

Ensuring no one has to face GIST alone



In Loving Memory: Glenita Muncal, J. Robert Hall, Frank Vondrasek, Steven McLaughlin, Ron Smelser, Richard Haan

Living with ostomy: One LRG member's story

By: Mildred Menos

Assistant Program Director and

Mary Garland

Marketing and Communications Associate

Charlie Burke has developed a thick skin when it comes to cancer. After surviving bouts with colorectal, thyroid and skin cancers, he was well acquainted with the routine of doctor's appointments, hospital visits, surgeries and regular treatment that accompany disease by the time a GIST tumor was discovered in his colon. However, as any of our members will tell you, GIST comes with its own unique lexicon to master and

set of challenges to overcome.

Coping with a diagnosis of GIST can be stressful for both the patient and caregiver. Since surgery is considered the gold standard of treatment for a primary tumor, a diagnosis of GIST in the colon or rectum can be especially stressful, as the potential for a temporary or permanent colostomy is possible. GISTs arising from the colon are rare (about 2%), but about 20 percent of GISTs do originate from the jejunum or ileum. The small and large bowels are ba-

[See Ostomy, Page 8](#)

LRG Research Team members contribute to new research findings

By: Jonathan Fletcher

LRG Research Team Leader

In a recently published article in Nature Genetics, several prominent cancer researchers and GIST experts, led by Dr. Dr. Yuexiang Wang and including Dr. Jonathan Fletcher of Brigham & Women's Hospital and Dr. Matthew van de Rijn of Stanford University Center, who are both members of the LRG's research team, discuss new research findings that may potentially help identify GIST patients with

[See Research, Page 8](#)

Find out how to register and more on Page 6 & 7



July 13th 2014 - Chicago • Los Angeles • Miami • Virtual

Expert patient training program a success

By Pete Knox

Strategic Planning Director

The LRG is proud to announce that the inaugural class of our GIST Expert Patient Training Program has been completed. The class, which was open to GIST patients, caregivers, and other members of the extended GIST community, was comprised of just under 20 students and was a comprehensive offering designed to help participants better understand the science behind GIST. In so doing, they are enabled not only to learn more about their own disease, but to help other patients and caregivers in their journey as well. Graduates of this program are eligible, after receiving additional training, to serve as GIST Ambassadors and/or Patient Registry volunteers.

The course was delivered in an innovative fashion via cutting edge technology. Participants read preparatory materials each week that were provided via website, and then attended a weekly virtual class that

was provided through interactive videoconferencing software that enabled participants to hear the lecturer's voice, and also see materials such as slides and websites, via the instructor's shared desktop. These classes, which were offered both in the morning and afternoon, were recorded, and participants were able to view them prior to taking online exams – both weekly ones on specific topics and a final comprehensive one in the last session.

Both the video and tests were also delivered via website. The course was conducted over six weeks, and participants were expected to devote about 30 total hours to their training after



Erin McBean, Expert Patient

completing an orientation phone call discussing what the course entailed and what their expectations were.

Topics covered in the class included Introduction to GIST, Basic GIST Biology and Mutations, Risk of Recurrence, Adjuvant Treatment, Treatments and Managing Side Effects, Radiology, and Clinical Trials. The class was truly a global one, with students logging on from the United States, Central America, Europe, and Africa.

“It really was a wonderful experience being able to pass this knowledge on to people so

[See Training, Page 9](#)

LRG member Eileen Glasser creatively networks to support GIST Awareness Day

By: Mildred Menos

Assistant Program Director

As July 13's GIST Awareness Day draws closer we are encouraging all of our members to make the day their own by spreading the word in their local communities. Raising awareness about GIST eases obstacles to education, treatment and research that make this disease so difficult to battle. GIST Awareness Day puts the power to help bring about this change in the hands of you, our members, who have been most profoundly touched by GIST. Through the course of our daily lives, we are all a part of so many networks—schools, religious groups, fitness classes, friends and family to name just a few. As LRG member Eileen Glasser found out firsthand, the impact of a simple conversation with just one of these networks can have amazing ripple effects.

