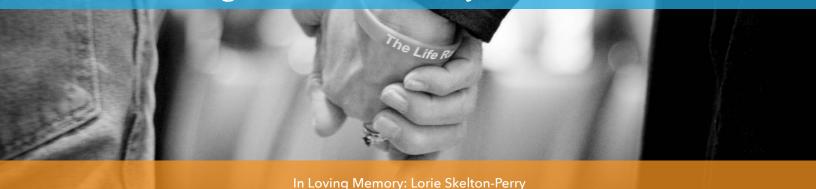


# Ensuring no one has to face GIST alone



# Happy Holidays to All!



## **Delivering Hope: A Modern Day Miracle of Birth**

by Carolyn Tordella, Assistant Director of Communications

April Lopossa lives in the quiet hometown where she grew up in Indiana, with husband Tyler, between their two large families, with their own two girls and three dogs. Last November when she discovered she was pregnant with their second baby, they never could have imagined what the following year would bring in addition to a new baby. The couple received the worst possible news at one of the best times of their lives and during a pandemic.

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This GIST iourney began when her first child, Athena, was only five months old. April began experiencing chronic diaestive issues. Housebound except for an intense work schedule. she could barely eat more

than some pretzels or an apple.
Then in November of 2019, April discovered she was pregnant again.



Amelia, Athena & April Lopossa

Due to her work schedule and healthcare provider issues, April had trouble securing an appointment with a new primary doctor. The problem steadily worsened. At her pre-natal visits, her medical team said that hormones can cause a lot of issues and suggested more fiber for the diarrhea.

In January, when she was finally able to get blood tests, they showed inflammation but there was nothing to be done about that while she was pregnant.

This story continues on page 3.



2000 was a dark period for a group of patients who had no viable treatment for their rare cancer. Most had been misdiagnosed and for many, it felt as if there was no hope.

And then came a ray of light in the darkness. A scientific breakthrough gave a name to their cancer-gastrointestinal stromal tumor, which led to new options. Through the efforts of dedicated researchers and the tenacity of a pharmaceutical executive who dared to bring an obscure treatment to market, hundreds of lives were saved, including that of my beloved wife, Anita.

2020 has also been a period of great darkness. Since our beginning, the Life Raft Group and our members worldwide have been furiously paddling to keep GISTers alive. Suddenly, this year, we found ourselves in rougher seas, with the light dimming as our patients faced the challenge of getting essential treatments during a global pandemic. We were in uncharted waters.

But the Life Raft Group is built on a foundation of love and persistence that enables us to do great things together. In this dark year, we were not only the life raft for patients, but also the lighthouse, shining light where there was little.

Of all that we have strived for this year, there are two examples of those points of light that touched me deeply. This past April we were contacted by a young mother in Ireland whose seven-year-old daughter was diagnosed with GIST. Her primary treatment team suggested an operation that would be severely life-altering for this young girl. It was critical for her future to have more viable solutions from the best experts available. Within days, we assembled a team of 12 renowned GIST specialists from around the globe who sacrificed time out of their busy schedules in the middle of a pandemic to collaborate on options for the child's treatment. This LRG Virtual Tumor Board provided a lifeline for this young patient and changed her outcome considerably.

Her treatment team in Ireland worked closely with these GIST specialists, and a new plan was developed that would spare this beautiful young girl from undergoing what would have been a daunting challenge to her quality of life.

June brought another significant point of light into our lives when the National Institutes of Health (NIH) asked us to facilitate a virtual version of their Pediatric & Wildtype GIST Clinic. Since 2009, we have been instrumental in establishing and supporting this clinic, which provides both expert consultations and a chance for these young GIST patients and their families to bond.

Faced with the Covid-19 pandemic, the clinic was not able to meet in-person. The NIH called on the Life Raft Group to help arrange a virtual event, which resulted in a review of challenging cases by a group of renowned GIST specialists from around the globe - an amazing collaboration across borders of country, organization, and cultures.

These points of light are just two that stand out to me. I am in awe of the selflessness of our medical professionals, the hard work being done by our staff, and most importantly, the way our GIST community of patients and caregivers have been there for each other.

It is my hope that you will help us through this dark time by continuing to support our efforts with your donations. Needless to say, the pandemic has put a dent in our funding while the need for our interventions has grown.

Let's continue to be points of light for each other.

- Norman J. Scherzer



#### This story is continued from cover

"I was told that when you go for your anatomy scan, have them check your gallbladder and if that's fine we'll do a colonoscopy after you have the baby and see what that shows," said April.

In early March of 2020, April woke up with severe pain. She went to work anyway, but ended up having to leave and call her primary who told her to call the obstetrician right away. The obstetrician saw her and sent her to the emergency room. After twelve hours, April learned that her gallbladder had been giving her all this trouble. An ultrasound confirmed all was good otherwise, but the surgeon said the gallbladder had to be out before her third trimester otherwise it would be very difficult to remove. The

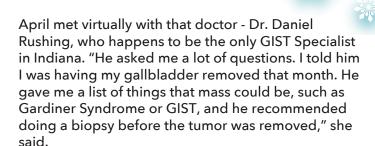
surgery couldn't be performed right away, however, because the Covid pandemic had just hit the United States and all non-essential services were curtailed.

