

Ensuring no one has to face GIST alone



In Loving Memory: Alma Klindera, Gwendolyn Mae Perrewew, David E. Jordan

Life Fest 2014: A celebration of the LRG community

By **Diana Nieves**, Director of Operations

Our biennial Life Fest convention was held November 7th – 9th at the Teaneck Marriott at Glenpointe in New Jersey. It was a spectacular event filled with stories, laughter and tears shared by GISTERS, caregivers, medical professionals, pharmaceutical representatives, staff, board members, and many friends. There were over 190 people who participated throughout the weekend.

Throughout the weekend participants had an opportunity to be photographed next to an amazing display of over 130,000

origami boats that were made by the GIST community and their supporters from around the world based on a global effort to come together for a common goal and raise awareness about this disease. Thank you to our volunteer photographers Kim Tallau, Steve Tallau, and Michele Mattioli who not only took fabulous pictures of people by the display but also during the gala, general sessions, workshops, etc.

Our weekend was filled with general



LRG Members gathering around the Life Fest 2014 origami display

[See Celebration on page 5](#)

Epidemiology of GIST: Interview with Dr. Jason Sicklick

By **Mary Garland**, Marketing & Communications Associate and **Pete Knox** Director of Strategic Planning

In a recently published study, Jason Sicklick, MD, surgical oncologist at the University of California, San Diego Health System, and his team of researchers published their findings on the epidemiology of GIST.



SICKLICK

His findings, which have been somewhat controversial, indicated

that certain populations have a higher incidence of being at risk for GIST, including patients of Asian/Pacific Islander and African American descent.

Dr. Sicklick spoke recently with the Life Raft Group about the study, which will appear in greater detail in the December issue of the LRG GIST Cancer Journal.

Questions have been raised about the

integrity of the data from the SEER database, which Dr. Sicklick and his researchers used for analysis. He explained that the database represents 28 percent of the United States population, and reflects those patients whose data has been reported by registrars in the medical institutions where they were treated.

Dr. Sicklick admitted that the database has its limitations. For example,

[See Epidemiology on page 10](#)

LRG-NIH Virtual GIST Tumor Board goes global

By Sara Rothschild, LRG Program Director

The Life Raft Group, in partnership with the National Institutes of Health, is pleased to announce that the second meeting of the NIH-LRG Virtual GIST Tumor Board was held on October 3, 2014.

The purpose of the Virtual GIST Tumor Board is to bring together leading experts to discuss pediatric/wild-type GIST cases, while serving as an educational resource for local physicians.

In 2008, the National Institutes of Health (NIH) launched an in-person clinic for the Pediatric GIST and Wildtype* GIST community which brought together clinicians and scientific researchers from across the world to collaborate and learn more about this rare disease as well as to meet patients and their families first-hand. However, despite the surge of knowledge researchers have gained from this clinic, decreases in government funding have now reduced the number of in-person meetings held to once per year, with much needed additional staffing and resources becoming difficult to obtain.

The NIH-LRG Virtual GIST Tumor Board provides valuable access for patients and doctors who would ordinarily not be able to attend an in-person clinic due to resources or distance. The Virtual GIST Tumor Board not only provides local doctors with the most up-to-date treatment options, trials, and studies, it also encourages collaboration between GIST experts, ensuring the best care is offered to patients.

The process is an augmentation of how virtual tumor review boards work. If selected, doctors of GIST patients are invited to log on and present their de-identified patient case to a panel of experts by using the internet, secure servers, and video conferencing software. The LRG uses cutting-edge technology to connect local treating physicians and their team



Life Raft Group members participating in the second Virtual GIST Tumor Board held in October this year.

with key GIST opinion leaders. Panelists have real-time shared view access to radiology films and other necessary medical reports in order to review the case and provide advice.

For the second Virtual GIST Tumor Board, Wildtype* cases were reviewed from the United States, Latin America and Eastern Europe. Local treating physicians were accompanied by

See VTB on page 9

10 ways to combat the flu

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

Flu Season is upon us. Before you know it, the temperature will plummet, and the season when flu flourishes will be here.

