

# Ensuring no one has to face GIST alone

In Loving Memory: Peggy Beyers, Jill Heinrich, Wayne Bennett, James Caswell, Tara Garcia, Paul Bailey, Joseph McKamey

## A 'Clinical Trial of One' Finding Unique Solutions

By **Carolyn Tordella**, LRG Assistant Director of Communications

*Though not officially in a clinical trial, painter Douglas Morgan found himself with a rare GIST mutation and no treatment options until an innovative oncologist and a compassionate gesture by a pharmaceutical company gave him a chance to receive a unique treatment.*

Douglas Morgan knows about life-changing events. Educated as a mechanical engineer, Douglas spent twenty years successfully navigating San Francisco as a commercial real estate professional before changing course to pursue painting in his 40's. Other events that make this time memorable for him: a new relationship with his wife of 23 years and an incident he suspects might be the real beginning to his GISTory.

In 1995, just as his romance with his wife Bonita was blooming and his art career was still in its infancy, Douglas was experiencing small bowel bleeding. An ulcer was suspected. Upon surgery, a lemon-sized tumor, which had ruptured, was removed from his small intestine.



*Douglas and Bonita Morgan*

▶ see TRIAL OF ONE on page 2

## Health Decisions Tour in Latin America Advocacy and Patient Participation

By **Piga Fernández**, LRG Global Relations Coordinator

I was very fortunate to be invited to represent the patient's voice in three separate, relevant meetings. The meetings occurred one after the other, so I could attend all, although I have to admit, it was quite an intense week!



▶ see HEALTH TOUR on page 4

## LRG Data Leads to Change Revised CAP Guidelines Released

By **Sara Rothschild**, LRG VP Program Services



COLLEGE of AMERICAN  
PATHOLOGISTS

The College of American Pathologists (CAP) just released updated versions of its GIST Biopsy and Resection Cancer Protocols. Why is this important? Pathologists use CAP Cancer Protocols in the process of diagnosing a disease from tumor tissue surgical samples and to prepare standardized synoptic surgical pathology reports.

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In the movie *Network*, newscaster Howard Beale (played by Peter Finch) leans out the window and shouts to the world, *"I'm mad as hell and I'm not going to take it anymore!"*

That describes perfectly how I feel today. It is almost 20 years since we created The Life Raft Group and I have had the honor of serving as its Executive Director since the beginning. I am tired of seeing cancer patients die, not because we did not have the right treatment, but because they could not find a physician with the expertise to deal with their rare cancer, or did not receive the right mutational test to permit the selection of a drug and a dosage that would target it; or could not afford the out of pocket costs for the drug; or did not receive the side effect management support needed to enable them to actually take an oral drug every day.

The world of cancer care in the United States, and the 67 countries The Life Raft Group is engaged in, presents a survival maze of challenges that makes an Olympic track event shrink in comparison.

Ironically the more scientific knowledge increases the more daunting the logistics for survival become. Rare cancers like GIST, the focus of The Life Raft Group, become even rarer with each scientific success in identifying different subtypes often requiring a different treatment approach. It is simply unacceptable that most patients still do not receive the available mutational tests that would tease out the right treatment target either because the doctor failed to order them, or the insurance company refused to pay for them.

## From Our Executive Director Norman J. Scherzer



Further, a diagnosis of cancer is often a blueprint for financial disaster not only for the patient but for the entire family. I recall a personal episode years ago when my wife had surgery at Memorial Sloan Kettering for her cancer and we received an out of pocket bill for \$215,000 because Oxford, her health insurance, was not accepted there. Fortunately, I had the experience and tenacity to negotiate a resolution but I know that many could not have. Financial toxicity is a topic by itself which we will continue to address, including the unsustainable costs of new drugs for rare cancers.

When a plane crashes or a building collapses we expect a transparent investigation to determine the cause. Imagine if we did the same when a patient dies from cancer and that we included on the death certificate the contributing factors to the death: whether the patient received the appropriate tests, whether the patient was seen by an appropriate specialist, whether the patient was able to access and afford the prescribed treatment and whether the patient received the side effect support to actually be able to take the treatment. If any of these things did not happen, we would document the reason why.

Imagine what we would do with the data if *"we were mad as hell and not going to take it anymore."*

### ▶ TRIAL OF ONE continued from cover

GIST was never mentioned because before the year 2000, GISTs were previously misclassified as other types of soft tissue sarcoma (STS), including tumors of smooth-muscle origin (most commonly leiomyosarcoma, and also leiomyoma or leiomyoblastoma). The tumor was removed, and no follow-up treatment was indicated.

Fast-forward to March 2017. Douglas had a non-symptomatic bulge that he ignored for a long time because he assumed it was a hernia. After consulting with his doctor and scheduling surgery, he chose to see

Dr Kevin Hiler, a renowned surgeon for a second opinion. Dr. Hiler ordered a CT scan which revealed a 21 cm mass hanging off Douglas' liver. Identified as a GIST, Douglas debated for almost a month whether or not to take neoadjuvant Gleevec for three months or go directly for surgery. He opted for the surgery with Dr. Carlos Corvera at UCSF, who removed a 3.2-pound GIST with negative margins, along with 30 percent of his liver.

"After waking up and hearing the surgery was a success, I was a happy guy because that was that," he said, "and then about two and a half months later I started Gleevec

for three weeks, only to discover through my oncologist, Dr. Michael Korn, that I did not have a KIT mutation (which typically defines a GIST diagnosis).

As far as adjuvant treatment goes, he was out of options for a preventative treatment protocol because the potential side effects of the available drugs made it unwise to take them.

"So, I went on my way starting with a three-month CT scan here, then a six-month CT scan there. Everything was going smoothly. We were getting ready to move from California to another state," said Douglas.





*Road Warriors, 15 x 30, Oil*

*Douglas Morgan*

Then, in early 2019, he began to experience intense and debilitating facial flushing. Various causes were suggested, including carcinoid syndrome. All were eliminated through extensive testing. Walks and daily meditation alleviated the worst of the flushing, but Douglas' painting and other activities became almost impossible.

On June 10, 2019, a CT scan revealed a massive recurrence, including several tumors and numerous lesions. A biopsy revealed that the GIST had returned and it was a BRAF mutation although he did not understand what that meant.

"It was stunning and terrible news, and I was in shock," Douglas shared. My January scan was fine, and I had always understood my particular GIST to be a slow growing slug!"

Currently, there are no drug treatments available for the BRAF mutation in GIST. During his visit with Dr. Michael Korn of UCSF, who did extensive research, Douglas was told that BRAFTOVI® and MEKTOVI® produced by Array BioPharma, which are currently used for melanoma, would be the most effective combination to combat his mutation. Douglas said that Dr. Korn remarked that 'we were taking a 'leap of faith.'

