

# Special Edition: Life Fest 2010

**O**n June 25, the Life Raft Group kicked off its fourth annual Life Fest—an event that occurs only once every two years and brings together patients, loved ones, doctors and representatives from the pharmaceutical industry in a setting that fosters learning and encourages the kind of camaraderie that you

can only find amongst people who have been in your shoes.

What made this Life Fest special was the Friday night gala event commemorating ten years of GIST treatment.

Doctors, researchers, patient advocates and other key figures in the GIST community were inducted into the



newly-formed GIST Hall of Fame. The weekend continued with awards for Humanitarian of the Decade, Clinician of the Year and Volunteer of the Year, a star-filled dinner cruise on the Hudson, and numerous presentations and workshops, on topics like complimentary medicine, plasma testing, coping and survival strategies.

## GIST 2010: A Decade of Difference

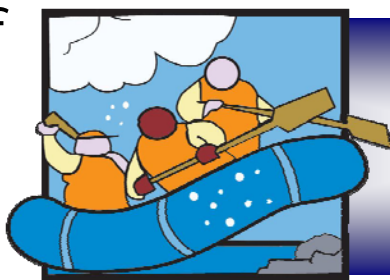
Friday night gala event  
is a smashing success

By Anita Getler,  
NJ Local Group Coordinator  
& Janeen Ryan, LRG Member

**T**he Life Fest 2010 Friday Night Gala was a simply spectacular evening. The first day of our wonderful weekend began with registration and an informal meet and greet in one of the lovely ante-rooms of the hotel. The staff of the LRG as usual made everyone feel so welcome as well as making everything go as smooth as silk. Goodie bags filled with information, our itinerary for the weekend, LRG pins, GIST bracelets, plus T-shirts to commemorate the GIST community's 10<sup>th</sup> anniversary and more were given to everyone attending.

**I just wanted to say how exiting it was to meet everyone at Life Fest! It was such a blessing for us to meet and talk first-hand with fellow GISTers and caregivers. The staff was wonderful at helping us feel welcome and guiding us to the right locations.**  
-Ken Brecko

Battling gastrointestinal stromal tumor



## LIFE RAFT GROUP

**SPECIAL EDITION: LIFE FEST 2010**



Ten-year survivors were honored on Saturday in a special ceremony with David Epstein, Division Head at Novartis Pharmaceuticals.

Pictured from left to right: (Standing) Chris Carley, Theresa Hausbeck, Elsie Hernandez, Estelle Lecointe, Jerry Call (on behalf of wife, Stephanie Call), Jas Kiran Kaur, David Epstein, Paula Vettel, Alice Sulkowski, Anita Scherzer, LRG Executive Director, Norman Scherzer, Norma Siegel, Dan Cunningham (Seated) Dr. Joel William Sherr, John Poss, Garnette Draper & Tom Overley.

## FRIDAY

From Page 1

One highlight were the “Trees of Life” cards at each place setting. When you sat down you were greeted to someone else’s GIST journey, all the good things that came into his/her life since s/he was diagnosed with GIST. It was a touching addition and by the end of the night they were being traded like baseball cards!

There was plenty of time to mingle and meet new and old friends before we all had to get ready for dinner.

A Life Raft display was erected in the hotel for any and all who wanted a photo-op moment aboard the famous Raft. It was fun to see so many people get aboard that raft and ham it up for the camera.



Butch & Jeannie Eller say cheese in the Raft



One member's "Tree of Life"

Before dinner Norman welcomed us all with his usual charm, wit, and heartfelt thanks for all who make up the LRG – GISTers, staff, physicians, researchers, as well as everyone who has contributed to

keeping the hope for a cure alive. Norman then led us in a touching tribute to those who have lost their battle in the fight against GIST. Special candles were placed at each table with a taper candle to light the centerpieces in memory of our lost friends, GISTmates and fellow warriors. That flame burns on within us all to ensure they will never be forgotten.

