

CLL Live 2018 Summary

Education is key for patients and their loved ones to be true partners in their treatment. The **CLL Live 2018** conference provided participants with an opportunity to hear from leading experts in CLL research and care from Canada and the United States. As a result, conference attendees are better informed and able to discuss their treatment options with their doctor. CLL can feel isolating and affect emotional well-being. The conference also provided opportunities to network with others facing similar problems and to participate in sessions about the psychological challenges of CLL.

CLL Live 2018 brought together **over 224 patients, caregivers and other supporters**, with attendees from Canada, the United States, France and Lebanon. Participant feedback was overwhelmingly positive, a report will be released soon.

The conference was chaired by Dr. Graeme Fraser. To ensure participants had a basic understanding of CLL, Dr. Nicole Lamanna began the conference with a short overview of the disease. This was followed by Dr. Carolyn Owen, who described key prognostic markers, their implications for treatment and for the probable course of the disease. Then Dr. Versha Banerji described new treatments for untreated and treated patients and what we know about their effectiveness. Using clinical cases of patients, Dr. Lamanna described what doctors consider when making treatment recommendations to patients.

After lunch, keynote speaker Dr. Thomas Kipps described new treatments that are still in trials and therapies that combine more than one drug. Dr. Spencer Gibson spoke about the CLL Cluster project in Winnipeg and their multiple CLL research projects. Dr. Mathieu Crupi of the Ottawa Hospital Research Institute explained the CAR-T process and their plans for a CAR-T trial in 2019. Then conference participants broke into three groups to discuss the psycho-social implications of CLL. They were led by facilitators Esther Schorr for the caregivers, Stephanie Hubbard for the untreated and Christina Russomanno for the previously treated group.

The second day began with the Patient Panel. Andrew Schorr spoke about being treated after a 17 year FCR induced remission. Lorna Warwick described how the CLL Advocates Network brings together CLL organizations from around the world. Mark Silverstein spoke about the challenges of failing multiple treatments and risking a stem cell transplant. Marcyne Heinrichs explained how she found purpose in her diagnosis by offering others information through her newsletter. The medical doctors and scientists then came together as a Doctors Panel and answered questions submitted by the audience. The conference ended with a presentation on self-care and secondary cancer awareness by Erin Streu.

Thank you to the sponsors for allowing us to provide the conference free-of registration charge to participants: Platinum Sponsors – Janssen, Gold Sponsors – AbbVie and Roche, Silver Sponsors – Astra Zeneca, Gilead and Lundbeck.