In the United States, BRAFTOVI in combination with MEKTOVI are approved for the treatment of unresectable or metastatic melanoma with a BRAFV600E or BRAFV600K mutation, as detected by an FDA-approved test. BRAFTOVI

is an oral small molecule BRAF kinase inhibitor and MEKTOVI is an oral small molecule MEK inhibitor which target key enzymes in the MAPK signaling pathway (RAS-RAF-MEK-ERK). Inappropriate activation of proteins in this pathway has been shown to occur in BRAF-mutant unresectable or metastatic melanoma.

[arraybiopharma.com/our-products/braftovi-mektovi](http://arraybiopharma.com/our-products/braftovi-mektovi)

"Bonita and I, being completely unaware, thought, ok, we'll get these drugs in a day or two and, of course, nothing like that is possible because there are no BRAF mutation inhibitor GIST drugs approved by the FDA and Medicare Part D, only for melanoma. Gleevec is different because it's approved for GIST patients."

Before connecting with Array ACTS®, which is the patient assistance division of Array BioPharma, Inc, the Morgans discussed selling their home to pay for the expensive drug regimen. Fortunately, with the help and diligence of the staff of UCSF and Array ACTS®, compassionate use of BRAFTOVI/MEKTOVI was approved though the end of 2019, under the supervision Dr. Korn.

Douglas began the treatment therapy on July 17th. A miracle occurred on the first evening Douglas started the regimen when the flushing disappeared. For the first few days, he and Bonita were afraid to mention to each other the absence of the symptoms because it was so extraordinary.

On September 23, Douglas had his first CT scan since starting the drug therapy. The next day he was informed of the results, which were

extraordinary. After reviewing the report, the oncologist told the Morgans that all the tumors had shrunk more than fifty percent and the innumerable lesions are gone.

"So, the drugs are working nicely. They are doing their job. Not only do I feel normal, but I feel great!"

Douglas was very emotional about this and he continued, "The thing with all these drugs was that I was very afraid of the side effects. Eye problems, fatigue, rashes - all kinds of really bad stuff because they are powerful, targeted therapies. I even wondered if I could take a lower dose for starters and work my way up." Douglas said, "And also because these drugs had never been used on a GIST patient - I was taking the melanoma dosage. Bonita described it as shock and awe."

Douglas experienced stomach issues for a few weeks and a slight rash, but no serious side effects. He is able to eat normally and to continue his normal schedule of painting (five to six hours a day). Figuratively, he considers himself a 'clinical trial of one' and wanted to share his story so that doctors around the world could learn that there's another BRAF mutation inhibitor produced by ARRAY BioPharma and that it is working.

***We will be discussing the BRAF mutation in an upcoming issue of LRG Science.***

*Harbor Red, 8 x 10, Oil*

*Douglas Morgan*





## ▶ HEALTH TOUR continued from cover



*Participants at ISPOR LATAM in Bogotá*

The first meeting was ISPOR LATAM 2019, held in Bogotá, Colombia, to which I was invited to participate in two sessions. The first one was: **"Patients Involvement and Advocacy in Health Technology Assessment in Latin America."** The meeting included patient representatives from Argentina, Brazil, Colombia, and Peru along with academicians, researchers, and government and Health Technology Assessment (HTA) representatives. We discussed the importance and the need for patient participation in HTA, the barriers we share in Latin America, and the future steps we can take to achieve patient participation in decision-making concerning health policies.

One result of the meeting is our new goal to develop a white paper describing the role of the patient's participation in HTA, publish it, and also to implement it as a framework for patient organizations' advocacy work in Latin America.

I also attended an Educational Workshop for Latin American Journalists, organized by ROCHE, whose objective was to deepen their knowledge of the health economy, especially in HTA, and of the importance of innovation and personalized medicine in the Latin American context. Together with patient advocates from Colombia and Ecuador, we participated in the panel: **"How to Involve Patients in Health Decision-Making."** We shared our experiences in our respective countries and gave the journalists a patient's perspective on how to increase patient participation and the value we give innovation.

I discussed the importance of the advocacy work done by patients in Chile, illustrating how they created social pressure to make the needs of the patients visible, especially regarding access to on-time diagnoses and treatments. Our efforts resulted in the promulgation of the Ricarte Soto Law. For the first time, patients can truly participate. In the process of the promulgation of the

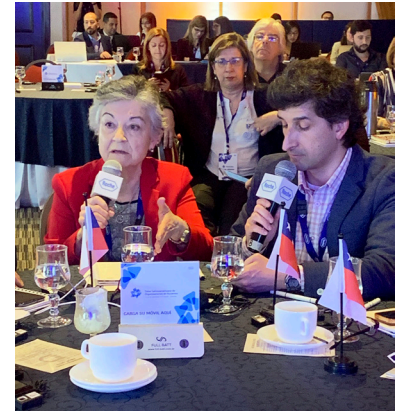
National Cancer Law, the President signed its approval. However, our job is not done. The patients are working fiercely for the special budget assigned to it.

My principal takeaway from the ISPOR Conference was this: The importance of having the patients in the center of all health decisions has become evident, mentioned not only in the panels in which I participated, but in almost every session, and not only that, but also the value of the participation of patients as panelists in many sessions and forums.

The next meeting was a **Latin American Workshop of Cancer Patient Organizations**, organized by ROCHE. This interactive workshop addressed the role of the patients and their organizations in the elaboration of health policies in Latin America. Invited to participate in a panel focused on sharing patient advocacy efforts, I shared the experience and achievements in Chile regarding the importance of the patient's personal voice and social pressure in the process of creating two important laws: The Ricarte Soto Law and The National Cancer Law.

Workshop participants were divided by countries, allowing us to analyze the special needs of each country and set concrete actions to be made to achieve solutions to them.

My principal takeaway from this workshop was this: Collaboration among patient groups and working together in setting common goals is vital. Together we can have a stronger voice to achieve our participation in



*Left to right: Piga Fernández, Jorge Fernández Serpi at the Latin American Workshop of Cancer Patient Organizations in Bogotá, Colombia*



*Chilean representatives at the Latin American Workshop*



*Participants at SELNET in Mexico City*

the decision-making on health issues, but we have to be very respectful in recognizing that each group has its characteristics, personality, and idiosyncrasies.

