



The Life Raft Group

Hyatt Regency
O'Hare
Chicago, Ill.

**LIFE
FEST
2008**

September
12-14, 2008

WELCOME!



**LIFE
FEST
2008**

❖ 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 introduces us to a new era as we once again meet and confront the need to strengthen our efforts to keep patients alive as we continue our research to find a cure. Once again it is vital that survivors meet, share, support and learn from each other and the medical professional of the GIST community.

❖ WE WOULD LIKE TO THANK...

- ⇒ All of the GIST survivors and caregivers who have traveled from places around the world to be here
- ⇒ Our distinguished speakers and workshop facilitators
- ⇒ Dick Kinzig and the Chicago-Area Life Raft Group for their hard work and dedication
- ⇒ Genentech, Novartis & Pfizer Pharmaceuticals for their contribution to this meeting

❖ PLEASE JOIN US FRIDAY EVENING... GRAND BALLROOM D, ENTRY LEVEL

6:00 p.m. Welcoming Reception

7:00 p.m. Dinner is served

Welcome Address by Dick Kinzig, Chicago-Area Coordinator

7:15 p.m. – 7:30 p.m. Remarks by Norman Scherzer, LRG Executive Director

8:15 p.m. President's Welcome, Jerry Cudzil, LRG Board President

8:30 p.m. Presentation of the Allan Tobes Volunteer Award by Kendra Tobes.
Presentation of Certificate of Appreciation to ACOR, by Norman Scherzer.

Presentation of Humanitarian Award by Ray Montague, LRG Director



2008 LIFE FEST AGENDA



❖ HONOREE

❖ HUMANITARIAN OF THE YEAR



LIFE FEST 2008

Dr. Lee Helman

Dr. Lee Helman earned his M.D. at the University of Maryland School of Medicine in 1980. His internship and residency were completed at the Internal Medicine at Barnes Hospital Washington University. His fellowship training was at the National Cancer Institute, where he continues his research. In 1993, he became the head of the Molecular Oncology Section of the Pediatric Oncology Branch. He became the chief of the Pediatric Oncology Branch in 1997 and was named a Deputy Director of the Center for Cancer, National Cancer Institute in 2001. In 2005, Dr. Helman was named Acting Scientific Director for Clinical Sciences, Center for Cancer Research, National Cancer Institute. Currently, Dr. Helman's lab is investigating the role of growth factors and the mechanisms of metastases for pediatric sarcomas.



❖ SATURDAY

❖❖ BREAKFAST: GRAND BALLROOM F

❖❖ GENERAL SESSIONS: GRAND BALLROOMS D-E, ENTRY LEVEL



7:30 a.m. – 8:45 a.m. Breakfast is served

9:00 a.m. General Session Convenes,
Welcome by Jerry Cudzil, Board President

9:15 a.m. GIST Update by Dr. Bruce Brockstein, Evanston Hospital

10:00 a.m. FasterCures by Kristen Schneeman, FasterCures

10:30 a.m. LRG Research Evolution by Marisa Bolognese, LRG

11:00 a.m. Break (Refreshments served)

11:15 a.m. LRG Research Team Update by Dr. Brian Rubin, Cleveland Clinic

12:00 p.m. – 1:30 p.m. Lunch, Research Q&A with Dr. Rubin, Jerry Call & Marisa Bolognese

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SATURDAY WORKSHOPS

2:00 p.m.—5:00 p.m.



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LAMBERT ENTRY LEVEL

L.A.X. A ENTRY LEVEL

L.A.X. B ENTRY LEVEL

2:00 p.m. Coping for Patients:
Pam Lewkovich,
GIST survivor

GIST 101:
David Josephy,
LRG Canada

Drug Development:
Karen McDougall, Novartis,
Respondents: Dr. Brian Rubin,
Cleveland Clinic & Tom Over-
ley, LRG General Counsel

3:00 p.m. Coping for Caregivers:
Marisa Bolognese, LRG

Side Effects Management:
Donna Mazzone, RN,
Lutheran General Hospital

Accessing Treatment:
Norman Scherzer, LRG

4:00 p.m. Celebrating Life:
Marisa Bolognese, LRG

Nutrition:
Alice Sulkowski,
Nutritionist, GIST survivor

Clinical Trials Explained:
Jim Hughes, LRG Director

5:00 p.m.

BREAK

5:30 p.m. Please join us for the LRG's traditional candle ceremony to honor our friends and loved ones whom we have lost to GIST. (View map on last page for ceremony location)

SUNDAY

BREAKFAST: GRAND BALLROOM F

GENERAL SESSIONS: GRAND BALLROOMS D-E, ENTRY LEVEL

7:30 a.m. — 8:45 a.m.