Being exposed to others who have colds or the flu is tough to avoid, however. There are several proactive measures you can take, to reduce your chances of becoming sick with the flu this year.

See Flu on page 11

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.

Tips for relieving your holiday stress

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

Christmas carols playing in the background everywhere you go, menorahs lit in the windows, Kwanzaa displays in storefronts, incessant toy commercials – it's the holiday season.

Whether or not you celebrate a holiday this time of year, it is hard not to get caught up in the pressures that the holidays bring- shopping, cooking, decorating, being cheerful.

That is true for everyone, but it is especially true for cancer patients and their caregivers. You may be dealing with physical aches and pains,

side-effects of your medication and treatments as well as with feelings of depression.

It is vital that you protect yourself from these stressors, as elevated stress can negatively affect the healing process, even suppressing the immune system.

According to the National Institute of Mental Health, "With chronic stress... your immunity is lowered and your digestive, excretory and reproductive systems stop working normally. Once the threat has passed, other body systems act to restore normal



functioning. People under chronic stress are prone to more frequent and severe viral infections, such as the flu or common cold, and vaccines, such as the flu shot are less effective for them." This time of year, it is vital to protect yourself from stress as much as possible to assure that you don't become sick.

Here are 10 tips for relieving stress in this busy season:

- 1. Make a list of the things that you know cause you stress** during this time of year. Either eliminate those tasks, ask others to help with them, or simplify them.

- 2. Keep your planning simple.** Sit down with your loved ones and find a way to simplify your rituals. Prioritize your rituals, and divide the labor.

- 3. Make yourself the number one priority on the list.** It is vital that you keep up with all your treatment protocols, and that you are focused on your recovery.

- 4. Be aware of your stress levels and physical limitations.** Try to limit your tasks to ones you truly enjoy, and that won't push you too far.

- 5. Don't forget your healthy living routine.** Plenty of rest, eating healthy foods and exercising will help you to have more energy to spend with family and friends.

- 6. Don't ignore feelings of sadness.** The holidays can be difficult, as you deal with not only the limitations your illness places upon you, but also the financial strain a serious illness brings. These feelings are normal. Seek support of loved ones, a support group or a professional if these feelings become debilitating.

- 7. Find moments of comfort for yourself.** Take a bubble bath, listen to your favorite music, cuddle up with a cup of tea and a good book or your favorite pet, watch your favorite holiday movie, or plan to have lunch with a friend.

- 8. Try one of the holistic healing activities** that other cancer survivors have found helpful in relieving stress: Meditation, yoga, reiki, art and music therapy are all excellent tools.

- 9. Remember to have fun.** If you could do just one thing during the holidays to have fun, what would it be?

- 10. Find the true meaning in the holidays for yourself.** Concentrate on that, whether it be spiritual meaning, time with family and friends or remembering holidays past, it is not the hectic pace and unrealistic expectations that truly make a holiday special.

Remember that you are not alone. The Life Raft Group community is here for you, during the holiday season, and all year long. ■

One Hundred and Thirty Thousand Wishes: Life Fest 2014

By **Erin MacBean**, LRG Member

One hundred and thirty thousand wishes, tributes, memories, goals, and dreams greeted me on arrival to the Life Raft Group’s Life Fest 2014. They were in the shape of origami boats. From a distance, the boats formed a colorful display of water, two life rafts, and a lighthouse backdrop to guide the way. Yet up close, each boat had a name, a message, and personality. In that moment I realized it is in our nature to group things together to see a number – a statistic, but the display gently reminded me that it only takes a moment to look close and see the individuality in a gathered mass. From that point on – as many patients, caregivers, researchers, and supporters filed in – I didn’t see the number of a gathered mass, I saw individuals.

