

August 2016 • Vol 17 Issue 4

# THE GIFT OF TIME

Thankful  
For  
Having time  
with my  
Kids -  
Linda

opportunity  
to celebrate  
birthdays  
with my  
grandfather!

TIEMPO CON  
MIS SOCRS QUERIDOS  
Y MI ESPOSA.  
Y EL TIEMPO QUE  
HE VIVIDO DESDE  
DICIEMBRE Y  
ESTAR VIVO.  
♡

The opportunity to go home to  
father and go to appts. to spend  
time with  
travel with  
time.  
♡

Thankful  
for my  
daughters  
Strength  
♡

Joe's  
Graduation  
"GMU"

Thankful  
for my  
family

Thankful for  
my job that allows  
me to touch a  
person's life

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**2016 Life Fest  
Celebration**

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GIST Awareness Day

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# *A message from our Executive Director*



## **This was the best Life Fest ever!**

There is always something special about patients and caregivers with a rare cancer getting together either for the first time or to reaffirm that we are still here.

This year's event was particularly noteworthy because of the powerful and informative agenda, incredible array of speakers, a magical display of talent by Gordon and Meredith Simmons and Marie and Alia Coleman, and most of all by the surreal chemistry created by the interaction of so many survivors.

Thank you all for coming, and thank you in advance for working together with us to keep GIST patients alive and well. We still have work to do. As Dr. Moe Anderson so eloquently shared during her inspiring patient survival story, this is your race. How are you going to run it? Are you going to run until you finish?

I am calling for all of you "runners" to listen to Dr. Anderson's motivational story on our website again ([bit.ly/lifestest2016](http://bit.ly/lifestest2016)), and to make a donation to the Life Raft Group. Share her video with others, and ask them to help us finish the race. We are in this race together. We can run it together. And together, we can win it!

- Norman Scherzer





# July 13<sup>th</sup> 2016

GIST Awareness Day is celebrated on July 13th every year. It was created to raise awareness about GIST. The theme this year is the Gift of Time. Our logo is an hourglass, with each grain of sand in the hourglass representing a moment in time; a memory that we cherish.

Around the world, GIST Awareness Day was celebrated with educational seminars and celebrations with our Gift of Time theme.



*Redondo Beach, California*



*Philippines*



*Guatemala*



*New York  
Bethpage State Park*



*India*



*Mexico*



*Italy*



*Owensboro, Kentucky*



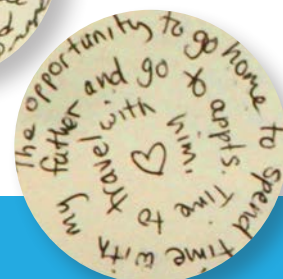
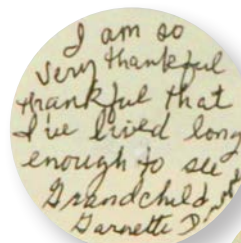
*Colombia*

View all the photos from GIST Awareness Day - [www.liferaftgroup.org/gist-awareness-day](http://www.liferaftgroup.org/gist-awareness-day)



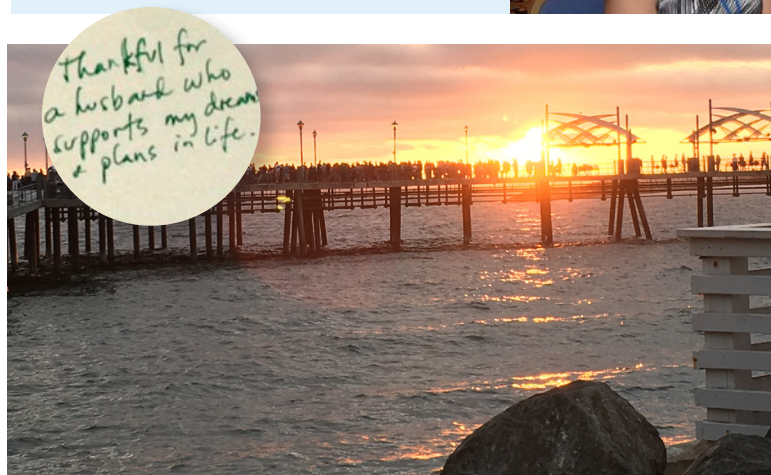


# LIFE FEST 2016



## A Celebration of Life - July 15<sup>th</sup>-17<sup>th</sup>

Life Fest 2016, our signature biennial event, brought together a passionate community from across the globe. A celebration of life emerged as new friendships were cultivated, names and faces connected and old friends shared memories.