On St. Patrick's Day during her anatomy scan, April learned she was having a girl and a mass was discovered in her abdomen. April recalls that moment, which she lived through alone (her husband wasn't allowed to be present due to the Covid rules).

"They were pressing on it and I remember them saying, 'Does it hurt, do you feel it?' I couldn't feel it. I didn't know there was anything there. They sent me for an MRI. I was about 22 weeks pregnant by this time."

"I got a call from my doctor about the MRI results and he said it was a desmoid cyst, just a clump of cells. He said

they'd just take it out when I had the baby. He also let me know that this wasn't his specialty, but that the surgeon would know more. I appreciated the honesty. So, I did my own research and learned that desmoid tumors are actually really rare and they say that if you have surgery on them that they can grow back even more aggressively, so it's best to not do surgery. I learned this all on Instagram, searching hashtags, and found a story about a woman who had a desmoid tumor and her doctor. I connected with her," April shared.



In April 2020, April had an ultrasound biopsy, and two days later, at 26 weeks, she had her gallbladder removed. After the gallbladder surgery was when she actually got to see a picture of her tumor. Her surgical team praised her for calling Dr. Rushing - otherwise they would have removed the tumor and it would

> have just been noted as a random benign tumor and it might not have been identified as a GIST thus postponing treatment.

Once the biopsy was performed and the mutation revealed as exon 11, the dilemma for Dr. Rushing and the Lopossas was whether or not to give April Gleevec before the baby was delivered in order to shrink the tumor which had a mitotic rate of 6.

April was the sixth person diagnosed in her town with GIST, and though this is an interesting fact, there appears to be no correlation between the causes and cases known at this time. Anecdotally, 30 years ago, toxic waste from dry cleaning was

dumped regularly into nearby water supplies and there do appear to be an unusual

April, Athena & Tyler Lopossa

number of cancers diagnosed in the area, but again, no direct correlation has yet to be proven. April says that many in her family suffer from stomach issues so they remain suspicious. To date, there is no known cause for GIST, so the contamination is an unlikely suspect at this time.

By her third trimester her OB determined April was past the risk of birth defects, so Dr. Rushing, as





#### Ccontinued from front cover.

her oncologist, needed to

decide whether the baby could tolerate the effects of Gleevec. April did not want to risk anything with this baby. Delivering by c-section and extracting the tumor at the same time was considered risky due to the necessity of two cuts, requiring a much harder recovery and higher risk of infection.

Dr. Rushing asked the Lopossas if he could submit April's case to the Life Raft Group's Virtual Tumor Board so that he could confer with a group of worldwide GIST experts who would weigh in on this situation. April and Tyler carefully considered the options and choose a c-section at 36 weeks with surgery to remove the tumor later with no Gleevec pre-op. At 36 weeks and four days, Amelia Lopossa was delivered weighing in at 6 pounds 15 ounces.

Five weeks later, April had to leave her toddler and newborn with family for five days for the surgery. The surgeons removed a 7 cm tumor and only bit of intestine. The surgeon reported clear margins and that it was good they got the tumor out when they did because it was barely holding on. The recovery from the surgery was tough with a toddler and a newborn but

April's mom and sister helped her through it. Tyler wasn't able to take a paternity leave.

"Being pregnant made me even more worried about it all," April said, in reference to the discovery of the tumor. "I want so concerned about her (Amelia). I did not expect to have her. She is my little lifesaver. My miracle baby. I did not expect any of this! My highrisk OB joked saying that I had a greater chance of winning the lottery than I did of any of this happening to me. I say Amelia saved my life, because without her, how would they have found my tumor?"

Imatinib is her current treatment and April has had two clear scans since her surgery. Her next scan is in January. April said their life is beginning to become 'normal' again. "I didn't expect to be a full-time mom, but with the surgeries, the medicines, and Covid, and juggling the kids, it is better this way. It's our new normal," said April. Her side effects have lessened with some adjustments and she's been able to add some exercise to her routine. Tyler was able to switch to the weekend shift so that he's home more during the week to spend time with his young family.

April jokes about her positive, cheery attitude, "It's the meds. I didn't have time to be sad because I had a toddler. She moves non-stop. I just didn't have time to

> be down. If I had a time to cry about it, it would have been in the shower because that's the only time I was alone."

> April also had to deal with the doctor's visits, monthly MRIs, five ultrasounds, gallbladder surgery and the tumor surgery on her own because of the Covid rules. Tyler was allowed to be there for the biopsy and the Amelia's birth. The couple relied heavily on help from

their family to make it through this obstacle course of events.