Breakfast is served

9:00 a.m.

New Treatments Update by Jim Hughes, LRG Clinical Trials
Coordinator

10:00 a.m.

GIST Survival Strategies by Jerry Call

11:00 a.m.

Building a Personal Survival Plan by Norman Scherzer

12:00 p.m.

Adjourn



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WHO'S WHO?

GENERAL SESSION SPEAKERS

Dr. Brian Rubin

Dr. Rubin is the director of Soft Tissue Pathology at Cleveland Clinic. He currently shares appointments at Cleveland Clinic in the Department of Molecular Genetics at the Lerner Research Institute and in the Department of Pathology.

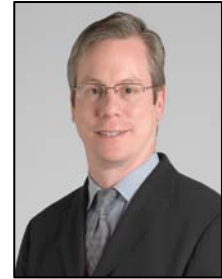
Dr. Rubin is regarded as an international leader in research for improved diagnosis and classification of soft tissue neoplasm's, especially sarcomas.

He serves on the board of the Connective Tissue Oncology Society and is a founding member of the International Society of Bone and Soft Tissue Pathology.

Dr. Rubin's research focuses on pathogenesis of sarcomas with the major aim of developing targeted therapies. He was a member of the WHO Classification of Tumors of Bone and Soft Tissue in 2002. He recently has developed a mouse GIST model and has been exploring signal transduction and targeted molecular therapies in this model.

Dr. Rubin received his undergraduate degree in Cell Biology from the University of California, Berkeley and medical and doctoral degrees from Cornell Medical College. He completed a residency in Anatomic Pathology at Brigham and Women's Hospital and continued with a fellowship in soft tissue pathology. He also received fellowship training in bone pathology at the Mayo Clinic and completed postdoctoral research training at Brigham and Women's Hospital.

Dr. Rubin served as Associate Professor in the Department of Pathology at the University of Washington. He was awarded Pathology Faculty Teacher of the Year at the University of Washington Medical Center in 2000, and has been published more than 70 times in peer-reviewed publications. He has also been the author of numerous reviews and book chapters in sarcoma.



Kristin Schneeman



Kristin Schneeman joined *FasterCures* in April 2005 as a Program Director. She brings to the team more than fifteen years' experience in public policy, politics, academia, and the media. Kristin served for three years as a senior adviser and policy director to a gubernatorial candidate in Massachusetts, as a policy aide to a U.S. Congressman, and for four years as the front-line manager and chief-of-staff for a senior adviser to Vice President Al Gore. At Harvard University's Kennedy School of Government she directed a research project – the top priority of the Dean of the School – on future challenges facing governments, and at Harvard Business School she worked with a noted professor who specializes in analyzing and advising on complex negotiations in business, politics, and international relations. Kristin began her career as a producer of documentary films on political and social issues, for which she was the recipient of an Emmy Award in 1990.

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WHO'S WHO?

GENERAL SESSION SPEAKERS

Dr. Jonathan Trent

Jonathan C. Trent, MD, PhD is an assistant internist and professor of medicine in the Department of Sarcoma Medical Oncology at The University of Texas, M. D. Anderson Cancer Center in Houston, Texas.

Dr. Trent has published numerous abstracts and research articles in leading journals, as well as book chapters, and is a frequently requested lecturer.

He is the chief editor of the sarcoma section of Cancer Investigation and on the editorial board of The Chinese Journal of Clinical Oncology and has served as a journal reviewer on a number of journals, including Nature Medicine, Lancet, Cancer, Clinical Cancer Research, and Cancer Research, and has received a number of honors for his work in cancer research. His clinical interests focus on GIST clinical trials and translational research. He is the principal investigator, as well as a collaborator, on several ongoing clinical trials that are examining the use of Gleevec alone and in combination with novel drugs in patients with primary and metastatic GIST. He is also a principle investigator of the ongoing GIST registry. He is the recipient of a 5-year NIH K-23 grant to study the mechanisms of activity and resistance of imatinib in GIST.

Dr. Trent earned his undergraduate degree in chemistry at Southeastern Oklahoma State University and his MD and PhD in cancer biology from The University of Texas Health Science Center. He completed an internship and residency in internal medicine at The University of Texas Health Science Center, and a fellowship in medical oncology at The University of Texas, MD Anderson Cancer Center while serving as chief fellow. Dr. Trent is board certified in internal medicine and medical oncology.



