



The Life Raft
GROUP

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SPECIAL EDITION

THE CELEBRATION ISSUE!

**Come Celebrate
with Us!**

The Life Raft Group's
13th year anniversary

GIST Awareness Day
and #ShowUsYourRare

15 years of treatment
options for GIST

CELEBRATING 13 years as The Life Raft Group



The Life Raft Group

The Life Raft Group became a formal non-profit on June 10, 2002. Our one-of-a-kind patient registry began. The first formal patient gathering was held in Cambridge, Mass.

2002



The first "official" Life Fest took place in Orlando.

2004



The LRG Research Team was created.

2006

GIST SPECIALIST DIRECTORY

The first international GIST medical specialist directory is up and running on the Life Raft Group Web site, www.liferaftgroup.org. The initial entries include GIST specialist physicians from 12 countries and can be sorted both alphabetically and by location (country and state).

The first GIST specialist directory was created.

2003



The LRG held the first Pediatric GIST Conference in Montreal, Canada.

2005

A Word from our Executive Director, Norman Scherzer

The nighttime summer sky is dark, clear and cloudless. Suddenly a burst of brightly colored light explodes across the sky. Fireworks illuminate the dark night, bringing promise and hope.

The journey of the Life Raft Group mirrors this. In 2000, a group of men and women with a deadly cancer were without hope. In the summer of that year, a new diagnostic test to determine the presence of an enzyme called c-kit ushered in a clinical diagnosis for a cancer called Gastrointestinal Stromal Tumor (GIST). The next light in the darkness was a new oral targeted drug called STI-571 that had an amazing breakthrough in treating another rare cancer. A clinical trial for GIST was started for a small number of patients.

An informal group of these patients came together to share their experiences and their hope for the future. That was the humble beginning of the Life Raft Group.

In 2002, we became incorporated as a non-profit organization. The milestones we have reached are like fireworks in the sky: illuminating the GIST community with research, education, support and advocacy.

Now, 13 years after the formal start of the LRG, and 15 years after the development of the first viable treatment for GIST, we can celebrate our milestones together. But it is not enough. Fireworks are transitory. We need to create new paradigms in the war on GIST. We can't sit back while many patients are resistant to treatment.



We have so much to celebrate in 2015! The LRG has been a formal non-profit for 13 years, our GIST Awareness Day and #ShowUsYourRare campaigns united our global community in raising awareness and we recognize 15 years since imatinib, "The Magic Cancer Bullet" was developed. We've come a long way!



Dr. Jonathan Trent presented LRG's first webcast.

2007



The first Virtual Tumor Board was held in collaboration with the NIH. The GIST Cancer Journal was published.

2014



The LRG joined OVAC and CTTI. GIST Kids was created.

2015



The first NIH Pediatric Clinic was held. GIST Clinical Trial database was created.

2008



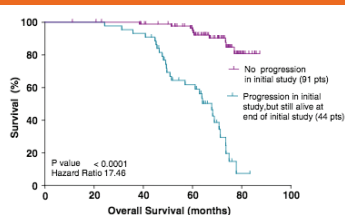
The first GDOL was held in Miami.

2012



The new LRG website was launched.

2013



LRG's first research study was published in Journal of Gastrointestinal Cancer.

2009



The first Alianza GIST Meeting was held.

2010



LRG presented a long-term follow-up study at CTOS.

2011

CELEBRATING Our Second GIST Awareness Day

From Iowa to India, our second successful GIST Awareness Day celebration brought together members, medical professionals and friends of the LRG in person and via social media to raise awareness about GIST. It was a true celebration of the power of community.

Community

Global Reach

International Reach to over 50 countries

GDOLs

Over 200 Facebook Posts

Awareness

Members

**175 entries to our
#ShowUsYourRare
contest**



GIST
AWARENESS DAY

And #ShowUsYourRare

Our social media campaign, #ShowUsYourRare, highlighted what is unique and special about all of us. Thousands of images from around the world made this a global celebration.

Over 1,000 images
in our mosaic



Dedicated



EVENTS

#ShowUsYourRare
2613 tweets

Unique

Rare at the Fair



Over 1000 visitors to our
Meadowlands Booth



Special



Show Us Your
Rare

CELEBRATING 15 years of lifesaving treatments for GIST

Without the development of STI-571, which became Gleevec, there would be less to celebrate today. It is an unprecedented story of innovation, persistence and courage which led to the development of other lifesaving treatments such as Sutent and Stivarga, paving the way for future discoveries.



