

# CLL Live 2015

## Recent Developments in CLL Treatments

European, American and Canadian Perspectives

### SPEAKER BIOGRAPHIES

#### Keynote Speaker



**Michael Hallek, MD**

Chair, German CLL Study Group

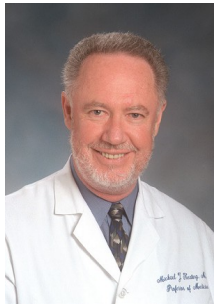
Director, Center for Integrated Oncology Köln-Bonn (Center of Excellence)

Professor of Medicine and Director and Chair of the Department of Internal Medicine, University of Cologne, Cologne, Germany

Dr. Hallek received his MD degree from the University of Munich, Germany, in 1985. He trained in pharmacology and internal medicine from 1985 to 1990 at the University and Technical University of Munich. From 1990 to 1992, he spent two years as a research associate at the Dana Farber Cancer Institute at Harvard Medical School, Boston, USA, before returning to the University of Munich where he continued his training in internal medicine and in hematology and oncology. From 1994-2005, he was also head of the Gene Therapy Program at the Gene Center of the University of Munich and at the National Centre for Research on Environment and Health (GSF), Munich. In 1994, he founded the German CLL Study group and has served as the chairman since its induction. In 2003, Dr. Hallek became Professor of Medicine, Director and Chair of the Department of Internal Medicine at the University of Cologne, where he oversees internal medicine, hematology, hemostaseology, oncology, intensive care, infectious diseases, and immunology. In 2007, Dr. Hallek was appointed as Director of the Center of Integrated Oncology (CIO), the joint comprehensive cancer center of the Universities of Cologne and Bonn. Dr. Hallek is the principal investigator for the CLL-8 clinical trial.

---

#### Featured Speaker



**Michael J. Keating, MB, BS**

President and CEO, CLL Global Research Foundation

Internist, Hematology, University of Texas MD Anderson Cancer Center

Professor of Medicine, University of Texas MD Anderson Cancer Centre, Houston, USA

Dr. Keating has been a member of the faculty of MD Anderson Cancer Center (MDA) since 1977 and works as a physician in the Leukemia Department. Since the mid-1980s, chronic lymphocytic leukemia (CLL) has been the core of his research with a large effort centered on the drug fludarabine. His career is marked by close collaboration with laboratory scientists, but his major focus has been on delivery of effective, compassionate care to patients with leukemia. In 1988, Dr. Keating won the

Service to Mankind Award from the Leukemia Society of America and in 1993 was the recipient of the Faculty Achievement Award in Clinical Research at MDA. In 1996, he was voted one of the best doctors in America by the American Health magazine and has repeatedly been voted this honor. He was given the Charles A. LeMaistre Outstanding Achievement Award in Cancer at MDA in January 2002, and in March 2002, the Rai and Binet Award at the International Workshop on CLL. March 2007, he was awarded the MDA Gerald P. Bodey, Sr. Distinguished Professorship and in 2008 was awarded the Rofeh Yedid (Physician and Dear Friend) Award from the Aishel House and received the State of Israel Maimonides Award from the State of Israel Bonds. In 2009, he was presented with the Dr. Jenaro Haddock Award by the Puerto Rico Society of Hematology. His major pursuits at the present time are developing new, potentially curative therapies for CLL and developing rational combinations of new agents in the treatment of all leukemias and other hematologic malignancies.

---

### Featured Speaker



**Spencer Gibson, PhD**

Scientific Chair, CLL Patient Advocacy Group

Director, Manitoba Institute of Cell Biology, Winnipeg, Manitoba, Canada

Professor and Manitoba Chair, Departments of Biochemistry and Medical Genetics and Immunology, University of Manitoba

Dr. Gibson attended the University of Toronto where he gained his PhD in the Department of Laboratory Medicine and Pathobiology. During his PhD studies, he traveled to M.D. Anderson Cancer Center in Houston, Texas as a pre-doctoral fellow where he completed his PhD. Dr. Gibson was a post-doctoral fellow at the National Jewish Medical and Research Center in Denver, Colorado. Dr. Gibson has been a member of the faculty at the University of Manitoba and a Senior Investigator at the Manitoba Institute of Cell Biology since 1999. In 2008, the Manitoba Health Research Council awarded Dr. Gibson a Manitoba Research Chair to support his scientific efforts. At the Manitoba Institute of Cell Biology (MICB), Dr. Gibson is Director of Translational Research, where he contributed to the creation and expansion of the Manitoba Tumor Bank and initiated new translational research projects. He was appointed Director, MICB in 2012, to provide leadership for cancer research within the province of Manitoba.

