

The Life Raft Group

Life Fest 2006



Sept. 15-17,2006

**Adams Mark Hotel
Dallas, Texas**

WELCOME TO LIFE FEST 2006!

The first gathering of GIST patients and their loved ones was in Cambridge in 2002. There are patients at this meeting that can tell you of that experience. That, in and of itself, is a true miracle. In 2004, Life Fest was held in Orlando, Florida. We learned at these meetings that there is truly no substitute for relating to someone, face to face, who shares your greatest hopes and fears.

Joining us will be key individuals responsible for so many patients' survival. We hope you enjoy this weekend. Most of all, we hope you gain the information, strength and hope you need to fight our battle against GIST.

WE WOULD LIKE TO THANK...

All those patients and caregivers who journeyed from around the world to join us

All our guest speakers and workshop facilitators

Kerry Hammett and the Southwest Life Raft Group for their hard work and hospitality.

LRG volunteer meeting planners Bob & Sarah Buch and the Adams Mark Hotel Staff for going beyond the call of duty to develop the groundwork for this meeting

Novartis Pharmaceuticals for bringing us so many special guests and for Gleevec

And Bristol Myers Squibb, Infinity, and Pfizer Pharmaceuticals for contributions to help sponsor this meeting

PLEASE JOIN US FRIDAY EVENING....

HOUSTON BALLROOM, 3RD FLOOR, CONVENTION CENTER

Please note that the convention is across the street from the hotel.

Please use the Skybridge on the Second Floor to cross over.

6:00 p.m. **Welcoming Reception**

7:00 p.m. **Dinner is Served**

Greetings from Kerry Hammett & John Poss of the Southwest LRG Chapter

**Introduction of Dr. Daniel Vasella, CEO of Novartis:
Anita Scherzer & Josalin Dunn**

Keynote Address by Dr. Daniel Vasella

**Presentation of LRG Scientist of the Year Award to Dr. Jonathan Fletcher
by Dr. Vasella**

Closing Remarks: Norman Scherzer

Special thanks to Michael Filak for our wonderful dinner music.

HONOREES

THE VOLUNTEER OF THE YEAR AWARD



RICHARD PALMER
LRG NEWSLETTER EDITOR EMERITUS

Richard Palmer is the former newsletter editor of The Life Raft Group; in the June 2006 issue, he bid a fond farewell to this position. Richard was one of the founding members of the LRG back in 2000 and has helped it grow all these years. He has contributed numerous articles to the newsletter and great advice on the listserv. Richard has been an observer, a peacemaker, and friend to so many people in the GIST community.

In 2002, Richard met Dr. Daniel Vasella, CEO of Novartis, who was accepting the Humanitarian of the Year award; four years later Dr. Vasella is back, delivering the keynote address and **Richard** is accepting the award: Volunteer of the Year.

THE RESEARCHER OF THE YEAR AWARD



JONATHAN FLETCHER, M.D.
ASSOCIATE PROFESSOR OF PATHOLOGY AND PEDIATRICS,
HARVARD MEDICAL SCHOOL.

Dr. Fletcher is a medical and pediatric oncologist whose clinical activities are in cancer diagnostics, with a focus on molecular and cytogenetic methods. His laboratory program is studying tyrosine kinase (such as KIT and PDGFRA) mechanisms in sarcomas. He has developed novel methods for rapid profiling of tyrosine kinase activation in frozen human tumors, and these techniques have identified effective therapeutic targets in several types of sarcoma, including GIST. His primary research aims are to identify therapeutic strategies that can synergize with KIT inhibition to cure GIST.

Fletcher received his medical degree from Boston University in 1981. He went on to do his internship and residency at the University Hospital in Boston. In 1984 he became their chief resident in medicine. In 1986, Fletcher moved on to become a clinical and research fellow of pediatric and adult oncology at the Dana-Farber Cancer Institute and the Children's Hospital. Fletcher became a research fellow in pathology at Brigham and Women's Hospital in 1988, where he remains today.

In addition to his experience in clinical oncology, he has developed diagnostic methods to detect DNA and chromosome aberrations in GISTs and other sarcomas. He oversees a clinical lab service in which chromosome abnormalities are analyzed to determine the correct diagnosis and prognosis for each patient.

He has been a vital member of the research team that is leading the way to overcome Gleevec-resistant GIST. He and his team will be giving an initial progress report at this meeting. He will also be a part of the expert panel.

