audience

understand GIST, information via video clips will help cut back on reading material, yet deliver important educational information in an innovative way.

We also agreed that to maintain web traffic, there needed to be more than just GIST-related articles. The younger patients especially didn't want a site that constantly reminded them about cancer. They want to spread hope, celebrate life, and show that there is life outside the diagnosis, so the GISTKids Stage developed. This page on the website will be blog-like, highlighting GISTKids members who want to send in and share samples of their passions – whether it is in the form of writing, art, music, sports, or other achievements. The stories will be shared to inspire others to get out there and live life to the fullest.

The panel also discussed that the website needed to provide a place for the GIST community to grow. Some ideas under development are:

- Virtual Map – where members can pin their location as a visual aid to show GIST patients that they are not alone
- GISTKids Forum – where questions, answers, and conversations can flow



- Events Page – a page designed to highlight events and fundraisers
- Social Media – outreach through all social media sites will be utilized

One of the more exciting ideas that the group produced is the use of mobile and web-based games as a way to draw in traffic of all ages to the site. It even has the potential to pull in the population outside of GIST while advocating, and perhaps even fundraising for GIST at the same time. The first game under development is called GIST Keep Swimming. It features the GISTKids logo in a simple one-touch/click game that navigates the GIST fish underwater dodging obstacles and gathering coins. We agreed that a friendly little competition combined with video clips or ads highlighting our GISTKids members

See **GISTKids** on page 8

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 Erin Kristoff, the Marketing & Communications Director, at ekristoff@liferaftgroup.org of any errors.

Life Raft Group attends Partnering for Cures meeting

By **Marisa Bolognese**, Acting Deputy Executive Director

The sixth annual Partnering for Cures meeting sponsored by FasterCures was held November 16-18 in New York City. Over 1,000 attendees from biopharma, governmental agencies, academia, philanthropy and patient advocacy organizations came together to explore the latest research trends, find collaborative partners and problem-solve with science and industry leaders.



Partnering for Cures meeting sponsored by FasterCures was held November 16-18 in NYC.

Conversation Threads

The top 10 threads at the conference sessions included:

1. Patient reported data matters.
2. "Coopetition" is healthy. We need cooperation AND competition.
3. Passion and emotion are even more powerful when quantified.
4. The clinical trials system can be disrupted.
5. Culture & incentives in academia are starting to shift to better value translation and entrepreneurship.
6. Really complex issues, like brain disease, can be hacked.
7. Citizen science is powerful.

8. To get things done, we need multiple disciplines to come together.
9. "21st Century Cures" are within our reach.
10. Unwavering and driven patients are improving and accelerating the search for cures.

The Life Raft Group team made some great connections. Check out the links below where you can read summaries of each session from Partnering for Cures as well as see videos of entire presentations. For more information about FasterCures go to their website: www.fastercures.org.

Partnering for Cures Media

To view summaries of each session as well as videos for those of you who may wish to see entire presentations go to www.partneringforcures.org/program/agenda/

To view photos from the event www.partneringforcures.org/ 

LRG research team member Anette Duensing receives 2014 GIST award

By **Helga Meier**, GIST Group Switzerland

The GIST Group Switzerland recently awarded its Science Prize to Dr. Anette Duensing, Assistant Professor of Pathology at the University of Pittsburgh Cancer Institute, and a member of the LRG's Research Team.

GIST Group Switzerland, the association for the support of persons affected by GIST, has awarded the science prize for the fifth time. The 2014 GIST prize, endowed with CHF 10,000, was awarded to Dr. Duensing for the study "Unbiased Compound Screening Identifies Unexpected Drug Sensitivities and Novel Treatment Options for Gastrointestinal Stromal Tumors," published in *Cancer*

Research 2014; 74:1200-1213 (Boichuk et al).

The award was presented by Dr. Roger von Moos, Chief Physician of Oncology/Hematology, Kantonsspital Grisons Chur, Vice President of the Swiss Group for Clinical Cancer Research (SAKK) and Member of the GIST Group Award Committee.

The ceremony took place on November 20, 2014 during the semi-annual meeting of the Swiss Group for



From left to right: Helga Meier, Anette Duensing, and Roger von Moos

See **AWARD** on page 8

Understanding generic drugs

By **Mary Garland**, Marketing and Communications Associate

With the onset of the patent expiration on Gleevec for CML expiring in July and for GIST in June 2022 in the United States, it becomes more important than ever to understand the implications when a brand name drug becomes available as a generic. Navigating the waters of generic vs. brand drugs requires an understanding of what this means for the consumer. Equally important is being aware of the existence of substandard and counterfeit drugs in the marketplace.

A generic drug, according to the FDA, “is identical—or bioequivalent—to a brand name drug in dosage form, safety, strength, route of administration, quality, performance characteristics and intended use. Although generic drugs are bioequivalent to

their branded counterparts, they are typically sold at substantial discounts from the branded price.”¹

Before being approved by the FDA, they undergo a quality control process to identify quality, purity, strength, potency and the ability to reach required levels in the bloodstream at the right time and to the same extent.