---

### CLL Live 2015 Medical Chair



**Graeme Fraser, MD, FRCPC**

Clinical Hematologist, Juravinski Cancer Centre, Hamilton Health Sciences

Associate Professor, Department of Oncology, McMaster University, Hamilton, Ontario, Canada

Dr. Fraser graduated from the University of Western Ontario (UWO) and completed post-graduate training in Internal Medicine and Hematology at UWO and McMaster University respectively. His malignant hematology training was supported by a National Cancer Institute of Canada - Terry Fox Foundation Clinical Research Fellowship. His research interests include the care of adolescent and young adult cancer patients, clinical trials in CLL/lymphoma/myeloma, and practice guideline development as a member of the Cancer Care Ontario's (CCO) Program in Evidence-Based Care.

---

*Deborah's picture is not included as she is still untreated & "in the closet"*

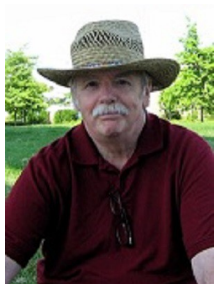
**Deborah Baker**

Chair of the Board, Chronic Lymphocytic Leukemia Patient Advocacy Group (CLL PAG)

Diagnosed with CLL, 2004

When diagnosed, Deborah was told by her family doctor that she had a 'good' cancer and not to do any internet research. At the first hematologist appointment, four long months later, she was told there was nothing she could do other than Watch & Wait. She became an advocate for CLL patients as a founding member of the CLL Patient Advocacy Group (CLL PAG). She has been a Co Chair, Acting Chair and Chair of the Board since CLL PAG formalized in 2007. Her duties include maintaining financial and meeting records, as well as acting as the official spokesperson for CLL PAG. Deborah has grown the volunteer CLL PAG Board of Directors into a working board consisting of ten national Directors. Deborah built the CLL PAG database into a tool that is used for surveying international CLL patients and their caregivers to prepare submissions for government bodies on what it is like to have CLL, with the end goal of increasing access for Canadians to new therapies. Patients are also kept informed of CLL events across Canada. She has also been part of the organizing committee of all four international CLL Educational Conferences presented for CLL patients, their caregivers and health professionals in cooperation with The Leukemia & Lymphoma Society of Canada and/or Lymphoma Foundation Canada (now Lymphoma Canada), Juravinski Cancer Centre and CLL PAG.

---



**Chris Dwyer**

British Columbia, Canada

Diagnosed with CLL, 1998

Christopher Dwyer lives near Vancouver, British Columbia, Canada and is a former graphics designer/photographer and Mac programmer who was diagnosed with CLL in 1998. While Christopher has developed aggressive complications of the disease called a Richter's transformation, and significant side effects from treatment, he has turned to his computer to be a leader in the CLL Community in Canada and worldwide, especially through social media. With warmth and compassion, Christopher is the model of welcoming the newly diagnosed and bringing them to a better place, with guidance and education.

---



**Ronan Foley, MD, FRCP**

Clinical Hematologist & Director of the Stem Cell Laboratory and Cell Diagnostic Units, Juravinski Cancer Centre, Hamilton Health Sciences

Associate Professor of Pathology and Molecular Medicine at McMaster University, Hamilton, Ontario, Canada

Dr. Ronan Foley, a clinical hematologist, is the Director of the Stem Cell Laboratory and is a previous Chair of the Clinical Trials Network, and is a Past President of the Canadian Blood and Marrow Transplant Group (CBMTG). An Associate Professor of Pathology and Molecular Medicine at McMaster University, Dr. Foley completed his medical and subspecialty training in Hamilton and Toronto. Following this, he completed a Terry Fox Fellowship under the supervision of Dr. Gauldie at

the Centre of Gene Therapeutics, McMaster University . During this time, he became interested in the evaluation of cellular gene transfer in the context of cancer immunotherapy, which led to his current research focus: the development of therapeutic cancer vaccines.