Our meal was served while got to know our tablemates, snap some pictures and share stories with each other. When dinner was almost done, Norman once again took the floor to share some memories of the last ten years and the people who filled that decade with laughter, love, joy and tears. Presentations followed with Dr. George Demetri receiving one of two Humanitarian of the Decade Awards. His speech was, as always, eloquent, informative and full of hope that one day soon, we will find a cure for GIST.

Dr. Daniel Vasella, Chairman of the Board of Novartis Pharmaceuticals received the second award for his work in developing Gleevec and the continued efforts he puts forth in helping to find even more new drugs to combat GIST.

The inaugural inductees to the GIST Hall of Fame came up one at a time to receive their awards— plaques with little life vests in them!

The night ended with a beautiful song for the LRG by George Teren.

It was a wonderful start to an amazing weekend, we’re looking forward to Life Fest 2012!

## The Life Raft Group

Who are we, what do we do?

**The Life Raft Group (LRG) directs research to find a cure for a rare cancer and help those affected through support and advocacy until we do.**

The LRG provides support, information and assistance to patients and families with a rare cancer called Gastrointestinal Stromal Tumor (GIST). The LRG achieves this by providing an online community for patients and caregivers, supporting local in-person meetings, patient education through monthly newsletters and webcasts, one-on-one patient consultations, and most importantly, managing a major research project to find the cure for GIST.

### How to help

Donations to The Life Raft Group, a 501(c)(3) nonprofit organization, are tax deductible in the United States.

You can donate by **credit card** at [www.liferaftgroup.org/donate.htm](http://www.liferaftgroup.org/donate.htm) or by sending a **check** to:

The Life Raft Group  
155 US Highway 46, Suite 202  
Wayne, NJ 07470

### Disclaimer

We are patients and caregivers, not doctors. Information shared is not a substitute for discussion with your doctor.

Please advise Erin Kristoff, the Newsletter Editor, at [ekristoff@liferaftgroup.org](mailto:ekristoff@liferaftgroup.org) of any errors.



The inaugural inductees of the GIST Hall of Fame. Please see page 7 for more pictures from Friday night.



# Saturday: Sessions and speeches, workshops and presentations, awards and ...a cowboy hat?

By Erin Kristoff  
LRG Newsletter Editor

Saturday was a day packed with informative and supportive sessions and workshops. It began with an LRG Research Update by Dr. Jonathan Fletcher of Brigham & Women's Hospital, the LRG Research Team Leader. It was a wonderfully informative presentation that helped to put GIST research in a more understandable format for the audience.

Dr. George Demetri of Dana-Farber Cancer Institute gave a very well-received GIST update presentation. His personable demeanor, joking nature and grasp of all things GIST related impressed the audience. As one attendee noted, "He gives this patient hope and the feeling that medical people are working together for patients."

After a small refreshment break, a Drug Development panel, moderated by LRG Science Team member

Jim Hughes and consisting of Drs. Safi Bahcall, Synta; James Christensen, Pfizer; Jenna Fan, Novartis & Dan Flynn, Deciphera, answered the audiences questions about the process and



Dr. Jonathan Fletcher & Dr. George Demetri presenting at Life Fest 2010.

costs associated with drug development.

Next up were Drs. Su Young Kim, National Institutes of Health (NIH); Jonathan Trent, MD Anderson; & Meg

detailed and knowledgeable answers in return. One audience member stated that the expert information was worth the cost of the trip!



Anne Pacifico, right.

**This was my first Life Fest and I felt right at home. I feel so lucky to have such a great support system. I can't put into words how much I appreciate Norm, Jerry and the Life Raft staff. Thank you all for all you do. The doctors, lecturers and all of you, my friends, made this such a positive experience. I got a chance to meet so many of you and received lots of hugs and kisses from Pat [George]. God bless all of you for being so upbeat despite our issues.**