“Health professionals and consumers can be assured that FDA approved generic drugs have met the same rigid standards as the innovator drug. To gain FDA approval, a generic drug must:

- contain the same active ingredients as the innovator drug (inactive ingredients may vary)
- be identical in strength, dosage form, and route of administration



- have the same use indications
- be bioequivalent
- meet the same batch requirements for identity, strength, purity, and quality
- be manufactured under the same strict standards of FDA’s good manufacturing practice regulations required for innovator products”²

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

Generic drugs are not required to contain the same inactive ingredients of the brand drug, however. This can include flavorings, fillers and preservatives. For some patients, this can mean that your body may react

[See **GENERIC** on page 12](#)

Dating with GIST: navigating the waters

By **Erin Kristoff**, Marketing and Communications Director
Reprinted from the February 2011 Newsletter with updates.

With Valentine’s Day looming, thoughts turn to relationships. There are often unrealistic expectations of the day: a dozen red roses, a satin heart filled with fine chocolates, a romantic dinner – even a proposal.



But for many, this is a difficult day, especially for those who are not in a significant relationship. This is even more difficult for those with a cancer diagnosis.

When dating, people with a cancer diagnosis often avoid talking about their illness. Fear often stands in the way of revealing this, especially in the early stages of a relationship.

One of our LRG members, now a happily married man with two children, shared his thoughts with us back in the day

when he was dating.

“With GIST, we are lucky that most of

[See **DATING** on page 14](#)

The 2015 GDOL series kicks off in San Diego

By **Mildred Menos**,
Assistant Program Director

On Saturday, January 24, the Moores Cancer Center in sunny San Diego played host to the first of our 2015 GIST Days of Learning. Nearly fifty GIST patients, caregivers, family members and volunteers participated in the event at the University of California San Diego Medical Center campus.

A GIST Day of Learning (GDOL) is a free, one-day program that

[See **GDOL** on page 14](#)

In Memoriam

Stephanie Call

June 19, 1955 - December 26, 2014



“ Your loss saddens us
Your memory sustains us
Your courage inspires us
You are disease free at last”
- Norman Scherzer

“ To many in the LRG, Stephanie was a symbol, a beacon of hope. A testament to how love can move mountains & stop time. But she was so much more to those who knew & loved her. Stephanie radiated possibility & tenderness, adventure & calm. She was the unstoppable force and the immovable object. She was and is simply and perfectly, Stephanie.”

- Erin Kristoff

“ We are all touched by the road Stephanie forged and that Jerry followed to make this disease known and explained. Stephanie and Jerry are personal heroes, and I am grateful for that. We need a new “purple medal” for those like them, honoring the life they had together and what they were able to do under extreme difficulties which they turned into solutions for others.”

- Cathy Freeman

When I am gone, release me, let me go.
I have so many things to see and do.
You mustn't tie yourself to me with tears,
Be happy we had so many years.
I gave you my love, you can only guess
How much you gave me in happiness.
I thank you for the love you each have shown,
But now it's time I traveled on alone.
So grieve awhile for me, if grieve you must,
Then let your grief be comforted by trust.
It's only for a little while that we must part,
So bless the memories within your heart.
I won't be far away, for life goes on,
So if you need me, call and I will come.
Though you can't see or touch me, I'll be near.
And if you listen with your heart, you'll hear
All of my love around you, soft and clear.
And then, when you must come this way alone,
I'll greet you with a smile and say,
“welcome home.”





#GIST31WISHES CAMPAIGN

We highlighted one GIST wish every day in the month of December, turning our hopes and dreams into visions for the future. Members and staff shared their heartfelt wishes such as:



▶ **“To be able to support patients and doctors around the world by using virtual technology to connect them with leading GIST experts, ensuring that have the knowledge necessary to beat this disease!” - Sara Rothschild, LRG Program Director**

“My wish is for my daughter, Alia, to obviously be cured once and for all, as well as all the people who suffer with GIST. But until then, my wishes are for the research to advance in finding more targeted therapies with less harsh side effects, for the insurance agencies to work with their patients and approve them when they are seeking out a GIST specialist not in the network, and lastly, I wish for more funding and support that goes directly to the research for GIST.”

– Marie Coleman, LRG Member and mother of Alia.



▶ **“I wish for strength, patience and support from family and friends for the GIST caregivers so that they have help coping with the stress of being a caregiver.”**
– Mia Byrne, Member, LRG Board of Directors

“My GIST wish is for everyone to partake in a healthy lifestyle. We can all use the excuse that we work too much and there is not enough time in the day to worry about what we eat or if we work out. We need to be proactive if that headache or stomach pain does not go away. If we all take a little time every day to take care of our bodies, I think we can achieve a healthier lifestyle.” – Jess Nowak, LRG Office Manager



WISHES THAT ARE COMING TRUE:

“I hope that every GIST patient in Chile receives the treatment that he or she needs to keep on living.” – Piga Fernandez, LRG Global Consultant and Alianza GIST representative for Chile

On January 9th, Piga was present to witness the Chilean president sign a law assuring that the state would evaluate the funding of treatment for patients with rare diseases like GIST.