Through the course of her frequent volunteer visits to the office the past few months, Eileen learned all about the GIST Awareness Day effort we are all so hard at

work on, and the Guinness World Record attempt for the largest display of origami boats we are spearheading to promote it. Like many, Eileen originally claimed she had no artistic skills and did not have high hopes for her boat making abilities.



Eileen Glasser, LRG Volunteer

However, she quickly mastered folding the simple shape and it wasn't long before she set to work on bringing news of GIST Awareness Day and the origami boat project to her area schools. As a retired teacher herself, Eileen has great familiarity with the school system and thought that

this would be something the area's service-oriented Kiwanis, Key and Builder's Clubs might like to participate in.

Her efforts to date have been an amazing success with over 7,500 boats and counting. Five area New Jersey schools have committed to participating in the origami boat project to date, with the Hebrew Academy of Morris County having contributed over 1,000 boats alone. Recently the entire school celebrated with a “dress down day” in which students donned the Life Raft Group colors of orange, blue and white to celebrate GIST Awareness. Eileen continues to stay engaged by making weekly trips to the committed schools and picking up the completed boats which she later delivers to our office by the garbage-bag full. We are so thankful for all her efforts!

For more ideas on how to get your community involved in GIST Awareness Day contact Mildred Menos at mmenos@liferaftgroup.org and check out our GAD website at www.gistawarenessday.org

The faces of 'We Are the Cure' – Teena Petersohn

By Mary Garland

Marketing and Communications Associate

In December, 2013, the Life Raft Group launched its "We Are the Cure" campaign to fund GIST research in response to the shrinking pool of available funds. As a rare disease, GIST research is impacted more than other more common cancers like breast and colon. Institutions like the National Cancer Institute are funding just four to five percent of all research proposals which means that a rare cancer like GIST is lost amongst the roughly 200 cancers competing for funding.

Over the past seven years, thanks to the dedication and support of the GIST community, the LRG Research Team has challenged the traditional cancer research norms and set new standards for how research can be accomplished. This is an exciting time for GIST research as our researchers have reached milestones, identifying many new treatment options in the last few years alone. Today, nine

laboratories comprised of the world's best GIST researchers are collaborating on innovative projects.

"We Are the Cure" is a collaborative effort of all members of the LRG community: GIST patients, caregivers, patient advocates and family and friends to support and partner with our researchers to find a cure. To date, team members have raised over \$48,000 to support these efforts.

What inspires someone to become a part of the "We Are the Cure" campaign?

For Teena Petersohn, the inspiration came from a plea from the Life Raft Group's Executive Director, Norman Scherzer, when he let it be known that if we don't get funds, we won't find a cure.

That was enough to spur Teena into action. "This is something I can do," she

stated. Recognizing that even a small effort can bring about results, she planned her strategy.

Teena waited until after the holidays were over, and then targeted friends and family on her Christmas card list. She sent them a letter, explaining what GIST was, and how it affected families and communities.

"I left it up to the people," Teena reports. Although she would have liked more donations, she recognizes that everyone she contacted is at least now aware of GIST and its impact.



Teena Petersohn, LRG Member

She has found great support in her family and friends. "They care about what I care about. They will ask me questions about GIST, which raises awareness."

See Petersohn, Page 9

Alianza GIST meets in Zurich, Switzerland

By Piga Fernandez

LRG Global Relations Coordinator

Alianza GIST members from Argentina, Bolivia, Brazil, Colombia, Chile, Cuba, Venezuela, Guatemala, Mexico, and Spain joined representatives from the Life Raft Group in Zurich, Switzerland from May 14 to 17.