SATURDAY

PLEASE JOIN US IN THE REMINGTON ROOM, 4TH FLOOR FOR GENERAL SESSIONS

- 7:30 a.m. **Continental Breakfast is served**, Remington Room, 4th Floor
- 9:00 a.m. **General Session Convenes**, Welcome, Stan Bunn, President of the LRG Board of Directors
- 9:15 a.m. **LRG Update**, Norman Scherzer, LRG Executive Director
- 9:50 a.m. **Presentation of Volunteer of the Year Award** to Richard Palmer by Jerry Cudzil, LRG Board of Directors
- 10:00 a.m. **Report by LRG Research Team**, Dr. Jonathan Fletcher and Team Members
- 11:00 a.m. **Medical Update**, Dr. Jonathan Trent, M.D. Anderson
- 12:00 p.m. **Lunch, Remarks by David Epstein**, President of Novartis Oncology Worldwide
Presentation of Survivor Awards by David Epstein
- 1:15 p.m. Moderator Rodrigo Salas
Expert Panel: Dr. Chris Corless, OHSU, Dr. Jonathan Fletcher, Dana-Farber, Dr. Laurie Letvak, Novartis, Dr. Alberto Pappo, Texas Children's Cancer Center, Dr. Jonathan Trent, MD Anderson, Dr. Maria Debiec-Rychter, Catholic University, Leuven, Belgium, Dr. Matt van de Rijn, Stanford, Dr. Brian Rubin, Univ. of Seattle

WORKSHOPS

	CITY VIEW 6, 4TH FLOOR	CITY VIEW 7, 4TH FLOOR	CITY VIEW 8, 4TH FLOOR	CITY VIEW 3, 4TH FLOOR
2:45 p.m. ~ 3:45 p.m.	Nutrition, Alice Sulkowski, Clinical Dietitian & Diabetes Educator	Medicare and Other Medical Insurance, Kerry Hammett & Guest Speaker	Clinical Trials Updates, Jerry Call, LRG Science Coordinator	Pediatric GIST Families Workshop
BREAK				
4:00 p.m. ~ 5:00 p.m.	Coping for Caregivers, Jim Hughes	Coping for Patients, Richard Palmer	Side Effects Management, Monica Davey, Oncology Nurse, Fox Chase Cancer Center	Pediatric GIST Families Workshop
5:15 p.m.	<p>Please join us for the LRG's traditional candle ceremony to honor our friends and loved ones whom we have lost to GIST.</p> <p>(Please use the Bryan St. exit and cross the street to the Cancer Survivors Park)</p>			

SUNDAY

- 7:30 a.m. Continental Breakfast is served, Remington Room, 4th Floor

WORKSHOPS

	CITY VIEW 6, 4TH FLOOR	CITY VIEW 7, 4TH FLOOR	CITY VIEW 8, 4TH FLOOR
9:00 a.m. ~ 10:00 a.m.	GIST Explained, Jerry Call	Local Outreach Forum, Dick Kinzig and Kerry Hammett	Pediatric GIST Kids Workshop

- 10:00 a.m. Moderator Estelle Lecoite
Compliance, Dr. Laurie Letvak, Novartis
- 11:00 a.m. Moderator Chris Carley
Surviving GIST: Connecting the Dots: Jerry Call and Norman Scherzer
- 11:30 a.m. Moderator Silvia Steinhilber
Pediatric GIST Update, Dr. Alberto Pappo, Texas Children's Cancer Center
- 12:00 p.m. Farewell
- 12:30 p.m. Adjourn

DISTINGUISHED GUESTS

DANIEL VASELLA, M.D. CHAIRMAN AND CHIEF EXECUTIVE OFFICER (CEO)

Daniel Vasella, M.D., is Chairman and Chief Executive Officer (CEO) of Novartis AG. He was appointed Chairman in April 1999, having served as CEO and Head of the Group Executive Committee since the merger that created Novartis in 1996.

As the first CEO of Novartis, Dr. Vasella had a leading role in the merger of Sandoz and Ciba-Geigy. Under Dr. Vasella, Novartis has strategically focused its business on health care with Pharmaceuticals as its core.

During his tenure as Chairman and CEO, Dr. Vasella has enhanced the company's corporate governance policies in line with best practices and listed Novartis on the New York Stock Exchange. He has also strengthened the research capacity of Novartis in leading technologies by creating the Novartis Institute for BioMedical Research and moving the company's research headquarters to Cambridge, Mass., to be closer to top scientific talent as well as patient and hospital networks. He also established The Genomics Institute of the Novartis Research Foundation, which is focused on developing therapeutics from the data generated from the mapping of the human genome.