**-Anne Pacifico**

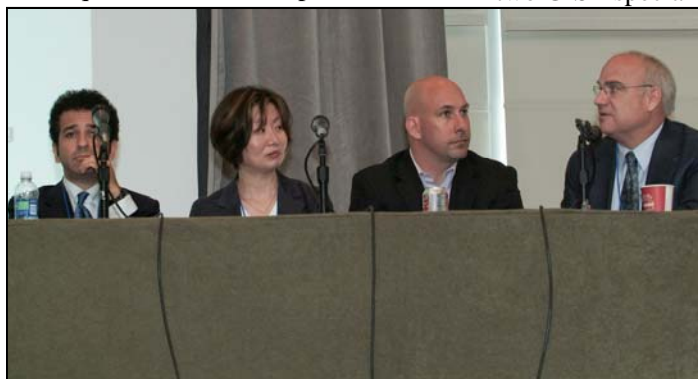
During lunch, more awards were given out, beginning with the 10-Year Survivor Awards. The awards were given out by David Epstein, Division Head of Novartis Pharmaceuticals, who also gave out the 5-Year survivor awards at Life Fest 2006.

The NIH defines a cancer survivor at

von Mehren, Fox Chase Cancer Center, for the Ask the Expert Panel. Audience members walked to the microphone and voiced their concerns and issues for the two GIST specialists and received very

five years. At this truly remarkable event, patient after patient took to the stage and barked at that figure celebrat-

See SATURDAY, Page 5



The Drug Development (left) & Ask the Experts panels (right) were great resources & learning tools for Life Fest attendees.

# Cruisin' on the Hudson: Good food, good friends & a surprise fireworks display

**By Janeen Ryan**  
LRG member

**S**aturday night at Life Fest 2010 was the favorite part of the down time for all the people who attended. After a day of learning, absorbing as much information as possible at the many classes that were offered, many of the group gathered together for a dinner cruise on the Hudson.

We were treated to the indoor pavilion where we could gaze out at the glittering lights of the skyline of New York and



Janeen & Larry dance the night away.

Jersey City. The weather was perfect for our cruise as the rain held off seemingly just for us. We were greeted at the top of the plank by the cruise boat captain and welcomed inside for what turned

out to be a wonderful evening of entertainment, food and revelries.

The waiters were not only there to accommodate our culinary desires but, they were also very accomplished singers. They regaled us with song and dance numbers as we sailed out along the shoreline. Before long we were dancing in our seats to the beat of the 80's hits and not long after it just spilled out onto the dance floor.

Each table was called individually to the buffet and many of us loaded up, some of us even went back for seconds. The buffet featured meatballs, chicken, salad, rolls, potatoes, prime rib, ham and more. Something to satisfy every taste and cooked to perfection.

About the time desert was being

served we were informed by the crew that we should hurry outside to the upper decks to enjoy a fireworks display like no other. It wasn't July 4th but the city was practicing for the holiday festivities.

There's nothing like watching fireworks over the water, with the double joy of seeing the night sky lit up in multicolored patriotism and, the same reflection on the water. This 'practice' was better and more spectacular than my hometown's actual celebration!

Soon after the fireworks we began to circle the Statue of Liberty. Having the opportunity to see her that close is a memory I will not soon forget. We were enjoying a full moon on the 26th and



Happy New Year? No! Just happy people celebrating a night to remember forever.

that added an amazing ambiance as well as a spectral beauty to our cruise.

There's something about a full moon and a dance floor that just gets a party rocking, cheek to cheek or hip to hip we danced that boat right back to the dock. It's a memory that so many will cherish for years to come. I know I will.

A surprise "practice" fireworks display was a special treat for those enjoying the Spirit Dinner Cruise on the Hudson River, as was the spectacular views of the Statue of Liberty. See page 9 for more pictures of the Saturday Night Cruise.





## SATURDAY

From Page 3

ing ten or more years of GIST survival. There was no one left in their seats when the group of survivors held up their certificates with pride for the many people clapping and snapping pictures with support, admiration & hope. (Please see page 1 for a picture of the 10-Year survivors).

Following that uplifting experience, LRG member and Pediatric GISTer, Carolina Ponce-Williams delivered a tearful introduction for her mother, LRG Latin American Coordinator, Virginia (Vicky) Ossio, the recipient of the Allan Tobes Volunteer of the Year Award.