"I also have a great mentor, Kay (Kay Stolzer, LRG GIST Mentor), and that helped, having her to talk to as well as the LRG GIST Support Group. It helped that I had the baby (Amelia) to focus on instead of myself, so I didn't really focus on me until after she was born."

Mentor or attending a virtual **GIST Support Group?** email: dnieves@liferaftgroup.org

**Are you interested** 

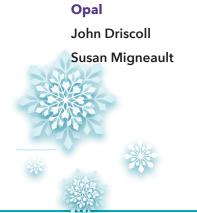
in connecting with a GIST



Thank you to all who have signed up so far to be a GEM. Thank you for your committment to Give Every Month to support the LRG & #GISTresearch!

**Emerald** 

**Robert Sholiton** 



## Ruby

Rene Carillo

**Sharon Genovese** 

Derek Kaufman

Janet Hines

Jennifer & Owen

Moore

Rick Paczewski

**Rob Taylor** 

#### **Sapphire**

**Colleen Carney** 

Gilbert Tisdale

Alberta Tate

John Van Hise **Danielle Williams** 

#### **Diamonds**

David & Jodi Alexander

Liana Baldor

**BST Consultants** 

**Dolores Hawkins** 

Teena Petersohn

# Venezuela

# Angel Selena Rodriguez Caracas, Venezuela

## **Normal Life Interrupted**

Angel Selena was living what she considered a very normal life. She was studying medicine, playing violin in an orchestra, and enjoying painting and drawing, and university in Venezuela. This GISTory begins with a chronic case of anemia that no doctor could diagnose.

"My story is full of doctors! I only had anemia but no doctor could discover the cause, I went to gynecologists, nutritionists, gastroenterologists, hematologists. They even thought I had anorexia or something like that."

When it became obvious that there was upper digestive bleeding in October 2016, the doctors had a reason to perform an endoscopy which revealed a tumor in the curvature of the stomach. Angel had surgery in December, and then, she began taking Glivec (imatinib), 400 mg, in February 2017.

This was an effective course of treatment until November of that year when the situation in Venezuela became untenable - no medicine, no doctors, no food. It was a terrible time for the Venezuelan people. When she could no longer find a pharmacy that had imatinib, Angel made the decision to travel to Argentina in September of 2018 and began taking imatinib a few months later. But the time off from Glivec did not benefit Angel. Her doctor in Argentina found that her GIST had metastasized, and her dose was raised to 800 mg.

"At that time, I was working, studying, and living alone in Argentina. But though I was coping with the side effects, I was not able to do all that by myself and I returned to Venezuela a year ago. Now, The Max Foundation is giving me

the treatment here (in Caracas) and I can say I'm getting better, I'm feeling good," said Angel, "This is one of the hardest parts of all that because I really want to become a



Angel Selena Rodriguez

doctor but it has been tough for me."

Now, in addition to returning to her studies to become a doctor next year, Angel wants to help others dealing with GIST. Angel was (and is) a part of a foundation in Venezuela called FUNDALMC, and she said, "Wait, if I'm part of this, maybe there is some institution for patients with GIST that I can join too. I was just searching on Google until I found the Life Raft Group, and I was like, "yeah, that's what I was talking about." I sent the application form and received an email from Piga Fernández (LRG's Global Relations Consultant, based in Santiago, Chile) some days later.

"I have received a lot of help and support; I think it's the reason why I'm still alive because sometimes I wanted to give up but there was always someone to help me out even if I just wanted to cry. I don't know why but I feel my life is just teaching me that this time hasn't been a bad part of my life, but a lesson, and our lives are full of lessons that we have to accept, learn and teach to others, so I want to do my part and help people to cope with this," said Angel.

Bienvenida, Angel, as the LRG's liaison in Venezuela!



## **2020 Women in Sarcoma Award Recipients**

Women Paving the Path Forward

Innovative Sarcoma Leadership Innovative Sarcoma Leadership Young Female Sarcoma Leadership

Patient Leadership Award Global Patient Leadership Award













Denise Reinke, MS, NP, MBA

Event emcee

Dr. Gina D'Amato

Dr. Breelyn Wilky

**Dr. Lillian Klug** 

**MaKayla Evans** 

Florence Thwagi

The first annual Women in Sarcoma gala was held virtually on Thursday, December 10th, 2020. It was a fantastic evening where the Life Raft Group celebrated some phenomenal women within the community. There were over 120 people registered and over \$30,000 raised through sponsorships from Credit Suisse, Jefferies, Morgan Stanley and Pfizer plus individual donations from the Life Raft Group's GEMs and others.

Diana Nieves, Senior Director of Outreach & Engagement, acknowledged our sponsors and donors and kicked off the Gala. Diana was followed by Senior Vice President of the LRG, Laura Occhiuzzi, who welcomed the participants. Vice President of Programs, Sara Rothschild, shared sentiments about the vibrant and powerful Nikki Morales, patient and volunteer advocate, whose loving memory the event was held in. Mistress of Ceremonies, Dr. Monica "mOe' Anderson provided a motivating speech about her own journey as a GIST warrior.

