CLL SOCIETY

The CLL Bloodline

February 2020

Over the course of a year of monthly meetings, the CLL Bloodline will teach the BASICS needed to understand CLL, bring news, help with the acronyms and new vocabulary, and offer simple fun quizzes.

MONTHLY QUIZ: Chemo-immunotherapy (CIT), specifically FCR (fludarabine, cyclophosphamide, and rituximab), can give very long remissions that are starting to look like cures as frontline therapy for some CLL patients who:

1. Are missing the short arm of chromosome 17, also known as deletion 17p.
2. Have mutated IgHV.
3. Have unmutated IgHV.
4. We can't predict who is more likely to respond to CIT.

Correct Answer is #2. FCR has been proven the best CIT in CLL for young healthy patients. It has resulted in extremely durable remissions for some low risk patients with mutated IgHV, and no other negative prognostic factors including no 17p or 11q deletions or mutated TP53. Sadly, most CLL patients won't fit in this group. But for those who do, quoting from the medical journal Blood, Jan. 2016: "*The 12.8-year PFS (progression free survival) was 53.9% for patients with mutated immunoglobulin heavy chain variable (IGHV) gene (IGHV M) and 8.7% for patients with unmutated IGHV (IGHV-UM)*". That means over ½ of those patients with mutated IgHV had no CLL progression for almost 13 years when the data were published. And more recent reports show no new cases of progression or deaths up to four years later.

In fact, for healthy young patients with all the best prognostic factors, if FCR gets them to where there is no measurable disease (U-MRD or undetectable minimal residual disease), then they have a greater chance, almost 80%, of never needing any more treatment for CLL. However, if one doesn't fit into that low risk group, odds are much worse. Testing for IgHV mutation, a simple blood test, should be mandatory for anyone considering FCR. Our motto is: **TEST BEFORE TREAT**™ but unfortunately it is often not done in community hematology practices.

In summary, there is only a very small group for whom FCR may make sense as their first treatment in the light of all the new therapies that are now available, but for those few it still may be an option worth considering.

NEWS:
On January 8, 2020 Medicare approved payment for clonoSEQ, a new and better way to test for MRD. It uses genetic testing that can detect as few as 1 in a million CLL cells. For comparison, the more commonly used test, flow cytometry can find 1 cancer cell in 10,000. While the data are early, they do suggest with deeper remissions, responses are more durable so more sensitive testing makes sense. We will be discussing MRD testing more in future Bloodlines.

THE BASICS: What to do when first diagnosed.
CLL is a slow growing or indolent lymphoma of the B-lymphocytes that gives you time to plan your therapy. Don't neglect your preventive care, especially age and gender appropriate cancer screening such as PAPs, mammography, PSA, colon cancer screening and especially skin checks, as CLL increases the risk of many secondary cancers, including skin cancer. Stay up to date with vaccinations and get the annual flu jab, but avoid live vaccines such as yellow fever or MMR as they are not known to be safe in CLL. Most importantly, put together your team (get help at the CLL Society's online toolkit), join a support group, and frontload your knowledge about your disease.

WORD/ACRONYM OF THE MONTH: Lymphocyte
Lymphocyte are one type of white blood cells that are part of our immune system. When seen under the microscope, they have a large simple nucleus and contain no granules, unlike neutrophils. There are three types of lymphocytes: B lymphocytes or cells, T cells, and natural killer (NK) cells. CLL is a cancer of the B cells. B cells mature into plasma cells that make antibodies, part of the liquid or humeral immune system, T cells are soldiers in our cellular immune system, and NK cells are part of our nonspecific innate immune system. Unlike T cells, NK cells don't need to be primed to kill virally infected or cancer cells. Quite the team!

If the nonprofit 501c3 CLL Society has helped you or a loved one, please consider making a tax-deductible donation.