Vicky has been a tremendous asset, assisting the Life Raft Group with various projects including the translation of educational materials, coordination of international meetings and most recently, helping to launch the Latin American GIST Coalition.



Carolina Ponce-Williams presented her mother, Vicky Ossio with the Allan Tobes Volunteer of the Year Award.

The final award, GIST Clinician of the Year, was given to Dr. Jonathan Trent of MD Anderson Cancer Center in Houston, Texas. New Jersey resident, Butch Eller's nomination of Dr. Trent was chosen not only for the clear admiration in



Long-time LRG member, Tom Overley, shakes hands with David Epstein after receiving his 10-Year Survivor Award.

to the stage, you instantly knew that he not only considered Dr. Trent a fantastic doctor, but also a valued friend.

Dr. Trent started his speech humbly and appreciative of the award, but soon turned the tables on his patient by presenting him with his very own cowboy hat from Texas (and if you've ever met or spoken with Butch, you know how well it suits him) and declaring him GIST Patient of the Year!

Soon, Life Fest attendees shuffled off to different rooms for the first round of workshops.

The Side-Effects Management and Nutrition sessions were back this year, led by LRG members Joy Knopp and Alice Sulkowski, respectively. Both women did a wonderful job education their audiences.

Newcomer to Life Fest, Kristin Sorlie, of CancerCare, led "Balancing Needs & Roles as a Caregiver" and many of the attendees found it helpful to share storied with others in their situation.

For the second round, LRG Executive Director, Norman Scherzer led a helpful

his writing but also for the over 20 Trent-authored research abstracts he faxed to the LRG office! When Butch came up

session on coping for patients. Dr. Su Young Kim, coordinator of the NIH Pediatric & Wildtype GIST Clinic worked with a group of patients battling that rare and complicated subset of GIST, and LRG Science Coordinator, Jerry Call presented on the new and complex topic, "Understanding Mutation & Plasma Testing".

For the final round, President of Life Raft Group Canada and biochemistry professor, Dr. David Josephy was back for GIST 101, which is always a very

clear and informative session.

The information taught in Laurel Gregory's, presentation on Medicare/Insurance & Financial Issues, was very helpful to people struggling with Medicare and their insurance companies. Laurel is new to Life Fest



Left: Clinician of the Year Award.

Above: Butch gets his own cowboy hat!



and works for the Patient Advocate Foundation, a great resource for any cancer patient.

Also new to Life Fest was Sharon Yeskel, a Reikki practitioner who led a Complimentary Healing workshop. Most of the attendees who left that room commented on the good tips they learned and how relaxed they felt.



Raise your hand if you're enjoying Life Fest! Patients & caregivers get interactive in one of Saturday's workshops. Please see page 8 for more pictures from Saturday.

# Sunday: Life-saving information, raffle prizes & tearful goodbyes, what a combination!

By Erin Kristoff  
LRG Newsletter Editor

Sunday started with a Clinical Trials presentation by Jim Hughes. Updates on developing trials are crucial to patients who are resistant to Gleevec and Sutent because new and innovative trials and trial changes occur every day. Jim presented this clearly and concisely, helping interested patient navigate this complicated world.

Science Coordinator, Jerry Call and LRG Database Administrator, Roberto Pazmino followed with a presentation on "Life-Saving Information", a look at the

LRG Patient Registry and patient-led research. Most of the audience commented on how useful and important the information they received was.

A break followed this presentation and the LRG staff gave out raffle prizes that attendees had been buying tickets for all weekend. The raffle pulled in over \$500 for the LRG and prizes included a time share vacation, a free night at the Hyatt Regency, a bag of Trader Joe's goodies, a basket of hair products, necklaces, and a piece of art by a local artist.