2001

May 10, 2001 - FDA approves Gleevec for CML in the US - approved in two and a half months- the fastest drug review in the agency's history.

2002

February 1, 2002 - FDA approval for advanced GIST

2005

2005 - Sutent clinical trial ends early due to efficacy

1990s

2001

2003

2005

2000

2002

2004

2006

2000

Initial clinical trials for GIST conducted by researchers with dramatic results.

2004

March 1, 2004 - Sutent (SU11248) clinical trials

Prior to 2000

Patients with GIST were often misdiagnosed with leiomyosarcoma. Patient had no viable treatments. Many were on their deathbeds.

1990s

Three events converge to birth the age of targeted therapy:

- Members of the Ciba-Geigy (now Novartis) drug development team, Alex Matter, Nick Lydon, Brian Druker, Jurg Zimmermann and Elisabeth Buchdunger develop compounds to target CML
- Brian Druker discovers that one of the compounds, STI-571, was effective in killing CML cells.
- Hirota and Kitamura's group discover c-Kit gene mutations prevalent in most GIST cases, which are later found to respond to STI-571



2006

January 26, 2006 - FDA approves Sutent

Gleevec was the start of the targeted therapy approach to cancer treatment. Who could have predicted that it would pave the way for other cancers to be classified as a chronic illness instead of a terminal one?



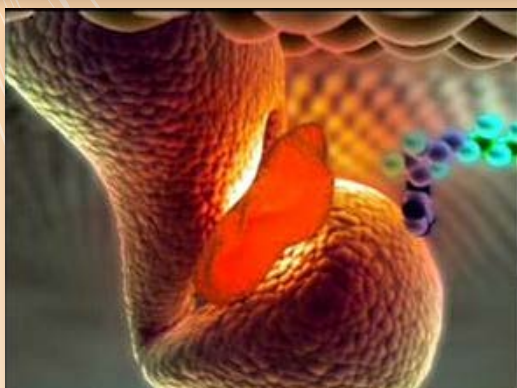
2013
February 25, 2013 - Regorafenib (Stivarga) approved for advanced GIST

2007 2009 2011 2013 2015

2008 2010 2012 2014



2008
FDA approves Gleevec for adjuvant treatment.



The FUTURE:
Promising research conducted by the LRG Research Team. Clinical trials for new drugs and combination therapies.

2012
FDA extends approval for adjuvant treatment with Gleevec to three years.

AS WE CELEBRATE, WE PAUSE TO REMEMBER THOSE NO LONGER WITH US.