Southern California was the ideal backdrop, with its breathtaking sunsets over the Pacific Ocean, perfect weather, and a hotel equipped with fire pits for evoking casual conversation.



Over 150 people attended the weekend-long event which began on Friday, July 15<sup>th</sup> with our GALA and opening remarks from Executive Director Norman Scherzer.

The gala evening ended on a personal note as Bill Hinshaw, Executive Vice President of Novartis US Oncology, presented our 10-year survivors with a certificate in what can only be described as very special moments.



# Honorees

The evening honored those that dedicate themselves to patients and caregivers and the LRG's mission. Accepting these awards were, Erin MacBean, Allan Tobes Volunteer of the Year; Ronald DeMatteo, MD, Jeroen Pit Science Award; Matthew Lurin, MD, Arnie Kwart Philanthropist of the Year; Friends of Max-India, Global Award of Excellence; Jason Sicklick, MD, Clinician of the Year; Ray Montague, GIST Hall of Fame and Michael LaQuaglia, MD, GIST Hall of Fame.



Erin MacBean accepting the Allan Tobes Volunteer of the Year Award for her work with the Pediatric and Wild Type GIST community from Dina Wiley.



Jason Sicklick accepting the Clinician of the Year award in recognition of the unique way he brings research into practice for his patients and for saving countless lives.



Viji Venkatesh accepts the Global Award of Excellence on behalf of Friends of Max-India for the unique way they bring GIST patients together to raise awareness for this rare disease.



Board President Jerry Cudzil presents Dr. Matthew Lurin with the Arnie Kwart Philanthropist of the Year Award in honor of his work on the annual Water of Life event which contributes to GIST awareness.



Emilie van Karnebeek presents the Jeroen Pit Science Award in memory of her husband to Dr. Ronald DeMatteo for his contribution to research and his ability to convey complex science concepts for the layperson. He is responsible for helping countless patients including Emilie's late husband Jeroen.

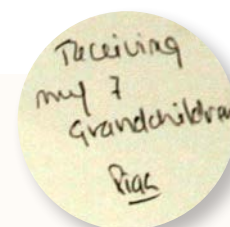
## GIST Hall of Fame



Ray Montague was inducted into the GIST Hall of Fame in honor of the lives he has touched through his generosity to the Pediatric & Wild Type GIST community.



Dr. Michael LaQuaglia was inducted into the GIST Hall of Fame for his medical achievements on behalf of the Pediatric & Wild Type GIST Community.



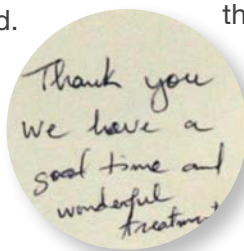


# Sessions

This year, we were very excited to provide not only our general session but a parallel Wild Type GIST session. Members were truly grateful to have the opportunity to listen and learn from some of the best and brightest in the field.

In our general session, Dr. Arun Singh started off the day with an update on “Clinical Management of GIST.” This was followed by a panel of surgeons, Drs. Ronald DeMatteo, Michael LaQuaglia and Jason Sicklick who discussed distinctive and cutting-edge surgical cases. The morning concluded with a session entitled “The Future of Cancer Care.” Dr. Singh presented on Mutational Testing, Dr. DeMatteo on Immunotherapy and Dr. Brian Van Tine talked about understanding your cancer’s metabolism. A question and answer session followed.

In the Wild Type GIST session, Dr. Lee Helman from the NIH provided both an overview of Wild Type and Pediatric GIST



**Dr. Arun Singh**

and updates from the NIH Clinic. Dr. Michael LaQuaglia spoke about “The Role of Surgery in the Treatment of Wild Type GIST.” Dr. Jason Sicklick presented “Demystifying Rare Subtypes – Quadruple Wild Type GIST” and Dr. Brian Van Tine discussed “Is Wild Type GIST About Glutamine or Glucose?” The morning session had two panels: One on important updates with Erin MacBean, Sara Rothschild and Phyllis Gay, the other, a Wild Type GIST Q&A expert panel with Drs. LaQuaglia and Sicklick. The morning session ended with a discussion on how the community can make a difference.