Alianza GIST meeting participants

The major focus of the meeting was to develop a new methodology in order to move towards Alianza GIST autonomy. One of the workshops focused on identifying projects for the coming year according to the principal issues concerning Latin

America. Each project will be led by one country, and will be coordinated by Piga Fernandez and Rodrigo Salas, board member and Mexico representative. Projects include:

- Argentina – Updating the Alianza GIST website
- Mexico and the LRG – Vigilance and

- Surveillance – Global Patient Registry
- Colombia – Education on GIST for future medical generations
- Guatemala – Education to patients and doctors in Central America
- Cuba – Latest scientific information

available for physicians

- Bolivia – Online patient support
- The meeting was an opportunity for representatives to share their progress, concerns and hopes for the future, as well as a chance to interact in the peaceful setting Zurich provided.

Alianza GIST is a partnership of patient advocates representing 14 Latin American countries that have convened to create the Latin American GIST Initiative for the GIST community, focused on four key principles:

- To improve the knowledge of patients and physicians.
- To increase patient access to adequate treatment and resources.
- To support local patient support organizations, including the creation of new ones.
- To encourage collaboration and coordination with the physician community.

For more information please visit our website: www.alianzagist.org

New Horizons takes place in Zurich, Switzerland

By Sara Rothschild
Program Director

With the beautiful mountains of Switzerland and Lake Zurich in the background, 44 GIST Patient representatives from 28 countries and 32 patient groups/organizations convened in Zurich for the New Horizons GIST meeting from May 14-17, 2014.

The GIST New Horizons Conference is an essential event where patients from the international GIST patient community come together, can interact with top experts in an informal setting, have access to state-of-the-art medical and scientific information prior to the ASCO conference and can exchange best practices together in terms of patient advocacy.

As Dr. David Josephy of Life Raft Group Canada stated, "The recent New Horizons GIST meeting was the strongest ever, in

terms of the number of countries represented, the strength of the international interactions, and the 'bench-strength' of the doctors and researchers present.



New Horizons meeting participants

presentations describing new drugs under development, possible combination-therapy approaches, and advances in molecular diagnostics.

It was also exciting to see the innovative ideas of GIST support groups around the world, such as the French group's success in sponsoring GIST research even on a small budget, and the patient-driven establishment of the first wild-type GIST clinic in the U.K."

Over the course of the three days, partici-

There was a lot of optimism in the air, with

[See New Horizons, Page 10](#)

NIH Clinic provides support and a healthy dose of fun

By Mildred Menos
Assistant Program Director

The 12th Pediatric and Wildtype GIST Clinic was held May 21 to 23, 2014 at the National Institutes of Health in Bethesda, Maryland. Coordinated by Dr. Sospitros Boikos, and based out of the NIH Pediatric Oncology Department under the direction of Dr. Lee Helman, the Clinic is collaboration between clinicians and researchers to collect data, investigate and develop treatment for GIST patients who do not have either c-KIT or PDGFRA mutations. This includes patients with Carney's Triad, Carney-Stratakis Dyad, and Wildtype GIST. These tumors frequently stain negatively for a protein called Succinate Dehydrogenase, a condition referred to as being Succinate Dehydrogenase-deficient (SDH-deficient).

Wildtype GIST patients from around the country come to this clinic for their case to be reviewed by top experts in the field. While there, they undergo a round of appointments including blood work, pathology, dermatology, a meeting with a

social worker and a panel review of their case complete with all the consulting NIH physicians on hand. These physicians have reviewed the case and offer their suggestions and advice for future course of treatment. This year there were nine patients in the clinic. As Wildtype GIST does primarily affect younger people the majority of patients were around their teenage years, but there were a few older patients,

just once per year. A virtual clinic cuts overhead costs and allows international patients who wouldn't otherwise be able to make it to Bethesda a chance for their case to be reviewed by top experts.

Specialized support services were tailored to a patient's age and family members' caregiver status. Seminars were held on topics ranging from Anxiety, Nutrition, Active Living and Alternative Medicine.



Participants at the NIH Clinic in Bethesda, MD

a testimony to how difficult this subtype is to successfully classify.