The final meeting was **SELNET 2019**, the annual meeting of the Sarcoma European Latin American Network, held in Mexico City. SPAEN's (Sarcoma Patient Euronet - LRG GIST partners in Europe) invitation was to represent the patients' voice. SELNET is a four-year international research project of a collaborative model that receives support from the European Commission. Its main objective is to create a network of multidisciplinary specialists from Europe and Latin America as an answer to problems we commonly face in some countries. Such problems include: delay in diagnoses, limited access to specialists, inadequate funding for research, as well as identifying sarcoma centers of excellence. During the meeting, I was able to learn from specialists from Spain, Italy, France, Mexico, Brazil, Argentina, Costa Rica, and Peru.

A very interesting project that opens the possibility for Latin American sarcoma fellows and specialists of the countries involved in it is to work together with European specialists, increasing their capacities and knowledge and sharing experiences and case studies.



*SELNET panel, left to right: Dr. Jorge Martínez Tlahuel, Dr. Javier Martín-Brotto, Dr. Abelardo Meneses, Dr. Mario Cuellar*

As in the previous meetings, SELNET addressed the importance of the patient's voice in the patient's health journey. Patient representatives are a bridge between the specialists and the patients, contributing real world data from patients living with a sarcoma diagnosis, and by acting as a channel for the dissemination of information.

As a patient and an advocate, the main value of my participation in these meetings was to be a voice for patients, to illustrate the importance of patient participation in health decisions, and

to emphasize the value of patient organizations, not only as support groups, but also as important players in decision-making for health policies through their relentless advocacy work.

#### ▶ CAP GUIDELINES continued from cover

The Life Raft Group, collaborating with the Pediatric & SDH-Deficient GIST Consortium and key opinion leaders among the GIST pathology community (with Brian Rubin, MD, PhD, taking the lead), played a significant role in changing these protocols.

The LRG identified that there is disparity among pathologists in the testing of certain subtypes of GIST and testing procedures (i.e. genomic testing) that were being underutilized. This pattern was observed in the LRG Patient Registry where the data illustrated that only 30% of wildtype patients had received advanced mutational testing (or SDHB staining) that was sufficient to identify their subtype of GIST.

The team collaborated on a new diagnostic algorithm that illustrated the need for wider use of targeted diagnostic procedures and submitted the algorithm to the CAP's GIST editorial board.

We are happy to announce that the CAP has incorporated both SDHB and SDHA testing paradigms into the updated GIST protocols which were published in August 2019. Access the protocols here: <https://www.cap.org/protocols-and-guidelines/cancer-reporting-tools/cancer-protocol-templates>

We believe this will be a huge step forward in better diagnosing, identifying, and eventually treating many more GIST patients. We encourage other groups that advise on guidelines to follow suit. This is a great example of a patient advocacy group utilizing real world evidence derived from a patient registry to influence protocols for treatments that affect GIST patients on a large scale.



## Collaborations Accelerate Research

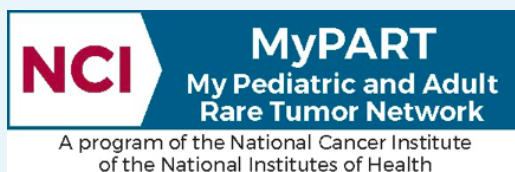
### First Symposium on Personal Control of Genomic Data for Research Held at NIH

By **Sara Rothschild**, VP Program Services

A few years ago, President Barak Obama call on Vice President Joe Biden to lead a national 'Moonshot' initiative to eliminate cancer. The aim was to accelerate cancer research and to make more therapies available to more patients, while also improving our ability to prevent cancer and detect it at an early stage through individual projects. Though the Biden Cancer Initiative has suspended operations indefinitely, the projects initiated by the foundation continue.

As part of the initiative the National Institutes of Health (NIH) hosted a Symposium on Personal Control of Genomic Data for Research at the end of September. They shared activities of how they directly engage rare tumor communities, of which MyPART (My Pediatric and Adult Rare Tumor Network) was featured. The Life Raft Group is pleased to be a new partner in the MyPART Network because advocates are essential partners in the design, conduct, and governance in the research that benefits our community. One of the big takeaways from this conference was that individuals should have control over how/if their data is used for research. The LRG has been a leader in the pursuit of this important mandate for quite some time as we have been conducting a research study with our patient registry and tissue bank for many years.

We look forward to continuing partnerships with the advocate and scientific community on data with the goal of enhancing the survival of our patient community.



The LRG has entered into a new partnership with the National Cancer Institute's MyPART Network (My Pediatric and Adult Rare Tumor Network). MyPART's mission is to engage patients as partners in rare tumor research. As an advocacy partner, our aim is to improve the outcomes of patients with rare tumors and identify and engage patients through education and the dissemination of information.

MyPART addresses rare tumor research challenges by collecting data and biospecimens and conducting rare tumor clinics. Genomic and other molecular data on SDH-deficient GIST tumors are collected and then matched to clinical data and patient-reported outcomes. Researchers receive longitudinal data as they are collected.

The clinics are a continuation of the annual NIH Pediatric &

Wildtype GIST Clinic which the LRG helped found. This clinic gathers experts to focus on the effects of SDH-deficient GIST and to examine therapeutic options. People with rare tumors benefit from having their cases reviewed by many experts at once and by spending time with others with the same disease. Experts benefit by seeing many patients at the same time and exchanging ideas on the best treatment options. This particular clinic was instrumental in our collaborative work with the NIH and other medical institutions.

The NIH Pediatric & Wildtype GIST Clinic is now under the umbrella of the MyPART Network and, through this partnership, we will raise awareness and provide our community with education about these rare GIST tumors. When the multidisciplinary team of experts has updates on their research activities and clinical trials, we will share this important research in a timely way with our GIST patients and their families.

MyPART:  
<http://bit.ly/MyPART-info>

### NCCN FOUNDATION®

The Life Raft Group is pleased to announce a new partnership with the NCCN Foundation, a non-profit founded by the National Comprehensive Cancer Network (NCCN) devoted to empowering people living with cancer and advancing oncology innovation.

The NCCN Foundation produces patient booklets that contain evidence-based disease information and important guidance to help patients formulate questions that are important to them. The Life Raft Group, a leading patient advocacy organization, is working with the Foundation to endorse these guidelines.



To view the 2018 version of this booklet, please view GIST information here on Page 48:

<https://www.nccn.org/patients/guidelines/sarcoma/48/index.html>

For more information on the NCCN Foundation, please visit:

<https://www.nccn.org/patients/foundation/default.aspx>



**SELNET**

The Life Raft Group is pleased to announce a new partnership with SELNET, a project which is creating a multidisciplinary network of European and Latin American clinical and translational specialists. This project's goal is to improve diagnosis and clinical care in sarcomas and establish guidelines for referral policies,

diagnostic methods, clinical practice guidelines among other necessary changes to current practices. The project seeks to create a collaborative, replicable model of diagnosis and care that can be used in the treatment of all rare tumors and in other countries.

