## **Blood Cancer Conference 2014**

# **Agenda & Sessions**

8:00 a.m. Registration, Exhibit Tables and Continental Breakfast Open

9:00 a.m. Special Address

Patricia Flynn, President, Board of Trustees, Greater Los Angeles The Leukemia & Lymphoma Society's California Southland Chapter

**Opening Remarks** 

Amanda Termuhlen, M.D., Master of Ceremonies (Trustee)

The Leukemia & Lymphoma Society's California Southland Chapter

**Advocacy & Patient Access** 

Scott Riccio, Sr. Vice President, Patient Access, Education & Advocacy

The Leukemia & Lymphoma Society's Office of Public Policy

10:10 a.m. Break

10:25 a.m. Disease Breakout Sessions\*

12:00 p.m. Lunch

1:00 p.m. Quality of Life Sessions\*

2:15 p.m. Break

2:30 p.m. Quality of Life Sessions\*

3:45 p.m. Break

4:00 p.m. Research Update & Closing Remarks

Louis DeGennaro, Ph.D.

Interim President & CEO / Chief Mission Officer

The Leukemia & Lymphoma Society

## Local Sponsors









**SeattleGenetics** 







Santa Barbara Airbus

Cottage Health System

















<sup>\*</sup>Please see the reverse side for a list of sessions & speakers.

#### **DISEASE BREAKOUT SESSIONS**

#### **QUALITY OF LIFE SESSIONS**

#### Acute Leukemias (AML & ALL)

sponsored by Boehringer Ingelheim Michael C. Lill, M.D., Cedars Sinai

#### **Chronic Lymphocytic Leukemia**

sponsored by AbbVie
Herbert Eradat, M.D., UCLA Medical Center

### **Chronic Myeloid/Myelogenous Leukemia**

David Snyder, M.D., City of Hope

#### **Multiple Myeloma**

sponsored by Onyx Pharmaceuticals
Sarah Larson, M.D., UCLA

### Non-Hodgkin Lymphoma (Low Grade)

Sven de Vos, M.D. & Ph.D., UCLA

# Non-Hodgkin Lymphoma & Hodgkin Lymphoma (High Grade)

sponsored by Eli Lilly Lauren Pinter-Brown, M.D., UCLA

### Myelodysplastic Syndromes (MDS)

Ronald Paquette, M.D., UCLA

# Información General sobre el Cáncer Sanguíneo (En Español)

sponsored by Providence Health & Services
Miriam Hernandez
Latino Health Promoter Supervisor

#### Nutrition

Carolyn Katzin, MS, CNS, MNT, UCLA

# Managing the Emotional Roller Coaster of Survivorship

Aakash Kishore, M.A., C. Phil, UCLA Natalia S. David, MS, California School of Professional Psychology

# How Does Healthcare Reform Affect People with Blood Cancer?

Stephanie Fajuri, Cancer Legal Resource Center

#### **Clinical Trials**

sponsored locally by Gilead Sciences, Inc. sponsored nationally by Millennium Pharmaceuticals & Celgene Maria Delioukina, M.D., Cedars Sinai

### **Becoming A Self-Advocate**

Brian Koffman, M.D., St. Jude Heritage Medical Group

### Covertura Médica: Covered California (En Español)

Hugo R. Ramirez, Visión y Compromiso

#### Jugando Bingo (En Español)

Maria Cruz & Maria Romero Latino Health Promoters

# **Blood Cancer Conference 2014**

# **Meet the Speakers**

#### General Sessions

#### Amanda Termuhlen, M.D. (Master of Ceremonies)

Dr. Amanda Termuhlen is the Medical Director of the Jonathan Jacques Children's Cancer Center at Miller Children's Hospital and a Professor of Clinical Pediatrics at the University of Southern California Keck School of Medicine. Prior to joining Miller Children's Hospital, Dr. Termuhlen was the Associate Division Chief of Pediatric Hematology/Oncology/Blood and Marrow Transplantation at Nationwide Children's Hospital and a Professor of Pediatrics at the Ohio State University College of Medicine, where she led the pediatric hematology/oncology clinical research office, the Blood and Marrow Transplantation program, and the Cancer Survivorship Program. Dr. Termuhlen did her Pediatric Hematology Oncology Fellowship at Cincinnati Children's Medical Center. Dr. Termuhlen's clinical interests are in pediatric Non-Hodgkin Lymphoma, pediatric cancer survivorship, and adolescent oncology. She is an active clinical researcher in the Children's Oncology Group, the Childhood Cancer Survivor Study, and several national consortia focusing on experimental therapeutics, clinical trials for lymphoma, and studies of the late effects of cancer treatment.

