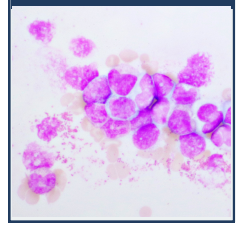


# START HERE CLL

## PROGRAM RESOURCE GUIDE

- ✓ Get information about choosing a CLL specialist or treatment center
- ✓ Talk with family and friends about how you feel and how they can help you
- ✓ Find out what your insurance covers
- ✓ Talk openly with your doctor about your fears or concerns
- ✓ Determine if financial assistance is available
- ✓ Learn about the most current tests and treatments for CLL

### CLL CELLS



## CLL TREATMENT OPTIONS

- ibrutinib
- acalabrutinib
- zanubrutinib
- rituximab
- obinutuzimab
- venetoclax

## TREATMENT OPTIONS IN DEVELOPMENT

- mosunetuzumab (available in follicular lymphoma)
- pirtobrutinib (available in mantle cell lymphoma)

## GLOSSARY OF TERMS

**CAR T-cell therapies:** CAR stands for chimeric antigen receptor. It is a biologic immune therapy where doctors take a patient's own T cells (lymphocytes in the blood) or use a donor's T cells, modify them with a new receptor, and then reintroduce them to the patient.

**BTK inhibitor:** Stands for Bruton Tyrosine Kinase inhibitor. Obstructs the enzyme BTK, which is a crucial part of the B-cell receptor signaling pathway. Certain B-cell leukemias and lymphomas use B-cell receptor signaling for growth and survival. The rationale for using BTK inhibitors in CLL is to block this signaling and to trigger the death of cancer cells.

**IGHV mutation:** Stands for immune globulin heavy light chain variable region. The IGHV gene contains instructions for making a part of immunoglobulin proteins (also known as antibodies), which help your body fight off infections. In CLL, these genes are either mutated or unmutated. About half of CLL patients have the unmutated IGHV gene. Your doctor should do a genetic marker workup before beginning treatment to determine your status; this can help personalize treatment options to your specific CLL.

## CLL EXPERT TIPS

**START HERE TIP:** "If you are going to start treatment, you're requested by guidelines to check for a prognostic workup. I would really encourage patients to ask their oncologist, 'What are my prognostic markers?' The big three tests are the FISH analysis, IGHV mutation analysis, and TP53 mutation analysis." - Dr. Ryan Jacobs

**START HERE TIP:** "It's really important for patients to know, that if you go into a clinical trial, you won't be given nothing or a placebo. You're going to be given the standard of care or whatever it's being compared to. If it's a fixed duration clinical trial, it can be a nice 'medication vacation' for patients." - Dr. Ryan Jacobs

**START HERE TIP:** "If a patient doesn't need treatment, we're fortunate that this is a blood cancer that most of the time we can follow with a simple blood count and lymph node examination. Your doctor will want to know if your lymph nodes are causing a lot of pain, if you're waking up drenched in sweat or having a dramatic amount of fatigue that can't be explained. This is called active surveillance. There's a list of criteria that your oncologist should know in terms of when you need treatment or not." - Dr. Ryan Jacobs

**START HERE TIP:** "If you have the ability to go to a cancer center that has a CLL specialist, even if it's just a one-time visit and you go back at important time periods where you need a second opinion, I think it's worth doing. It makes sense to go to someone who really focuses on this area, and the data actually reflects this. The outcomes are better if you can get access to seeing a specialist." - Dr. Ryan Jacobs

## CLL FACTS

- CLL is the most common chronic lymphoma/leukemia
- Average age of CLL patient is age 70
  - Scientists believe this might have to do with the aging effect on the DNA of the B lymphocyte

## CLL RESOURCES

- [ACCC](#)
- [CancerCare](#)
- [Cancer Grace](#)
- [Family Reach](#)
- [CLL Society](#)
- [Cancer Support Community](#)
- [LLS](#)
- [Triage Cancer](#)
- [CLL Support \(UK based\)](#)
- [Leukemia Research Foundation](#)