My sight wasn’t the only thing that changed during my stay. After a few

years of patient advocacy, my motivation tanks were near empty. As health-issues on top of life-issues weighed on me, I waived in my goal to do as much as I could while I could, but the Life Fest was exactly what I needed to refuel. I got the absolute pleasure to pull the pediatric patients, siblings, and young family members out of the adult GIST research meetings and hold our very own brainstorming session. I couldn’t write fast enough after first idea landed on the table, and I was inspired by this new generation of cancer fighters. We had so much to offer that we decided one morning session wasn’t enough. We joined again the next day and continued our



Over 130,000 Origami boats displayed at the Teaneck Marriott at Glenpointe in New Jersey for Life Fest 2014.

quest to represent our type of GIST better. If we can accomplish even half of the things on my list, I just know

[See Life Fest on page 8](#)

Life Fest 2014: What’s new in the science of GIST?

By **Pete Knox**, LRG Director of Strategic Planning

In addition to spending time catching up with fellow patients and caregivers and attending the myriad of useful workshops featured at Life Fest 2014, participants were treated to an update of what is new in the science of GIST. Drs. Anette Duensing and Brian Rubin, both from the LRG Research Team, gave the audience a comprehensive presentation that went into great detail about what the LRG’s Research Team has recently accomplished and



Drs. Anette Duensing and Brian Rubin from the LRG Research Team

also a bit of what we might expect in the future. Dr. Ramesh Bulusu, of Cambridge University Hospital and PAWS-GIST, both in the United Kingdom, also gave a presentation on the Management of GIST. These presentations were captured on video and will eventually be shared with the entire GIST community, but I will attempt to summarize them here.

Dr. Rubin set the stage by talking about his memories of the origins of

the LRG Research Team – his being approached by Norman Scherzer, LRG’s Executive Director, and Jerry Call, LRG’s Science Director – and also mentioned how thankful he was that in addition to funding from the pharmaceutical industry, a great deal of support had been provided through donations from LRG members. After showing a video that depicted GIST cells dying, he reiterated what the LRG Research Team was looking to accomplish: “Our goal is to kill GIST cells, because that would essentially represent a cure for GIST patients.”

After Dr. Rubin’s remarks, Dr. Duensing took the stage to discuss some of the team’s recent findings. Key among these was the finding that

[See Science on page 9](#)

Pictures and Reactions to Life Fest



Celebration from page 1

sessions and breakout workshops designed to inform, educate and provide tools for patients and caregivers alike. We are so grateful for our expert speakers and presenters who shared with us not only their knowledge but also their dedication and passion for the GIST community. Virtually all of the participants agreed that they would participate in many of our sessions and workshops again.

The New Horizons GIST conference was also held during the weekend, with six steering committee members

meeting in person and via Skype to discuss critical information about GIST that impacts the global GIST patient and medical communities. The current focus is to expand its outreach through technology.

A grand thank you goes to our corporate sponsors Novartis, Bayer, Pfizer, and Genentech. Without their sponsorship this weekend would not have been possible. We also would like to thank our generous Board of Directors who made it possible for 43 patients and caregivers to participate in the

event through their scholarship fund. And many, many thanks go to several volunteers* and staff who gave so much of their time, energy and talent to making this a fantastic weekend for all. ■

*Life Fest 2014 Volunteers:

- | | |
|-------------------|------------------|
| Rosalia Barberi | Erin MacBean |
| Michael DeStefano | Michele Mattioli |
| Garnett Draper | Cora Ramadan |
| Margi Hughes | Bella Rocco |
| Ken Kerian | Kim Tallau |
| Lindsey Kristoff | Phil Viega |
| Kate Krug | Dina Wiley |

Our 2014 Annual Report

This was a year of challenges and triumphs for the Life Raft Group as we continued our mission to find a cure for GIST, and to provide research, education, support and advocacy to help our members survive until we do. On a more personal note it was another year that our community of heroes and heroines faced death with the quiet courage and grace that defy description. Like the mom who managed to replace the absolute terror on her face with a smile to reassure her young daughter being moved into a CT Scan machine that everything would be alright. Or the wife hiding her pain as she got out of bed to go to the bathroom and the husband who pretended not to be awake and notice.

Research

This year we managed to commit new funding for our world class research team just in time to enable them to continue their search for a cure. This is particularly noteworthy given the decreases in funding that have left many researchers in dire straits.