Dr. Vasella has implemented strong pioneering initiatives to ensure access to medicines, which include the founding of the Novartis Institute for Tropical Diseases for research on neglected diseases of the developing world, the International Patient Assistance Program for the breakthrough GIST drug Gleevec/Glivec, an agreement to supply the novel malaria treatment Coartem® at cost to the World Health Organization and a pledge to donate the drug therapy needed to eradicate leprosy worldwide. Furthermore, under Dr. Vasella's leadership, Novartis subscribed to the UN Global Compact initiative.

A 2004 readership survey of the Financial Times selected Dr. Vasella as the most influential European businessman of the past quarter century. In 2003, Dr. Vasella was awarded The CancerCare Human Services Award and also the Harvard Business School's Alumni Achievement Award. Dr. Vasella was awarded an honorary doctorate by the Faculty of Medicine at the University of Basel in 2002, and he was given the Appeal of Conscience Award in February 2000. In 1998, he received the AJ Congress Humanitarian Award. He has been honored with the Ordem Nacional do Cruzeiro do Sul (Brazil) and holds the rank of Chevalier in the Ordre National de la Légion d'Honneur (France).

Before the Novartis merger, Dr. Vasella was CEO of Sandoz Pharma Ltd. and a member of the Sandoz Group Executive Committee. From 1988 to 1992, he was with Sandoz Pharmaceuticals Corporation in the US, prior to which he held a number of medical positions in Switzerland.

Dr. Vasella is a member of the Board of Directors of PepsiCo, Inc., United States. In addition, he is a member of the Chairman's Council of DaimlerChrysler AG, Germany, and a member of the Board of Dean's Advisors at the Harvard Business School. He is also President of the International Federation of Pharmaceutical Manufacturers Associations, a member of the International Board of Governors of the Peres Center for Peace in Israel and a member of the International Business Leaders Advisory Council for the Mayor of Shanghai.

Dr. Vasella is a two-time PharmaVOICE 100 winner, which is a life sciences magazine that annually profiles the men and women in the life-sciences industry who are truly making a difference. He is married and has three children.

Dr. Vasella was honored as the "Humanitarian of the Year" at Life Fest 2002 in Cambridge, Mass. This year he returns giving the Keynote Address.

DAVID EPSTEIN PRESIDENT AND CEO NOVARTIS ONCOLOGY

David R. Epstein is President & CEO, Novartis Oncology. In this position, he is responsible for leading Novartis' Global Oncology Business Unit, one of the world's top Oncology companies with five key marketed products – Glivec, Femara, Zometa, Sandostatin LAR and Exjade – and a leading pipeline recognized as exceptionally broad and deep. In 2005, Novartis Oncology's sales grew 20% and market share grew to 9.9%.

Epstein currently oversees a staff of more than 3,800 employees operating in over 50 countries. He is a member of Novartis AG's Pharma Committee and Pharmaceutical Executive Committee.

Epstein has held a series of positions of increasing responsibility since joining the company as a new product manager with Sandoz in 1989. Epstein most recently served as CEO, Novartis Specialty Medicines, overseeing the global Ophthalmics and Transplantation & Immunology Business Units in addition to his responsibilities leading Novartis Oncology. He previously served as Chief Operating Officer of Novartis Pharmaceuticals Corporation in the U.S and has held several positions in marketing and general management. During the planning process that resulted in the 1996 merger of Ciba-Geigy Ltd. and Sandoz Ltd., Epstein co-chaired the U.S. and Canadian Pharma Steering Committees as the Integration Officer, North America. In January 1997, he was promoted to Vice President, Marketing and Sales, Specialty Business Sector, responsible for U.S. business units focused on Oncology and Transplant/Immunology/Tissue Engineering. Prior to joining the company, he was an associate in the Strategy Practice of consulting firm Booz, Allen and Hamilton.

Epstein holds a B.S. degree in Pharmacy with high honors from Rutgers University College of Pharmacy and an M.B.A. in Finance and Marketing from the Columbia University Graduate School of Business.

Epstein will be giving a keynote speech Saturday at lunch.

**CHRISTOPHER CORLESS, M.D., PHD
OREGON HEALTH AND SCIENCE UNIVERSITY**

After undergraduate studies at the Univ. of California, Berkeley, Dr. Corless received his MD and PhD degrees from Washington University, St. Louis. He did his residency training in Anatomic Pathology at the Brigham & Women's Hospital, Boston, where he also completed fellowship training in GI Pathology and GU Pathology. In 1994, he joined the faculty of Oregon Health & Science University as an Assistant Professor.

