

# THE PRO-ACTIVE CLL PATIENT TOOLKIT

## Resource Guide



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### EXPERT TIPS FOR PATIENTS FACING A NEW CLL DIAGNOSIS

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- Know who is on your healthcare team. Understand who will be in charge of your treatment plan.
- Consider a [second opinion](#) from a CLL specialist.
- Understand that [Watch & Wait](#) is considered a treatment option. Not doing something is doing some if you don't need to treat the CLL.
- It's okay to ask repeat questions at each appointment.
- Ask your team for up-to-date online resources.
- Write down questions prior to your appointments, take notes and bring someone with you.
  - Download the [Office Visit Planner](#) from the [Pro-Active CLL Patient Toolkit](#).
- It's okay to ask for [more information](#) and about research opportunities.
- Obtain contact information for a nurse or support person to call with questions or concerns.

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### STEPS FOR LEARNING ABOUT CLL

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- Pick up informational booklets at the physician's office.
- Ask your medical team for information and online resources.
- Learn from other patients.
- Visit reputable websites.

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### CREDIBLE RESOURCES FOR CLL INFORMATION

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- American Cancer Society: [cancer.org](http://cancer.org)
- American Society of Clinical Oncology: [asco.org](http://asco.org)
- American Society of Hematology: [hematology.org](http://hematology.org)
- The CLL Society: [CLLSociety.org](http://CLLSociety.org)
- European Hematology Association: [ehaweb.org](http://ehaweb.org)
- The Leukemia and Lymphoma Society: [LLS.org](http://LLS.org)
- Lymphoma Research Foundation: [lymphoma.org](http://lymphoma.org)
- National Comprehensive Cancer Network (NCCN): [nccn.org](http://nccn.org)

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### GLOSSARY OF TERMS

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**Fluorescent in situ hybridization (FISH):** A chromosome test used to identify specific genes or chromosome changes.

**Gene Mutation:** A permanent change in the DNA sequence that makes up a gene. Changes can occur due to mistakes when the DNA is copied or as the result of environmental factors.

**Flow Cytometry:** Analysis of blood and bone marrow cells in order to classify the cell types and determine disease risk as well as appropriate treatment plan.

**Watchful Waiting (or Active Surveillance):** The period of time before treatment begins in which a patient is monitored for disease progression and symptoms