



## Life Fest 2012: Celebrating Ten years of Dedication

By Janeen Ryan  
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Life Fest 2012 was not only the premier gathering of the Life Raft Group community but a celebration of our ten year anniversary as well! And, what better venue to celebrate than Las Vegas! The glitz and glamour of this beautiful, legendary city could only be eclipsed by our immense joy of reconnecting with old friends, giving and receiving hugs and of course, meeting so many new faces. People from around the country and across the globe came together for three spectacular days of learning and fellowship.

On Friday night the Gala dinner and Awards Ceremony were highlighted by the acceptance of the Clinician of the Year award by Dr. Mike Heinrich, the Global Outreach Award to Alianza GIST accepted by Piga Fernandez and Vicky Ossio, the Jeroen Pit Science Award by Dr. Brian Rubin, and the Arnie Kwart Philanthropist of the Year Award by Emilie van Karnebeek. Kim Tallau, our resident volunteer photographer, was unable to make it, but accepted the Allan Tobes Volunteer of Year Award in spirit. Dr. Jonathan Trent was also unable to attend but accepted his award, Humanitarian of the Year via a video message. Sanofi, awarded the Patient Outreach Award, also accepted through a heartfelt video message. To end the evening, the following honorees were inducted into the GIST Hall of Fame: The Baldor Family, Dr. Jerzy Lasota, Dr. Markku Miettinen, Norman J. Scherzer, and The Max Foundation. Other highlights included a reading by board member & Life Fest honorary chair, Ray Montague of a classic Tom Overley poem, who we all believe was with us in spirit that night. The LRG staff also debuted a ten year anniversary video reminiscing on the last decade of memories, both joyous and sorrowful sprinkled with some amazing achievements. The food was delicious and the company lively.

The breakout sessions on Saturday were as always, a great way to learn more and share practical advice. The morning was spent hearing the latest on GIST research and management of the disease from Dr. Brian Rubin and Dr. Michael Heinrich, both of whom took questions from the group after their presentations as well as on an expert panel. They provided valuable insight that one cannot find any-



Honorees receive their awards at the Gala Dinner.



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where else. The group also heard the real facts about Drug Development from Novartis representative Chris Kier, and many attendees commented that they had no idea what goes into the making of drugs like those prescribed for GIST.

Lunch was then provided in conjunction with a special survivors ceremony where individuals who have been living with this disease for over ten years stood in front of the room giving testament that this disease



can be conquered. We all then broke for lunch before the workshops began, Coping for Patients with Paula Vettel, Side Effects Management with Patricia Simmers, GIST 101 with David Josephy as well as Balancing the Needs and Role as a Caregiver with Jim and Margi Hughes. Ira Allan was on hand for Economic Strategies for Managing the Cost of Cancer Care, LRG Science Director Jerry Call taught Strategies for those with Advanced Disease and Alice Sulkowski schooled us on Nutrition. Jim Hughes gave us insight into Clinical Trials and Dr. Alex Reimann taught about Complimentary Healing Practices.



Attendees enjoying the workshops and asking questions during the meeting.

Lastly, Norman led a candle ceremony honoring the lives of the GISTers who are no longer with us.

Saturday night everyone had the opportunity to go out on the town and visit the famous Las Vegas Strip or equally famous Old Las Vegas where lots of excitement awaited the group.

Sunday morning, the group gathered for the last time while Paula Vettel told her amazing GIST survivor story. LRG Administrative Director Roberto Pazmino then presented the LRG's Patient Registry and Tissue Bank and spoke of the importance of both to research for a rare cancer. LRG Communications Director, Erin Kristoff then joined Roberto on stage to discuss how to use technology to better manage your care. Erin unveiled the new LRG website and highlighted some of the great new features. This website is currently in progress and will be officially launched January 1, 2013. Roberto then showcased the new LRG mobile app, which allows you to bring the LRG right into your smart phone. You can download those through your iPhone (through the App Store) or Android (through Google Play) phones.

Jerry Call followed with a session on understanding mutational and plasma testing, and how it can aid GIST management. And finally, Norman Scherzer wrapped up the meeting by teaching us valuable survival strategies.

Sunday, another group visited Bonnie Springs Ranch and the majestic Red Rock Canyon—a fitting farewell to a wonderful weekend.



Rubin giving a Research Update to participants.



Enjoying a night out in downtown Las Vegas.



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Enjoying special moments with the Life Raft family.



Life Rafterers having a good time before the Gala.



Norman and Pat George.



Life Rafterers Oscar and Erlinda Adajar share a happy moment together.



Ralph and Debbie Farmer enjoying their first Life Fest.

## Special Thanks

The LRG would like to thank everyone who helped put this event together: Melissa Tribus from Red Rock Resort and Cheri Martinez from Suncoast Hotel. Thank you to Neill Miller of PM Digital Group for videotaping the event. Big thanks to our Presenting Sponsor, Bayer Pharmaceuticals; Gold Sponsor, Pfizer Pharmaceuticals; Silver Sponsor, Novartis Pharmaceuticals; Sapphire Sponsor, LRG Board President Jerry Cudzil; Ruby Sponsors, Sanofi, Genentech and Michael & Maggie Marcantonio; and Emerald Sponsor, Sylvester Cancer Center.

We would also like to extend special thanks to Nadine Sta. Brigida, Shun Otsubo and Matt Consoli for volunteering to photograph and take videos of the event.

Thank you to all those who volunteered to be mentors during the event as well as all of the LRG members who generously gave of their time to help us coordinate this event.