

Ensuring no one has to face GIST alone



In Loving Memory: Joyce Fredericks, Patricia Zeme, Pearl Payne, Marion Toby Koch, Richard Winstead, Alan Kahuhu, Stephen Wells, Anita Scherzer, Deborah A. Falck

Improving quality of life with SideEQ

By **Erin Kristoff**, Director of Marketing

Until cures are found, drug therapies are a lifeline to someone with cancer. Yet, the Life Raft Group's GIST Patient Registry has recorded over 800 reports of patients interrupting their drug therapy usage because side effects became too burdensome.

Months between clinician visits and a hesitancy to speak openly to doctors about side effects contribute to difficulty addressing these problems, which affect a patient's quality

of life and ability to maintain their drug regimen.

SideEQ allows patients to gain valuable insights into symptoms and side effects management which they can in turn share with their physicians and other patients. By finding ways to mitigate the negative side effects intrinsic to many medications, patients can optimize their overall health while improving treatment outcomes.

[See SideEQ on page 6](#)

LRG member La Verne Cook: Tackling side effects

By **La Verne Cook**, LRG Member

Side Effects can impact quality of life. Members sharing their stories and their strategies for coping with side effects can help others. In this article, LRG member La Verne Cook shares insights into one particular side effect.



COOK

Diagnosed in 2004, I was NED (No evidence of disease) until a recurrence in 2009, when I started Gleevec. Currently, I am on my 3rd drug line therapy. My side effects run the gambit: cracked corners of my mouth, appetite/taste, nine-pound weight loss, foot and leg cramps, thinning hair, dehydration at night, diarrhea, sore mouth, fatigue

[See MEMBER on page 4](#)

Using data to improve health in Latin America

By **Sara Rothschild**, Senior Director, Programs



As many of you know, The Life Raft Group has developed a sophisticated database to track GIST patients around the world and we have learned many lessons along the way. We have observed first-hand the gap in information as well as access to therapies among patients worldwide. Paired with these issues, there is a lack of disease-specific information that exists among the global medical community, where rare cancers like GIST are infrequently seen. Many physicians assume they know how to treat GIST as a one-size-fits-all approach with a simple prescription of an oral pill. However, as patient advocates, we know that, in order to monitor and treat a rare cancer like GIST, there is much more information necessary to optimize care. In addition to the clinical aspect, the

[See DATA on page 5](#)

Time for Medicare comparisons is here

By **Melissa Simpson**, Senior Program Manager, Center for Benefits Access, National Council on Aging



Generally, we like choices. But, when it comes to Medicare Advantage and Part D drug plans, the many choices and details can become overwhelming. Don't let the annual Medicare Open Enrollment period, Oct. 15- Dec. 7, pass by without looking at all your choices!



SIMPSON

steps detailed below to review your choices.

The first step is to compare your current plan in 2016 with its coverage in 2017. Find the thick packet your plan mails in late September called the Annual Notice of Change and Evidence of Coverage (ANOC/EOC) and open it up. With your ANOC/EOC in-hand, or online, answer these questions:

Not sure you want to spend the time comparing when you're happy with your current plan and can afford the increases? Remember, plans can change their costs, coverage, and networks annually and there might be a better deal out there. Or there might not be a better deal, but how will you know if you don't look? So, take the

1. Are my drugs are still on the drug list (also known as a formulary)?
2. Are my drugs on a different tier with different cost-sharing?
3. Do any of my drugs have new restrictions, like approval from the plan before getting my medicine?

4. Can I use the same pharmacies? Are there changes to the cost of using this pharmacy?

Once you've compared your plan in 2016 with 2017 coverage, then it's time for step two which is to compare your plan with the others available. It's pretty tough to do this based on the glossy mailers plans send this time of year. And, depending on where you live, you may have as many as 20 Part D drug plans and 25 Medicare Advantage plans to work with. How can you possibly compare all this? The best advice is to use the Medicare

See **MEDICARE** on page 8

Thank you to our Major Donors for July and August for helping support "The Gift of Time"

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The Life Raft Group

Who are we, what do we do?

The LRG has a simple focus: to cure a form of cancer — gastrointestinal stromal tumors (GIST) — and to help those living with it until then. To do this, the Life Raft Group focuses on three key areas: research, patient support & education, and advocacy.