“My wish is to see every state in the US represented with one (or more!) LRG leaders so that no matter where they live, GISTers have a network close to home to lean on.” – Mildred Menos, LRG Assistant Program Director

We have four new state leaders: Carrie Callister, co-leader for Utah, Barbara Auw, our new representative for Georgia, Jeff Davis representing West Coast Florida, and Cindy Betz for Kentucky. There are still some states without representation, but we know our members will come through to continue to make this wish a reality.



OUR 2015 RESOLUTIONS: MAKING WISHES COME TRUE THROUGH ACTION

Marisa Bolognese, aided by consultant Karen Kelley, led the LRG staff through a day of strategic planning in December. Creative ideas were shared through a number of team building and brainstorming exercises.

Our 2015 Organizational Goals are:

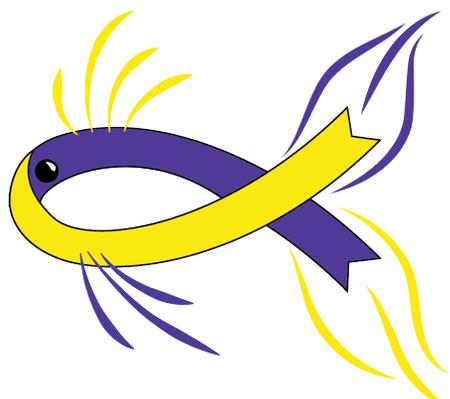
- To double patient survival within five years through education, outreach and advocacy efforts
- To leverage information gathering and technology
- Ensure long term viability of the organization through new initiatives

Task forces have been formed, and the major organizational goals along with the creative initiatives will be implemented in the coming year to support our three key areas: research, patient support and education, and advocacy.

Just a few of the many projects we will be looking to enhance in 2015 include:

- Virtual tumor board with the goal of providing greater access to treatment in the US and globally
- Developing a new Clinical Trials model
- Working towards the development of “GIST centers of excellence”
- Developing more opportunities for education through GDOLs, webcasts, etc.

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between rounds were great ways to spread the word on GIST. Future ideas are to create games that use in-app purchases that double as direct donations to the organization, which may help fund some of our goals.

Last, but certainly not least, is the need for funding. Research is minimal on SDH-deficient and wild type GIST, and lack of funding is part of the reason. In order to increase treatment options as well as awareness we will need funding. A page devoted to ideas on how to raise funds will be created to help guide GISTKids members. Every dollar donated will help make a difference.

As you can see, our youngest GIST members are big dreamers and these ambitious plans reflect only a portion of the ideas that came from our Life Fest 2014 meet up. I want to bring forth a branch of the Life Raft Group organization that represents the spirit of our young members, but I can't do it alone. If you, or anyone you know, want to volunteer and be part of this amazing adventure, please send an email to erin.macbean@gmail.com with the subject of GISTKids Volunteer. If, by chance, our work has inspired a donation, all donations can be made out to The Life Raft Group – earmarked GISTKids. Together we are not as rare as they make us to be, and together we will help make a difference for all. ■

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Clinical Cancer Research (SAKK) in St. Gallen, Switzerland.

In Dr. Duensing's study, her team performed a high-throughput drug screening to identify new treatment options for GIST patients.

The panel included 89 drugs that are already approved for cancer treatment by the FDA.

The experiments successfully identified two major drug classes as being very effective in destroying GIST cells – even those that are resistant to Gleevec. This was unexpected, because most of the drugs included in the collection were “classic” chemotherapeutic agents – drugs that are traditionally known as not being effective in GIST. However, the above notion comes from studies that had been conducted before a reliable diagnosis of GIST was possible (i.e., before 1999). Hence, a number of non-GIST malignancies may have inadvertently been included. Moreover, a systematic testing of chemotherapeutic agents in GIST has not been done, in part due to the rarity of the disease.

Drugs that the study identified as being able to effectively destroy GIST cells either belonged to the group of so-called transcriptional inhibitors or to inhibitors of a DNA repair enzyme called topoisomerase II. One drug of each class was chosen for further follow-up. The transcriptional inhibitor mithramycin A blocks the first step (“gene transcription”) in a cellular process that is needed to produce proteins – such as the mutant KIT molecules that are crucial for a GIST cell to survive. The team was able

to show that mithramycin A indeed kills GIST cells (at least in part) by depriving them of KIT. Inhibition of topoisomerase II by the drug mitoxantrone on the other hand leads to the introduction of DNA double-strand breaks, the most dangerous type of DNA damage for a cell. Accumulation of too many of such breaks inadvertently leads to cell death. The experiments confirmed that this is also the case in the GIST cell line models that were examined. Importantly, both drugs – mithramycin A and mitoxantrone – also showed significant anti-GIST efficacy in mouse models of GIST.