---



**James Johnston, MB, BCh, FRCPC**

Hematologist, CancerCare Manitoba

Professor Internal Medicine, Section of Hematology/Oncology, Department of Internal Medicine, University of Manitoba, Winnipeg, Manitoba, Canada

Senior Investigator, Manitoba Institute of Cell Biology

Dr. Johnston obtained his degree in medicine from Trinity College Dublin and carried out his subsequent training in Internal Medicine and Hematology/Oncology at the University of Manitoba. Following a research fellowship at the National Institute of Health he returned to the University of Manitoba as a Senior Investigator in the Manitoba Institute of Cell Biology and a clinical hematologist/oncologist at CancerCare Manitoba. Dr Johnston is a member of the Lymphoma Disease Site Group and his primary interest is in chronic lymphocytic leukemia (CLL). He is responsible for the CLL clinic at CancerCare Manitoba and is the Clinical Director of the Manitoba CLL Tumor Bank. His research activities relate to the epidemiology of CLL and to the mechanism of action of antitumor agents in this disease.

---



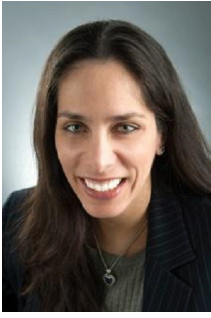
**Pat Kennedy**

Santa Paula, California, USA

Diagnosed with CLL, 2003

Pat is a fourth generation Californian who currently resides on a small avocado ranch. She is a graduate of the University of Southern California, BS and MS, with degree programs in Elementary Education and Church and Choral Music. She retired from teaching elementary school after 34 years, and is currently trying to figure out the ins and outs of farming. She is also involved in the local library, local animal rescue groups, and, for her sanity, sings in various church and community choirs. Pat was diagnosed with CLL in 2003, after telling her doctors for five years that something was very wrong. She was experiencing increasing symptoms and out of line labs, and was quite ill when she was finally referred to UCLA. Her particular CLL is somewhat unique in that it presents in the kidneys. Her experience trying to get a diagnosis and trying to find doctors who knew how to treat her, in combination with the fact that a few special fellow patients and others got her through her initial diagnosis and treatment, have left her with an interest in "paying it forward" through involvement in various on-line discussion groups, as well as local LLS events. She has added breast cancer and skin cancer to her cancer collection, and is doing well with both of those.

---



**Nicole Lamanna, MD**

Hematologist/Oncologist, New York-Presbyterian/Columbia University Medical Center  
Associate Professor of Medicine, Hematologic Malignancies Section, Hematology/Oncology Division,  
Columbia University Medical Center, New York, New York, USA

Dr. Nicole Lamanna earned her medical degree from Albert Einstein College of Medicine and completed her internal medicine internship and residency at NYU Medical center where she served as Chief Resident. She then completed her fellowship in Hematology-Oncology at Memorial Sloan-Kettering Cancer Center where she also served as Chief Fellow. She was a member of the Leukemia Service at Memorial Sloan-Kettering Cancer Center from 2004-2012 before joining CUMC in January 2013. She is a nationally recognized clinical investigator specializing in the lymphoid leukemias, specifically chronic lymphocytic leukemia (CLL) and acute lymphoblastic leukemia (ALL). Her research focus has been the development of novel combination therapies that include chemo-immunotherapy, immune-modulatory drugs, kinase inhibitors, and monoclonal antibodies. Her clinical research aims have also encompassed the development of safer and more effective therapies for older patients with CLL and the investigation of novel agents for all patients with the disease. Dr. Lamanna continues to provide compassionate care for patients with hematologic cancers as well as developing and leading clinical trials that offer patients the latest advances in the field.