How to help

Donations to The Life Raft Group, a 501(c)(3) nonprofit organization, are tax deductible in the United States. You can donate by credit card at www.liferaftgroup.org/donate.html or by sending a check to: The Life Raft Group 155 US Highway 46, Suite 202, Wayne, NJ 07470.

Disclaimer

We are patients and caregivers, not doctors. Information shared is not a substitute for discussion with your doctor. Please advise Mary Garland, Communication Director, at mgarland@liferaftgroup.org of any errors.

Flu season 2016-17 updates

By **Mary Garland**, Director of Communications

Autumn is here, ushering in the flu season. The flu can be a difficult illness for everyone, but for cancer patients, it can be devastating. Each year, millions of people contract the flu, hundreds of thousands are hospitalized, and thousands actually die from complications. Although there is no way to accurately predict severity and length of the flu season, it is important for GIST patients to receive their vaccinations as early as possible. Flu activity peaks between December and March in the United States.¹



The Center for Disease Control (CDC) recommends that cancer patients as well as their close family members be vaccinated by the end of October.

Important information about the flu:

- The flu shot is a seasonal vaccine. Each year it is designed to combat strains of flu expected to cause illness in the current season.
- Being a cancer patient puts you at an increased risk of complications, which can include pneumonia, hospitalization and even death.
- Choosing to get a flu shot is your best protection against the flu.



Always consult your physician before getting vaccinated. There may be certain medical contraindications to being vaccinated.

- For the current 2016-2017 season, the CDC recommends that the nasal spray flu vaccine should **not** be used this year.

See **FLU** on page 10

Last stop in the LRG 2016 GDOL series: St. Louis

By **Laura Occhiuzzi**, Assistant Director, Programs

The Life Raft Group completed the 2016 GIST Day of Learning series in St. Louis on October 8, 2016 at Siteman Cancer Center, Washington University in St. Louis. A huge thank you goes out to Dr. Brian Van Tine, Dr. Peter Oppelt and Jessica Andrews for their help in organizing the event.

An intimate group of patients and caregivers benefited from an impressive lineup of presenters from the Midwest. The passion, dedication and comradery of these presenters was evident as participants were able to ask questions throughout the four-hour session and receive answers from more than one physician.

Dr. Angela Hirbe started off the afternoon summarizing the services offered at Siteman Cancer Center. Dr. Oppelt (Siteman) continued with

an informative session on GIST and Clinical Trials. Dr. Hawkins (Siteman) followed with the surgical perspective, discussing when and why to have surgery and its benefit to GIST patients.

Dr. Scott Okuno from the Mayo Clinic gave an impressive presentation on Wild Type GIST and Dr. Mohammed Milhem from Holden Comprehensive Cancer Center at University of Iowa Healthcare spoke about immunotherapy.

Dr. Brian Van Tine (Siteman) rounded out the physician presentations



Petter Oppelt, MD, Mohammed M. Milhem, MD and Brian Van Tine, MD, PhD.

with a discussion about metabolism therapies coming to trial. The final session was on "Psychosocial Implications and GIST," and was presented by Yasmin Asvat, PhD.

See **GDOL** on page 9

MEMBER from page 1

and hoarseness (ugh! It's bad!) Many of these I have managed to reduce and/or learn to live with.

I have decided to write about one particular side effect -thinning hair, as I have had some recent success in dealing with this issue. I realize it is not often mentioned as a side effect, but I am hoping that will change.

A few months after starting Stivarga, the sink and floor in my bathroom was covered in my hair. It was simply breaking off. Just running my hands through my hair caused this to happen. Bald spots started showing on the back of my head. This was devastating. My hairdresser explained that the thinning hair was revealing the growth patterns. I set out to research the issue to see if there was anything I could do.

Here are some tips I found helpful:

Coconut Oil – My new best friend!! It is also inexpensive. I warm it between my hands and gently work it into dry hair. Typically, I do this once a week and let it set for 30-60 minutes. (Time may not matter). Afterwards, my hair has more texture and feels wonderful. I follow this with a gentle wash and cool rinse.

Reduce Washing – Only wash your hair when absolutely necessary. Many times I just wet it down and use a little conditioner if necessary. I started using sulfate-free shampoo. Does it help? Who knows, but remember, I was desperate.