Our Patient Registry was converted to a SQL-based platform to provide a foundation for web-based access to patients and researchers in the near future. Backed by our tissue bank housed at Stanford University, our Registry continued to serve as a vital source of research information and to provide empirical information helping guide patients and their physicians through survival decision-making in the absence of more formal clinical trial data.

We continued our support of the NIH in-person clinic for patients with Pediatric and Wildtype GIST. Due to a reduction in federal funding, the NIH had to cut the number of in-person clinics held per year. In response, we collaboratively launched our first Virtual GIST Tumor Boards, allowing

medical professionals to present cases to GIST experts remotely using cutting edge technology. Our second Virtual Tumor Board had global reach, with patients from the United States, Latin America and Eastern Europe. In 2015, we will be expanding to adult GIST cases.

The GIST scientific community was enriched by the launch of The GIST Cancer Journal, the official journal of the Life Raft Group, and the first academic journal devoted solely to GIST. Dr. Jonathan Trent was named Editor-in-Chief. This will not only facilitate the sharing of GIST research, but will bring about more knowledge and awareness to those on the front lines such as oncologists, gastroenterologists, radiologists, nurses and surgeons.



The LRG's GIST Cancer Journal launched this year.

Education and Support

Our patient education reach continued to grow in 2014, with GIST Days of Learning (GDOLs) held around the U.S. We continued to provide education through our webcasts, including the popular GIST 101 held by Dr. David Josephy, as well as our Virtual Roundtable series hosted by Science Director, Jerry Call.

Meetings around the world were hosted and attended by the LRG staff and members, including New Horizons in Switzerland, CTOS in Berlin, and the ICCC in Peru. New Horizons brought together 44 GIST patient representatives from 28 countries



GIST Days of Learning (GDOLs) provide education and support held around the U.S.

and 32 patient organizations. Alianza GIST members from throughout Latin America also joined the Life Raft Group in Switzerland.

Our members and their supporters are the heart of the LRG. We held our first Appreciation Dinner, inviting the local GIST community to join us just to say "Thanks" to all those who in big and small ways make someone else's life a little easier or happier.

Poker played a big hand in our fundraising efforts this year, with the Poker for Hope event in Caesar's Palace, Las Vegas and the Night to Fight Cancer tournament in New York. Both were events that brought together the community for elegant evenings of fun that raised over \$100,000 for our life-saving efforts.



The Night to Fight Cancer Poker tournament in NY contributed to LRG's fundraising efforts.

Support for our community both locally and worldwide was enhanced by our first GIST Awareness Day (GAD). As an offshoot of our

successful Rare13 campaign, the goal was to raise awareness about GIST, bringing together people in a collaborative effort to educate and inform the public. As a symbol of GAD and of hope, we raised the challenge of folding 20,000 origami paper boats. Little did we know that this would become a worldwide effort, with over 130,000 boats from as far away as Mumbai folded and delivered to the LRG in time to be displayed in a photo booth at Life Fest 2014.

The year culminated in our biennial Life Fest celebration, held in November in Teaneck, New Jersey. Countless dedicated hours were spent preparing for this successful event that brought together researchers, members, caregivers, holistic practitioners, pharmaceutical representatives, staff and honored guests. We came together once again to support and learn from one another, to cele-



First Appreciation Dinner held for LRG's members and their supporters

brate the lives of those whom we have lost and to increase the critical knowledge of those struggling to survive.

Science Director Jerry Call and Executive Director Norman Scherzer ended the weekend by introducing the Survival Plan, an ongoing series to be continued in 2015 that will outline strategies to double survival for those diagnosed with GIST.

Advocacy

LRG staff members joined together with One Voice Against Cancer in Washington, DC in July to lobby for a \$5.2 billion cancer research funding package to benefit some of the top GIST research facilities in the world, including the NIH and NCI.

We also held an informative webcast on "Affecting Change from the Top" that provided members with a format for advocating for change.

Our members are our most fervent advocates, with GIST Awareness Day

reaching hundreds of people through three main events in LA, Miami and Chicago, and also through booths at state fairs, book signings, local GDOLs and by placing articles in local newspapers.

