

**CLL SOCIETY**

*Smart Patients Get Smart Care™*

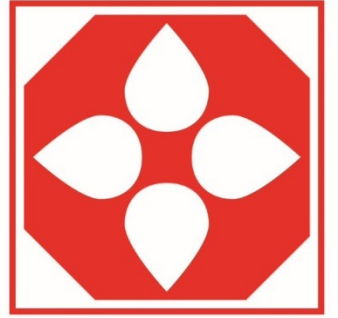
# The Importance of Front-Loading Your Knowledge During the Early Journey of CLL/SLL

April 12, 2023

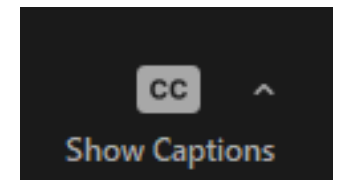
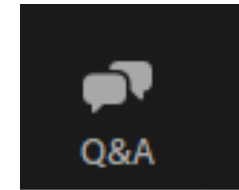
9:30 AM PT, 10:30 AM MT,  
11:30 AM CT, 12:30 PM ET

# Pre-Event Notes

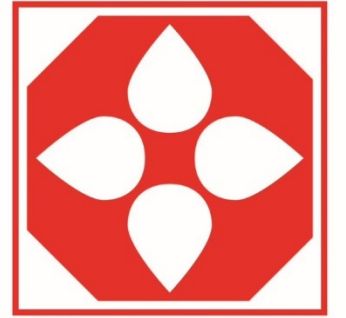
- The audience is muted
- Please direct your questions to CLL Society staff and speakers using the Q&A function (located at the bottom of your screen) at any time throughout the presentation
- Questions can only be seen by staff and speakers. We will do our best to answer as many questions as possible
- Please complete the short survey emailed after the event. Your response will help CLL Society plan future events
- The virtual event is being recorded and will be available on our website
- Closed captions are available. If you want to turn them on or off, go to Captions and select Show Captions or Hide Captions to turn them on or off



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This Program Was Made Possible  
Through Donors Like You and Grant  
Support From



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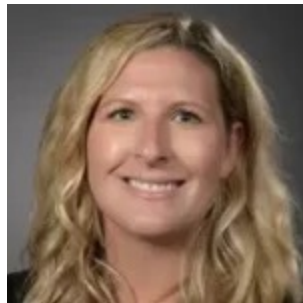


# Speakers



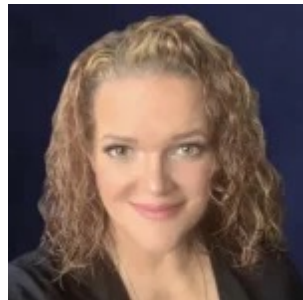
**Speaker and Moderator**  
**Stephen Feldman**

CLL Patient Advocate, Senior Support Group Advisor,  
Member CLL Society's Patient Advisory Board



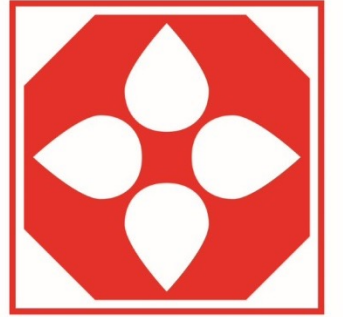
**Speaker**  
**Joanna M. Rhodes, MD, MSCE**

Director, CLL Research and Treatment Center  
Northwell Health



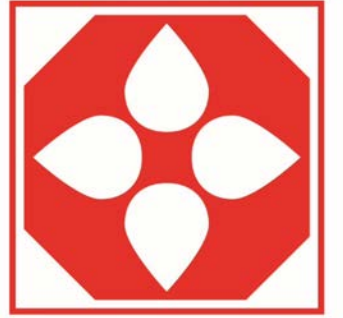
**Welcome**  
**Robyn Brumble, MSN, RN**

Director of Scientific Affairs and Research  
CLL Society



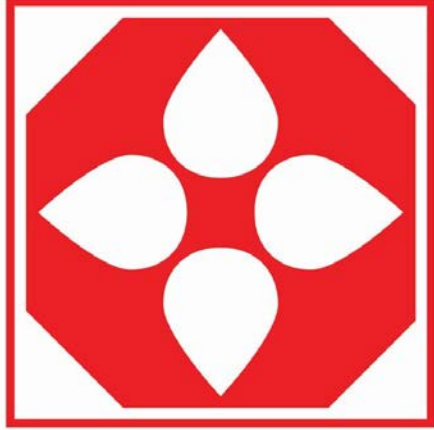
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# Poll Question



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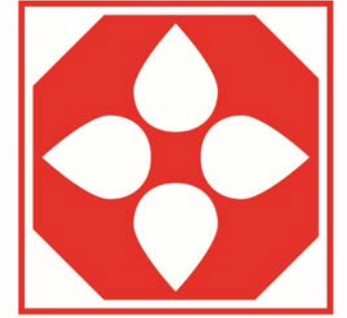
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# Early Journey – CLL Society Resources