In addition to the patient agenda, research experts gather to discuss updates on the clinical and genetic studies at NIH. During this physician meeting the Life Raft Group gave a presentation to the doctors on the inaugural meeting of its Virtual Pediatric/Wildtype Tumor Review Board. Due to budget constraints, the NIH in-person clinic has been reduced to happening

On the first evening, clinic members gathered at the NIH's Children's Inn for presentations from Dr. Chris Weldon who provided an overview of the science behind GIST and from the LRG about its upcoming GIST Awareness Day on July 13. LRG board treasurer Ray Montague hosted his annual dinner for all attendees and afterwards further socializing continued at a local restaurant for a relaxed conversation over snacks and drinks. This provided a much needed opportunity for everyone to meet and share stories. For many in attendance, it was their first time meeting another Wildtype GIST patient. Common themes of the discussion included how much the caregivers had learned about this disease in a short time given they had never heard of it prior to diagnosis, and the importance of connecting with a GIST specialist.

Poker for Hope proves to be huge success

By: Diana Nieves

Director of Operations

On Saturday, May 17th in the Caesars Palace poker room in Las Vegas, the Poker For Hope charity tournament took place, benefiting Tia's Hope www.tiashope.org, The Life Raft Group, and Phase One Foundation www.phaseonefoundation.org. Poker for Hope was started by these three non-profit cancer support organizations with ONE goal in mind...A CURE!

The first 100 poker players who registered early participated in a private VIP Celebrity Improv Show at Cleopatra's Barge the night before the tournament. Starring Camryn Manheim of Ghost Whisperer, Willie Garson of White Collar, Larmorne Morris of New Girl, Kevin McHale of GLEE, and Sara Rue of Rules of Engagement, it provided an opportunity to socialize before the big event. The players also received ticket vouchers to attend the Friday night performance of Absinthe at Caesars Palace, which were generously donated by the hotel.

The Poker for Hope event was hosted by professional poker player and former professional magician, Antonio Esfandiari, who also provided a private poker lesson to the players before the tournament started. There were 115 participants at the tournament. Cast members from Absinthe and stars of the VIP Celebrity Improv Show, served as celebrity guests at the tournament.

The first place winner was Steve Solaka. Other winners included Andrea Stanford, Gary Satin, Paul Alanis and Jeff Tahler. The event garnered almost \$165K which was divided among the three organizations. The Life Raft group is appreciative of the very generous support of Caesars Palace. The event wouldn't have been a success

without them. We also thank our sponsors who included: Four of a Kind- \$15,000; Rock Mafia; Full House - \$10,000; Natixis; Flush - \$5K; Robert Brkich Construction Corporation, Carpets and More, Daltile and Marazzi. We also thank Jess Ravich (founder of Tia's Hope), Jerry Cudzil (LRG's Board President), and Lissa Zanville (Executive Director of Phase One) for all of their hard work in making this event a huge success!

Events like Poker for Hope are inspired by the courage of all those who are fighting



Poker for Hope celeb guests from left to right: Kevin McHale, Sara Rue, Camryn Manheim, Willie Garson, and Larmorne Morris

cancer. One story of courage comes from Jess Ravich, the founder of one of the event sponsors, Tia's Hope.

A Tribute to Tia Palermo Tia's Story by Jess Ravich

On March 29, 2012, after 11 years of fighting cancer, my lovely, loving and beloved wife of 23 years, Tia, passed away. She died as she had lived - with dignity and grace and on her own time schedule. And, as in life, she died on her own terms - at home surrounded by her four daughters, family and friends.

She woke for a little while on Monday the 26th and we arm wrestled, as we had in the past. In all the years we've been together I never won. Usually it was because she was stronger, but other times I just let her win. She still had strength and won the first bout. She then grabbed my hand again for a re-match and pulled my arm

so I would win. She then took her fingers and with a significant amount of effort, she signaled OK. I could read everything in to that gesture or nothing, I choose to read everything. We had a unique relationship, unconventional for sure but it was a true love story.