#### Scott Riccio (Advocacy & Public Policy)

Scott Riccio is the Senior Vice-President of Patient Education, Access & Advocacy in the Office of Public Policy for The Leukemia & Lymphoma Society (LLS). Prior to joining LLS, Scott directed advocacy and health policy efforts for a biotechnology company, focusing on removing barriers to access for patients fighting cancer. Scott and his wife had previously founded their own 501c3 organization where he focused on educating legislators and regulators alike about how to help patients access the promise of real breakthroughs in the war against cancer. Before turning his focus exclusively to health policy issues, Scott spent a decade at Morningstar working with global financial organizations including non-profit foundations and endowments, helping them to better serve the needs of their constituents. Scott graduated from Middlebury College with a degree in political science and earned his MBA from the University of Chicago.

#### Louis DeGennaro, Ph.D. (Research Update & Closing)

Louis J. DeGennaro, Ph.D. was named interim president and CEO of LLS in February 2014. He also remains in his role as chief mission officer and is responsible for oversight of all LLS mission functions: public policy, patient access, education and advocacy services and research, with the goal of effectively deploying resources in pursuit of the LLS mission. DeGennaro has more than 25 years of research, drug development and executive management experience in academic and private-sector settings. He received his Ph.D. in biochemistry from the University of California at San Francisco and did his postdoctoral research at Yale University School of Medicine. His previous academic appointments include research group leader at Max Planck Institute in Munich, Germany, and associate professor of neurology and cell biology at the University of Massachusetts Medical School. DeGennaro's private-sector positions include senior director of molecular genetics at Wyeth Pharmaceuticals, Princeton, NJ, and executive vice president for research and development, SynX Pharma, Inc., Toronto, Canada.

#### **Disease Sessions**

#### Michael Lill, M.D. (Acute Leukemias - AML & ALL)

Michael C. Lill is Medical Director of the Blood and Marrow Transplant Program at Cedars-Sinai Medical Center. Prior to joining Cedars-Sinai, Dr. Lill served as Director of the Core Laboratory for Cellular and Gene Therapy at the University of California, Los Angeles (UCLA) Jonsson Comprehensive Cancer Center and was Medical Director of the UCLA Cord Blood Bank. Dr. Lill's research interests focus on myelodysplastic syndrome (MDS), bone marrow and peripheral blood



stem cell transplantation, cord blood transplantation, hematologic disorders, leukemia, lymphoma and growth factors. He currently has an active program in bloodless transplantation for Jehovah's Witnesses and is collaborating with cardiology to provide bone marrow stem cells for repair of the heart. Dr. Lill is listed as one of the "Best Doctors in America," as well as one of the "Best Cancer Doctors in America" in 2005, 2006 and 2007. He is Chair of the Bone Marrow Transplant Committee at Cedars-Sinai, which reviews cases presented for transplantation. He served as Chair of the Cedars-Sinai Cancer Committee and the Hematology/Radiation Oncology Performance Improvement Committee from 1997 to 1999. Dr. Lill has published numerous articles on bone marrow and stem cell transplantation in peer-reviewed journals, such as the British Journal of Hematology, Blood, Bone Marrow Transplantation, Leukemia, and Journal of the National Cancer Institute and Journal of Hematotherapy. He has written book chapters for Cancer Treatment, Cell Therapy and On Call In Bone Marrow Transplantation. Dr. Lill also served as a reviewer for several journals, including Blood, Bone Marrow Transplantation and Hematopoietic Therapy Index and Reviews. Dr. Lill received his bachelor's and medical degrees from the University of Western Australia, Perth. He completed his internship, residency and fellowship training at Sir Charles Gairdner Hospital in Nedlands, Western Australia. His fellowship training continued at the Royal Perth Hospital, Perth, Western Australia. In 1989 he joined the University of California, Los Angeles as a visiting clinical instructor and later as a full-time clinical instructor.