On the wings of heroes

As the year drew to a close, we experienced some heavy losses. Board member Dave Safford lost his courageous battle with GIST but showed us all what true heart looked like.

Shortly after, Michael Byrne, spouse of Board Member Mia Byrne, passed away having fought GIST for over a decade. He had planned to run the Chicago Marathon with a family friend Jennifer Hartzler. With no time at all to prepare, Mia decided to run two miles as a token gesture to honor Michael's memory. With strength that nobody could understand, that defied all logic, Mia kept on running and somehow managed to finish the 26.2 mile course. We choose to believe that she ran on the wings of Michael, her hero.

We will continue to "run the good race" in their honor in 2015, and going forward, their light will continue to shine in our hearts. ■

Hope for the future

A few days ago a young GIST patient posted to Facebook asking information about how to buy a cello. The mother of a young child with challenging funds, she noted in passing that she no longer had the breath to play the flute because of a tumor in her lung, but she wanted to continue to play music. However, the hundreds of dollars that a cello cost seemed quite out of reach.

As we go to press, we are happy to note that a giant-sized package just arrived at her door. Sometimes even small victories are so sweet.

And speaking of small victories, our own Sara Rothschild was blessed with the birth of Tehila Malka, her daughter who was born a few weeks before our Life Fest gathering. Seeing Tehila at Life Fest with her brought us all hope for the future.



Sara Rothschild with her daughter Tehila Malka

2014 BY THE NUMBERS

over **2000** participated
GIST Awareness Day

265 tweets, reaching
2,445,558 followers

13 radio airings
11,660,607 listeners

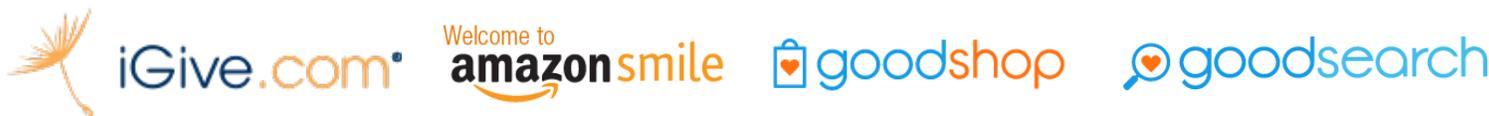
55 Facebook posts

4 New groups
established in 2014

Newspaper coverage
over **150,000** reached

Spread cheer with charitable giving through online shopping

By **Tom Cordasco**, Marketing & Communications Associate



Once again, it's the time of year to spread some cheer to our family, friends, and co-workers by purchasing holiday gifts online. Charitable giving by online shopping through iGive.com, Goodshop.com, and AmazonSmile allows you to make purchases while combining the act of donating to your favorite cause. Each service donates a percentage of your online purchases to the charita-

“Charitable giving allows you to make purchases while combining the act of donating to your favorite cause.”

ble organization of your choice. With partnerships from over 1,500 popular stores on all three networks, funds from iGive, Goodshop, and AmazonSmile, these donations help The Life Raft Group to continue to search for a cure for GIST.

All purchases trigger a donation towards non-profit organizations like the Life Raft Group. Remember to take note of each site's unique features such as registra-

tion. On iGive, you must register with a username whereas on Goodshop, no personal information is needed – just enter the cause you would like to support. AmazonSmile allows you to use your existing Amazon.com account if you have one, or create a new account on smile.amazon.com and search through tens of millions of products eligible for donation.

If online shopping isn't your thing, searching the web through goodsearch.com and isearch.igive.com, both powered by Yahoo, raises money for the Life Raft Group. So spread a little extra cheer this year and enjoy the gift of charitable giving. ■

Life Fest from page 4

pediatric and wildtype GISTers won't have to ask "what about us?" ever again.

It would take pages to write about all the wonderful and touching moments that happened during the three-day gathering. We laughed a lot, cried some, learned much, and bonded in ways most strangers never would be able to do. It wouldn't have been possible without a number of sponsors and generous donations. Nor would it have been possible without the countless hours the Life Raft Group staff and volunteers gave of themselves. I attended Life Fest by myself, but left an international family wishing me all the best. That in itself is priceless, yet the hope given to us all is the treasure we will cherish forever.