Lunch was enjoyed by all as Gordon and Meredith Simmons gave a touching rendition of “Amazing Grace.” While Gordon played his trumpet, Meredith sang her heart out leaving tears in the eyes of those listening. A 16-year commemoration video was shown afterwards, as the GIST community celebrates 16 years of treatment for patients.



**Drs. Sicklick (left) and LaQuaglia**

Our afternoon sessions were both informative and captivating. “Riding the Cancer Wave—a Spiritual and Emotional Journey” became a support group for many, as Michael Eselun led a guided discussion. Jeanne Peters, RD, discussed the relevance of proper nutrition. Dr. David Wong presented “The Role of Integrative Medicine in

*“I took away a better understanding of GIST and Wild Type GIST, how and what treatments are relevant and what to expect with surgery and meds.”*

**Presenters and participants found our new Wild Type track informative**



*“The highlight was meeting people with the same problem and talking to the doctors and leaders of the LRG.”*



Cancer Treatment” and discussed innovative therapies to achieve health in mind and body. Michelle Durborow discussed “Generic vs. Brand” and “GIST: Management Beyond Imatinib” in collaboration with David Josephy. Sandra Brackett, NP presented “Managing Your Side Effects.”

Other sessions in the afternoon included: “P.L.A.Y, Positivity Laughter Awareness and You,” and “Show Us Your Rare” with Jennifer Sherwood, “Knowledge is Power and Life” with Phyllis Gay and “The Healthy Mind Platter” with Dr. Katherine Puckett.

Saturday evening, we paid tribute to those we have lost to GIST in a Celebration of Life ceremony, followed by a beautiful hula dance by Marie and Alia Coleman. Saturday night was spent with friends and family in beautiful Redondo Beach.

On Sunday Dr. Monica Anderson inspired the audience by sharing her own personal journey of health challenges, surviving, thriving and loving life. Her presentation was both heartfelt and uplifting. Dr. Katherine Puckett gave a helpful exercise on “Healing Calm: The Practice of Stillness” and Michelle Durborow presented new data projects in “Advancing Health Data to Find a Cure.”

Norman Scherzer closed out the weekend with “The Personal GIST Survival Plan-Ten Steps to Surviving GIST.” Norman’s presentation was both inspirational and motivational. Patients and caregivers walked away with a sense of hope and togetherness. ■



There are many dedicated volunteers who helped us organize the event and gave of their precious time. We thank you for your spirit, passion, and commitment.

- Dina Wiley, South California state leader (Organization)
- Vicky Ossio (Registration)
- Teena Petersohn (Registration)
- Lleyton Schelesky, (Coloring Book)
- Shivani Jain (Photography)
- Garnette Draper (Registration)
- Anthony Cashin (LRG Support)
- Isabella Bolognese (Photography)
- Alyssa Occhiuzzi (LRG Support)
- Helena Mattioli (LRG Support)

*We thank our sponsors for supporting this event.*





# Help us grant the GIFT of Time by donating your time, talent and treasure to the Life Raft Group. We are looking for:



Volunteers to help with GIST Day of Learning Events (GDOLs), social media, become state leaders, write articles for our website and newsletter, photograph or videotape events

## VOLUNTEER



Fundraisers to join our Development Team, to hold fundraising events or share some of their contacts who may be willing to help in our efforts



GIST and Sarcoma medical experts to present webcasts, write articles, join in collaborative research or speak at our GDOLs

## DONATE



Advocates to spread awareness about GIST, attend local and national advocacy events

## COLLABORATE

### Thank you to our Major Donors for May and June for helping support "The Gift of Time"

- |                             |                    |                                  |
|-----------------------------|--------------------|----------------------------------|
| • Carlos Baldor             | • Helen Frey       | • Teena M. Petersohn             |
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Want to help out the LRG please contact Diana Nieves, Development Director, at [dnieves@lifteraftgroup.org](mailto:dnieves@lifteraftgroup.org)

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