Donna Johnson Marilyn Lee Hoch Michael Logan Christopher Patricia Hernandez Susan Rink Joyce O'Shea Louise Leonard Merlin W. Gesing Marije Govers-Moria
Pat Lemeshka Stephanie Call Robert Toy McLaughlin Mark A. Stanke Michael Pacillo Bill Glenwood David E. Jordan Michael Guillermo Fergau Steven Criag
Luckstead Alma Klindera John Lynch, Jr. Dominick Ferraro Gwen Perrewa Mary Pfeiffer Kenneth Witt David Safford Michael Byrne Sandy Wakeling
Louise Ladd Harry Smith Raul Ramirez Donald R. Samuelson Timothy Matsick Earle Heath Gerald Liu Lane Barton Ron Smelser Glenita Mungcal
Robert Toppi Richard Haan Bob Hall Walter Stampley Morton Wagman Mirja Voutilainen Timothy Duffey Joyce Tucker JoAnn Smith Paul S. Norton
SSGT USAF, (Ret) Debra Binkley Tadros Endrawes Tania McLaughlin Barbara Ehrhart Bruce Eric Krauch Mary Netting Morgan Konnick Julie Ann
Carlson Brian Eric Poe Jack Marsteller Susan Farmer Jean Huston Richard Bartenbach Stan Folda Terrance Spall Mary Corliss Daniel White Mary
Giles Laura Boughner Kath Kimball Helen Synder Neil Intindola Theodora Koumbouzis Steven McLaughlin Hank Walker Timothy Coughlin Nora Lynn
Webb-Winstead Erin Malnory Dr. Peter Joseph Quinn Edward Martinka, Jr. Mohammad Reza Yazdi Albert Paul Costa Jim Dunn Aimee Adcock Ralph
Farmer Shirley Ann McIntosh Marie Lagaluga Kenneth D. Huff Tereba Venita Berrian Terrance Spall John Janicki Cherie Lufkin Blackett Larry Ryan Kay
Jarman Betty Gunderson David Blender Bob Bridgewater George Logan Nely Jaquez Bob Book Larry Weaver Daniel Butt Richard Bodden Mitch
Kremer Harold Paulette Doug Horst Michael Lerner William Clyde Turner Maria Torres Harold Pedersen Paul Kaletta David Finkelstein Jennifer
Locke Michael Shorb Joan Smalec Joy Davis Darryl Wallace Ken Schou Chris Kaczmarek Dereck Juden Gayne Ek Richard Fosbrink Buddy Coats Jr.
Linda Brecko Mariane Malinowski Ann O'Malley-Luce Robert Hare Julie Newman Tom Overley Reinhardt Jesse Frank Tondo David Durham Betty
Arnett Jessica Woods Marchionda Nancy Reinhardt Jeroen Pit Debbie Brewster Edward Sauer Janice Aubert Vera Krstevski Sally Smith Rafael
Becerra John Smith Lynette Ferguson Janet Rowe Mark Walker Bob Tikkanen Goetz Wochinger Preston Ford Lawrence Glasser Richard Evans Diane
Ralston Dan Cunningham Jonathan Wilson Mervin Gangstead Victoria Zuber Katrina Rene Cordell Richard Palmer Jonathan West Ann J. Mancuso
Kaye Thompson Sandra Krizan Tina Pandolfino Simon Price William O'Brien Michael Lighle Matthew Guthrie Ricahrd Lowry Chenyu "David" Wang
Wendy Warren Stephen Bashaw Charles McCurdy Kitty Cartwright Mariette Dubois Rachel Tate Peter Genga Walter Scott Rick Abbiehl RoseMarie
Jackson Pu'a Galuvao Deborah Reney Robert "Butch" Eller Jennifer Sikes Edgar DeMunck Michel Timans David McCormick silvio Manzanares Stephen
Petrera Lisa M. Booker Franklin Whitaker Glen Banks David Brandis Rick Sorg Bill Buchanan Marke Szczesny Ben Redman Linda Hampson Jay
Hepner Eleanor Lewis Todd Gardner James Robinson Pam Lewkovich Omer Mercier Gary LaFrancis Matt Murff Henry Offen Louis Sill Kenneth
Schieffelbein Jr. Jeanne Noell Fred Weiss Gloria Richmond Mari Josephine Smith Jennifer Bayles Connie Arndt Carl Banker Gail Orso Clive Harrison Tommy
Crutchfield Lois Bond Laura Kukucka Rita Catherine Joyce Patient Matthew Arluck John Ryan Patricia Morrissy Anja Long Nancy Wisecarver Jones Selena
Hudson Herbert Moses Joseph Hamilton Jessica Macneil Kenneth Rowan Linda Chuyko Louise Teerink Ute Scheifling Nurit Mantz Neva Hageman
Jacqui Bromberg Brad Clark Mark Becker James Kwok Jack Dear Renate Croll Jerry Albright Dana Janet O'Bryan Kenneth Klipper Kitty Katt Kimbell
Joseph Mirenda III Howard Kemp Ulrich Schnorf Fatima Ouassini Dennis Janz Dan Wiseman Leland B. Emerson Berthe Gowdy Beverly Wishon Jeannette