He has served as the residency program director in Pathology and is currently medical director of surgical pathology for OHSU Hospital. He is also director of the Cancer Pathology Shared Resource for the Oregon Cancer Institute. In addition to practicing surgical pathology, Dr. Corless has expertise in the application of molecular diagnostics to the classification and prognostication of solid tumors. An author on over 125 publications, he was promoted to Professor of Pathology in 2004. Dr. Corless is a member of the LRG Research Team and lending his expertise as leader of Project C: Primary Resistance.

**MONICA DAVEY, RN, BSN, M.ED, MBA
CLINICAL RESEARCH COORDINATOR, FOX-CHASE CANCER CENTER**

Monica P. Davey is a clinical research coordinator at the Fox Chase Cancer Center and administrative supervisor at Frankford Hospital-Torresdale Division in Philadelphia, Pennsylvania. Prior to her current positions, she served as head nurse in the Emergency Department and staff development critical care/trauma educator at Frankford Hospital-Torresdale Division.

Ms. Davey earned her diploma in nursing from Abington Memorial Hospital School of Nursing, a bachelor of science in nursing at Gwynedd-Mercy College, a master of education in major health education at Pennsylvania State University and a master of business administration in management and a postgraduate certificate in clinical research operations at LaSalle University.

Ms. Davey is a member of the Society of Clinical Research Associates, the Oncology Nursing Society and the Eastern Cooperative Oncology Group. She has coordinated and taught numerous continuing medical education programs and has given presentations at the educational incentives for Patient Management and Compliance Issues with New Oral Oncology Therapies, Novel Cancer Therapies Grand Rounds, and gave a presentation entitled Management of Gleevec Complications, at a GIST Symposium. She has authored, or co-authored articles appearing in journals such as *Clinical Cancer Research*, *Sarcoma*, *Clinical Journal of Oncology Nursing*, and *Cancer Research*.

Specific to GIST, Monica worked on the original B2222 Novartis trial which started in 2000, so she has been working with the GIST population since the beginning. She has also coordinated other Gleevec trials, the Sutent trial, the Amgen trial and more recently the AMN and RAD trials. Ms. Davey will be leading the Side Effect Management workshop at this year's Life Fest.

MARIA DEBIEC-RYCHTER, M.D., PHD
CATHOLIC UNIVERSITY OF LEUVEN, BELGIUM

Dr. Maria Debiec-Rychter obtained her M.D. degree (1978) and Ph.D. degree in Somatic Genetics (1986) from the Medical University of Lodz, Poland. She remained at the University of Lodz as an Associate Professor until 1989, when she became a visiting scientist to the Michigan Cancer Foundation, Detroit, MI. Since then Dr. Debiec-Rychter has worked with Wayne State University, Detroit, MI and the Armed Forces Institute of Pathology, Washington, DC. She has been appointed as an Associate Professor at Catholic University of Leuven, Belgium since 1999. Her research interests are related to the cytogenetic and molecular characterization of solid tumors, and cancer related targeted therapy. Currently, she is involved in the studies of the molecular mechanisms of resistance to imatinib in GIST patients. Dr. Debiec-Rychter is a member of the LRG Research Team and leading Project D: Stable Disease.

LAURIE LETVAK, M.D.
NOVARTIS ONCOLOGY

Dr. Laurie Letvak heads the Gleevec/Glivec and AMN107 Global Medical Affairs programs at Novartis Oncology. Her responsibilities include providing hematology and oncology expertise to the International Gleevec/Glivec and AMN107 project teams and providing strategic direction for the Phase IV clinical trials programs. The Gleevec/ Glivec program includes numerous trials answering additional questions in CML and GIST, as well as exploratory trials in other hematology, oncology and non-oncology indications. The AMN107 Phase IV program will focus initially on CML.

Dr. Letvak is board certified in internal medicine, hematology and oncology, having received her undergraduate and medical degrees at Cornell University. She has worked in the pharmaceutical industry for over 15 years, first at Lederle and then at Novartis. She has had experience in Clinical Research, Medical Affairs, as well as Business Development and Licensing.

Dr. Letvak is joining us as a member of the LRG Resistance Research Team and she will also be speaking on Gleevec compliance issues.