The gala continued with Dr. mOe inspiring everyone through her introductions of each awardee - Denise Reinke, Dr. Gina D'Amato, Dr. Breelyn Wilky, Dr. Lillian Klug, and GISTers MaKayla Evans and Florence

Thwagi. Each awardee shared their personal stories about inspirations throughout their own journeys. During the gala we were also entertained by Jessica Nowak, LRG's

Director of the Outreach and Engagement department, who provided a mixology lesson on a Classic Negroni, an alcoholic beverage that was created by Dr. Sandra D'Angelo to honor Dr. D'Amato and Dr. Wilky. There was also a dance performance by the Henzo Kenya group.

If you would like to support the continuation of the Women in Sarcoma program, please donate at: https://liferaftgroup.org/donate-2/











Jessica Nowak

Diana Nieves

Laura Occhiuzzi

Sara Rothschild

Thank you to our Women in Sarcoma Sponsors!



**Jefferies** 



Morgan Stanley



Carlos Baldor, Sr.

# In Memoriam Carlos Alberto Baldor, Sr.

### Friend of the LRG & Major Donor

Carlos and Liana Baldor have been major donors of the LRG since 2002. Their daughter, Ana Maria Baldor-Bunn, died from GIST on April, 19, 2002 after a two-year battle. Even through his own health battles, Carlos Albert Baldor Sr. continued to donate to the LRG and even increased his giving

during the COVID-19 pandemic.

Carlos lost his own battle with cancer on August 5, 2020. Carlos was an entrepreneur who founded his own business, BST Data Systems, in Tampa, Florida, which grew to be BST Global, where he served as President and CEO for 50 years. He was a private, humble, kind, and faith-filled family man with a spirit of compassionate generosity that knew no bounds. He had great faith and loved

and cared for his family and the BST family as his own. He quietly gave to all in need that he came across especially children, widows, and those suffering with cancer to name a few.

High school sweethearts, Carlos and Liana Garcia Muñoz, grew up in Cuba and married in 1964 in New York City. They shared 56 years as a married couple. Carlos and Liana Baldor have not only been generous major donors, but great friends of the GIST community inspiring innovation in GIST research.

His daughter, Ana Maria Baldor-Bunn was also a kind and compassionate human being. She was diagnosed with the disease in May 2000, while pregnant with her first child with husband Stan Bunn, and underwent emergency surgery the day her son William was born. Ana was an inspiration to her close-knit family. Stan Bunn still serves as one of LRG's Board of Directors. Ana believed that it was the little things in life that truly make people happy, not money or worldly possessions. She was known to her friends & family as having the "heart of a lion and the soul of an angel."



Ana Maria Baldor-Bunn

The LRG is indebted to the Baldors and full of gratitude for the generosity of the Baldor family over the years. If you would like to honor Carlos Baldor and his daughter Ana Maria Baldor-Bunn or any loved one that has passed, please feel free to light a candle on our In Memoriam website, which is dedicated to Ana Maria Baldor-Bunn and her father Carlos.

You can light a candle for a loved one on our In Memoriam website: https://lrginmemoriam.org/

#### Thank you major donors for October & November! Azad International **Idea Village Products Ellen Seagraves** Corp Deepa Balakrishnan **Helga Schnorf** The Julius Fleischman Iris Berke **Teren Family Charitable** Foundation, Inc. Fund, American **BST Consultants** John Kirk **Endowment Foundation Andrew Colman** Teena Petersohn **Judy Timmons** Sara Gould

## **Points of Light During 2020**

As 2020 comes to an end, we acknowledge that it has been a dark time. But as we look back on what the Life Raft Group has accomplished despite the challenges we faced, we began to see there were points of light along the way giving us hope.

#### **COVID Resources**

Established section of our website to provide information on COVID-19

Provided numerous articles and resources for patients

Supported patients in finding telehealth consultations

Presented information in webinars

Received Rapid Response Seed Grant from NORD for our efforts

#### **New Board Members**

**Steve Pontell** 

**Eric Biegansky** 

# Virtual Tumor Boards -two to replace NIH Clinic, three altogether

- NIH asked us to take on the responsibility for the VTBs to replace the annual in-person NIH Pediatric & Wildtype GIST Clinic
- Young pregnant patient who went on to give birth to a healthy child
- Young girl in Ireland who was prevented from a life altering surgery

# Engaging international specialists in finding solutions for challenging cases

#### **GIST Entertainment**

- Mindfulness Series
- Trivia
- Book Club
- Yoga
- Meditation

#### **GIST Days**

- Seattle -66 registrants
- Tampa -70 registrants
- Denver -45 registrants

#### **GIST Do It Walks**

- Seattle, WA
- Verona, NJ

#### **Webinars**

New Treatment Options for GIST and Concerns about Coronavirus

**GIST, TKI Treatments and Effects on Memory** 

How to Read a Pathology Report

GIST 101 presented to Henzo Kenya

Genetics

Conversations with the LRG: COVID, GIST Mentors (2)

