



CLL SOCIETY

CLL Society Bloodline

FEBRUARY 2019

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 acronym 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 IgVH.
3. Have unmutated IgVH.
4. We can't predict who is more likely to respond to CIT.

Correct Answer is #2. FCR has resulted in extremely durable remissions for some low risk patients. Having mutated IgVH generally predicts for less aggressive CLL. Quoting from the journal Blood, January 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). The almost 13 years survival rate is not showing any drop off. Three years later the data is even stronger.

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 almost an 80% chance 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 IgVH mutation, a simple blood test, should be mandatory for anyone considering FCR. Our motto is: TEST BEFORE TREAT

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

NEWS: On January 22, 2018 Celgene announced they had acquired Juno Therapeutics. Juno's CAR-T, JCAR017, looks very promising in CLL and is very similar to the CAR-T that I took in my successful clinical trial. One year later, on January 3, 2019 Bristol-Myers Squibb announced plans to acquire Celgene.

On January 28, 2019 the FDA approved ibrutinib in combination with obinutuzumab for frontline therapy for CLL, making it easier to get insurance to pay for this powerful combination.

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

WORD/ACRONYM OF THE MONTH: Lymphocyte. White blood cells that are part of the 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, T-lymphocytes and natural killer (NK) cells. CLL is a cancer of the B lymphocytes.

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