#### Herbert Eradat, M.D. (Chronic Lymphocytic Leukemia)

Dr. Eradat specializes in hematology and oncology at the UCLA Medical Center. Dr. Eradat is certified by the American Board of Internal Medicine in hematology, medical oncology and internal medicine. Dr. Eradat's clinical interests are: antiphospholipid, bone marrow transplant, chronic myelogenous leukemia, general hematology, hematologic malignancies, leukemia, lymphoma, multiple myeloma, mycosis fungoides, mylodysplasia, sickle cell anemia, stem cell transplant and Waldenstrom's disease.

#### David Snyder, M.D. (Chronic Myeloma Leukemia)

Dr. David Snyder has been involved in basic research and clinical research for over 30 years. He is currently the Associate Director and a Division of Hematology/Hematopoietic Cell Transplantation member at City of Hope. Dr. Snyder was part of the original Data and Safety Monitoring (DSM) Committee created at City of Hope over 10 years ago. He served as chair and chair emeritus for several years. He continues as an active member of the DSM committee and also serves as chair of the Islet Cell DSMB for the Southern California Islet Cell Consortium.

#### Sarah Larson, M.D. (Multiple Myeloma)

Dr. Larson is a member of the Hematopoietic Malignancies and Stem Cell Transplant Program at the David Geffen School of Medicine at UCLA. She specializes in the treatment of lymphoma and multiple myeloma. As part of the Translational Oncology Research Laboratory at UCLA, her research interests include the identification of novel pathways and therapeutics for patients with multiple myeloma. She has also studied the use of chimeric antigen receptors (CARS) in hematopoietic stem cells as immunotherapy. Dr. Larson received her medical degree from the University of Minnesota and completed her residency at the University of Chicago. She received fellowship training at the University of Chicago and at UCLA. She is currently an associate program director for the hematology/oncology fellowship program at UCLA.

#### Sven de Vos, M.D. and Ph.D. (Non-Hodgkin Lymphoma - Low Grade)

Dr. Sven de Vos specializes in hematology and oncology at the Ronald Reagan UCLA Medical Center with clinical interests in lymphoma and stem cell transplant. In addition to his roles as a physician and associate professor, Dr. de Vos also serves as a member of the Jonsson Comprehensive Cancer Center (JCCC) Cancer and Stem Cell Biology Program Area and as director of the JCCC Data Safety Monitoring Board Shared Resource. Dr. de Vos earned his medical degree from Universitat Tubingen in 1989 and his Ph.D. from the University of California, Los Angeles (UCLA) in 2002. He is certified through the American Board of Internal Medicine in hematology, medical oncology and internal medicine. Dr. de Vos' research is focused on novel approaches to treat several types of lymphoma.

#### Lauren Pinter-Brown, M.D. (Non-Hodgkin Lymphoma - High-Grade & Hodgkin's Lymphoma)

Dr. Lauren Pinter-Brown is a hematologist-oncologist who has been on the UCLA faculty since 1990. She earned her MD degree from UCLA Medical School, completed her internship and residency in Internal Medicine at Harbor-UCLA Medical Center, and completed a fellowship in Hematology and Oncology at University of Southern California. She remained on



the faculty at the University of Southern California in the Hematology division until 1990, when she returned to UCLA having hospital privileges at Olive View-UCLA Medical Center and UCLA Center for the Health Sciences. She has a longstanding interest in lymphoproliferative disorders, particularly in skin and T-cell lymphomas

#### Ronald Paquette, M.D. (Myelodysplastic Syndromes)

Dr. Ronald Paquette is a Clinical Professor in the UCLA Division of Hematology/Oncology. He is a member of the Aplastic Anemia and MDS International Foundation, Inc. Medical Advisory Board. Dr. Paquette's work has been funded by the National Institutes of Health (NIH) and The Leukemia & Lymphoma Society (LLS). He has a longstanding research interest in bone marrow failure disease including aplastic anemia and myelodysplastic syndrome. He has conducted research and clinical trials for chronic myeloid leukemia. In his clinical practice at UCLA, Dr. Paquette treats bone marrow failure diseases and blood malignancies using standard therapies, experimental drugs, and stem cell transplantation.