#### **Support**

First Virtual Support Groups for Patients and Caregivers

Serving 115 Mentees through our GIST Mentors program

#### **Global Surveillance Team**

Presented interesting cases and thought-provoking questions on a regular basis

#### **Publications**

Four Newsletters published

Profiled heroes and long- term survivors in our June Hope Issue

Three issues of LRG Science published

**Annual Report published** 

#### **Virtual Life Fest**

- 196 attendees
- Virtual cooking demonstration

#### **Patient Registry Support**

- Telehealth coordination during pandemic
- Expanded registry membership
- Profiled Patient and Caregiver of the Month
- Expanded registry fields to collect side effects data & quality of life data
- Salud con Datos-Latin American registries
  established

#### **Revitalization of our Medical Advisory Board**

#### **Lifeline for other non-profits**

- Providing help for Giant Cell community

#### **New Horizons Conference Virtual**

#### Collaborations

**Foundation Medicine** 

**New Tissue Bank at OHSU** 

Columbia Presbyterian

Pediatric & SDH-Deficient GIST Consortium algorithm for standardization of diagnostic testing, accepted by CAP and NCCN

Co-authored white paper with other organizations on consistent terminology for testing

#### **Organizations/Virtual Conferences**

- SPAEN
- SELNET
- ASCO presented poster on algorithm
- CTOS Sara Rothschild was an member of GIST expert panel, Jerry Call presents poster
- ISPOR Pete Knox actively involved
- Faster Cures David Josephy participated in conference
- CTTI Jerry Call is part of this initiative
- MyPART (Pediatric & Adult Rare Tumor Network)
- OVAC Virtual Lobby Day
- NORD LRG staffers attended conference
- Norman Scherzer, Executive Director, on the Herbert Irving Center Advisory Board at Columbia Presbyterian

#### **New Initiatives**

Women in Sarcoma Programs & Gala

#### International

Welcomed multiple, new country liaisons

Piga Fernández's advocacy efforts resulting in cancer law enacted in Chile

Webinar for international advocacy groups on COVID

Record participation worldwide for GIST Awareness
Day despite the pandemic

#### **Membership**

Increased membership

#### **Additional Events**

**GIST Awareness Day** 

#### **Real World Evidence**

Creation of Science Forum

Algorithm published

Launched survey of long term survivors

#### **LRG Staffers**

Quickly developed new ways of working together virtually

Most importantly, kept the Life Raft Group afloat in spite of the turbulent waters this pandemic has created.

We thank all of you, patients, caregivers, medical professionals, researchers, donors, board members and friends for being our points of light this year, and always. Love from The Life Raft Group!

Remember to use

amazonsmile

and designate the Life Raft Group as your charity.



by Carolyn Tordella,
Assistant Director of Communications

**Artistic expression is an important** psychosocial activity. Sometimes we can express ourselves visually or musically when we can't express our experience verbally. Music, drawing, painting, and creating sculpture provide a means of communication and self-expression- and a way to alleviate stress. Art also helps us to change our moods, come out of depression, or simply relax. What do people who are already creative do when they are faced with a cancer diagnosis? Does it help or give hope in the situation? In this two-part series, these GISTers - professional and amateur creatives, share their stories.

**John Paul Zagami** 



Pratt institute graduate, John Paul Zagami studied industrial design.

Subsequently, as a professional he gained experience in advertising, doing storyboards for commercials and illustrations for publications, animation, and package design. After working for high profile companies like Avon he eventually landed at Polo Ralph Lauren, Inc. His tenure there as a highly skilled computer graphic artist and designer spanned the Home Collection, Men's Designs, and culminated in a position designing high-end watches.

John's journey with GIST began with unexplainable digestive issues. Months prior to his July 2019 diagnosis, he suffered persistent diarrhea. A colonoscopy revealed nothing but after suffering a kidney stone attack which led to an ER visit, a mass was found.

"This was my first experience with cancer so it was a shock to me," John shared. "The doctor told me I had GIST and he thought it was benign but took out an orange-sized tumor with clear margins. And I had a high mitotic rate. It was a surreal experience and initially I spun out of control thinking I was going to be dead. This oncologist didn't paint a rosy picture either saying there was a 50% chance of it coming back."

John began Gleevec after healing from surgery and went for a second opinion from a GIST specialist, who looked over his records and told him he could expect to be cancerfree with treatment.

"After initially reading all I could about GIST, I've stopped researching, but that whole mindset that there are multiple paths to take is really what guided me and helped me keep my sanity during this whole experience. And that pretty much guides everything I approach from politics to health to design. I examine many viewpoints. I think

Designs by John Paul Zagami











Designs by John Paul Zagami

artistically having that type of mindset has helped me," said John.

Industrial design certainly fits his mindset and with Ralph Lauren, John was able to combine his passion for watches with finding solutions in design and function.