In summary, by applying the high-throughput screening study the researchers were able to successfully identify two classes of FDA-approved cancer drugs that are highly effective in GIST cell lines and GIST in vivo models. Clinical trials to test these drugs in GIST patients are currently being initiated.

This study was described at length in an article written by Dr. Duensing and Dr. Maria Debiec-Rychter of KU Leuven, Belgium, another member of the LRG Research Team in our October newsletter. ■

Help Us Further GIST Research.



If you would like to participate in the Life Raft Group's Tissue Bank, please contact Michelle Durborow, the Patient Registry Director, by phone 973-837-9092, Ext. 125 or email: mdurborow@liferaftgroup.org

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GIST. But in her native country of Chile, she has been a part of a grassroots effort that recently bore fruit.

Since 2013, she has been part of an advocacy movement to pass a new law in Chile to require the state to cover high cost treatments of rare and chronic diseases like GIST. The movement is called “Los enfermos tambien marchan,” (Sick People Also March). The movement was started by a very popular media personality named Ricarte Soto, who passed away last year. His widow, Cecilia Rovaretti, continued the battle in his honor. The law is called “Ley Ricarte Soto.”



Piga Fernandez global advocate for GIST patients.

The movement held several marches, but Piga became more involved in November of 2014, when she was invited to a meeting where she met the members of the Chilean congress who were trying to push forward the law to be discussed in congress. She fearlessly approached three senators and the head of the Superintendence of Health, giving them her card and outlining what she was doing for GIST patients.

Two days later, she was invited to the Health Commission meeting at Congress and had the opportunity to present to the congressmen and health authorities including Dr. Burrows, the Undersecretary

of Public Health, the needs of GIST patients regarding access.

The President of Chile, Michelle Bachelet, had promised that the new law would enter Congress before December 31, and when this did not happen, a protest campaign on social

media raised a lot of awareness.

Piga was then invited to speak with a group of leaders of organizations for diseases that would be affected by this

law to begin the process of working together to discuss how to push it forward.

In the meantime, the Health Minister resigned, and Dr. Burrows took her place until a new Health Minister could be elected.

On Monday, January 5, Piga was invited to the Ministry of Health together with four other leaders of patient organizations to meet with a senator, Carolina Goic, and Dr. Burrows, and to make the announcement that the law would be read to enter Congress before January 15, 2015. When the press interviewed her, she stated that it was a huge step that patient organizations' opinions were being considered, and that she was looking forward to being invited to discuss this law.

On Friday, January 9, Piga got to see all those efforts deliver tangible results. She was invited to La Moneda, the Chilean equivalent of our White House, to a ceremony where the President would sign the law. It will now go to the Congress for evaluation.

Advocacy is not always a quick process, but joining together for a common cause and channeling the power of social media can be effective tools for change. The battle is not over, but significant steps have been taken. Bravo, Piga. ■

Latest GIST Cancer Journal out!

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

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tunity to be a light despite my own battle with darkness. So I am a survivor, and so are you.”

An entrepreneur, best selling author, motivational speaker, widely published journalist and a Doctor of Dental Surgery, Monica has had a rich and successful life. When she ended up in the emergency room in 2012 with food poisoning, she had no idea she was about to receive a diagnosis that would be life altering.

Dr. mOe's GIST Journey

She had no symptoms, and had just had a physical in January of 2012, and now, one month later, in the middle of the night and alone, she was told they found a mass. This was the lowest point in her GIST journey. She felt as if the world stopped on its axis.

“I cried for days. I didn't know I could make so many tears.”

Another low point for her was a recurrence at the two-year mark, “I felt like I was doing everything the medical professionals told me. I followed the rules.” But in spite of following courses of Gleevec, Sutent, Tasigna and Stivarga, with side effects that were challenging, she had to undergo a difficult surgery back in December. All of this was in the middle of promoting her book, being a good mom and grandmother and mentoring

others. Balancing all her feelings at this time was challenging.

The high point of her GIST journey has been coming through two major surgeries, and meeting people, especially through the LRG. By talking



“Never close your heart unless it's temporarily under reconstruction.”

about GIST, not only is she raising awareness, but she is also empowering herself.

Advice for the Newly Diagnosed

What advice would she give to someone newly diagnosed with GIST? “Go outward, not inward. When I was first diagnosed, I thought it was the end of the world. You can get very depressed. Empower yourself by reaching out to family and friends. Empower yourself with information. Don't be afraid to ask questions of your healthcare team. Ask about different modalities of treatment. I wish I had spent more time educating myself. Also, make sure you have a GIST specialist as part of your treatment team, and don't be rushed in your decision-making.”