ALBERTO PAPPO, M.D.
TEXAS CHILDREN'S CANCER CENTER

Alberto Pappo is a pediatric oncologist. He graduated from Medical School in Mexico City and did his pediatric residency in San Antonio, he also did his fellowship in pediatric hematology oncology in Dallas. He worked at St. Jude's Children's Research Hospital, Tenn. for 11 years and then moved to the Hospital for Sick Children in Toronto for five years where he headed the solid tumor program. He is now the head of the solid tumor section at Texas Children's Hospital in Houston (affiliated with Baylor). Dr. Pappo's main interests are bone and soft tissue sarcoma, specifically melanoma and GIST. He would like to meet pediatric GIST families at Life Fest, raise awareness on this condition and serve as a resource for other physicians who are treating these unfortunate children. He will also be heading a collaborative effort with SWOG to better study this disease in patients less than 30 years of age.

MATTHEW VAN DE RIJN, M.D., PHD
STANFORD UNIVERSITY MEDICAL CENTER

Matt van de Rijn received his MD and PhD degrees from the University of Amsterdam in 1986. Subsequently he performed a postdoctoral fellowship in the laboratory of Dr. Irving Weissman, which was followed by residency training in surgical pathology at Stanford University Medical Center. He next worked as an assistant professor in the Department of Pathology and Laboratory Medicine at the University of Pennsylvania Medical Center in Philadelphia. In 1998 he returned to Stanford and is now an associate professor of pathology. Upon his return to Stanford he started collaborating with the combined laboratories of Drs. Pat Brown and David Botstein and developed an interest in gene microarray analysis as used for gene expression profiling and comparative genomic hybridization. These techniques, combined with the technique of tissue microarrays in which gene array data can be validated by immunohistochemistry and in situ hybridization studies, now form the core of his laboratory. In his laboratory his work is mainly focused on sarcomas with specific emphasis on leiomyosarcomas and gastrointestinal stromal tumors. His research is translational in nature and is focused on the discovery of new diagnostic markers, the discovery of new tumor subsets with different prognoses and/or different response to various treatments and the identification of new therapeutic targets. As a member of the LRG Research Team, Dr. van de Rijn is both hosting the Adult Tissue Bank and acting as Group Leader for Project B: Kit/PDGFRa Wild Type GIST.

**BRIAN RUBIN, M.D., PHD
UNIVERSITY OF WASHINGTON**

Brian Rubin graduated from University of California, Berkely with a BA in Cell Biology in 1983. He spent the next 3 years in the Peace Corps working for the WHO malaria control program in Thailand. He moved on to work as a research technician at Amgen from 1986-1987. He attended the MD/PhD program at Cornell University Medical College from 1987-1995. Dr. Rubin was a resident and fellow at Brigham and Women's Hospital from 1995-2000 where he did focused fellowships in soft tissue pathology with Chris Fletcher and a post-doc in the lab of Jonathan Fletcher working on genomics of sarcomas including GIST. In 2000, he moved to the University of Washington where he spent the last five and 1/2 years as the Director of Bone and Soft Tissue Pathology. Currently, Dr. Rubin's lab is focused on genomics and proteomics of sarcomas, targeted therapies of sarcomas and developing mouse models of sarcomas. Dr. Rubin is a member of the LRG Research Team, acting as Group Leader for Project G: Mouse Imatinib Sensitive and Resistant Models.

**JONATHAN C. TRENT, M.D., PHD
M.D. ANDERSON CANCER CENTER**

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.

**MR. NORMAN SCHERZER
THE LIFE RAFT GROUP**

Norman J. Scherzer is executive director of The Life Raft Group, an international, non-profit organization supporting people with Gastro-Intestinal Stromal Tumors (GIST). Norman Scherzer began a career in public health as a disease management specialist for the Centers for Disease Control. He has served as a director of the New York City Department of Health's Sexually Transmitted Disease Program and as a director of the New York City Prison Health Services Program.

After serving as the New York Regional Consultant for Disease Control for the United States Public Health Service, Norman went on to become the Assistant Commissioner of Health for New York City where he helped spearhead the city's childhood immunization initiative and its response to the AIDS crisis.

Following his formal retirement from public health, Norman became the Chief Executive Officer of Graham-Windham services to families and children, the oldest non-sectarian child care agency in the United States, founded in 1806. Norman then became the President and CEO of a health policy and management consulting firm called 22nd Century Health Concepts, Inc. whose clients included the Harvard University Institute for International Development. When his wife, Anita, a GIST patient entered the first clinical trial for GIST, Norman helped found the Life Raft Group. He has served as executive director since 2002.

THE LIFE RAFT GROUP

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