"I've been a watch collector since I was sixteen years old. I always loved and collected watches, so when I heard that Ralph was partnering with Richemont, the Swiss luxury goods company, to design and manufacture a fine watch and jewelry line, I wanted to be involved," said John.

Ralph was aware of John's passion for watches as they'd discussed John's collection each time he wore a different piece, so when John

approached him with his desire to design watches, Ralph was intrigued and asked to see some designs. John presented 20 original designs which his boss loved. John worked directly with Lauren on the watches and eventually became VP & Lead Designer for that department, a role he fulfilled until 2016, when company-wide layoffs curtailed production somewhat.

Since GIST, John has freelanced as a designer, taught college-level accessory design and package design and substituted at the local elementary schools.

Creativity has played a large part in John's entire life: "One of the things about creativity and design is that there are lot of different solutions visually and functionally. That tempered my thoughts in art and music. There are always different paths to take."

John commented that creativity also plays a part in staying focused. The pandemic and some unrelated (to GIST) health issues have slowed working and teaching so he concentrates on his creative skills.

"Yes, playing guitar and creating designs, keeping up with design software, have kept me focused. I'm playing

around a lot now. More often and longer, exploring new graphics software, not with an urgency but it's important to me to maintain those skill sets because it's who I am. I've always been able to draw much better than I could write. It's always been a part of my identity. And when I was using those talents, I was always very passionate about them. I thrived on the challenges Ralph Lauren posed during my 25 years there. And studying jazz, there's so many ways to play, hundreds of ways. I look up different ways to play different things and it can be challenging because I'm not a professional musician who plays eight hours a day."

View more of John's gorgeous watch designs on his website: https://johnpzagami.wixsite.com/mysite



#### Tim Watkins

You may have spotted a creation by May & Watkins Design and not even realized it. They create public art, or industrial sculptures - art that is commissioned for public spaces. The partnership of artists, Carol May and

Tim Watkins, began after meeting as 20-somethings on scholarship at the Skowhegan School of Painting & Sculpture in Maine. Married for almost 40 years, he is a sculptor; she, a painter. They joined their creative energies professionally in the 90s appreciating their complementary styles, for an illustrative, enduring career creating public works of art.

"We decided to give up our personal shows and that routine because we decided to work together to do public art - because it's in the public and it's not hidden away - it's for everyone, out there," said Tim.



Connections, Gainesville, FL by May + Watkins Designs

"Our process? We fight. We have strong discussions. Carol is the brains. She is very creative and I'm more mechanical. Our skills mesh very well. She'll start doing sketches and I'll research materials."

Tim Watson's GIST journey intersected with his artistic path in 2008, when a seven-pound tumor was removed from his abdomen. The couple had never heard of GIST and the information available at the time was dismal and sparse.



Leaf Dance, Oregon City, OR by May + Watkins Designs

To date, Tim has been on several drug treatments and is currently on ripretinib. Though there have been many side effects along the way, the most poignant effect was on how he views life and art now.

"I do have a little trouble dealing with the idea of GIST being terminal, but I have a clock ticking louder than it used to tick in terms of how long I'll be around. It's something I've given a lot of thought to. I am older and now I have this diagnosis, but it has not hamstrung me. All the things we look at are statistics but we are not statistics," said Tim. "Yes, I'd say this diagnosis has given me a finality. A sense of purpose. I want to keep 'making' art because it's what I love to do."

This story continues on page 12

#### This story is continued from page 11

"It's awesome for the little model to became an 18-foot sculpture."

Tim shared more on creativity and the drive to create.

"It is the answer for me, speaking in terms of spirituality. The answer to 'why am I here?' I came to art late, in my teens, searching for what was going to satisfy me. Money wasn't it. It's not a priority for me. What's going to make my life meaningful here on earth? I was looking and I stumbled into art. My original idea was to teach art and history and I took classes and I fell in love with making art."

The seed for public art was planted during Tim and Carol's time at Skowhegan.

"One of the lecturers there spoke about public art and it made sense to me getting it out there. It's not just a commodity, a product. It's meant to be shared and experienced by all. My first installation was created in 1979. Our careers were still separate, we weren't working together yet, she

was still painting and showing. This has been our lives, making art."

Tim dismisses the thought that public art is somehow less personal than a Rembrandt or a Picasso. The nature of the work is that it is commissioned and several artists will compete by jury to win the commission. The jury appraises the individual proposals and the artists' portfolio of previous installations and though the proposed designs are unique they need to meet a specific criteria.

"It's very personal, we're very proud of it. Is it on the level or Rembrandt or Goya? No, it's not like that. I love that people get to experience our art on a bigger level than they would if it was in a gallery. Offering a ladder of understanding, you can enter it, say it's fun. That's what an artist is. The projects have a lot of our personality. Whimsical. We get to be kids."