Dr. Anderson also advises, “Don't keep it to yourself.” She shares openly with family and friends and other GISTers. In fact, many of her friends send her research articles, and share recipes with her. Her mother, who is in her seventies, is one of her biggest

researchers, handwriting her notes, and faxing them to Monica. “Seeing her handwriting is as comforting as when she would comb my hair as a child.”

New Inspirations and Challenges

Her mentoring, counseling and coaching inspired Dr. Anderson's latest book.

In the first chapter, “Lesson One: Prescription for Happiness,” she outlines ten strategies. When asked which had been most influential in her GIST journey, she stated, “Number Ten: Never close your heart unless it's temporarily under reconstruction. Years ago, people wouldn't mention cancer, referring to it as ‘the big C.’ It is one of the most frightening diagnoses you can receive. I think when people have a loss, our reaction is to become bitter and angry, and we stop loving ourselves. We consider ourselves unworthy of self-love and forgiveness, and perceive ourselves as not being whole. When we have a setback, it is hard to practice these, as we tend to shut down. That is the time to rehabilitate and take a moment to nurture your spirit so that you can open your heart again.”

When asked what her next venture would be, she responded, “I am always looking for new adventures. Last year, even with all my GIST health challenges, I produced a short film and wrote a play. This year really opens up new possibilities, especially with the lessons GIST has taught me. There are so many opportunities out there, but as a ‘type A’ personality, I don't want to over commit. I want to honor my recovery. That will be something new for me.”

We can't wait to see what comes next. Dr. Anderson is truly an inspiration. She completed the interview by saying, “I believe I demonstrate that love and hope rather than the trials I am going through are what define me.” ■

**CALENDAR OF EVENTS****APRIL 14**

GIST Day of Learning Chicago

FEBRUARY 23-28RARE Disease Week
<http://rareadvocates.org/rdw/>

SDH from page 1

“epimutation” in the promoter area of the SDHC gene. “Epi-” means “above or over.” In this case the epimutation is in the methylation structure or packaging surrounding the actual gene molecule and not the gene itself, so there is no exon. Gene methylation is a natural condition which determines which genes are expressed. Hypermethylation indicates a gene that is over-methylated and is not able to be expressed normally. SDHC is part of the SDH complex which requires normal expression of all components in order for the complex to function. This means that the SDH complex was not able to function normally in these patients. A disrupted SDH complex leads to disrupted cell metabolism and to cell growth and blood vessel growth and has been identified as a cause of tumorigenesis in a number of cancers. This SDHC epimutation was the only defect that was found for these 16 patients. Additionally four patients who had SDHC gene mutations also had evidence of the SDHC epimutation. Interestingly, of the eight patients in the study with Carney’s Triad, six of them (75%)

had the epimutation.

These findings have a number of implications:

- “SDHC-epimutant GIST” is now

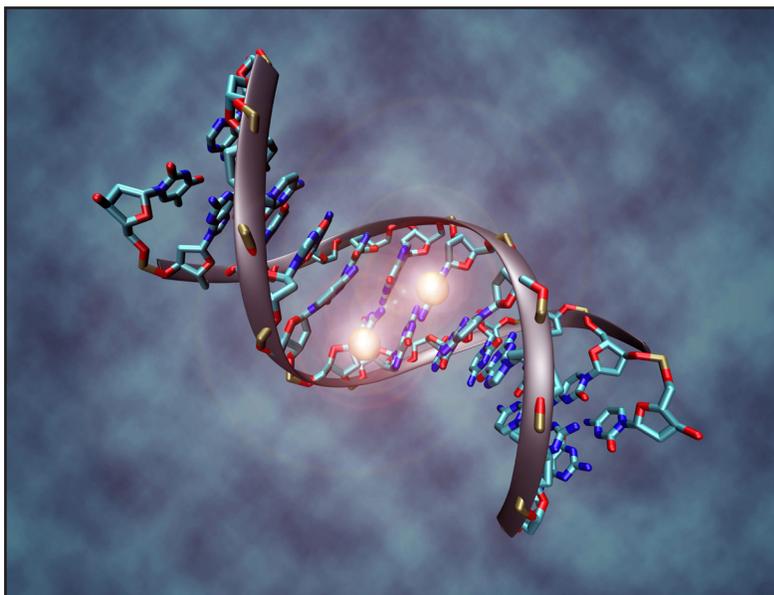


Illustration of a DNA molecule that is methylated at the two center cytosines.

Artwork by Christoph Bock (Max Planck Institute for Informatics) http://commons.wikimedia.org/wiki/File:DNA_methylation.jpg

identified as a specific subtype distinct from SDHX mutant GIST. The researchers also found hypermethylated SDHC promoters in blood and saliva taken from the 16 SDHC-epimutant patients and suggest these findings implicate a postzygotic (early embryo development) mechanism in the establishment and maintenance of SDHC epimutation.