Brushing – Don't. Use either a wide tooth comb or vent brush that has a lot of width between the teeth. This reduces drag on the hair.

Products – Try to avoid them. I've

noticed that things like hair spray makes the hair feel more compromised. Once my hair was healthy again, I researched my hair products for drying ingredients. Even now, I only use them on special occasions.

Silk or Satin Pillowcases – Wow! I've heard how they save your style. It's true. The silk is gentler on the hair, causing less friction/pull than cotton.

Be gentle. This is key.

It wasn't long after beginning this program that I noticed there wasn't nearly as much hair on the bathroom floor. My hair isn't growing back at the rate it once did, but I'm not losing the hair I have. After about six months of this routine, my hair is looking healthy and it's growing back slowly. (Very slowly). It's coming back curly along the neckline. Yet another issue to deal with –ha! I'll take it. ■

These are suggestions shared by an individual and not a medical professional.

CANCERVERSARIES



Paula Vettel 15 YEARS

“ I am so fortunate to be celebrating 15 years of continued life, thanks to Gleevec. I have enjoyed life with my wonderful husband Phil, and seen my boys grow into men. I am looking forward to more years of family and fun.”



Mike Ginsberg 10 YEARS

“ Thanks Life Raft Group and Gleevec for the gift of time! Little grandchildren in this picture I would have never have known, and my participation in Bar Mitzvahs, weddings, birthdays, sports events, all make me grateful for being able to celebrate my 10-year Cancerversary.”

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

DATA from page 1

cancer research culture is seeded with competition, and collaboration remains a rarity when sharing data and tissue.

Through discussions with patients, physicians, and others, the LRG identified the need to convene a meeting to discuss how data collection and sharing can be a useful tool across disease groups, institutions, and countries. If there are ways we can coordinate the collection of empirical data to help clinicians and researchers make informed decisions, this can also help impact our advocacy efforts in these countries. We saw the need to collect smart data to help keep patients with a rare cancer alive!

In collaboration with Alianza GIST, a Latin American GIST coalition (www.alianzagist.net), we organized a two-day meeting called Salud Con Datos (Health with Data) to discuss how we can work together on the collection of data to learn more about our diseases and advance our advocacy efforts. The meeting raised the following questions:

Objective 1:

What is the feasibility of sharing data and cross-collaboration in Latin America?

Objective 2:

What are the elements necessary to make a data set functional?

Objective 3:

What are the roles and responsibilities of each participant?

Twenty representatives from six different countries (Argentina, Brazil, Chile, Mexico, Peru and the United States) were in attendance. Meeting participants included



Salud Con Datos participants build partnerships for future work in Latin America.

patient advocates, clinicians, researchers, data scientists, and representatives from academia and the pharmaceutical industry.



Participants gained the following from the conference, which showed synchronicity with their pre-meeting expectations:

Collaboration - Connected with different stakeholders and worked to build partnerships and discussed issues regarding health data and availability.

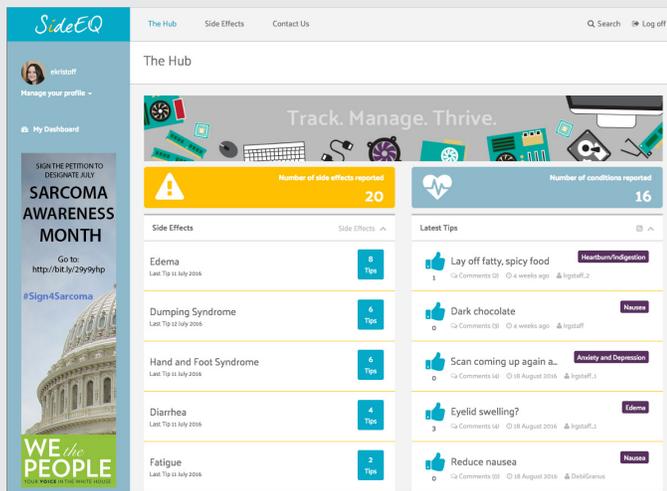
Registries - Viewed best practices of data collection platforms and focused on a proof of concept to test a platform with a dataset in Latin America.