Tim says that Covid-19 hasn't slowed down their work much considering that most government



Oasis, Memphis, TN by May + Watkins Designs

agencies had money for these types of installation already set in their budgets for 2020. He admits that he and Carol could retire if they wanted to, but he says, "What does that mean? We'd just find another way to make art."

View more of May + Watkins inspiring designs at: https://maywatkinsdesign.com



#### **Claire Monaghan**

Claire has always loved art.
She counts her grandmother,
an embroiderer, and a family
friend, a painter named Virginia
Cantarella, as strong influences.
Claire spent many hours as a child
sitting next to her grandmother

as her grandmother embroidered monograms by hand on shirt pockets, towels, and handkerchiefs for income. Her grandmother was also known for creating beautiful designs on tablecloths using an Irish embroidery technique called "sprigging." Claire also spent a lot of time with a close neighbor and friend, Virginia, as she painted realistic landscapes and abstract work.

Over the years Claire has dabbled in many art techniques. "I enjoy learning how to create art in a variety of ways. Through YouTube videos I learned to weave, twine rugs. crochet and quilt. But quilting has had the biggest impact on me."

Claire took one quilting class in her twenties at a local quilting store, Sew Brooklyn, but it wasn't until twenty years later, before her GIST journey began, that she rediscovered quilting. Claire was working as a preschool teacher at the time and relearned some sewing skills in order to teach her preschool students how to make stuffed animals. She had as much fun as



Landsacape 11x14, 2019

her students during this project and was inspired to continue quilting. "My favorite type of quilting is art quilting. Unlike traditional quilting art quilts are quite like painting with fabrics and thread.

Recently I have realized that my art quilts are in many ways a combination of my love for my granny's embroidery work and my friend Virginia's landscape paintings."

GIST happened soon after her first quilt was accepted into a quilt exhibit and after participating in her first holiday craft show last December. Every GIST patient has a unique story about how they were diagnosed and where their journey takes them but Claire can literally credit a recurrence of her sister's ovarian cancer in January as the reason she found her GIST tumor. Claire had decided to have her ovaries removed preventively in response to her sister's illness and a preoperative sonogram in February revealed a large mass. Initially Claire's doctors thought the tumor was ovarian cancer but during surgery it was discovered that the tumor was GIST and attached to her small intestines.

Diagnosed in March 2020, at the beginning of the pandemic, her tumor biopsy showed that Claire had a 10.2 cm small intestinal GIST tumor with a mitotic rate of 35/50 which is considered high risk for a recurrence. Her genetic testing



Brooklyn Bridge, 12x12, 2019

found that she has Exon 11 GIST and she began taking 400 mg of Imatinib in April. Claire's response to the news of being high risk is to take life "stitch by stitch." Claire says, "I try not to worry about what is going to happen in the future. I just focus on what I need to do next in my self-care and advocating for myself as well as appreciating my health, family and friends." Claire says she learned about the importance of Therapeutic Drug Monitoring through the LRG and is eager to continue having her Imatinib levels taken. "I feel it is important individually but also as a GIST community to collect data on Gleevec and Imatinib levels so we can compare it to patient outcomes. We can't study the data if there is no data." Claire switched from Memorial Sloane Kettering Cancer Center to Columbia Presbyterian in August because "Dr. Schwartz at Columbia Presbyterian is open to TDM and has created a lab at

Columbia Presbyterian that is capable of testing Gleevec/Imatinib levels."

Claire has found that creating art has helped during her recovery from surgery and helps with selfcare. "I find stitching very calming and therapeutic. I love that I can do it even when I am at home or not feeling my best. I have a studio in my dining room so I always have a space to create when I am able to." She continued, "You know how when people get cancer they begin thinking about what is on their life bucket list? The nice thing for me is that my bucket list is to spend more time with my family and to create more art and I am able to do both of those things at the same time while at home."

And next for Claire? She recently learned how to create cell like shapes on fabric using a marbling technique. She thinks one of her next projects will be to make a quilt using this newly learned technique to "explore designs with cells, especially GIST cells." She would also like to make an art quilt to sell as a fundraiser for the Life Raft Group since this organization and its members have "already helped me so much."

You can see more of Claire's art at:

https://www.facebook.com/ ClaireMonaghanStudio



#### **Christine Gonzales**

Christine, a former elementary school teacher, lives about 30 miles outside of Albuquerque, NM, and is raising three sons with husband Adam. She doesn't feel that creativity has always had a place in her life, but teaching elementary school always

provides opportunities for innovation and creative thinking so perhaps it's a matter of perspective.

Christine applied just that kind of thinking when faced with hours on her own during her participation in the guadecitabine trial held at the National Institutes of Health (NIH) in Washington, DC, during 2017.



This story continues on page 14

#### This story is continued from page 13



"I was flying out to Maryland from New Mexico every three weeks and I had a lot of time on my hands. I needed something to do and this occupied my time and my mind. It gave me a purpose. I didn't know much about research but I thought if I made this jewelry and sold it then I could donate the funds to research for GIST. That's how the idea got started," said Christine.