Once the fun was out of the way, it was back to work with a Survival Plan presentation by Norman. Using a resource guide he developed, Norman

helped the audience affirm their commitment to their own care and finding the best possible treatment for themselves (Please email [liferaft@liferaftgroup.org](mailto:liferaft@liferaftgroup.org) to request a copy of the Survival Plan).

After emotional closing remarks by Norman, it was time to say goodbye to Life Fest, Jersey City and each other. There were lots of hugs, numbers and email addresses exchanged and I, for one, left the conference feeling that, like Life Fests before, something amazing.

We are adding pictures, video and presentations to the Life Fest page on the LRG site at [www.liferaftgroup.org/members\\_lifest.html](http://www.liferaftgroup.org/members_lifest.html).  
**Check back for updates!**



Jim Hughes, Norman Scherzer & Jerry Call delivered wonderful presentations at Life Fest 2010.



LRG NJ Group leader, Anita Getler does her best Vanna White impression while assisting the LRG staff with raffle prize give-out.



Michael Ginsberg and Ellen Rosenthal were just two raffle prize winners on Sunday. Mike won a time-share visit donated by the Ellers and Ellen won a stay at the Hyatt Regency that the hotel donated.

Congratulations to all the winners at Life Fest!



Anna Costato of Italy & Helga Schnorf of Switzerland say their goodbyes.



# More Friday night pictures...

Estelle & Samantha Lecointe from France hop in the Raft.



Kristen & Anita Getler



Norman Scherzer lights a candle for our loved ones lost. At home, dozens of once-caregivers lit candles with us.



Dr. Demetri enjoyed Norman's introduction



Dr. Dan Vasella & Pediatric GISTer, Josalin Dunn meet again after four years!

Scherzer, Vasella, Demetri, Hugues Joblin, David Epstein, Vicky Ossio, Anne-Laurence Vasella, Elizabeth Barret, Meg von Mehren & Debra Friere.



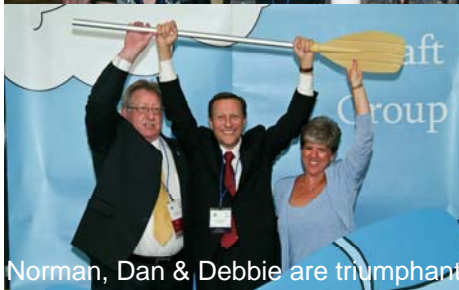
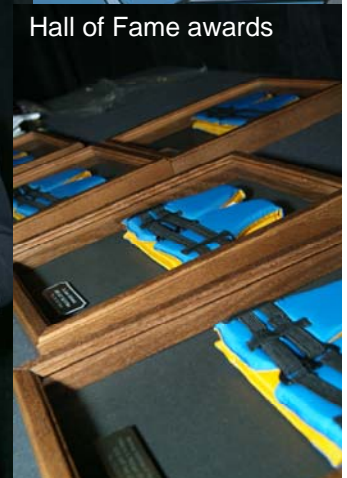
Board President, Jerry Cudzil welcomes us all to Life Fest 2010.



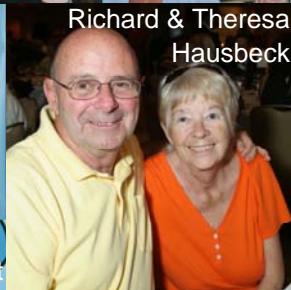
Chris Carley & Melinda Poss fight it out!



Hall of Fame awards



Norman, Dan & Debbie are triumphant



Richard & Theresa Hausbeck



# More Saturday pictures...



Pat Bonda-Swenson, Pat George & Joy Knopp listening to speakers.