# Miriam Hernandez (General Information About Blood Cancer / Información General Sobre El Cáncer Sanguíneo)

Miriam Hernandez graduated from the Autonomous University of Baja California and School of Medicine in Mexicali, Mexico. She completed her internship in Mexicali's General Hospital in Mexicali, Baja California and fulfilled her social services at the Community Center of the Colonia Herrera in Tijuana, Baja California. In 1989, she obtained her professional degree as a Medical Surgeon and Midwife from the Autonomous University of Baja California, Mexico. Miriam worked as a General Practitioner in Tijuana, Baja California for 10 years, serving low the income community. She served as the director of a Health Unit in the Community Center of the Northwest Ibero-Americana University. Miriam Hernandez planned and implemented a Health Promoter Program. She was a teacher at the Nursing School of the Ibero-Americana University, where she taught Rehabilitation, Physiology, and Scientific Methodology. In 1996 Miriam concluded an HIV-AIDS, mini-residency in San Diego, California. In 1998, she completed a Diabetes postgraduate in Tijuana's Autonomous University. In 2000, she obtained a U. S. Bachelor's Degree in Medical Science. Miriam has worked as a Parent Center Coordinator at San Fernando Elementary School. She has been employed by Providence Health & Services in the San Fernando Valley for ten years and is currently the Manager of the Latino Health Promoter Program.

#### **Quality of Life Sessions**

#### Carolyn Katzin, MS, CNS (Nutrition)

Carolyn Katzin is President of Fountain Resources, Inc., a consulting company focusing on health and wellness. Ms Katzin is a Certified Nutrition Specialist with twenty-five years of experience in clinical nutrition with an emphasis on optimizing health and wellness. Her special expertise is in the field of nutrigenomics. In 2013, she joined the Simms/Mann UCLA Center for Integrative Oncology as an Integrative Oncology Specialist with a special focus on wellness, nutrition and physical activity. Ms Katzin also counsel patients at Eisenhower Medical Center in Rancho Mirage and at the Beverly Hills Cancer Center. At UCLA, she provides nutrition counseling at the University Executive Physical Program, director A. Shawn Veiseh, MD, Carolyn received her graduate degree in nutritional science and completed her internship in nutrition at UCLA and her undergraduate degree in nutrition at King's College, University of London. Carolyn has been an active volunteer with the American Cancer Society since 1989 and has served at the all levels of the Society. She served as Chair of the Board for California Division Board of Directors (2011-12) and has been a member of the board since 2002. She has served on the Mission Delivery Team since 2007 serving as Chair of Nutrition and Physical Activity Team and Chair of the Wellness Team. She is a member of the Los Angeles Regional Council and past President of the Los Angles Coastal Cities Unit. Carolyn is a media spokesperson for ACS California Division and represents ACS and UCLA as past Chair and current member of California Dialogue on Cancer (CDOC) Coalition Prevention: Nutrition and Physical Activity Implementation Team and Cancer Plan Revision Committee. She also serves on the California Governor's Council on Physical Fitness & Sports Advisory Board as a representative of the American Cancer Society. She is a member of The Wellness Community West Los Angeles (now renamed Cancer Support Community Benjamin Center) Medical and Professional Advisory Board and is member and past Chair of the Dean's Advisory Board for UCLA's School of Public Health. She was nominated to the UCLA School of Public Health Hall of Fame in its inaugural year 2002 for outstanding community service. She is also a recipient of American Cancer Society's Life Saver Award and completed the two-year



ACS National Leadership Development Program in 2011. Ms Katzin has been listed in many of the Who's Who publications including the Millennium Edition of *Marquis Who's Who in America* and *Who's Who in the World*. Carolyn has completed two certification programs in the field at UC Davis and with the European Union's consortium NuGO. She is a published author of four books and a regular writer for "Women and Cancer" and "Healthy living" magazines. Her most recent book is "The EVERYTHING Cancer Fighting Cookbook".