In contrast genetic mutations in GIST (KIT, PDGFRA) have traditionally been identified as occurring either randomly in adults or as inherited. Work will be ongoing to further characterize the epimutation mechanism. The authors note that the high percentage of females with SDHC-epimutant GIST may implicate a role for sex chromosome or hormone biology.

- Knowing more about the molecular specifics of this subtype allows clinical researchers to get more precise definitions of risk for these patients and also begin clinical trials for patients with this specific subtype.
- This now unifying understanding of SDH deficient GIST can point to treatments targeted specifically at the epimutation. The authors raise the possibility that demethylating agents currently available, such as decitabine, could be used to do just that.

The LRG was proud to provide some of the funding for this study. The next step would be to begin clinical trials for treatments designed to counter the hypermethylation. When these trials have begun, we will be sure to keep you informed, and will also list any trials in the clinical trials database on the LRG website: liferaftgroup.org/gist-clinical-trials/. ■



NHS in the UK announced plans to halt funding through the Cancer Drug Fund for regorafenib (Stivarga), preventing access for GIST patients. Read full article at <http://bit.ly/1HkwbSN>

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differently to the fillers in the generic medication.

The generic version of your medication may also differ in size, shape, color, packaging.

Manufacturers of generics need to prove that their drug is bioequivalent to the brand name drug.

An example of bioequivalence would be the rate and extent of availability of the active ingredient after administration. Scientists perform tests to measure the differences between the way the brand and generic drugs are absorbed into the body. Bioequivalent value is within the 80-125 percent test reference ratio. The FDA has conducted studies that show that the average variation is 3.5 percent.³

The FDA reviews the bioequivalence. All generic drugs must also have their manufacturing process, packaging and testing sites held to the same quality standards as the brand name drugs.

Cost Factor

Most generic drugs carry a significantly lower price than the brand name equivalent. This does not necessarily mean lower quality, but the consumer should monitor information about the generic form of their medication, discussing it with their physician.

The high cost of medications often leads the consumer to seek alternative sources for obtaining the drugs at lower costs. Unfortunately, this can lead to unsafe purchasing practices, including seeking to purchase low-cost medication via the internet.

Counterfeit and substandard drugs

Fraudulent online pharmacies may attempt to sell illegal generic forms of medications.

Referred to as “counterfeit,” these medications are fake versions of brand

name medicine. They may contain the wrong active ingredient, or contain the right ingredient at an inaccurate dosage level.

As defined by the FDA, “Counterfeit drugs [are] those sold under a product name without proper authorization. Counterfeiting can apply to both brand name and generic products, where the identity of the source is mislabeled in a way that suggests that it is the authentic approved product. Counterfeit products may include products without the active ingredient, with an insufficient or excessive quantity of the active ingredient, with the wrong active ingredient, or with fake packaging.”⁴

The FDA estimates that counterfeit medications make up more than 10 percent of the global medicines market and are present in both industrialized and developing countries.

The World Health Organization defines a counterfeit drug in this way, “A counterfeit medicine is one which is deliberately and fraudulently mislabeled with respect to identity and/or source. Counterfeiting can apply to both branded and generic products and counterfeit products may include products with the correct ingredients or with the wrong ingredients, without active ingredients, with insufficient active ingredients or with fake packaging.”⁵

Taking these medications can be extremely harmful to your health.

As a consumer, it is important to know that the only way to ascertain if a drug is counterfeit is through laboratory analysis.

The Food and Drug Administration acts as a watchdog agency to assure that consumers are protected against counterfeit or unapproved medicines. They work closely with other agencies to provide alerts to the public when these medications are discovered.

The LRG is a member of The Partnership for Safe Medicines, which is

another source of valuable information on counterfeit drugs.

It is vital to obtain your medications through a reliable source such as licensed pharmacies.

The FDA provides a Consumer Safety Guide to buying medicine online on their website.

Substandard drugs are products generally produced by legitimate manufacturers whose composition and ingredients do not meet the correct scientific specifications resulting in inefficiency of therapeutic results, which may harm the patient. They fail to meet the regulatory authority’s specifications.

Unlike counterfeit medications, substandard drugs may occur due to human error, negligence, lack of resources to provide quality manufacturing processes, or inadequate quality control processes. There are different standards among regulatory authorities.

Although counterfeit drugs are also “substandard,” there is a more deliberate intention to deceive the consumer.

More attention is paid to counterfeit drugs, but negligent production can pose a significant risk to the health of the consumer. “Different amounts of active ingredients lead to different health outcomes, prices and potential remedies. With no correct active ingredients, falsified drugs constitute no treatment at all, and may even be directly harmful.”⁶

According to a study cited by the *British Journal of Clinical Pharmacology*, “Substandard drug manufacture also leads to morbidity and mortality. A formulation with insufficient API (active pharmaceutical ingredient) may lead to a lack of clinical response, and possibly death. Adverse events can also occur

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GENERIC from page 12

due to drug-drug interactions with contaminants, the presence of excess API, contamination with poisonous substances or allergic reactions to contaminants or substituted excipients.”⁷

Patient exposure to substandard drugs is more prevalent in developing countries. There is only an estimated less than one percent of substandard drugs identified in developed countries with strong regulatory agencies like the FDA.