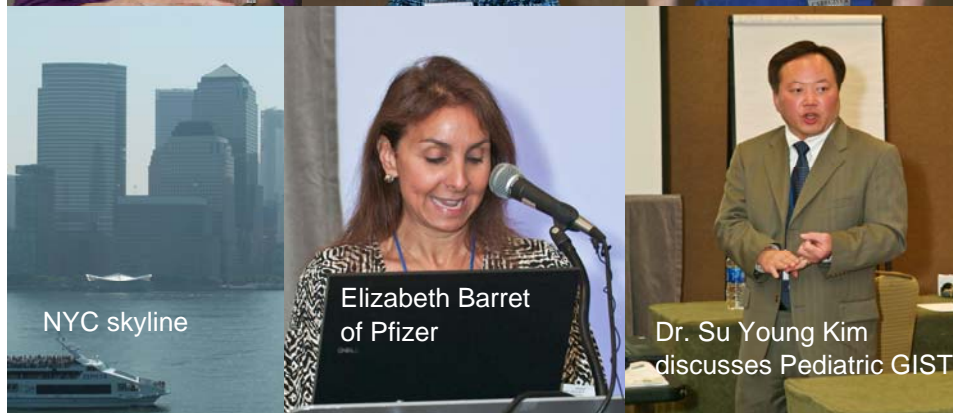


Jerry receives the 10-Year Survivor Award on behalf of his wife.

Mia Volkeneing, always smiling!

Alice Sulkowski is proud to receive her award!

Sharon Yeskel, Laurel Gregory & David Josephy led 3 of Saturday's workshops



NYC skyline

Elizabeth Barret of Pfizer

Dr. Su Young Kim discusses Pediatric GIST

## A LOOK BACK AT LIFE FESTS PAST

**Life Fest 2002** in Cambridge, Massachusetts was our first gathering and an opportunity for patients with a rare cancer called GIST to walk into a room and meet others confronting the same diagnosis. For many this was the first time they had met other GIST patients. Early reports of responses to treatment with Gleevec filled the meeting with hope.

**Life Fest 2004** in Orlando, Florida was a time for exhilaration as we celebrated hundreds of patients dramatically responding to treatment with Gleevec.

**Life Fest 2006** in Dallas, Texas brought us face-to-face with our research team and our plans to find a cure for GIST. Issues of what to do about growing Gleevec resistance began to command attention as we updated all about the host of new drugs entering clinical trials.

**Life Fest 2008** in Chicago, Illinois introduced us to a new era as we once again met and confronted the need to strengthen our efforts to keep patients alive as we continue our research to find a cure. Once again it was vital that survivors meet, share, support and learn from each other and the medical professional of the GIST community.

**Life Fest 2010** in Jersey City, New Jersey looked back at the key scientific and medical milestones over the last ten years as well as forward to the most promising treatments and new discoveries that are just a glimmer on the horizon.

*Life Fest has always been a celebration of survival and hope. We recognize the enormous courage of every patient and family member who has battled and continues to battle GIST.*



# More Saturday night pictures...



Half on the bus and half on the train, everyone heads off to the dock for a fun-filled night



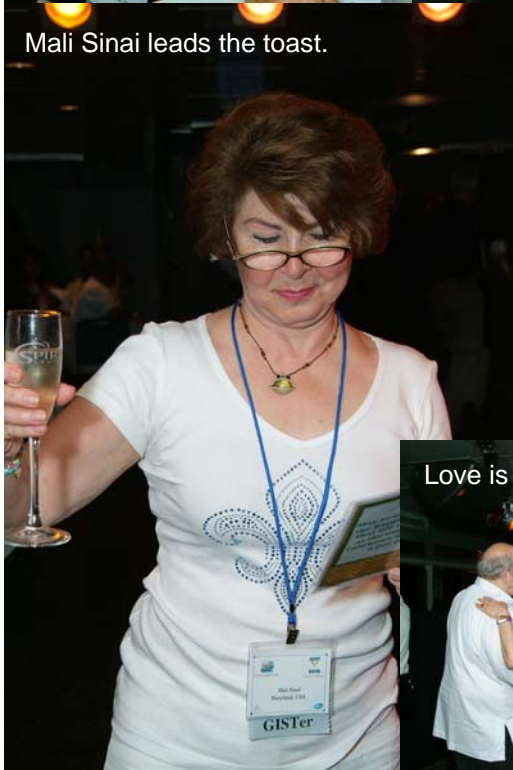
Joyce O'Shea & Eileen Fuller say cheese!