Data - Tackled the issue of patient reported outcomes as an important perspective in data collection and sharing.

As convener of the meeting, the Life Raft Group is pleased with participants' active involvement and the focused meeting outcomes identified by the group. As we move forward, we plan to expand participation and broaden perspectives by inviting other countries and stakeholders to join in this collaboration to improve health with data in Latin America. ■



To sign up today go to
www.mysideeq.org



The “Hub” is the public face of SideEQ, which displays site news and the most talked about tips and side effects.

Registration is easy, and is guided by whether you are a Patient/Caregiver or Healthcare Professional.

Once a patient has filled out the quick registration, their account has been created! However, filling out the profile page will make for a much better experience. Entering key information like gender, age and most importantly—diseases and drug treatments will help you compare your side effects more easily on the Dashboard.

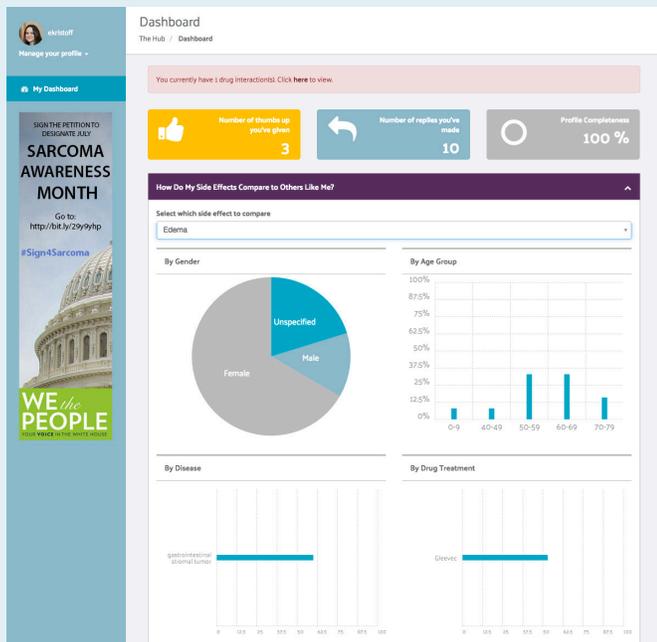
Alerts let you know how you are progressing throughout the process.

2

Once you have entered any diseases and medications you wish to, you can mark any side effects you have, as well as their severity and how they have affected your quality of life.

3

The **Dashboard** is personalized to you. It shows your activity and statistics about how your side effects compare to others like you. You can compare yourself to others by age group, gender, disease and drug treatment. For example, you can view how many people with GIST experience Hand and Foot syndrome.



My Saved Side Effects

- Diarrhea (4 Tips, Last Tip 11 July 2016)
- Fatigue (2 Tips, Last Tip 11 July 2016)
- Hand and Foot Syndrome (6 Tips, Last Tip 11 July 2016)
- Muscle Cramps (2 Tips, Last Tip 11 July 2016)

Tips I Follow

- Foot creams (Hand and Foot Syndrome)
- HFS and Sutent (Hand and Foot Syndrome)
- A few suggestions (Muscle Cramps)
- Iron supplement work... (Muscle Cramps)

You can also view any side effect pages or tips you have book marked here for easy access.

SideEQ News

Announcing SideEQ!
12 July 2016 by Irigstaff

Welcome to our new site! You can learn all about various side effects, recommendations for their treatment, and the ways people are coping with them. You can also follow different discussion threads, and if you enter information on your profile, compare your side effects with others on the site. Feel free to sign up, take a look around, and post some tips of your own!

SideEQ Polls

Take Our Poll - Have your side effects gotten better over time?

- A- Yes: 53%
- B- No: 32%
- C - I'm not sure: 16%

Since the dashboard is designed to be your personalized one stop shop, you can also find site news and polls here, as well as important information about drug warning and interactions.

Side Effects

A - B - C - D - E - F - G - H - I - J - K - L - M - N - O - P - Q - R - S - T - U - V - W - X - Y - Z

Altered Taste
Dysgeusia or parageusia is a distortion of the sense of taste. Dysgeusia is also often associated with ageusia, which is the complete lack of taste, and hypogeusia, which is a decrease in taste sensiti...