For the patient who depends upon life-saving medications, it becomes imperative to be aware of potential

issues that arise when their medication becomes available in a generic form, and to arm themselves with the information and resources to make informed decisions.

In the next article in this series, strategies for navigating the change to generics and how to advocate for access to brand name medications will be discussed. ■

REFERENCES

1. FDA. Gov <http://www.fda.gov/Drugs/ResourcesForYou/Consumers/BuyingUsingMedicineSafely/UnderstandingGenericDrugs/ucm144456.htm>
2. FDA.gov, <http://www.fda.gov/Drugs/ResourcesForYou/Consumers/BuyingUsingMedicineSafely/UnderstandingGenericDrugs/ucm144456.htm>

3. Bernstein, Linda, Generic Drugs: Answers to Common Questions, Webmd.com, <http://www.webmd.com/healthy-aging/guide/generic-drugs-answers-to-common-questions?page=2>

4. FDA.gov <http://www.fda.gov/Drugs/DrugSafety/ucm169898.htm>

5. World Health Organization, www.who.int/en/

6. “What To Do About the Deadly Threat of Substandard Drugs,” Forbes.com, 06/03/2014)

7. (Johnston, Atholl & Hot, David w., British Journal of Clinical Pharmacology: Volume 78: Issue 2, November 29, 2013)

CANCERVERSARY



Monica F. Anderson, D.D.S.

“In the three years since I was diagnosed I have learned a lot about GIST and a lot about myself. In my new normal, I tire more easily and love more easily and forgive more easily and forget more easily. The list of pros continues to outmeasure the list of cons.”



Anita Getler

“I am so thrilled and truly blessed to be cancer-free for nine years as I celebrate life and love on a daily basis. To enjoy my family and friends in good health is truly a blessing!”



Clifford Kopp

“This year marks my 2nd cancerversary, and I have many mixed emotions to say the least. I now take a little extra time to appreciate things around me, I appreciate the present since we don’t know what the future will bring.

While cancer is something nobody wants, to me it was a blessing as I have met many wonderful people and made several new friends that I would never have met otherwise.”



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

DATING from page 4

us still have the ability to date without the other party having to jump the emotional and mental hurdle of a deformity,” states Jason DeLorenzo, Pediatric GIST survivor, “However, what will happen when this person knows that I face my death every day, and life with me will force you to face that reality yourself.”

The American Cancer Society cautions against keeping silent for long, “Sometimes you can ignore the cancer for a time. But when a relationship gets serious, silence is not the best plan. If you don’t talk about it, cancer can become a secret that will limit your closeness to your partner. A loving partner needs the chance to accept you as you are.”

You can avoid rejection by avoiding dating, but then you miss out on the chance to have a happy healthy relationship.

A few years ago Eric Tan, a young

GISTer in Singapore offered this insight, “Ask yourself this question, ‘Do I want to have a relationship or not?’ If you are unsure or feel negatively about it, then I suggest you find a lot of hobbies (that can last you until old age), pay more attention in building your friendships and be happy for as long as you are alive. However, if the answer is yes, then use GIST as your strength instead to pick up your lazy hand and dial that number and ask out someone for a date!”

“Dating with a GIST leads to two major difficulties,” says Estelle Lecointe, Pediatric GISTer and founder of Ensemble contre le GIST, The first one being to announce the disease, the second one to explain the induced collateral damages and personal sacrifices. It’s very difficult to find the right time to bring these topics in the discussion, as these aspects can be very scary for someone who’s never faced this kind of situation. If I say it at the very first date, I know by experience I might never see the man again

because human nature tends to prefer simplicity rather than what I have to propose.”

A big issue in dealing with GIST and dating seems to be timing. If not on the first date, then the second? Third? When is the right time to broach the subject?

Cancer.net feels that the talk should occur as your relationship starts to deepen. “The right time to talk to a partner about cancer differs for each person. However, it may help to wait until you and your new partner have developed a mutual level of trust and caring. It is also best to tell a new partner before a relationship becomes serious.”

Many GISTers have dated and have gone on to have long-term relationships, have married and started families. In part two of our series on relationships which will appear in our April newsletter, tips on approaching the subject, new ways to meet people, and a few GIST love stories will be shared. ■

GDOL from page 4

provides both education and support to the GIST community. Medical professionals who have specialty experience with GIST patients give presentations on issues relevant to their fields. GDOL’s 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.