The LRG's diverse experience with global partnerships will enhance these efforts by harnessing our global connections and leveraging our real world data.

In 2016 we embarked on an initiative called Salud con Datos (Health with Data) which works collaboratively with Latin American partners in the collection of data to learn more about rare diseases and advance advocacy efforts for cancer patients.

The SELNET network will focus on conducting an international registry-based observational study to assess clinical management and prognosis of sarcomas as well as the development of intercontinental sarcoma biobanks, preclinical models, and a translational study with drugs in rare sarcoma subtypes.

We believe our ongoing collaborations with Salud con Datos will complement the overall objective of the SELNET project.

For more information on SELNET, please visit:

<https://selnet-h2020.org/>

## News from the 17th NIH Pediatric and Wildtype GIST Clinic

By **Becky Owens**, GIST Support International

The 17th Pediatric and Wildtype GIST Clinic was held at the National Institutes of Health in Bethesda, Maryland on September 25-27, 2019. The Clinic was a collaboration amongst researchers, specialists, patient advocates, patients and family members, with the goal of furthering the knowledge of SDH-deficient gastrointestinal stromal tumors (GIST) in order to develop more effective therapies. The following is a summary, written by Becky Owens (patient advocate), of the keynote address given by Dr. Lee Helman at the Clinic kick-off presentation.

In 2008, given the rarity of the disease, Dr. Helman wasn't sure whether they could find any patients to attend the first Pediatric and Wildtype GIST Clinic. He recalled the emotions evident amongst the 12 patients and family members who attended the first Clinic, as they realized that they weren't the only ones in the world with the disease. In the presence of such an ultra-rare disease, it's a very therapeutic thing to connect with others in a similar situation. Subsequently, the Clinic has continued to be held on an annual or semi-annual basis every year.

### What have they learned as a result of the Clinic?

The Clinics have allowed researchers to gain a better understanding of how the molecular characterization of different Wildtype GIST tumor types determines the clinical outcome. In all but one case, the primary tumor initially developed in the stomach. Frequently, there was more than one tumor present at the time of diagnosis. The most frequent location of metastasis was in the liver. These tumors did not have a mutation in either the KIT or PDGFRA gene, as do approximately 90% of GISTs. As a result of what they've learned, it is now recommended that tumor samples from patients without a KIT or a PDGFRA mutation have immunohistochemical (IHC) staining performed in order to determine the presence or absence of the SDHB protein. If the sample stains negative, indicating a lack of the SDHB protein, the tumor can be classified as being SDH-deficient.

There are multiple consequences of having a loss of SDH function, which results in a buildup of Succinate within the mitochondria: The presence of too much Succinate poisons the methylation cycle, resulting in a process known as hypermethylation, which turns "off" some genes that should be "on." Elevated Succinate also poisons the proliohydroxylase enzyme, causing the cells to think that they are aren't getting enough oxygen, even though they actually are.

▶ **NIH CLINIC continued on page 8**

This process, called pseudohypoxia, stimulates blood vessel growth into the tumors. Lastly, the presence of increased Succinate poisons histone function, changing the way the genes are expressed.

Analysis of the tumor samples of the first 85 Clinic participants revealed that approximately 75% had a mutation of the Succinate Dehydrogenase (SDH) gene. Eight out of ten of these SDH mutations were identified as being “germline,” meaning that the mutation was present not only in just the tumor, but also in every cell of the patient’s body. We have two copies of each gene. Those who develop tumors had, for some unknown reason, lost the second copy of the SDH gene in the tumor cells. Patients with a germline mutation can potentially pass the gene on to their offspring. There was a 60% female vs. 40% male prevalence pattern in the GIST Clinic with SDH mutations. Genetic counseling is indicated for family members of patients whose GIST tumor has occurred as the result of an SDH germline gene mutation. The NF1 gene has also been identified as an inherited germline mutation that can cause GIST.

The majority of the remaining 25% of the Clinic participants demonstrated a dysfunction of the SDH gene complex without an identifiable SDH gene mutation. Epimutant GISTs are not caused by a coding sequence alteration, but rather by an alteration in the environment outside of the DNA. These patients can be described as being “epimutant”. In such cases, SDHC function is shut off by a process called methylation. These patients are typically younger, with an average age of 15 at the time of diagnosis, and are overwhelmingly female (with a 99% female predominance). Family members of those with epimutant GIST are not felt to be at risk for tumor development therefore genetic counseling for family members is not indicated.

SDH-deficient patients, whether mutant or epimutant, should be screened for paragangliomas, which have been noted to occur in about 33% of the Clinic participants. The median age for development of the paragangliomas was approximately 40 years of age, so awareness should be maintained that they can occur later in life. A paper recently published in the U.K. recommended the following guidelines for

children with inherited SDH mutations: Those with SDHB mutations should begin being screened (physical examination and blood draw looking for markers of paragangliomas) beginning as early as age 5; with full body MRI screening commencing at age 10. Physicals and lab work should be initiated for those with SDHA, C, or D mutations at age 10; with full body MRI screening commencing at age 15. Early detection of paragangliomas is important as paragangliomas often occur singly, and early surgical removal can be curative.

Future directions: Further study is needed to understand how specific SDH mutations and epimutations will predict how a patient’s tumors will behave. SDH-deficient GIST tumors don’t respond to Gleevec; though it is felt that Sutent and regorafenib most likely slow tumor growth due to inhibition of the VEGF pathway. SDH-deficient mouse models and cell lines are needed which could help to be predictive of the effectiveness

of a therapy before trying it on patients. There is a cell line available that has an SDH plus a RAS mutation; however, the presence of the RAS mutation could influence the results. They’ve had a hard time growing single-mutation SDH-deficient GIST and paraganglioma cells and are trying really hard to do so.

Current trials: There are currently two open trials for SDH-deficient GIST. Trials recruiting patients can be identified by typing “SDH-deficient” into the search criteria box at the [www.clinicaltrials.gov](http://www.clinicaltrials.gov) website. A trial using Temozolomide (Temodar) for SDH-deficient GIST is recruiting patients at UC San Diego. The guadecitabine trial at NIH has just enrolled their last GIST patient. They will release the results once the data is analyzed.

In his concluding statements, Dr. Helman expressed his gratitude to the Clinic patients, past and present, for their participation. Through their help and cooperation, much has been learned about the biology of SDH-deficient GIST. The researchers and specialists involved with the Clinic are working diligently to apply this knowledge in order to develop better therapies.



