The CLL Bloodline

February 2017

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 are of chromosome 17, also known as deletion 17p
2: **Have mutated IGVH (correct)**
3: Have unmutated IGVH
4: We can't predict who is more likely to respond to CIT

FCR had resulted in extremely durable remissions for some low risk patients. Quoting from the journal Blood, from 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)*. And they conclude: *The high rate of very long-term PFS in patients with IGHV-M after FCR argues for the continued use of chemo-immunotherapy in this patient subgroup outside clinical trials; alternative strategies may be preferred in patients with IGHV-UM, to limit long-term toxicity*.

That almost 13 years survival rate is not showing any drop off. It has plateaued with no more folks progressing. In fact, for healthy patients with the best prognostic factors, if FCR gets them to where there is no measurable disease (MRD or minimal residual disease negative), then they have an 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.

In summary, there may only 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 is an option well worth considering.

NEWS:

Jan. 10, 2017: Venetoclax was finally approved in Australia, the country where the first basic research was done and the drug was originally developed. It is still between 14 and 30 months away from being on the national formulary and thus easily available to CLL patients in the country that brought it to the world.

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 as CLL increases the risk of secondary cancers. Get up to date with vaccinations, but avoid all live vaccines such as shingles or yellow fever as they are not known to be safe for those with CLL. Most importantly, put together your team (see the online CLL Society Toolkit for help), join a support group and learn more about your disease.

WORD/ACRONYM OF THE MONTH: (2 words and one acronym this month)

Petechiae: Small red or purple pinhead spots on the skin. They are caused by bleeding under the skin and are usually the result of a shortage of platelets. They are similar to **purpura**, but are much smaller in size. In CLL, some patients' immune system destroys their own platelets. This is called **ITP** or **Idiopathic (or Immune) Thrombocytopenic Purpura** in which the body's dysfunctional immune system attacks its own platelets. This results in bruising including petechiae and purpura and/or bleeding.