Speakers for Saturday’s event included Malcolm Aste, Director of Development of Moores Cancer Center and Mildred Menos, Assistant Program Director at Life Raft Group, who provided an overview of their respective organizations’ missions and services. LRG state leader Dina

Wiley greeted current LRG members and invited new ones to join the educational and support group meetings she organizes around Southern California throughout the year. Expert medical presentations were provided by clinical oncologist Dr. Paul Fanta and surgeon Dr. Jason Sicklick. These doctors often work as a team to provide the best in personalized medical care. Both underscored the importance of mutational testing and incorporating mutational results into a treatment plan. Highlights included Dr. Sicklick’s video of an oral extraction of a GIST tumor via endoscopic surgical technique and the unique case study of a successful



Dr. Jason Sicklick presenting at the GDOL in San Diego.

treatment plan that Dr. Fanta recently published which featured a member of the day’s audience.

The next GDOL’s in our series will be taking place at Northwestern University in Chicago, on April 14 and in Miami on May 16. Please

keep tuned to the LRG website and our email communications for more information on these events and others.

Interested in having the LRG come to your city for our next GDOL? Email your ideas to Mildred Menos at mmenos@liferaftgroup.org. ■

Pat Lemeshka, loving wife mother and grandmother

Patricia "Pat" Lemeshka passed away on December 31, 2014.

Pat was born in Providence, Rhode Island, the daughter of the late Pat and Mike Murray. She was raised on Smith Hill and in Breakwater Village, Narragansett and attended St. Casimir's School and St. Patrick's High School. Pat graduated from Rhode Island College with her Bachelor's Degree in Elementary Education and earned her Master's Degree in Middle School Education from Brenau University. She won multiple Teacher of the Year awards, was named a Presidential Award Winning Science Teacher, was a highly regarded mentor to new teachers, and a graduate of NASA's Teacher in Space Program. Pat spent



many years teaching Science to gifted youth. She retired from teaching in 2001, after many years of teaching.

Pat loved summers at the beach and any time of year playing the slot machines. She enjoyed traveling with her family and friends and welcomed any opportunity to host a tea party at her home in Acworth, Georgia.

After being diagnosed with cancer in 1990, Pat became an active advocate for cancer patients all over the country. She was a volunteer of the Winship Cancer Center of Emory University and an Ambassador for the LiveStrong Foundation. Pat provided inspiration to countless others diagnosed with cancer, by demonstrating that it was possible to LIVE an active and positive life, in spite of cancer. She often made calls

and had meetings with newly diagnosed cancer patients and reminded them that they could fight the disease successfully. She would often recall that she had been told over twenty years ago that she had six months to live. Her courageous battle of nearly 25 years ended with dignity on December 31st at the age of 64.

Pat is survived by her loving husband of 39 years, Bob Lemeshka (Acworth, GA), daughter Niki Lemeshka (Acworth, GA), son Brian Lemeshka and his wife Toni (Canton, GA), beloved grandchildren Andi and Brooks, brother Jack Murray and his wife Patti (Scituate, RI), nephews Mark, James and Jay and his wife Devin, brother-in-law Jon Lemeshka (Marietta, GA), her large extended family of Murrays, Friels, and Clarkins, and BOFs (Best of Friends) Peggy Mills (Woodstock, GA), Denise Dixon (Acworth, GA), and Kathy Woods (Acworth, GA). ■

In loving memory of Mark Stanke, LRG member

Mark Alan Stanke, 52, of Lee's Summit, Mo., left this world on Friday, December 19, 2014 after a courageous battle with cancer surrounded by the family and friends he loved. Husband of Elizabeth, father of Brooke and Alec, Mark will be greatly missed by them and by his extended family.



Mark was born on March 2, 1962, in Oakland, California, the son of Robert Stanke and Portia Wassman Stanke, who moved their family to Independence, Missouri in 1969. Mark was an awarded athlete in high school and college. While playing football for Truman High School, he

was an All Area and All Conference 1st Team Offense and Missouri High School All Star Team. Mark was also an All American Junior Olympic volleyball player, and played on the national tournament championship team in 1980. At Graceland University, he played both football and volleyball and was Heart of America All-Conference his junior and senior years. Mark worked at Chrysler Corporation for 15 years before becoming a partner at ProCorp Images and Team Heads.

Mark loved watching his son play football at Washington University in St. Louis and was very proud of his daughter's accomplishments as an artist. He was also a passionate supporter of his twelve nieces and nephews, attending many of their

sporting events.

He was an avid hunter and fisherman, spending summers at their camp on Bog Lake in Northfield, Maine, and many hunting seasons at the family farm in northern Missouri. Additionally, he loved his Hawaiian heritage and visiting his Kon family in the islands.

Mark leaves behind a legacy of love, honor, hard work, intelligence, humor, friendship, strength, insight and a deep and warm quality of caring for others. He was well regarded by many as a kind friend who went out of his way to make others feel cared for. Most important to him was his family-his selfless commitment to his wife, children and extended family will live on through them. ■

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