



# CLL TIDBITS

## Bits and Pieces from the CLL Global Community

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October 2015

### Greetings Friends!

October has been full of treats for CLL Global. On October 25, in conjunction with our production partners at Patient Power, we hosted a "Living Well with CLL" Town Hall at MD Anderson Cancer Center in Houston, Texas. Over 300 people, including CLL patients, caregivers, and members of the health care community, participated in the event. In addition to the Town Hall, we held our semi-annual CLL Global Board of Directors meeting, planning our strategy for growth and development in 2016. To top off the month, many of our scientific partners are finalizing their abstracts for presentation at the 57th annual American Society of Hematology meeting to be held on December 5-8 in Orlando, FL. The remainder of 2015 looks to be a busy, productive, and exciting time for the CLL community.

### NEWLY DIAGNOSED

**If you have recently been diagnosed with CLL, you probably have questions.**

[Information about CLL](#)

[What we are doing to defeat CLL](#)

[List of CLL specialists around the world](#)  
(Provided by ACOR)

### LIVING WELL WITH CLL

#### Town Meeting

On Sunday, October 25, CLL Global and Patient Power hosted a CLL Town Meeting at MD Anderson Cancer Center (MDACC) in Houston, Texas. Despite the rain clouds in the area, over 100 people attended the meeting in person and more than 270 people participated in the meeting online. The onsite event was moderated by Patient Power founder Andrew

Schorr, while the online event was hosted by Andrew's wife Esther Schoor. Panelists included Dr. Michael Keating, CLL Global founder and CEO, and professor of medicine at MDACC, Dr. Zeev Estrov, professor of medicine at MDACC, and Dr. Nicole Lamanna, associate clinical professor of medicine at Columbia University Medical Center. Also on the panel were Jamie Lynn Gibbons, physician assistant at MDACC, and Purva Lad, LCSW, a social work counselor at MDACC.

### FEATURED VIDEO



#### The Emotions of Watch and Wait

The watch and wait process can be challenging and stressful. Psychologist Dr. Rena Szabo shares how her team works with patients to maintain a high quality of life throughout the process.

## FEATURED VIDEO



### **Ruxolitinib and Aerobic Exercise Help CLL Fatigue**

Can a JAK inhibitor such as ruxolitinib (Jakafi) help with CLL fatigue? CLL expert Dr. Nitin Jain discusses the efficacy of ruxolitinib in fighting fatigue in both CLL and myelofibrosis.

The agenda for the meeting was extensive. The morning session included discussions on what CLL is, how it progresses, what it means to "watch and wait", and how



best to monitor and treat the disease. The expert panel reviewed current treatment options including chemoimmunotherapy and stem cell transplant, and discussed exciting new treatment options in development such as Chimeric Antigen Receptor T-cells (CARs), checkpoint inhibitors such as Nivolumab, and inhibitor therapies including ABT-199, a Bcl-2 inhibitor.

## #GivingTuesday



**December 1, 2015 is Giving Tuesday, a day of bringing people together around the values of service and giving back.**

After the break-out session during lunch, the focus shifted to patient support from a more personal perspective. The need for patients and caregivers to reach out and ask for help when they need it, be it emotional, financial, or educational, was stressed. Patient panelists shared their personal journeys from diagnosis to "living well with CLL" and all they had been through in the interim. Andrew Schorr, a CLL patient himself, discussed the importance of patient education and participation in the larger CLL community, be it through volunteering and attending events such as the Town Meeting, or through online support groups and social media. He stressed that CLL is a part of a person's life, but it is not what defines that person.

## AMAZON SMILE



**Donate to CLL Global the next time you shop on Amazon. All you need to do is go to the AmazonSmile webpage (<http://amzn.to/1I5LVhk>), select CLL Global as the charitable organization you would like to recognize, and for eligible purchases the AmazonSmile Foundation will donate 0.5% of the purchase price to CLL Global.**

Towards the end of the meeting participants were offered the opportunity to ask questions of the expert panel. The questions ranged from what a patient's mutation status may mean for treatment options, to how to find financial assistance for increasingly expensive drugs, to how best to talk with friends and family members about a CLL diagnosis. Many audience members commented on how fatigue was a major obstacle to daily living. The expert panel stressed the need to communicate this with a patient's physician as there are ways in which to combat fatigue.

CLL Global would like to thank everyone who participated in the Houston Town Meeting. Plans are already underway to hold the next Town Meeting in spring 2016 at Columbia University Medical Center in New York. Similar to the event in Houston, the New York event will provide an opportunity for online participation. Details on the upcoming event, and a link to view a video of the Houston event, will be provided here, as

well as on our [website](#).

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## IN MEMORIUM

### Remembering Byron "Mack" Rankin, Jr.

Texan To The Core  
Believer In The Defeat Of Cancer  
Survivor To See It Happen  
Patron To Make It Possible  
Friend To Us All



Byron "Mack" Rankin, Jr. was the founding chairman of CLL Global. He was instrumental in launching our organization and making it into a successful and worthwhile entity. While Mack is no longer with us, his legacy will continue through our dedication to improving the lives of CLL patients and finding a cure for the disease.

## THANK YOU FOR SUPPORTING US!

We would like to thank everyone who participated in our "Living Well with CLL" Town Hall. It is only through working together and educating ourselves that we will be successful in ending CLL once and for all. Please consider supporting the foundation's research and patient education efforts on Giving Tuesday (December 1, 2015). "Good things come to those who wait, but better things come to those who go out and get them" - Anonymous. Help CLL Global go out and get the answers we need to find a cure.

**Sincerely,**

**CLL Global Research Foundation**

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