#### Aakash Kishore, M.A. (Managing the Emotional Roller Coaster of Survivorship)

S. Aakash Kishore is a Doctoral Candidate in Clinical Psychology at UCLA, where he studies the relationship between discrimination-stress and health among LGBT people and people of color. Aakash has received clinical training through the UCLA Psychology Clinic, the UCLA Center for Assessment and Prevention of Prodromal Schizophrenia, and the Veteran's Affairs hospital in West Los Angeles. He is currently an advanced psychology extern at UCLA's Simms/Mann Center for Integrative Oncology.

#### Natalia S. David M.S. (Managing the Emotional Roller Coaster of Survivorship)

Natalia S. David is currently a Doctoral student at the California School of Professional Psychology. She has a special interest in Psycho-Oncology, Pediatric Health Psychology, and Neuropsychological Assessment. Natalia is currently doing neuropsychological research with children with Sickle Cell Disease and Pica. She is receiving her clinical training at the UCLA Simms Mann Center for Integrative Oncology, and is a part of the multidisciplinary team in the Adult and Pediatric Live Strong Cancer Survivorship Clinic.

#### Stephanie Fajuri (How Does Healthcare Reform Affect People with Blood Cancer?)

Stephanie Fajuri is a Staff Attorney with Disability Rights Legal Center's Cancer Legal Resource Center (CLRC). As a CLRC Staff Attorney, Ms. Fajuri provides legal services to people with cancer-related legal issues, presents educational seminars throughout the nation, and drafts and submits grant applications on behalf of the program. Prior to this position, Ms. Fajuri was Development Coordinator with DRLC, worked with Axis Clinical Trials, and was a Coles Fellow at the Illinois Human Rights Commission in Chicago. Ms. Fajuri received a B.A. in History at the University of Michigan. She earned her Juris Doctorate at Illinois Institute of Technology Chicago-Kent College of Law, where she participated in the Public Interest Law Certificate program, and was awarded the Chicago-Kent Certificate of Service, Dean's Distinguished Public Service Award, Tuition Achievement Award, and served as Secretary of the Hispanic and Latino Law Student Association. Ms. Fajuri is a member of the State Bars of California and New York. She is also a member of Legal Voices, a chorus affiliated with the L.A. Lawyers Philharmonic.

#### Maria Delioukina, M.D. (Clinical Trials)

Maria L. Delioukina is a hematologist/oncologist in the Blood and Marrow Transplant Program at Cedars-Sinai. She is board certified in medical oncology, hematology and internal medicine. Prior to joining Cedars-Sinai, Dr. Delioukina was a member of the transplant department at City of Hope. Dr. Delioukina's clinical and research focus is on lymphomas. She has published numerous articles in publications such as Bone Marrow Transplant, Leukemia and Lymphoma, Mediterranean Journal of Hematologic Infectious Disease, Journal of Clinical Oncology, Annals of Hematology and Biology of Blood and Marrow Transplant. She has presented posters and abstracts and made several oral presentations nationally and internationally. In addition to being a member of the American Medical Association, Dr. Delioukina is a member of the American Society of Hematology the American Society of Clinical Oncology, the International Society of Cutaneous Lymphoma and the American Society for Blood and Marrow Transplant. Dr. Delioukina earned her doctor of medicine degree with honors at the First Medical Institute in St. Petersburg, Russia. She performed her internship in internal medicine at the First Medical Institute, followed by a fellowship in hematology/oncology at the Petrov Research Institute of Oncology in St. Petersburg, Russia. She followed this with a fellowship in bone marrow transplantation at Hadassah University School of Medicine in Jerusalem, Israel and a residency in internal medicine at Hennepin County Medical Center, University of Minnesota Medical School Affiliate in Minneapolis. She also completed a fellowship in hematology/oncology at the David Geffen School of Medicine at the University of California.