Anxiety and Depression
Depression and anxiety are different conditions, but they commonly occur...

Cold Intolerance
Cold intolerance is when you are extremely sensitive to cold temperatures.

Side Effects

Side Effect	Description	Tips	Comments
Altered Taste	Dysgeusia or parageusia is a distortion of the sense of taste. Dysgeusia is...	2	3
Anxiety and Depression	Depression and anxiety are different conditions, but they commonly occur to...	1	4
Cold Intolerance	Cold intolerance is when you are extremely sensitive to cold temperatu...	2	6
Diarrhea	Diarrhea describes loose, watery stools that occur more frequently than usu...	4	7
Dumping Syndrome	Dumping syndrome is a condition that can develop after surgery to remove al...	6	10

The side effects index page can be displayed in two different ways in order to make it easier for you to find what you're looking for.

4

All Tips
The Hub / Side Effects / Edema / All Tips

All Tips

- Eyelid swelling? (3 Comments)
- Potassium with Diuretics (1 Comment)
- Limit salt (1 Comment)
- Vitamin B6 (1 Comment)
- Lower leg edema (1 Comment)
- This is very helpful! (1 Comment)
- Licorice (1 Comment)

While only the most "useful" tips are displayed on the side effect page, you can easily click All Tips and find every tip submitted for a particular side effect.

Edema
The Hub / Side Effects / Edema

Best Practice

Edema can develop in different parts of the body and can therefore manifest in different ways

- Eye puffiness
- Swelling of lower legs
- Increase in abdominal girth
- Shortness of breath
- Weight gain

People typically experience puffiness or bloating in their abdomen, breasts, and around their eyes. Edema is a dose-related side effect that can occasionally be severe. In rare cases, fluid retention affects the lungs (pulmonary edema).

Library

- 2016 Jun 27: Perforation of the Colon During Imatinib Mesylate (Gleevec).
- 2016 Jul 23: Protective Effects of Imatinib on Ischemia/Reperfusion Injury in...
- 2016 May: Chronic Myeloid Leukemia Presenting as Bilateral Retinal...
- 2016 Nov: Teratogenic effects of the anticancer drugs on Xenopus...
- 2016 Jul-Aug: Imatinib induced melanoma-like pigmentation Report of five...

Related Tips

- Eyelid swelling? (3 Comments)
- Lower leg edema (1 Comment)
- This is very helpful! (1 Comment)

On each side effect page, you can view a best practice article written by an expert in the field, a library of scientific articles on the subject, as well as helpful tips submitted by other patients. You will have the chance to "thumbs up" a tip you found useful, respond to a tip you have thoughts on and submit tips of your own.

MEDICARE from page 2

Plan Finder at www.medicare.gov, work with your local insurance agent or broker, or ask for unbiased help from a local SHIP counselor through www.shiptacenter.org

And, what if your changing plans doesn't really make your copayments and medications affordable? Be sure to check these resources for help:

- Use www.BenefitsCheckUp.org to screen for more than 2,500 public benefit programs
- Check your eligibility for Extra Help and Medicare Savings Programs to help with Medicare costs with your local SHIP or county social services office
- Visit www.needymeds.org to find out if your state has a State Prescription Assistance Program (SPAP), the drug manufacturer offers a copayment assistance program, or if a foundation might help with some of the cost

Remember, it's up to you to review your choices and find the best fit! If you'd like to learn more about Medicare, visit the www.mymedicarematters.org website to learn more and take our MedicareQuickCheck for help with Medicare eligibility and enrollment guidance. ■

LRG Webcast Series

LRG webcast examines effects of sunitinib and imatinib on the kidneys



Dr. Benjamin D. Humphreys, Chief of the Division of Nephrology at Washington University at St. Louis School of Medicine, presented the LRG webcast entitled "Examining Kidney Toxicities of Sunitinib and Imatinib in Long-Term GIST Therapy" on September 19th. Over 100 viewers participated in this informative webcast. Relevant topics such as managing and monitoring hypertension as well as CAT scans and their relationship to chronic kidney disease were discussed.

To view this webcast visit:
bit.ly/KidneyToxicities

Navigating the medicare maze



On September 28, 2016, the Life Raft Group was pleased to have Melissa Simpson, Senior Program Manager in the Center for Benefits Access at the National Council on Aging share her knowledge and insight regarding medicare.