LRG COMPREHENSIVE SURVEY

Five years ago, the LRG did a study on short-term side-effects of Gleevec. In doing so, we were the first to report:

- Side-effects get better over time
- Were worse in women
- Were dose-related
- Side-effects could be minimized by escalating dose gradually

The LRG now hopes to expand this study by examining long-term side-effects. Our objectives are:

- To provide patients/caregivers and physicians with better information about the type and severity of side-effects for long term survivors.
- To evaluate the management of side effects and to provide patients/caregivers and physicians with a better understanding of who to go for guidance and what works to alleviate them.
- To continue to empower patients/caregivers in their relationship with physicians

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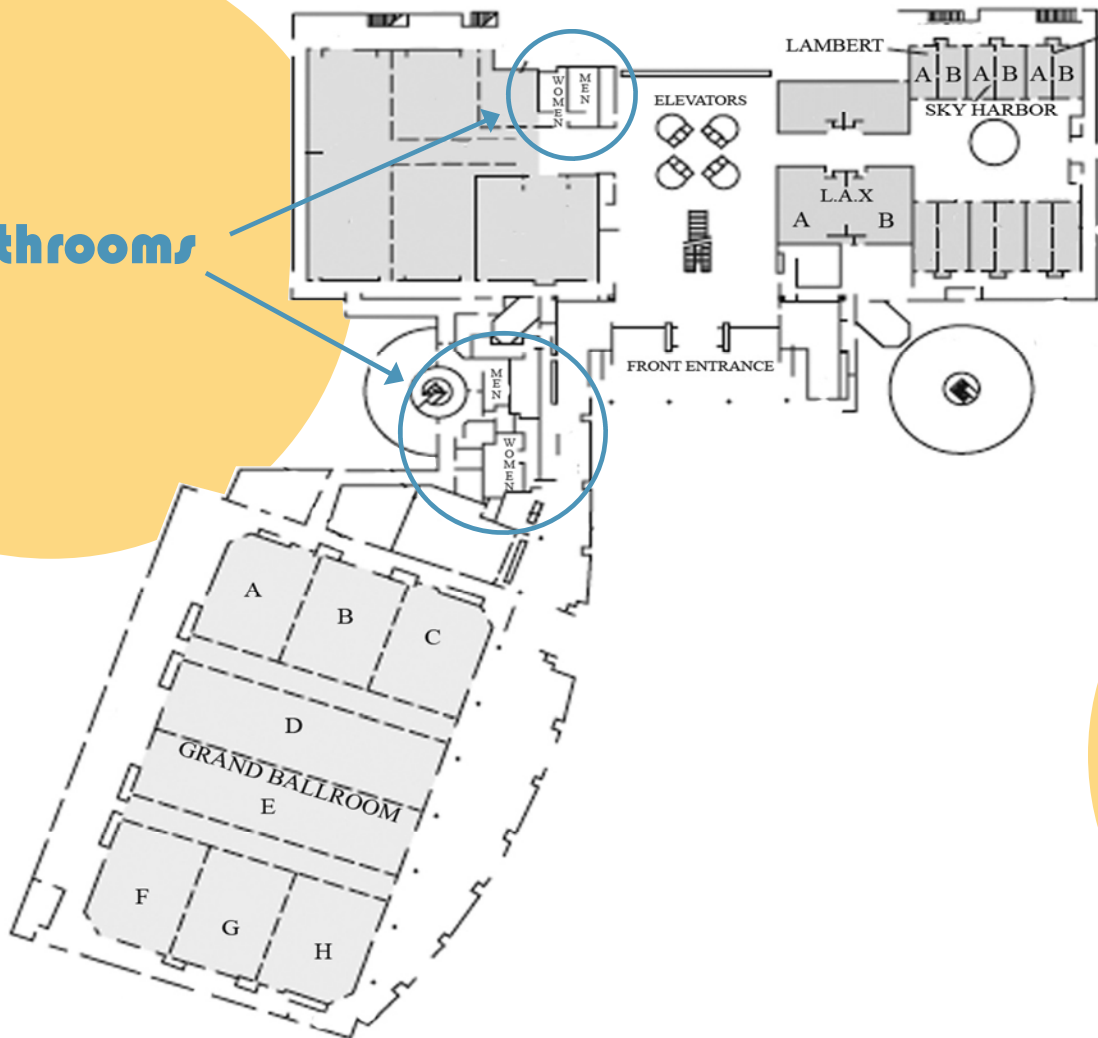
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- What we hope to achieve with this study is to have an understanding of how people manage their side-effects. We want to know if side-effects have changed and if there are new additions, and if adverse effects have a bearing on whether they can consistently take their medication. Using a GIST registry of over 1,000 medical records and participation from Life Fest attendees will allow the LRG to chart new territory in this area. We thank everyone who has or will contribute to this initiative.

HYATT O'HARE MAP



Bathrooms



Candle Ceremony

**WE WOULD LIKE TO THANK OUR SPONSORS,
GENENTECH, NOVARTIS & PFIZER PHARMACEUTICALS:**

