CLL SOCIETY

The CLL Bloodline
July 2020

MONTHLY QUIZ: **Concerning the reason we got CLL:**

1. CLL can be familial, but that is rare.
2. CLL incidence is increased in those exposed to Agent Orange in Vietnam and elsewhere.
3. CLL incidence is increased in those exposed to radiation from Chernobyl.
4. CLL is linked to benzene exposure.
5. All of the above.
6. 1, 2 and 3 are correct.

The correct answer is #6. CLL mostly occurs episodically with no known cause but occasionally CLL runs in families. Agent Orange is a recognized risk for CLL and exposed veterans who develop CLL may be entitled to compensation. For a long time, radiation was not considered a risk due to the lack of increase of CLL after Hiroshima, but we now know from the Chernobyl experience, that Hiroshima was the exception due to the very low baseline incidence in of CLL in ethnic Japanese. Benzenes and other solvents may increase the risk of other blood cancers, but there has been no link found with CLL. Usually we just don't know why we got CLL.

NEWS: At the EHA (European Hematology Association) Annual Congress, held virtually in June 2020, the CLL Society presented: IMPACT OF CLL SOCIETY'S FREE EXPERT ACCESS PROGRAM (EAP) FOR CHRONIC LYMPHOCYTIC LEUKEMIA PATIENTS that showed in the 108 patients enrolled during the study. The results indicated that 74% of consultations led to changes in care management, including 24% who planned to see a new doctor, 35% who planned additional testing, and 55% would consider a clinical trial. Expert Access Program is a free program open to all with CLL who live in the USA.

Our next webinar is scheduled on August 14th at 9:30 AM PDT with Dr. Anthony Mato who will discuss MRD: What Should it Mean to Me?

BASICS: Watch and Wait

Watch and Wait or Active Observation or as patients often call it, Watch and Worry, is at first glance the most counter-intuitive concept in CLL management. Basically, it is saying: Don't treat the CLL until it causes problems. With many types of cancer early detection is critical, and the prognosis gets worse with more advanced stages of the disease. That is the whole philosophy behind regular PAP smears, mammograms, colonoscopies, and skin checks – to catch the cancer early.

At EHA 2019, for the first time a clinical trial that compared ibrutinib to placebo in asymptomatic early stage high-risk patients proved that that ibrutinib significantly improves progression free and event free survival, and time to next treatment. But in CLL, still most data show that earlier treatment at the time of diagnosis doesn't help. Why?

1. Until recently, all treatment options were either relatively toxic or ineffective.
2. Some patients will never need treatment so treating only exposes them to toxicities with no benefits.

This may change for some high-risk (i.e., del 17p) patients with the EHA 2019 data, but with treatment moving towards fixed duration with novel agents, the place for this early intervention approach is controversial. Why take medicine for years that you may never need, or not need for years, and that has not yet been shown to improve overall survival when taken early? Is taking it when needed just as good? Outside of a clinical trial, watch and wait is still the smart option.

ACRONYM OF THE MONTH: TKI

TKIs or tyrosine kinase inhibitors are drugs that work by blocking activation of different proteins or enzymes. In CLL, they inhibit B cell's signaling pathway, preventing the cancer cell from communicating with other cells. Without the stimulation of communication, the CLL eventually cells die off. Ibrutinib, acalabrutinb, idelalisib, and duvelisib are oral TKIs approved to treat CLL and many others are in development.

If the CLL Society has helped you or a loved one, please consider making a donation.