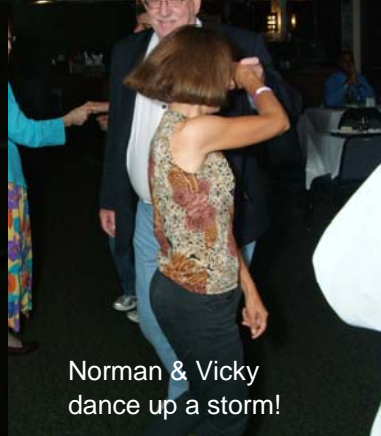
Michael & David Josephy waiting for the train.



**FIREWORKS!!**



Mali Sinai leads the toast.



Norman & Vicky dance up a storm!



Love is in the air...



Please enjoy all the pictures from Life at <http://www.pictage.com/863735>

## **Congratulations to all the award winners at Life Fest 2010!**

### **GIST Hall of Fame Inaugural Inductees**

Dr. J. Aidan Carney  
Dr. Christopher Corless  
Dr. George Demetri  
Dr. Brian Druker  
Dr. Jonathan Fletcher  
Mr. Gilles Frydman & ACOR  
The GIST Patient:  
Patient Advocacy Groups  
For Gleevec:  
Dr. Elisabeth Buchdunger  
Dr. Renaud Capdeville  
Dr. Laurie Letvak  
Dr. Nicholas Lydon  
Dr. Alex Matter  
Dr. Jürg Zimmermann  
The Gleevec Trial Doctors:

Dr. George Demetri  
Dr. Margaret Von  
Mehren  
Dr. Charles Blanke  
Dr. Heikki Joensuu  
Dr. Michael Heinrich  
Dr. Seiichi Hirota  
Mr. Jeffrey Kindler & Pfizer  
The National Institutes of Health  
Clinic  
For Sutent:  
Dr. Zuleima Aguilar  
Ms. Elizabeth Barrett  
Mr. Carlo Bello  
Dr. James Christensen  
Dr. Darrel Cohen  
Mr. Stephen Evans-  
Freke  
Dr. Joseph Schlessinger  
Dr. Axel Ullrich

Dr. Daniel Vasella & Novartis  
Dr. James Watson

### **Humanitarian of the Decade Awards**

Dr. George Demetri &  
Dr. Dan Vasella

### **Clinician of the Year Award**

Dr. Jonathan Trent

### **Volunteer of the Year Award**

Vicky Ossio



## **Special Thanks**

Thank you to our sponsors: Novartis Pharmaceuticals, Pfizer Pharmaceuticals, American Society of Clinical Oncologists (ASCO), Angel Flight Northeast, Genentech Pharmaceuticals, Synta Pharmaceuticals, Project Flag and the National Institutes of Health (NIH).

Thank you to the LRG Board of Directors for donating scholarships so that those experiencing financial hardship were able to attend the event.

Thank you also to the Hyatt Regency in Jersey City, NJ for hosting our event, specifically Neville and Carol, who were such a help throughout the weekend.

Thank you to George Teren for creating the wonderful Life Raft song and Diane Moser for entertaining us all with her piano skills on Friday night.

Special thanks to everyone who donated to our raffle: Arbonne International, Dickson Hairshop, Jeannie & Butch Eller, Fairway Market, Hyatt Regency, Brenda Jones, Lindsay Possumato, Trader Joes, Utterly Smooth Udder Cream & Venus Creations

A big thanks must go to Kim & Steve Tallau from Innovative Images for donating their photography services for the whole weekend.

We would also like to thank Nancy from Pine Needle Designs for the wonderful life vests we used for awards.

We must also thank the Life Fest Planning Committee and NJ Welcoming committee for making the event such a success. We could not have done it without you all!



# THE LIFE RAFT GROUP

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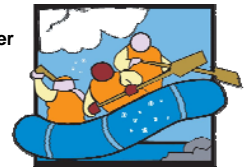
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## Life Raft regional chapters

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