Left to right: Dr. Justin Annes, endocrinologist at Stanford; Dr. Lee Helman, UCLA, Becky Owens, GSI, Sara Rothschild, LRG, Dr. Sosipatros Boikos, VCU Massey Cancer Center



# Increasing the Quality and Efficiency of Clinical Trials

## Clinical Trials in the Age of Technology

By **Jerry Call**, LRG Data Analyst



Progress in the war on cancer depends on research. Proof that the research is valid and treatments are safe and meaningful comes from clinical trials, yet fewer than 10% of cancer patients participate in them. The reasons for low participation include: patients don't know about suitable trials, they aren't offered a trial, they aren't eligible for a trial, and/or there is no suitable trial available for them locally.

The mission of the Clinical Trials Transformation Initiative (CTTI) is to develop and drive the adoption of practices that will increase the quality and efficiency of clinical trials. CTTI brings together members from more than 80 organizations including representatives from government, industry, patient advocacy groups, professional societies, investigator groups, academic institutions and other interested parties. The Life Raft Group is pleased to be one of these organizations and to participate on the steering committee.

### Clinical Trials in the Age of Technology

The latest CTTI meeting was held in Rockville, Maryland on September 10th, 2019. This meeting was focused on "Harnessing Technology & Real World Evidence for Tomorrow's Clinical Trials." The focus of this meeting was how

mobile technology has improved clinical trials and the challenges and opportunities for this technology to have a much bigger impact in the future. The second related key area of focus was on virtual clinical trials. Put the two together and you have a goal: To conduct virtual clinical trials using new technology including mobile health technology.

If fully implemented, this type of trial has the ability to lower costs to both the sponsors and to the patient while simultaneously increasing the quality of data generated. One goal would be to greatly reduce travel of patients to remote clinical trial sites. Travel cost and taking time off work for travel are often significant barriers to clinical trial participation. For example, a mobile device could track a side effect or biomarker of interest (i.e., blood pressure) much more frequently than visits to a doctor's office would allow.

### Harnessing Mobile Biomarkers

A number of organizations presented examples of using mobile technology in clinical trials and research. The largest trial was an example of both harnessing mobile biomarkers and conducting a virtual trial. In this study, over 419,000 Apple Watch owners virtually enrolled and participated in a clinical trial monitoring atrial fibrillation (Afib). The fraction of patients with an Afib alert from the device was small, about 0.5%, but that was still 2,161 patients. The clinical trial protocol then allowed for these patients to be referred to doctors for appropriate follow-up. This trial was conducted by Stanford University, funded by Apple, and was conducted in only eight months.



Representatives from both the FDA (Food and Drug Administration) and the EMA (European Medicines Agency) were panelists at the meeting. Both regulatory agencies were extremely interested and supportive of the mobile and virtual trial initiatives and they saw great potential to transform the clinical trials process.

Another interesting presentation was from Open mHealth, a non-profit that has developed standards for transferring data between various devices and platforms. Open mHealth has developed standards for both iOS and Android devices.

<https://www.openmhealth.org/>

### Digital Biomarkers Suggested

One of the more interesting stories of implementing digital biomarkers comes from Christine Taylor of the data science company, Orikami. Taylor tells the story of developing an app, MS Sherpa, that allows patients with Multiple Sclerosis (MS) to monitor and report their fatigue, mood, concentration, and stress. Using a process developed by CTTI, Orikami developed a set of digital biomarkers. One of these measures eye movements and another uses a two-minute walking test.

<http://bit.ly/biomarker-article>

The participants of the CTTI meeting see mobile technology and virtual trials not only as an important part of the future of trials, but also as transforming clinical trials of the future. They also pointed out that this is too big a job to be done alone. It will take many different specialists pooling their resources and talents to make it happen.

# Finding a Ride to Your Doctor's Appointments

## Overcoming an Obstacle that Comes with Regular Cancer Care

By **Belinda Gist**, LRG Contributor

Living with cancer is not easy but getting back and forth to your medical appointments should be. However, this is not always the case. In general, transportation issues are a major contributor to missed medical appointments in the US. Over 3.6 million people miss their medical appointments each year, preventing them from getting the care that they need or getting access to the medicine that could help them. People report that distance to the doctor's office, cost of the transportation, and access to a driver or public transportation as the main reasons that they are having a challenge with transport.



This is especially true for patients with a rare cancer like GIST. It is important for anyone with a rare disease to see a physician who has experience with and who treats many patients with a similar diagnosis. Often, these experts only work in centers of excellence, academic medical centers located in large cities. This leaves the patient with a significant transportation challenge.

GIST patients are not only challenged with transportation to see a GIST specialist, but also require regularly scheduled scans to assure that their treatments are working. Just as with the general population, people living with cancer regularly report that getting a ride back and forth to their treatment is a significant barrier to receiving care, leading them to delay or discontinue their therapy. "I couldn't find a ride," "I didn't have money to pay for cab fare," or "My daughter just can't take any more time off work to bring me back and forth" are commonly heard.

The good news is that there are several programs available to provide support to people during their therapy. A central point for transportation resources is the **American Cancer Society Road to Recovery Program**, which offers a

directory of available options, sorted by city.

The ACS Road to Recovery program partners with municipalities, faith-based organizations, and a network of volunteer drivers to provide the much-needed rides back and forth to appointments. More information on the program is available at <http://bit.ly/ACS-program> or by calling 1-800-227-2345.

**Uber Health** is a new option for patients and caregivers. Launched in the spring of 2018, Uber Health is an extension of the Uber ride-sharing platform for patients and caregivers.

Differing from traditional Uber rides, Uber Health rides are managed through the health care provider. The doctor's office has an account with Uber Health, and they can schedule rides up to 30 days in advance of an appointment, allowing for simple access to a ride when it is needed. Multiple visits can be scheduled at once, making it easier to take care of a series of treatments or follow-up visits and eliminating the stress of

finding a ride for every appointment individually. From the patient perspective, using Uber Health does not require a smart phone, unlike the standard Uber app-based service. Scheduling and arrangements can be made through text messages and traditional phone calls. Rides from Uber Health can be submitted to the health insurance provider and there are no increased costs over standard Uber rides associated with using this more personalized service.

**Lyft Concierge** offers a similar platform to Uber Health, also providing transport coordinated through the doctor's office. As with Uber, the Lyft rides can be paid for by a patient's health insurance provider, including Medicare and Medicaid in some cases.

**Chemo Cars**, available in Charlotte, NC and Amarillo, TX with plans to expand, has provided over 12,000 free rides since its inception in 2017. Founded by Zach Bolster after witnessing his mother's struggle with pancreatic cancer, Chemo Cars is a non-profit organization that partners directly with Uber and Lyft to provide free transport to and from medical visits. The cost of the rides is provided by donations to Chemo Cars, requested at \$12 per donor to pay for one ride.