She was an amazing person and everyone she touched is the better person for meeting her. We will all miss her and we will be sad for her not being in our lives, but at the same time we need to honor her memory and her struggle to stay with us over the last 11 years. She was determined to see her daughters become young women and no mother could have been prouder of her children than Tia was of Zoe, Rae, Ede and Ava. No matter how much she loved me, her family or friends (or even her cats), we all took a backseat by a far margin to her love for our daughters.

Over the last few months of her life, her family flew in from all over the country and they were a source of not only comfort but strength to her. She appreciated each and every visit and always asked me after her siblings had left about how soon they could return, as she began to miss them even as they were driving away.

We were fortunate to have my brother and his family so close by. Tia loved the fact that every Tuesday and Thursday our "fifth child" would be in the house for dinner and homework and on our equivalent to Shabbat dinner (lobsterfest Friday) we had the added benefit of Kate coming over. In addition, I don't know what I would have done without my brother to lean on during the last year.

And then there are her friends. Too many to count and their love was limitless. She loved, admired, respected and just had a good time with her girlfriends. Whether they were her childhood friends from back east, her girls from the hood, her village school moms, her golden door friends, her phase one friends, her photo shop friends or just her "shop" friends, she loved you all. She had more categories of friends than I have friends. I would come home from work and invariably some girlfriend was over visiting. They could be in the kitchen cooking, in the gym stretching, in the media room for movie afternoons, in

See Poker, Page 9



GIST AWARENESS DAY

Check out the website for info about
the event and to sign up for updates

www.gistawarenessday.org



GISTAWARENESS

JULY 13TH 2014 DAY

GISTAWARENESSDAY.ORG



Help us break a Guinness World Record!

We aim to have the largest display of origami boats (over 20,000). Go to our website to see how you can join the fun.



Make a donation to help us cure GIST!

Every penny counts towards research funding that will bring us closer to a cure.



Bring friends and family to a GIST Awareness Day event or host one of your own!

Attend one of our flagship events in Miami, Chicago or LA or host your own party and invite others to learn more about GIST.



Be proactive! Educate government officials, local doctors and medical centers about GIST!

Distribute GIST information to policy and decision makers and try to get them to declare July 13 GIST Awareness Day in your city or state!



Use the power of social media!

Shout out your GAD activities on Facebook, Twitter, Instagram or Pinterest using the hashtag #GISTAwarenessDay or #GISTkeepfolding.

Ostomy from Page 1

sically hollow tubes. Therefore, a segment where a GIST is growing may be removed and the cut ends reattached.

A colostomy refers to the creation of a new exit for solid waste matter by routing the colon to exit the body through a surgically created opening (stoma) through the abdominal wall. A collection bag is attached to abdomen in a permanent colostomy.

Undergoing any surgery can be stressful after a GIST diagnosis. Procedures that involve an ostomy can cause additional stress for the patient and the caregiver as the reality of dealing with the day-to-day management can be overwhelming. The idea of having such an extreme change in what has been a routine bodily function can be frightening and confusing for the patient as well. The reality of dealing so directly with waste material, and the physical changes of having a stoma on the abdomen leave most patients with a high

level of fear and anxiety. After receiving a colostomy as a result of his colorectal cancer, the transition period was something Charlie was coached through with the support of an ostomy nurse assigned to him at Massachusetts General Hospital.

Although having the colostomy did not interfere with the removal of his GIST tumor, like many GISTers, Charlie has since had to navigate the tricky path of learning which foods are able to be better tolerated and how to restructure his diet to be compatible with his new circumstances. It is vital to become thoroughly informed on the practical aspects of this change and what it means for daily living, including:

- Differences in colostomy pouching systems, how they work, and which one is best for you.
- How to change and empty your colostomy bags or pouches and how to maintain the area around the stoma to avoid skin irritation or infection.
- How to develop a routine.
- How to prepare for "accidents" and how to minimize their occurrence.