---



**Susan Leclair, PhD**

Chancellor Professor of Medical Laboratory Science, Department of Medical Laboratory Science,  
University of Massachusetts Dartmouth, Dartmouth, Massachusetts, USA  
Senior Associate, University of Massachusetts Center for Molecular Diagnostics  
Creator and Director, ASCLS Consumer Information Response Service

Dr. Susan J. Leclair has been a lab professional for more than 40 years and her clinical interests include clinical hematology and oncology, human genetics and bioethics. She has been a long term member of the CLL ACOR List, acting as a consultant on matters pathological. Her many posts contain a wealth of information. She works at the University of Massachusetts Dartmouth, a place that is always getting confused with Dartmouth, New Hampshire which also has a college (Dartmouth College). She is the Editor-in-chief of Clinical Laboratory Science, the professional journal for the American Society for Clinical Laboratory Science (ASCLS). Because of her involvement with these ACOR lists, she conceived and still runs the ASCLS Consumer Information Web Page which has both static information and the ability to submit questions concerning the interpretation of laboratory tests. Two years after that effort began, they took over the same function for Lab Tests On Line. There are teams of clinical laboratory scientists who volunteer their time to reply to these questions - usually within 24 hours.

---





**Nicole Mittman, PhD**

Executive Director, Health Outcomes and Pharmacoeconomics (HOPE) Research Centre, Sunnybrook Research Institute

Assistant Professor, Department of Pharmacology, University of Toronto, Toronto, Ontario, Canada  
Adjunct Faculty, Richard Ivey School of Business, Western University

Dr. Nicole Mittman has conducted and collaborated on notable research in the areas of meta-analysis, economic evaluations, outcomes research and drug/patient safety. Clinical areas of interest include oncology, cardiology, trauma, drug safety, and health policy. In her capacity at the HOPE Research Centre, she is responsible for designing, managing and executing health economics and clinical outcomes research projects from the government, hospital and pharmaceutical industry perspectives. Dr. Mittman is currently the co-chair of the Committee on Economic Analysis (CEA) at the National Cancer Institute of Canada. Responsibilities include embedding economic parameters in clinical trials, economic evaluations and guideline development. Funded by the Cancer Care Ontario/Ontario Cancer Research Institute, recent work is determining the burden of cancer from a Canadian perspective and developing economic guidelines for oncology products.

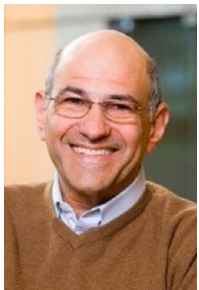
---

**Karen Running, RN, CON(C)**

Primary Care Nurse, Hematology, Juravinski Cancer Centre, Hamilton Health Sciences, Hamilton, Ontario, Canada

Karen Running cares for patients with various malignant hematologic diseases, including chronic lymphocytic leukemia (CLL). Karen has worked in hematology since 1982. She completed an Oncology Certification Course at McMaster University in 1998 and began working at the Juravinski Cancer Centre the same year. She earned her CON(C) certification in 1998. Karen is currently the Primary Care Nurse for Dr. Ronan Foley and Dr. C. Tom Kouroukis.

---



**Andrew Schorr**

Founder & President, Patient Power

Bellevue, Washington, USA; London, United Kingdom; Barcelona, Spain

Diagnosed with CLL, 1996

Andrew Schorr is a medical journalist who was diagnosed with CLL in 1996 and received FCR treatment in a phase II clinical trial in 2000. He believes it saved his life and he has had no treatment since. However, he was diagnosed with a second blood cancer, myelofibrosis, in 2011 and takes a daily oral medicine to allow him to lead a full life. Still energized, Andrew is the founder and driving force behind [www.PatientPower.info](http://www.PatientPower.info), a leading online CLL education channel and producer of “town meetings” for patients and caregivers. Andrew is the author of the acclaimed *Web-Savvy Patient*, a guide to health information online. With his wife and work partner, Esther, he divides his time between the U.S. and Europe.