<https://chemocars.org/about/faq/>

**More information about patient transportation assistance can be found here:**

[lifteraftgroup.org/financial-aid/](http://lifteraftgroup.org/financial-aid/)



## Across the Border Virtually

By **Pete Knox**, Senior Director, Research



**Pete Knox, LRG Senior Director, Research**

On September 28th, I had the pleasure of giving a remote presentation for the Ottawa GIST Day of Learning (GDOL) hosted by the Life Raft Group Canada. The event was well attended, with over 40 attendees and speakers from throughout Canada, such as the relatively local areas of Ontario, and Quebec, but also from as far away as British Columbia, New Brunswick, and even Nunavut, as well as New York and Massachusetts.

My topic was "SideEQ...The next step on the road to personalized side effect management." The presentation focused on two related things that remain important to optimizing patient outcomes. First, the existence of SideEQ, which provides a venue for patients and caregivers to record and rate side effects and the impact on quality of life; it also provides members with the option to view and post tips on managing those side effects. The Life Raft Group believes that doing this successfully will help patients stay on their medication longer, thus contributing to better outcomes, such as increased progression free survival and overall survival. Data presented included the impact of

side effects on compliance, how side effects may vary by gender, and the international scope of the users in SideEQ. Especially well received was the fact that, when looking at users outside of the U.S., Canada had the highest number of participants in SideEQ. <https://mysideeq.org>

In addition, I spoke about how side effects and their management should be personalized, as side effects vary by individual. When you read the prescribing information for a medication, you'll notice a number of side effects are often listed, but we know through the data collected via platforms like our Patient Registry

researchers, and patients so they can better understand what side effects may occur on an individual level. For a more in depth description of personalized side effect management and the role SideEQ can play, please read an article we published a few months ago, available on our website at <http://bit.ly/side-effects-article>.

Overall, the presentation was well received, with attendees remarking that it was "interesting," "useful," and that SideEQ seemed like a "great platform for sharing info." My thanks to Malcolm Sutherland and David Josephy of LRG Canada

for arranging the event and inviting my participation. Thank you also to the attendees for listening and participating, and to all of the users of SideEQ that have supplied their data and made these analyses possible.

Please visit GIST Sarcoma Life Raft Group Canada to view presentations from the GDOL:

<http://bit.ly/GDOL-Ottawa>



**Participants & speakers at the Ottawa GDOL**

that not every patient experiences every side effect, and even when multiple patients have the same side effect, intensity and/or duration can vary.

Finding out what contributes to the variation of side effects is one of the main reasons the LRG introduced SideEQ. It enables us to collect data to understand what contributes to the variations, and then to provide this information to physicians,

### Chicago Patient Support Group



The Chicago Area GIST Patients group made history this year! This group has been meeting the longest of any LRG support group - continuously since 2002.

## A Few Minutes with GIST Expert - Dr. Gina D'Amato

### Sylvester Comprehensive Cancer Center, Florida, USA

*Dr. D'Amato's passion for her patients guides her on this newest leg of her professional journey in Miami with mentor and GIST expert clinician and researcher, Dr. Jonathan Trent.*

This past February, oncologist Gina D'Amato left her practice in Atlanta, GA to join the Sylvester Comprehensive Cancer Center in Miami. A clinician with over 15 years of experience with GIST patients says the Center in Miami is similar to her previous practice with the exception that Sylvester is involved in research such as circulating tumor DNA and currently has three clinical trials in progress.

"It's encouraging for patients, knowing that they are going to be treated at a state-of-the-art institution that's on the cutting edge of what's being developed for GIST," said D'Amato. D'Amato did her undergrad work and residency at the University of Miami and her fellowship at Moffitt Cancer Center.

D'Amato has specialized in sarcoma and GIST since her fellowship and decided as a youth to be an oncologist after her older sister's battle with Hodgkin's lymphoma. Her sister is a survivor of 30 years. "I saw that cancer can be cured. But the cure is tough. And chemotherapy is barbaric and that we have to find better treatment options. I tried to keep an open mind when I went to medical school, about other specialties, but I was always focused on oncology. The need is great for improvements and better treatments with less toxicity."

Being a general oncologist can be a tough job because you have to know so much about so many types of cancer. D'Amato credits Dr. Trent with her specialization in sarcoma. Her plan had been to be a lymphoma expert, but Moffitt

Cancer Center needed a sarcoma specialist and Dr. Trent turned down the opportunity, so D'Amato stepped up.

D'Amato shared that delayed diagnosis in GIST is a continuing challenge. When a patient sees a doctor, a general practitioner, even a 'general' specialist, they are not likely to consider a rare sarcoma because it is not the most plausible scenario, particularly with young people. Cancer is not the first diagnosis on their minds.

"You don't learn about these diseases in medical school. The students aren't rotating to the clinic or through the oncology floor. They aren't exposed to it and when patients present with symptoms they are thinking of other diagnosis besides GIST. For example, GIST starts on the outside of the stomach, not the inside. So, when someone has stomach issues, they go to a GI. They're looking inside because that's where you can get an ulcer or stomach cancer or something else. They're not looking on the outside because it's so rare. Other cancers can have delays too, but other cancers have screening tools; breast cancer has mammograms to detect early; melanoma, skin checks. With GIST, there's delays in diagnosis, and late stage diagnosis because there's no screening tool for GIST and if the patient doesn't get a CT scan or an endoscopic ultrasound that would find the tumor diagnosis is delayed. Often a patient will get diagnosed by either an astute doctor or because they wind up going to the ER with bleeding or abdominal pain."

Dr. D'Amato says she learns from her patients. Not every patient can be treated the same, the nuances of GIST are different for everyone. For their emotional and physical well-being, she advises them to gather a

patient support team and lets them know that they have to take care of themselves.

"I try to tune into my patients when they're first diagnosed and throughout the course of their care. There's a certain amount of anxiety with a cancer diagnosis. I feel anger too, for those who haven't been diagnosed sooner, but I tell myself the same thing I tell the patients, you have to keep moving forward."

D'Amato says the patients who tend to deal better emotionally with the diagnosis are the ones that were diagnosed right away as opposed to those that had been undiagnosed and ailing for a while. The anger about the delay in treatment can keep patients from moving forward. Other patients can be confused or angry about a cancer diagnosis if they feel they've done 'everything right'. Why did it happen to them when they ate healthy and lived a healthy lifestyle?

"I tell them, yes, you've done everything right, and because you were healthy, that means you can tolerate the treatments and fight the cancer better," said D'Amato. "And I'm optimistic. People survive, against all odds. There are so many new treatments, so much research ongoing."