Charlie Burke,
GIST Patient

- Strategies for dealing with emotional issues, including developing a strong support system
- Where to go for support to share your concerns with others.

Having a circle of care that includes a GIST specialist, your medical team, support from other GIST patients and utilizing ostomy resources available can help to alleviate these fears and concerns. Now over a year past his GIST surgery, Charlie acts as a support counselor for others going through the ostomy process at his local hospital as well as serving as the Life Raft Group's Massachusetts state leader.

Making the adjustment to life with a colostomy may seem impossible, but sharing your fears and concerns with others can help to make the adjustment easier. It may take some time, but you don't have to do it alone. GISTers looking to connect with Charlie about his experiences may contact him at cfxburke@aol.com. More information on ostomies in general can be found at www.ostomy.org.

Research from Page 1

a future high risk for metastases.

The study validates that dystrophin, a protein key to the support of muscle fiber strength and mobility, is a tumor suppressor in human cancers with myogenic programs.

Lack of dystrophin expression is a key factor in the development of muscular dystrophy. Muscular dystrophy (MD) is the name given to a group of disorders which cause muscle weakness. There are many different types of MD. The different types vary as to how mild or severe they are, and which muscles they affect. The cause is an abnormal or "faulty" gene. Genes are made from a biological material called DNA. Genes are the "control center" of each cell in the body, including muscle cells. The genes control the proteins that the cell makes. Certain genes control the proteins for muscle fibers to work properly. It is these



genes that are involved in MD.

The "faulty" gene in MD means that one of the proteins needed by muscle cells (Dystrophin) cannot be made correctly. This leads to damaged muscle fibers and to muscle weakness. Depending on the exact type of faulty gene and faulty protein, different types of muscle weakness result. This is why there are different types of MD. Within the muscular dystrophy associated DMD gene, intragenic deletion of dystrophin is a frequent mechanism by which myogenic tumors progress to lethal sarcomas. Dystrophin inhibits myogenic sarcoma cell migration and invasion, acting as a tumor suppressor.

Dystrophin inactivation was found in 96 percent of metastatic GIST cases in the study.

This is a significant finding that impacts the direction of future research studies. The implication is that by detecting key genetic defects such as the lack of dystrophin in GIST patients, that it may eventually be possible to predict those who will develop metastatic disease. It may eventually lead to targeted therapies for both diseases.

According to Dr. Fletcher:

"Inherited inactivation of dystrophin causes the most common and severe form of muscular dystrophy (Duchenne Muscular Dystrophy). In this paper, Dr. Yuexiang Wang and colleagues show that mutational inactivation of dystrophin causes progression and metastasis in GIST. These advances provide a rationale for evaluating various therapies under development for muscular dystrophy as new therapeutic strategies for GIST. Indeed, we hope the research juxtapositions of GIST vs. muscular dystrophy will create opportunities for both fields. One very appealing aspect is that drugs going forward as potential chronic therapies for youngsters with severe muscular dystrophy....have to be well-tolerated."

As a rare disease, GIST does not garner the attention, both from the research community, and from the general public, that diseases with a larger number of patients do.

On the other hand, muscular dystrophy has a significantly higher level of public awareness. Since both diseases share these genetic commonalities, the opportunities for collaborative research studies are promising.

Petersohn from Page 3

Petersohn has raised awareness in other ways. After LifeFest 2012, she wrote an article for her local paper. A self-described "private person," she nonetheless stepped out of her comfort zone to contribute to GIST awareness.

"Doctors especially need to know about GIST. Very few in Iowa know about it."

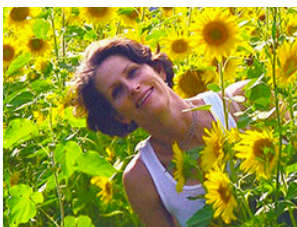
For Teena, the Life Raft Group has been an important lifeline. "I appreciate everything that you do. You are our backbone. I know I can call or email anytime and someone will help me."