---



**Esther Schorr**

Chief Operating Officer, Patient Power  
Developer, Patient Power Care Partner Center  
Care Partner to Andrew Schorr  
Bellevue, Washington, USA; London, United Kingdom; Barcelona, Spain

Esther Schorr has been a care partner since 1996 when her husband and business partner, Andrew Schorr was diagnosed with CLL. Even before that, she was involved in educating patients and their loved ones about how to be empowered to make their own health care decisions. Most recently, she has been developing a Care Partner Center on the Patient Power website to help connect care partners with each other for support and information sharing, as well as resources to help care partners navigate their special role in the health care and advocacy journey. Esther has 25+ years of experience as a business and marketing consultant and project manager, having worked across high technology, finance, hospitality, not-for-profit, and of course, the health care sectors. As a co-founder of early patient education entities with Andrew, Esther has a solid familiarity with health care regulatory issues/industry trends; extensive marketing/communications expertise, and business development experience working with medical device manufacturers, pharmaceutical and biotech companies.

---



**Erin Streu, RN, MN, CON(C)**

Clinical Nurse Specialist, CancerCare Manitoba, Winnipeg, Manitoba, Canada

Erin Streu received both her Bachelors and Masters in Nursing from the University of Manitoba. She has been an oncology nurse for 15 years and her clinical expertise is in lymphoma and chronic lymphocytic leukemia (CLL) and she is currently a clinical nurse specialist in this area. Erin also developed and implemented a new provincial subcutaneous immunoglobulin (SCIG) program for oncology patients with secondary immune deficiencies who require replacement therapy. Erin's research and clinical interests include second malignancies in CLL, quality of life and infectious complications in patients with lymphomas and CLL, as well as transitional care planning for patients with lymphoma. She has presented at local and national conferences, published in oncology nursing journals, and was the past president of her provincial chapter for the Canadian Association of Nurses in Oncology. Erin is currently an associate-editor for the Clinical Challenges column in Oncology Nursing Forum, which assists oncology nurses to gain a deeper understanding of complex clinical cases to optimize patient care.

---



**Wayne Wells**

Cameron, New York, USA  
Diagnosed with CLL, 2006

Wayne Wells has owned his own contracting business, working as an artisan in stone, tile and all phases of housing construction. He pursues the sports of atlatl, canoeing, X-country skiing, hiking, & Tai-Chi. Hobbies include stained glass, sculpting, reading and, since 2006, the study of CLL cancer biology. Wayne was diagnosed with CLL on Sept. 11, 2006 and

told he had a “good cancer” as he might never need treatment. Testing for IGHV mutation status, FISH and CD38 all predicted an indolent disease course. The one test (ZAP-70), which CLL specialists said was inaccurate, was 58% positive indicating that he might be discordant with a more aggressive CLL. Wayne was screened by the US Veterans Administration for his service in Vietnam where he had been exposed to Agent Orange. It was presumed at that time his CLL was caused by AO. By the beginning of 2009, Wayne was full of bulky nodes and a high ALC of 300k. He enrolled in the NIH (National Institutes of Health) study “The Natural History of CLL” but had to drop out to begin therapy with FR. 2nd Cycle FR put him at death's door with ATN (Acute Tubular Necrosis). FR was abandoned and Wayne relapsed in the summer of 2010. In early 2011 he was treated with high dose Rituxan that further damaged his kidneys and put him temporarily in a wheelchair. That summer he opted for a Phase Ib Clinical Trial with a new agent called PCI-32765, later renamed Ibrutinib. Since the end of June 2011, Wayne has been on Ibrutinib with an ever deepening remission hovering just above a CR.

---



**Nick York**

Wales, United Kingdom

Diagnosed with CLL, 2010

Nick York is a UK CLL patient advocate working in collaboration with other patient groups to improve access to current educational information, treatment and care to improve outcomes for patients and their families. He is an active trustee of the UK CLL Support Association where as a volunteer Nick leads several working groups of UK patients that are focusing on: patient involvement in drug regulatory appraisals; a study into the quality of life challenges for those living with CLL; the enhancement of on-line resources to support patients and their families. Nick is founder and co-administrator of the CLL Support on line community: <https://healthunlocked.com/cllsupport> and also supports patients through traditional methods at UK regional meetings, via the telephone and contributions to newsletters. He is also working as a member of the steering group setting up the European CLL Advocates Network. Nick is a retired builder who, when he is not busy with his CLL work, now is a portrait artist and avid gardener.