Go to bit.ly/NavigatingMedicare to listen to the LRG Webcast

Become an LRG state leader!

Have you ever wanted to become more involved in giving back to the GIST community but don't know how? Become an LRG State Leader! State leaders are an important part of the LRG network, providing important person-to-person contact to help members know they are not in this journey alone.

Responsibilities include:

- Being a point of contact for members in your state
- Welcoming new members
- Planning meetings and get togethers for your state

If you are interested or just want to learn more, please contact Laura Occhiuzzi at locchiuzzi@liferaftgroup.org



GDOL from page 3



Laura Occhiuzzi (LRG) spoke about the importance of data, joining the patient registry and donating tissue in the name of research. Participants left with a feeling of hope, knowing that new treatments and new trials are on the horizon.

We would like to acknowledge the sponsors that make GDOLs possible: Novartis, Bayer, Pfizer, and Genentech. Mark your calendars! We will begin our 2017 GDOL series in beautiful LaJolla, California on February 25. Please stay tuned to the LRG website and emails for more information on these and other events. ■

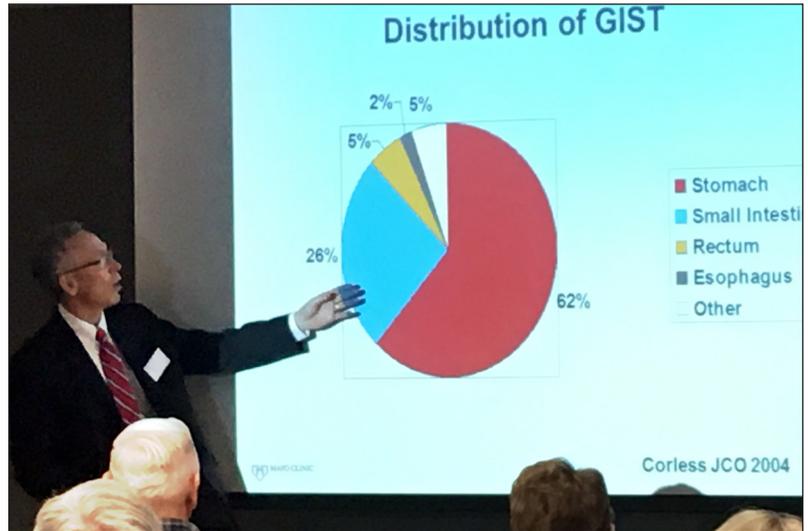


Opportunity to meet LRG members in your area

Looking for a way to meet locally with others who share a GIST journey?

Consider hosting a local meeting in your area. Sharing stories and meeting other patients and caregivers who understand what you are going through can be both therapeutic and fun!

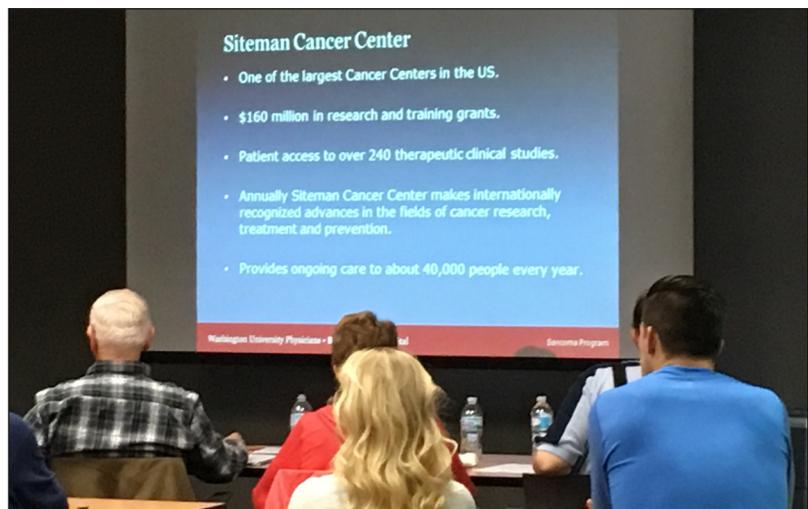
For help setting up a meeting in your neck of the woods, contact locchiuzzi@liferaftgroup.org



Scott H. Okuno, MD from the Mayo Clinic discusses Wild Type GIST.