With LRG members like Teena as part of "We Are the Cure," we can be assured of not only continued efforts to raise funds for research, but also to raise greater awareness about GIST, not only in Iowa, but in the world.

Poker from Page 5

her office laying out some photo design, in the back yard just enjoying the ocean or when she got sick, even laying on my side of the bed planning phase one events. Our home will be empty without her presence.

Tia had two basic speeds/moods during her life - happy and pissed off. She was rarely just sad. If something upset her, she got angry and did something about it. She wasn't one to just sit back and let the sadness wallow over her. She was a woman of action.



Tia Palermo

More often than not, though, she was happy. And her happiness was infectious. It is with this thought in mind that her family and friends will remember her.

Tia's memory lives on via the cancer support organization - Tia's Hope. TIA'S HOPE was founded in honor of Tia Palermo (1959-2012). To learn more about this organization please visit www.tiashope.org

Training from Page 2

eager to learn" said Pete Knox, LRG's Director of Strategic Planning and one of the course's instructors. He added, "The students really put in a lot of work. They were asking challenging questions right from the beginning. I really think the knowledge they've gained is going to help them get a much better understanding of their disease, which can't help but have a positive impact. They'll also be in a position where they're able to help others as well as themselves, so it's definitely a win-win."

Erin McBean, who was one of the course's participants, also added, "As a full-time patient advocate, I went into the Life Raft Group's Expert Patient Training Course thinking I would be brushing up on materi-

al I already understood. However, I quickly realized the information and tools taught during the online classes were priceless. The classes focus on building knowledge and explaining the complexities of GIST in an easy-to-understand way. I highly recommend other patients and caregivers to sign up for the next session of classes. This, by far, is one of the best ways to learn more about GIST and give power back to patients and caregivers."

The LRG intends to offer this class again in the near future, and will make everyone aware once a date has been announced, including explaining how you can participate if interested.

If you would like to learn more about the specifics of the course and how it is delivered, or have any additional questions, please send an email to Pete Knox at pknox@liferaftgroup.org.



CALENDAR OF EVENTS

JULY 13TH 2014

GIST AWARENESS DAY (GDOL IN CHICAGO/LA)
CHICAGO • LOS ANGELES • MIAMI • VIRTUAL

SEPTEMBER 11TH 2014

NIGHT TO FIGHT CANCER
NEW YORK, NY

NOVEMBER 7TH-9TH 2014

LIFE FEST
TEANECK, NJ

HAVE A LOCAL GROUP MEETING
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New Horizons from Page 4

Participants attended sessions that dealt with key topics including: GIST Overview and Diagnosis, Localized Operable Primary Tumors, Knowledge for Advocacy, Metastatic Advanced Disease, Progression of Advanced Disease under Drug Treatment, Quality of Diagnosis, Treatment and Care and How to Work with the Media.

Advocacy breakout sessions on discussing and collecting needs/challenges/performances of the Global GIST patient community brought participants together to formulate strategies for the future. Norman Scherzer, Executive Director of the Life Raft Group was joined by Dr. Jonathan Fletcher and Dr. Sebastian Bauer, members of the Life Raft Group Research team to present on Following the Research Journey in GIST.

Dynamic presentations on projects and initiatives around the globe promoting advocacy from Canada, Italy, the Netherlands, France, the United Kingdom and the United States highlighted the international scope and reach of New Horizons, and its value to worldwide GIST community.

One of the most significant accomplish-

ments of the conference was the Zurich Declaration. This document sets a precedent for the global patient community to assure that GIST patients are getting safe, quality effective medication. The principles were developed to assure that the transition to generic drugs for GIST patients protects them as the patents for the lifesaving drugs that have improved the management of GIST, including Gleevec (imatinib), Sutent (sunitinib) and Stivarga (regorafenib) expire.



Sara Rothschild, LRG Program Director, speaking at the New Horizons meeting.