Thank you, LRG, for making this possible, for leading the way in patient advocacy, but mostly for being the family that I am humbly honored to be part of. ■



Image courtesy of SARC

CTOS Highlights

By **Erin Kristoff**, Marketing & Communications Director

In October, LRG Marketing & Communications Director, Erin Kristoff headed to Berlin for the annual Connective Tissue Oncology Society meeting (CTOS).

CTOS is an international group comprised of physicians and scientists with a primary interest in the tumors of connective tissues. The goal of the society is to advance the care of patients with connective tissue tumors and to increase knowledge of all aspects of the biology of these tumors, including basic and clinical research.

“There is no substitute for getting all of these great minds in one room together. I learned so much about sarcoma research this year and made great connections, both with medical professionals and patient advocates. I look forward to collaborating and supporting each other throughout the coming year,” said Kristoff.

Epidemiology from page 1

the database doesn't have the granularity in the data that would reflect things such as socioeconomic factors.

The value of using this database is that it provided access to a population of over 6,000 patients. With a rare disease like GIST, this is a significant population sample.

Sicklick pointed out that this is the first study using GIST-specific histology codes, and thus the first not to factor in other diagnoses.

The study found that the overall incidence rate during the study period (2001-2011) was 6.8 cases per million, and that the rate has increased over time, from 5.5 cases per million in 2001 to 7.8 in 2011.

When asked why he thought there was such a change in the numbers, Sicklick stated that "Much of it is due to coding issues. Early on, coders had to figure out how to code GIST, and some of it was figured out on the fly. Now the codes are clearer."

Age is also an important factor to consider when looking at the numbers of patients with GIST. For example, the incidence rate for those diagnosed in the 70-79 years of age group was much higher, at 30.6 cases per million. "This is four and a half times that of the overall population in the study," Sicklick said.

The implications are that the disease often takes a long time to occur. "It can have a latency of many years before becoming symptomatic. As the population ages, the incidence will increase," he added.

Sicklick was asked to comment on the fact that African Americans are 2.1 times more likely to be at risk for

GIST, and what role access to care might play. He indicated that this would warrant further study, but that this particular finding was not new. Tran, Davila and El-Serag's 2004 study indicated that GIST was more common in the older population, men and blacks. In that study, risk factors for mortality included older age, black race, advanced stage and no surgical intervention.

When looking at incidence and risk factor, African Americans have both a higher incidence and a higher risk factor for overall survival. This contradicts previous studies (Cheung, Zhuge, Yang and Koniaris, 2009), which showed the disappearance of racial disparities in GIST.

What was discovered about the Asian/Pacific Islander population is new. The study indicates that they are 1.5 times more likely than other patient groups to be diagnosed with this type of tumor. Although identifying this population as at-risk has not been found before, the survival rate for this group is higher. At this point, the data does not differentiate between subsets of Asian groups.

The idea for the study came about from over two years of Dr. Sicklick seeing a higher number of patients in the target groups in his clinic.

What might be a risk factor specific to these target groups? Currently, he has not been able to identify one. This warrants further study.

In terms of further research, Dr. Sicklick is already working on outlining a few pilots. He would like to explore the Asian link further, collaborating with researchers on an international level. He cited some research he has been exploring,

and mentioned some of the exciting work Dr. Ron De Matteo of Memorial Sloan Kettering has done in genomic sequencing.

Dr. Sicklick is also working on studying the relationship of GIST to other cancers. Some of the work he has done in this area was recently presented at CTOS. For example, can we identify that GIST patients have a higher incidence for colon cancer? If so, would this then mean that GIST patients should be screened for colon cancer more frequently than the general population?

One thing that the LRG and Dr. Sicklick strongly agree upon is his statement, "People should be seen where people see a lot of it." This supports the LRG's Survival Guide premise of seeing a GIST specialist and being treated at a GIST center of excellence.