Christine's interest in GIST research began with her own rocky road with GIST six years ago. After unexplained blood loss and emergency surgery, Christine found herself at odds with her oncologist, who had diagnosed her with 'regular GIST' at 32 and started her on Gleevec post-surgery.

"I started to do my own research into GIST after this. It seemed to me that I was too young for the 'regular GIST' and I asked my oncologist if he thought wildtype GIST was a possibility? Should we look into mutational testing?"

Christine's doctor shut her down declaring that this was absolutely not the case and that for the sake of her health she just needed to take the Gleevec for the rest of her life. He also advised her to stay off the internet though he himself was Googling information on GIST right

in front of her. She was confused by this but Christine assumed the doctor knew what he was talking about. After remaining NED for two and a half years, Christine developed a massive metastasis. This tumor grew in a four-month period from nothing to a mass that spanned from her stomach to her liver.

This new tumor threatened to cut off blood flow to her liver. Her local surgical team could not perform this surgery and she was directed to the hospital at the University of New Mexico (UNM). To try and reduce the tumor, UNM doctors put Christine on a higher dose of Gleevec (800 mg), but after four weeks of no change, they switched her to Sutent. Mutational testing revealed her mutation to be wildtype (now more specifically SDHC). The side effects of Sutent proved to be too harsh for Christine to tolerate, and when that treatment

was terminated, she was told by UVM that there were no other options as surgery was still out of the question due to the size and location of the tumor.

A second opinion with a GIST specialist rendered an identical result and Christine and Adam began searching for answers. Christine connected with another LRG member and was told about the Pediatric & Wildtype NIH clinic. Christine attended the clinic in 2017 and Drs. Arnaldez and Davis committed to the surgery (#2) that saved her life.

"I spent two years suffering on a treatment that was doing me no good. That local oncologist's arrogance throughout the situation was disappointing and I wish he'd been open to what I had to say. And then when the second surgery was refused by the larger hospital, I felt like I was being told to go home and wait to die. I was a 30 something year-old mother with three little sons. In hindsight, I guess I'm grateful that I didn't get that second surgery at that time, because these experiences lead me to the NIH." reflected Christine.

Christine remained NED for a few years until the tumors returned and metastases were found in her liver and pancreas. She endured another surgery, her third, in 2019, due to tumor growth, is currently not on any treatment and is being closely monitored.

Her drive for #GISTresearch is further fueled by the fact that Christine's mom, aunts, and children, all carry the gene, though are currently asymptomatic. While all are being closely monitored, being SDH she understands the need for new treatments and patient advocacy.



The Gonzales Family

"The research is so important to me also, because all three of my children are carriers of the gene as well. The NIH is also monitoring them. Advocacy is the biggest lesson I have learned. Maybe they

This story wraps up on page 15

This story is continued from page 14 really do try, but it's hard when the

people you are supposed to be counting on fail you so miserably. The level of involvement the doctors at the NIH has had with my team in NM has been amazing. They have consulted with our surgeons out here and Dr. Davis even called me from his family vacation to ask how I was doing post-op. When you've been seeking

out doctors that have the knowledge you need and then you find them and they have first-hand knowledge - that's refreshing."

See more **Gewelry for GIST** on Facebook at:

https://www.facebook.com/Gewelry-For-Gist-1435663539904375







## **Changes to Medical Updates**

The Life Raft Group is committed to ensuring your GIST journey is as manageable as possible. We want you to thrive! Our patients are the foundation of our organization and the focus of our mission. We want to ensure that we expand our resources in order to help patients stay on their treatment longer by helping them to manage their side effects.

Because we understand the importance of knowing, understanding, and managing side effects, we have created new data fields within our patient registry platform. This data will help us further analyze side effects that patients face and in turn we can help patients manage their side effects and thrive.

These new questions will be asked every time you submit a medical update. Our team will be able to provide comparative data on how other GISTers are managing side effects as well as provide you with a summary of how your side effects have changed over time.

To learn more about this or to discuss your side effects, please contact the Patient Registry Department: patientregistrydepartment@liferaftgroup.org or call us at: 973-837-9092.

## **SPREADH@PE**

# donate

Contribute to our Holiday
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Donate today liferaftgroup.org/donate

Need more info? Contact: **DNieves@liferaftgroup.org** 

As the holiday season approaches, the LRG is dedicated to doing everything we can to assure that there are no empty chairs at a celebration because a patient has not had access to an accurate diagnosis and effective treatments. This is our unfinished business. Please help us continue our efforts with your continued support and donations. We aim to accomplish this by assuring that GIST patients have access to the right diagnosis and treatment, and by supporting research to develop new treatments for those patients for whom current treatments are not effective. Help us with your donation today.

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Interested in Volunteering?

Contact: Diana Nieves, LRG Senior Director, Outreach & Engagement <u>dnieves@liferaftgroup.org</u>

Interested in serving on the LRG Board of Directors?

Contact: Laura Occhiuzzi, LRG Senior VP

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