Although generally generic drugs are welcomed by a patient population as they have the potential to dramatically lower costs and improve patient access to lifesaving drugs, there are many concerns

about the preservation of quality and patients' rights to optimal treatment.

The declaration was developed, agreed upon and signed by representatives of worldwide GIST Patient Advocacy Groups, and included eleven specific principles that include placing the patient first, providing corporate transparency, practicing the "precautionary principle", maintaining good manufacturing practices, evaluating "bioequivalence", treating GIST as a

unique disease entity, evaluating efficacy, assessing patient stress, informing patients of changes to their drug treatment, practicing pharmacovigilance, and honoring the "no substitutions" principle.

The New Horizons GIST Steering Committee developed a strategic plan to share these principles and advocate for action as we move closer to the dates when the patents on these lifesaving drugs expire.

For details of these principles and to view the 2014 Zurich Declaration in its entirety, please see our website: www.liferaftgroup.org/2014/06/new-horizons-zurich-meeting

Ron Smelser Passes Away at age 58

Ronald (Ron) Roy Smelser 58 years old. Born April, 1956 in Denver, Colorado to Mary and Frank Smelser passed away on April, 15, 2014.

He is survived by his wife, Judy Wilmore Smelser; his mother, Mary Smelser; his daughter and son, Mandy Smelser Redabaugh and Tim Smelser; his sister, Marilynn Gonzales; and 5 grandchildren: Kalea 11, Abrianna 10, Allie 8, Annalyse, 4 and Mitchell, 2.

Ron was a member of Grace Church in Arvada, Colorado, where he has been part of small groups and many other ministries. Ron had such a strong faith and it brings peace to those who love him to know he is in Heaven.

Ron was loved by many and will be missed by all.

In Memory of Richard J. Haan



It is with sadness that we share the news of Richard Haan's passing on February 23, 2014, following his long and courageous 16 year battle with GIST.

Richard was born in Grand Rapids, MI to the late Roger Allen Haan

and Etta Mae McInval Haan. He was a graduate of Kellogsville High School where he excelled in football, as well as Western Michigan University where he excelled in chemistry and biology. He was employed in the pharmaceutical industry as a packaging engineer for UpJohn, Schering Plough and most recently GlaxoSmith-

Kline. He was very innovative holding 5 patents in his industry. Richard was an accomplished guitarist entertaining friends and family. Richard was a loving and devoted husband and father. He traveled the world and touched many lives along the way.

He is survived by his wife of 39 years, Cindy R. Haan; daughters, Rebecca Joy Haan; and Sara Elizabeth Haan; sister, Ann Cronkright and her husband, Mike of Grand Rapids, MI; Father-in-Law James and Shirley Steward and several niece and nephews.

Funeral services were held at Mitchell Funeral Home Chapel in Raleigh.

The family would like to thank Dr. Mark Yoffe and the staff at Rex Healthcare for their loving care and support.



REGISTRATION NOW OPEN

The Life Raft Group is proud to celebrate the 7th anniversary of our biennial Life Fest convention. At this unique event hundreds of patients and caregivers have the opportunity to gather for a weekend of camaraderie and unprecedented access to global leaders in the field. For many attendees, Life Fest marks the first time they had the opportunity to meet another GIST patient or caregiver.

Each year brings a wealth of new information and patients are eager to hear about the latest advancements in GIST. This year we plan to highlight our outreach and advocacy efforts generated from the launch of GIST Awareness Day. We will share our call-to-action advocacy plan with participants as well as attempt to break the Guinness World Record of the largest display of origami boats. These boats have been 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.

www.lrglifefest.org

THE LIFE RAFT GROUP

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| Latin America Liason | Vicky Ossio |
| Clinical Trials Coordinator | Jim Hughes |
| Photographer | Kim Tallau |
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| | Jim Hughes |
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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 liasons: Learn more about the Global GIST Network & find contact info for your rep at www.globalgistnetwork.com

| | | | | | |
|----------------|--------------------------|-------------|-------------------------|--------------|-----------------------|
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