#### Brian Koffman, M.D. (Becoming a Self-Advocate)

Dr. Brian Koffman earned his medical degree from McGill University and completed his Family Practice residency at the University of Western Ontario, and his Psychiatry Fellowship at McMaster University. Dr. Koffman taught at the University of Waterloo and is a retired Clinical Professor at the University of Southern California, Keck School of Medicine where he also completed his Masters of Science in Medical Education. He is licensed and Board Certified in Family Practice in both the United States and Canada. His primary care practice is with St. Jude Heritage Medical Group, Diamond Bar California. As the medical director of Primary Care Network (PCN), he has been involved in providing medical education for community physicians on various topics including blood cancers, sleep disorders, gout, migraine, pain management and many other practical primary care topics. His passion however is as a doctor turned patient, where his popular blog (http://bkoffman.blogspot.com) and the wide scope of his volunteer efforts in other community and online patient advocacy and education has added an increasingly meaningful new dimension to his life's work.

#### Hugo R. Ramirez, B.S. (Covertura Médica: Covered California)

Certificado como: Trabajador de Salud Comunitario y Consejero de planificación Familiar, Certificado como Instructor de Clases de Padres, Especialista en Comportamiento de niños, Certificado en Terapia de Reemplazo de Agresión y Manejo de Estrés Postraumático. Durante los últimos 15 años Hugo ha creado y estado a cargo de "Programas en focados en Salud Preventiva para la Comunidad y Familias Saludables" en el Valle de San Fernando, y recientemente se ha unido a Visión y Compromiso como Gerente del Programa Covered California. Hugo es además, Coordinador del Comité de Promotores de Salud del Valle de San Fernando. También es miembro de diversas coaliciones en pro de la salud en las comunidades menos favorecidas, siendo algunas de ellas: L.A. Access for Health Coalition, Covering Kids & Families Statewide Coalition, con los que ha participado en múltiples foros, seminarios, summits y talleres, como presentador, y miembro de el comité organizador. Además de planear y presentar en retiros profesionales para organizaciones comunitarias y compañías privadas. Como miembro de grupo de trabajo de la coalicion L.A. Access for Health participo activamente en la creación y dirección de Los Angeles Certificated Application Assistor (CAA) Network.

#### Maria Cruz (Jugando Bingo)

Maria recibió su Diploma como Secretaria Legal en Junio de 1962. En 1975, realizó sus estudios de Psicología Infantil para trabajar como Ayudante de Maestra trabajando en la escuela de Pre-Kínder en la Head Start de la ciudad de Northridge, Ca. En 1997, Maria inicia como voluntaria en el Programa de Promotoras de Salud para la Comunidad Latina del Hospital Providence Holy Cross, y en 1998 recibió el curso de Promotora de Salud. Desde entonces ella trabaja con la comunidad del Valle de San Fernando, impartiendo talleres de educación y prevención en los centros de Padres de las Escuelas del Distrito de Los Angeles, en las Iglesias y Centros Comunitarios. Estudié para dirigir el grupo de sobrevivientes del Cáncer con la organización Wellness Community Center, durante 4 años. Actualmente facilita el Grupo de Apoyo de Diabetes en la Iglesia de María Inmaculada en Pacoima, CA. En 1999, recibió la Certificación para ayudar a la comunidad en la registración de Cobertura Médica. Actualmente trabaja como Promotora de Salud de tiempo completo en el Programa de Promotoras de Salud para la Comunidad Latina de Providence.

#### Maria Romero (Jugando Bingo)

María desde muy pequeña inicia a enseñar a otros a leer, lo cual era algo que le fascinaba Es así como inicia su idea de estudiar para Maestra. En 1999, tomó el curso para Promotores de Salud de Providence. Su idea inicial era tomarlo para que cuando fuera a su comunidad natal pudiera compartir con sus vecinos lo aprendido. María inicia como voluntaria del programa por dos años. En año 2001, le ofrecen una posición para trabajar en el programa. María trabaja actualmente como promotora de tiempo completo para el Programa de Promotores de Salud para la Comunidad Latina de Providence.