Dr. D'Amato is currently seeing patients two and a half days a week, potentially expanding to three, and is hoping to have students rotating with her from the University in the future.



#### Need a GIST Specialist?

Search our database for U.S. and Global experts here:  
[lifteraftgroup.org/gist-specialists/](https://lifteraftgroup.org/gist-specialists/)

#### Need help finding a specialist?

Contact [dnieves@lifteraftgroup.org](mailto:dnieves@lifteraftgroup.org)



**The Life Raft GROUP**

QUESTIONS TO ASK YOUR DOCTORS TO BEGIN YOUR GIST EDUCATION

<b>At Diagnosis:</b>	<ul style="list-style-type: none"> <li>Was any immunohistochemistry staining performed to confirm that I have GIST? This includes CD117 and/or DOG1</li> <li>What is my Risk of Recurrence (ROR)/chance of tumor coming back? ROR is measured by tumor size, location, mitotic rate and tumor rupture - all of which can be found on the pathology report. ROR classification method/nomograms were developed for GIST, as some experts believe that all GISTs can have malignant potential. If recurrence or metastasis has already happened, ROR does not apply.</li> <li>How many other GIST patients do you treat?</li> <li>If I have a question between appointments, will you be accessible? How can I reach you? This includes outreach via phone or email or contact to the doctor's primary oncology nurse for questions and concerns between appointments.</li> </ul>
<b>After Surgery:</b>	<ul style="list-style-type: none"> <li>Did I have clear margins? Clear surgical margins means that the tumor was removed without bleeding, and did not leave cancerous cells in the tissue.</li> <li>How will this affect my quality of life? Post-operative GIST patients may need to make changes in diet and lifestyle in order to avoid symptoms and perform daily activities.</li> <li>Do I need to start a new diet?</li> <li>How often will I be having scans as follow-up? According to the National Comprehensive Cancer Network (NCCN), it is recommended to have scans every three months for the first three years depending on the tumor staging (if it is single tumor or metastatic).</li> </ul>
<b>Starting a New Medication:</b>	<ul style="list-style-type: none"> <li>Do you know my mutation? Or will you perform a mutational analysis on my tumor? The National Institute of Health (NIH) defines a gene mutation as a permanent alteration in the DNA sequence. Mutational testing can determine more details on a patient's GIST tumor, so that an individualized treatment plan can be established.</li> <li>What role does my mutation play in treatment? Some tumor mutations are more responsive to higher dosages of treatment, while others may not respond to treatment at all.</li> <li>How does my GIST medication work? Most GIST medications belong to the drug class Tyrosine Kinase Inhibitors (TKIs) which are targeted therapy inhibiting the enzymes that are part of cell growth and division. Examples include Imatinib, Sunitinib, Regorafenib.</li> <li>What side effects should I expect?</li> <li>What should I do if I experience side effects?</li> <li>How and when should I take my medication? This includes details such as coordinating medication around meals, or splitting dosages and managing frequency.</li> <li>Am I starting at the lowest dose? Will I ever need to increase this dosage?</li> <li>How does my ROR affect in how long I'll be on treatment?</li> </ul>

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## Update on a New Clinical Trial Offered to Eligible GIST Patients



### Deciphera Pharmaceuticals is testing an investigational drug called ripretinib (DCC-2618) as a potential new treatment option for patients living with GIST.



#### About Ripretinib

Ripretinib is an oral investigational drug designed to treat GIST that are growing because of changes in specific genes. By targeting the inhibition of signals from the genes that cause cancer to grow and spread ripretinib may provide benefit to patients living with GIST.

#### Study Overview

The INTRIGUE study is a Phase 3 clinical trial testing the investigational drug ripretinib (DCC-2618) for patients living with GIST that are no longer on imatinib due to progression or intolerance. The study is being conducted to learn more about the safety of DCC-2618 and how well it works against cancer, as compared to sunitinib (Sutent), in patients who have previously received imatinib (Gleevec).

Approximately 358 GIST patients will participate in the trial worldwide. In addition to meeting other eligibility criteria, patients may be eligible to join the study if they:

- Are at least 18 years old
- Have been diagnosed with GIST and received prior treatment with imatinib only
- Are willing and able to comply with study procedures

#### For more information contact:

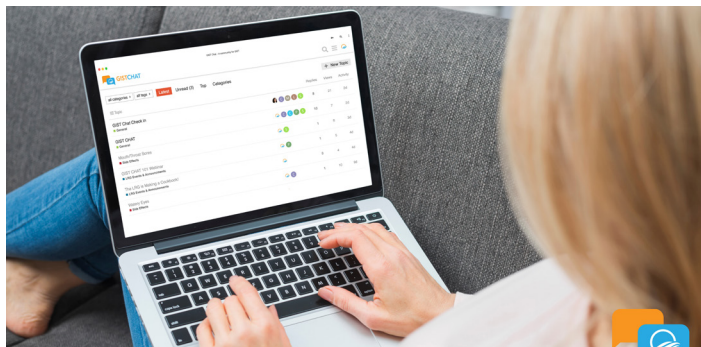
**clinicaltrials@deciphera.com or visit [clinicaltrials.gov](http://clinicaltrials.gov)**

**Disclaimer:** Please note that DCC-2618 has not been approved by the United States Food and Drug Administration (FDA) or any other regulatory agencies for sale or use by the public.

The information contained wherein is provided solely to inform patients about the existence of this trial, and does not in any way constitute endorsement by the LRG nor is it intended to serve as medical advice. Any questions about how this trial may fit into your overall treatment plan should be discussed with your healthcare team. Sutent and Gleevec are approved for the treatment of GIST by the FDA and other regulatory bodies around the world.

### Need a checklist to take to your Doctor's Visit?

A pdf is available to print out at:  
<https://bit.ly/DoctorsChecklist>



### Take steps now to join GIST Chat, our new online community for GISTers and Caregivers!

We currently have a numbers of topics under discussion, including our members sharing their photos and GIST Stories.

If you are a current ListServ member you should have received an email to join GIST Chat. The message came from [gistchat@discoursemail.com](mailto:gistchat@discoursemail.com).

If you would like to join GIST Chat and are an LRG member please email us for an invite: [outreachandengagement@liferaftgroup.org](mailto:outreachandengagement@liferaftgroup.org)

You can also check out our webinar which will guide you through setting up your account and discuss how to navigate the new platform.