McIntosh Francis James Benninger Ed Shtang Sarah Blanche Ferris Ellen Sarko Heppler Donnie Chadrick Thomas Gjertson Severo Lopez Dr. Arnold
Kwart Sharla Ellingham William Nichols Bill Roth David Paulson Robert Spiegel Richard Boynton Shuzhen Gao Bonnie Girard Ben Shtang Dean F. Wilhelm
Linda Martinez Jan de Kort Keeley Bihr Amanda S. Starnes Rose Ellis Jim Toyne Mahlon Sparks Jan-Elnar Moe Gholamali Amirfarhad Butch Schade
Joseph Trinca Tony Petruzzello Alice Greenwood Brian Denkers Ronna Lindeken Richard Inlander Tony Paonessa Robert Spar Xiangjie Mu McGhee
(Mac) Ellis Harold R. Greene Nancy Romero Rene Kerremans Doris Talley Shaoqiu Hu Cheng Ralph Mattison Cherie Ashburn Andrea Fuller Dan Scherban
Ken Lundell Ellen Heppler William (Bill) Fraser Erin (Nan) Mustard Edward Friedman Gerald Snodgrass Judy Earle Patricia Friedmann Roig Michelle
Scheirpeter Russ Jones Bob Caraway Kittie Tomson Joe Marlatt Lee Kavaloski Bruce Staffin Peter Richetti Peter van der Meer Joe Simas
Herbert Flom Lauralee Bucholtz Bernd Becker Matt Deveney Marcel Szyzkowski Marcel Schaddelee Mary Parker Kenichi Kushida Robert
Donohoe Robert P. Keefe Richard Singleton Theodore Pantelakis Carlos Ramos Goran Demo Gerald Hui Maria Adela Ruiz Leslie Millers
Scott McLaughlin Gregory Boitnott Wilbur Stevens Stephen Gratz Gerard Hettterscheid John Leary Mark Thomas Shehadeh Moujaes
Lee Cousins Peggy Howe Rita Raj Jennifer Kelly Nicoletta John Tom Kwasigroch Thuy Tran Jaime Peralta Carolyn Reinheimer Peggy
Weathers Anna Salerno Omer Cloutier Camille Severini James Copperdec William Scholz Betty Rosenbluth Jani DeHart Luann
Stanaland William Verrieter Peter Thomas Henrietta Olsen Josephine Vernon Marilyn Bohan Nellie Stein Paul Isaak Gloria Krafcik
Sheila Murphy Ted Kessler Roy Barton Alex Smolyar David Rankin Alfred A. Urban Major Thomas M. Quigley Leo William Frisk
Russell South Peter Y Du Allan Tobes Eric Irons Matthew Duran Meng Yen Yee Cordelia Salas Fritz Dutro Don Baney Ken
Garabadian Norma Christian Gertie Hegge Roberta Gibson Candace Frank Patricia Novicki Daniel Wieland Carlo Pacquee
Peter Moran Lewis Thorp Ineke de Keijser Richard Correa Dick Greene Marlies Bruinsma-Bol James Olive Henry Lange Terri
Stevens Dale Cross Daniel Hoffman Connie Kehr Ilkka Ovaska Carol Donnell Diane Henry Martina (Matt) Maisu John Engberg
Robert Danielson James Boucher Nancy Hughes Welsh Avraham Anidijar Alan Fink Anping Tang Barry A. Rushing Christine
Gibson Maher Samet Rudi Holzapfel Krmo Benkrid Rafi Aghababian Karen Sales Hans Englund Ara Jelderian Marty Scharf
John Weir Raymond Carbott Myrtle Brickman Barry Jordon Sandi Merriman John Mabree Thomas Cooper Bernie Kaplan Stan
Natanson Karen Westfall Pamela Bowden Nelly Beel Sasidharan Menon Carol Berres Arnout Ernens Mike Matthews Wayne
Brehaut Mitsuru Hayami Paul Roothoof Lupe Zertuche Leif Blixt Tom Fredgren Frank Massaria Terry Davis Sidney Locker Darlene
Vaughn James Mulcahy Arthur Dakota Rhea III Curtis R. Berry Jeanne Lindval Don Radulovic Carolyn Lee Lenkszus Mark Sprecker Leonore
Mendelsberg Gust Vasiliades Dean C. Gordanier Jr. Donald Morenstein Jerry Sidfrid Donald Kew Lois Freyholtz Tuomas Hemminki Ray
Copple Ann Pampreen Frank Weigand Mae Pakenham Pat Ford Maryann Klein Laura Blanchette William Lawson RR Unnithan Melvin Ryan Abdul Hai
Kurt Herzberger Cynthia G. Whitson Kathy Colwell Susan Karp Howard Delapenha Nora Shaulis Chet Duszak Vaughn Enquist Randy McKinney Todd Hendrickson
Rev. Philip R. Johnson Jill B. Meyer Jerry Pat Rylant Ana Maria Baldor-Bunn Stewart "George" Wolf Michael Cornwell Mary Golnik Robert Lecca Jonathan Montague
Jacob W. Waller III Robert Carr Bruce Gunn Ehud Nehemya Ronald Martinez Jeff Prichard Amy Barney James S. Perham Jim Ackerman Debbie Nance Rodney Guccini

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