It will be exciting to see what this dynamic researcher does next. We hope that the LRG can aid him in the task of identifying risk factors for GIST, and even in finding ways to reduce the risks that are within our control. ■



CALENDAR OF EVENTS

January 24, 2015

GIST Day of Learning San Diego
*UC San Diego Moores
Cancer Center*

June 10, 2015 - June 12, 2015

All Day NIH Wild Type GIST
Clinic National Institutes of
Health (NIH),

Flu from page 2

10 ways to combat the flu

1. Get a Flu Vaccine - Many local pharmacies offer flu shots, making it more accessible. Most insurance plans will cover the cost.
2. Wash your hands regularly with soap and water. Use hand sanitizer if soap is not available.
3. Use a tissue to cover your mouth when coughing or sneezing, and be sure to throw the tissue away after you use it.
4. Keep your hands away from your eyes, nose or mouth so germs don't spread.
5. Make sure you maintain your healthy lifestyle: healthy diet, exercise and plenty of rest.
6. Avoid crowds if you can, and stand far away from anyone displaying symptoms of illness.
7. If you become ill, stay at home until 24 hours after your fever is gone except to get medical care or for other necessities.
8. Keep a "flu survival kit" on hand: over-the-counter medications as approved by your doctor, tissues, and alcohol-based hand sanitizer
9. Maintain your medication schedule unless otherwise advised by your doctor.
10. Keep a written record of the type of cancer you have, treatment you have received and when you received it, the name and contact information for your doctor and a list of medicines you are taking.

If you have the following symptoms, notify your doctor:

- Earache or drainage from your ear
- Pain in your face or forehead along with thick yellow or green mucus for more than a week
- Any temperature 100.4 degrees Fahrenheit or higher in an infant less than 3 months of age
- Temperature higher than 102 degrees Fahrenheit in older children or adults
- Hoarseness, sore throat, or a cough that will not go away
- Wheezing
- Vomiting
- Persistent or worsening symptoms



Go to the doctor immediately if you have trouble breathing, chest pain, confusion, seizure, fainting, or difficulty staying awake.

For further information on receiving a flu shot, contact your doctor or go to the American Cancer Society's website.

<http://bit.ly/15P7ixY> ■

CANCERVERSARY



Piga Fernandez

What does Celebrating Christmas means to me?

Life, hope, gratitude, a GIFT!!!

After seven hard years living with a wrong diagnosis, in 2002 we found out that what I really had was a GIST – a rare cancer for which there was a new drug that might work. "The magic bullet," it was called.

Twelve years ago, I was able to start my treatment with Gleevec. This meant for me 12 years of life:

12 years during which I have been able to see my sons and daughters grow, develop professionally, get married and give me 7 marvelous grandchildren. 12 years that I have been able to work in order to help GIST patients; 12 years in which, as one of my sons said, "We have been able to look towards the future with different eyes, eyes of hope." It has been 12 years celebrating Christmas and thanking God for the gift of life!

If you have a Cancerversary please contact info@liferaftgroup.org



THE LIFE RAFT GROUP

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Strategic Planning Director	Pete Knox
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Latin America Liason	Vicky Ossio
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 Roberto Pazmino, Janeen Ryan

Life Raft regional chapters: Find your reps info at liferaftgroup.org/find-a-support-group/

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Delaware	Cindy Bones	Missouri	Katie Bloss	Utah	Mike Ginsberg
Florida	Anny Riley	Montana	Dirk Niebaum	Virginia	Sally Jackson
Idaho	Janet Conley	Nevada	Joan Smith	Wisconsin	Rick Ware
Illinois	Jim Hughes	New Hampshire	Julie Thorne		
	Marlene Nei	New Jersey	Anita Getler		
		New York	Pat Bonda Swenson		
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Canada	David Josephy	Japan	Sumito Nishidate	Saudi Arabia	Mohamed-Elbagir Ahmed
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China	ZeeZee Zhenxi Zhong	Kenya	Godsent Odero	Singapore	Kie Go
Colombia	Maria Helena Matamala	Korea	HyunJung Yang	South Africa	Annette Mentasti
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