#### Webinar link:

<https://www.youtube.com/watch?v=qKGF6ealHXc>

**Volunteer Spotlight**  
**Jason DeLorenzo, Virginia, USA**



*The DeLorenzo Family*

Jason DeLorenzo has been a GISTer since 2003. After moving to Virginia, Jason returned home to New Jersey to visit his family. His visit with his family went much differently than planned as he become ill and wound up in the emergency room. Doctors originally believed his pain was from an ulcer, but soon they realized it was pediatric GIST. Jason took Gleevec for a year and tried to live as normally as possible. In 2007, he had a recurrence and would continue to be monitored by doctors. While being a young adult with a GIST diagnosis was scary for Jason, he continued to persevere and met his wife Jill in 2010. With the support of his wife, Jason became more active and engaged in the GIST community. In 2012, he underwent surgery to remove the tumor found in 2007. Jason became a patient at the NIH Pediatric Wildtype GIST Clinic and would continue to be placed under surveillance post-surgery. Three years later, in 2015, Jason learned of a third recurrence and he will continue to monitor the progression.

Raising awareness for the GIST community is important to the DeLorenzo family. Recently they held their 14th annual barbecue where friends and family gathered to fundraise for #GISTresearch in support of The Life Raft Group. They use this event as an opportunity to raise awareness about GIST and put a face to the disease. Jason and Jill believe it is important to support the GIST community and educate their children.

The DeLorenzos take each day as it comes with a spiritual, God-centered living philosophy. They believe in supporting each other and playing on the same team. Their message for others on their GIST journey is to not let your sufferings get you down, but rather use it as an opportunity to grow.

**Global Representative Spotlight**  
**Atul Upadhyay, Nepal**

In February 2018, GIST came to me as a surprise, as I was at the hospital only for a regular checkup. During that checkup, the doctors also asked for USG (ultrasonograph), and the radiologists assumed the movement in the stomach to be GIST! The radiologists were able to do so because, a similar case had been reported in that hospital a couple of weeks before. To confirm, I had to do FNAC (fine needle aspiration cytology) and then a CT Scan. Once confirmed, I was operated on in two weeks time, with a GIST size of 5 cm and mitotic rate less than 50. A few months back, I had to go through another laparoscopic surgery to remove incisional hernias (4 to be precise) that occurred on the incisional sites.

Unfortunately, the general public in Nepal is not aware of this tumor and the medical system in the country is also not well developed. As a representative for the country, I would first like to identify the number of GIST cases in the country. My next task would be to raise awareness about this tumor, and let people realize that it is manageable with medical treatment. I will also discuss with relevant policy makers how to develop policies regarding GIST.



*Atul Upadhyay*

**Thank You to Our Major Donors  
for August & September!**

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GIST ASK is the LRG Patient Registry's new initiative to answer any GIST-related questions that you may have. Every month we will feature one popular question with a detailed answer. This will not only help fellow GISTers understand more about the disease, but it will also will help empower patients to become advocates of their own GIST journey. Email your questions to: [skaur@liferaftgroup.org](mailto:skaur@liferaftgroup.org)

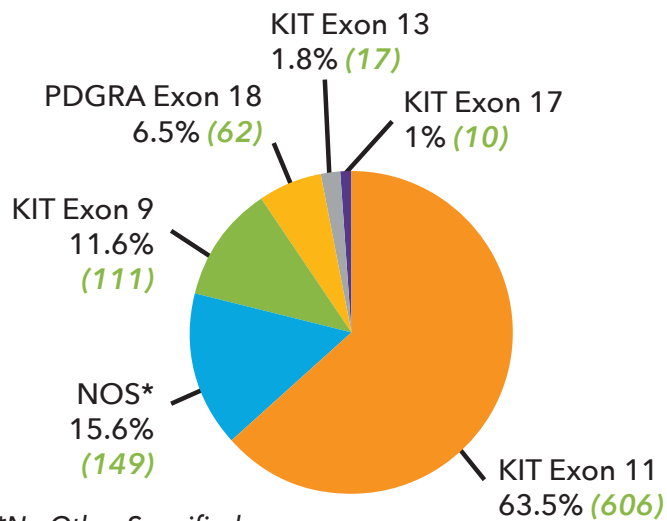


## Patient Registry Data

**Patients in the Registry: 2050**

**Male: 1006 - Female: 1044**

Percentage of mutation types (# of patients)



\*No Other Specified

## LRG Cookbook Fundraiser

The Life Raft Group's Outreach & Engagement department is excited to announce that we are launching a LRG community cookbook which will be sold at the upcoming Life Fest in July 2020. This cookbook was inspired by LRG volunteers Julie Durkee and Kay Stolzer.

We are looking to have recipe submissions by patients and caregivers. These recipes can include any type of comfort food, or any family recipes you just want to share!

You can label what type of category this recipe would fall under, and the recipe name as well. You may add a short note about the inspiration of the recipe, dedication and/or the origin for this recipe if you would like.

**Submission deadline is November 22, 2019.**

Submit your recipe via the form below:

<https://lifteraftgroup.org/cookbook-recipe-form/>

You can also print the form and mail it to:

The Life Raft Group  
Attn: Joanna O'Rourke  
155 US Highway 46, Ste. 202,  
Wayne Plaza II,  
Wayne, NJ 07470



If you have any questions or need more information, please contact Joanna:  
[jorourke@lifteraftgroup.org](mailto:jorourke@lifteraftgroup.org).

## The LRG Calendar

See what a GDOL can offer you - visit this link to see presentations, photos, and posts about past GDOLs:  
<https://lifteraftgroup.org/gist-day-of-learning/>



March 28, 2020, Moffitt Cancer Center. Register:  
<https://lifteraftgroup.org/event/gdol-tampa-2020/>



May 16, 2020, University of Colorado, Anschutz Medical Campus. Register:  
<https://lifteraftgroup.org/event/gdol-denver-2020/>

See past Life Fest Events:

<https://lifteraftgroup.org/life-fest/>



Life Fest 2020 - New Orleans

Register: <https://lifteraftgroup.org/event/lifestest2020/>

For questions or more information about GDOLs or Life Fest, please visit the links provided or contact Diana Nieves in Outreach & Engagement at [dnieves@lifteraftgroup.org](mailto:dnieves@lifteraftgroup.org)

# The Life Raft Group Global Community

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### Interested in Volunteering?

Contact: Diana Nieves, LRG Senior Director, Outreach & Engagement  
[dnieves@lifteraftgroup.org](mailto:dnieves@lifteraftgroup.org)

### Interested in serving on the LRG Board of Directors?

Contact: Laura Occhiuzzi, LRG Senior VP  
[locchiuzzi@lifteraftgroup.org](mailto:locchiuzzi@lifteraftgroup.org)

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## Life Raft Regional Chapters Find info for a local & global reps at [lifteraftgroup.org/find-a-support-group/](http://lifteraftgroup.org/find-a-support-group/)

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