William G. Hawkins MD, FACS with Mohammed M. Milhem, MD.



GDOL participants benefited from expert presentations.

Help Us Further GIST Research.



If you would like to participate in the Life Raft Group's Tissue Bank, please contact Kathrena Aljallad, the Senior Patient Registry Associate, by phone 973-837-9092, Ext. 114 or email: kaljallad@liferaftgroup.org

FLU from page 3

- The composition of U.S. flu vaccines is reviewed annually, and updated to match circulating flu viruses. For 2016-2017, three-component vaccines



are recommended, containing A/California/7/2009 (H1N1) pdm09-like virus, A/Hong Kong/4801/2014 (H3N2) virus and B/Brisbane/60/2008-like virus (B / Victoria lineage). Four component vaccines include the same three viruses plus an additional B virus called B/Phuket/3073/2013-like virus (B/Yamagata lineage).²

- Since cancer patients are at increased risk for pneumonia, talk to your physician about the pneumococcal vaccine when you discuss the flu shot. ■

If you haven't yet done so, make an appointment for your flu shot today!

1. www.cdc.gov/mmwr/volumes/65/rr/rr6505a1.htm?s_cid=rr6505a1_w
2. www.cdc.gov/flu/index.htm



CALENDAR OF EVENTS

DECEMBER 4, 2016

Patient Gathering Meeting
The Life Raft Group
55 US Highway 46, Suite 202
Wayne, NJ 07470 USA

Joyce (Hodnett) Fredericks: Loving wife, mother and grandmother

Joyce Frances (Hodnett) Fredericks, 64, loving wife, mother and grandmother, died peacefully on Tuesday, September 13, 2016 after a long battle fighting cancer.

In loving memory!

Services were held from the Keri Memorial Home, 125 Main Street, Lincoln Park, N.J. Mass was held on Saturday, September 17, 2016 at St. Pius X Church, Montville, N.J. followed by private cremation.

Born in Jersey City, N.J. on January 24, 1952 to the late William and Lorraine Hodnett, Joyce moved to Montville, N.J. after marriage. She leaves behind her beloved husband of 45 years, Ralph; children, Joy Lynn, Brent and Ashley; four grandsons, Liam, Landan, Joseph and Ben, and granddaughter, Zoey, as well as two sons-in-law; her sister, Lorraine Hennessy and husband, Dennis.

Joyce was a small business owner for many years, operating "The Cow's Tale" in Boonton, N.J. She was a fabulous homemaker.

In lieu of flowers, donations to the Life Raft Group, 155 Rte. 46, Suite 202, Wayne, N.J., 07470 would be appreciated. ■

Every life leaves something beautiful behind

Contact the LRG at liferaftgroup.org for ways to honor your loved one.



The LRG celebrates the lives of those who are no longer with us. Honor your loved one by lighting a virtual candle.

lrginmemoriam.org

In Memoriam

Anita Scherzer

October 11, 1941 - September 29, 2016

The Life Raft Group is saddened by the loss of Anita Scherzer, wife of Executive Director, Norman Scherzer.

A beloved wife, mother, nana and hero to so many, Anita touched the lives and hearts of everyone who knew her. She had a quiet strength which radiated and inspired all to find their own strength within.



This is a tribute to a woman that inspired a movement. Anita, may your spirit shine bright and your memories never fade. We stand with the Scherzer family and Life Raft.

The bravest and strongest woman I know. She fought the great battles with undeniable courage and is now at peace. The next journey has begun.

Anita made a huge impact on this world and together with Norm they improved the lives of all GIST patients. Thank you both.

I think that Anita was fortunate to know that "her" cancer led to so many good things. Not all of us are so fortunate to realize how many lives we touch! Her living presence will be missed but her spirit and contributions will be without end! Quite a legacy!

Dear Anita, your love & commitment to GIST patients will live on in our memories.

Anita was the light of the Life Raft Group. She will always be remembered.

THE LIFE RAFT GROUP COMMUNITY

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

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Life Raft Country Liaisons: Learn more about the Global GIST Network & find contact info for your rep at www.globalgistnetwork.com

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