Stephen Feldman

April 12, 2023

# CLL/SLL Patient Education Toolkit



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## Introduction/Overview

- [Overview of CLL Society Programs](#)

## About CLL/SLL and its Treatment

- [What is CLL, and What is SLL?](#)
- [CLL Symptoms](#)
- [CLL Staging and Other Prognostic Factors](#)
- [Test Before Treat™](#)
- [Watch and Wait \(Active Observation\)](#)
- [Brief Overview of Types of Treatments](#)
- [CLL Approved Medications](#)
- [FAQ — Treatment](#)
- [FAQ — Overall Health, Well-Being and Risks](#)
- [CLL-Related Fatigue](#)
- [Complications of CLL](#)
- [Managing Side Effects of Oral Targeted Therapies in CLL](#)

## Getting to Know Your Body

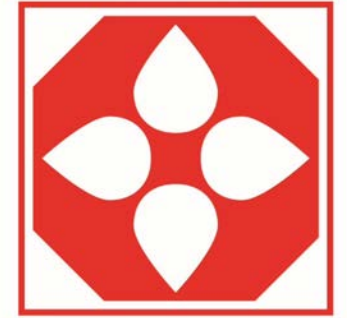
- [What is Bone Marrow?](#)
- [What is a Lymph Node?](#)
- [What is the Spleen?](#)
- [What is Blood Made Of?](#)

## CLL Tools

- [Abbreviations and Acronyms](#)
- [Glossary: Blood \(Hematology\) Tests](#)
- [Normal Lab Values](#)
- [Keeping Track of Lab Results](#)
- [Clinical Trial Phases, the Drug Approval Process, and Measuring Responses](#)
- [Putting Together a CLL Team](#)
- [CLL Society Resources](#)
- [Financial Assistance Part 1 — Nonprofits and Government](#)
- [Financial Assistance Part 2 — Industry Sponsored](#)

<https://cillsociety.org/toolkit>

# Keeping Track of Lab Results



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## Lab Values

Be the first to know!

Routine lab tests are a staple of good cancer care!

Understanding how to interpret your blood tests will empower you to ask appropriate questions and get the follow-up needed to ensure your best care.



Normal Lab Values

<https://cllsociety.org/lab-values/>

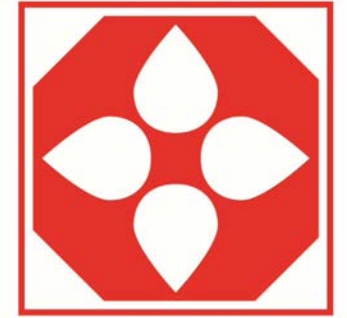


Keeping Track of  
Lab Results

<https://cllsociety.org/cll-sll-patient-education-toolkit/keeping-track-of-lab-results/>



# Test Before Treat™



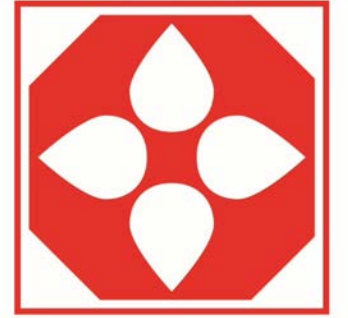
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**TB4T! One of the most important things you can do.**

Predictive and prognostic testing are critical before choosing any therapy for your CLL. Your life may depend on getting the appropriate testing before treatment, as these tests will determine which therapies will work and which will not. Incorrect treatment can be tragic.

<https://cillsociety.org/tb4t>

# Putting Together a CLL Team



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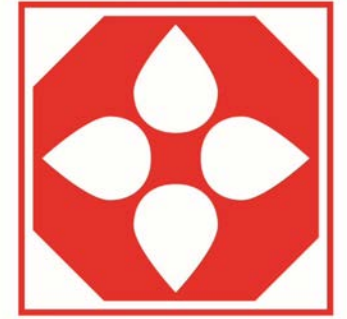
## My CLL Team

- The World Expert
- The Local Expert
- Dermatology, Primary Care, etc.
- Note Taker
- Personal Support
- Financial Navigator
- CLL Support Group



<https://cclsociety.org/cll-sll-patient-education-toolkit/putting-together-a-ctl-team/>

# CLLS Expert Access™ Program



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**WORRIED  
ABOUT YOUR CLL?**

Apply to the CLL Society Expert Access™ Program  
—it's free to see a world-renowned physician

*"I went from fatalistic to  
hopeful in 30 minutes!"*

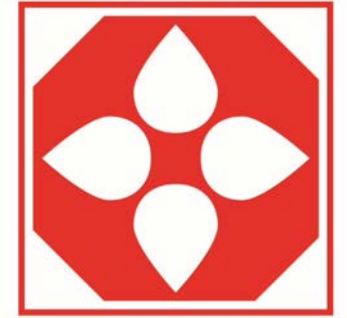


A CLL expert physician  
can give you a second  
opinion online at no  
cost to you.

Visit:

<https://cllsociety.org/eap>

# CLL Society Support Groups



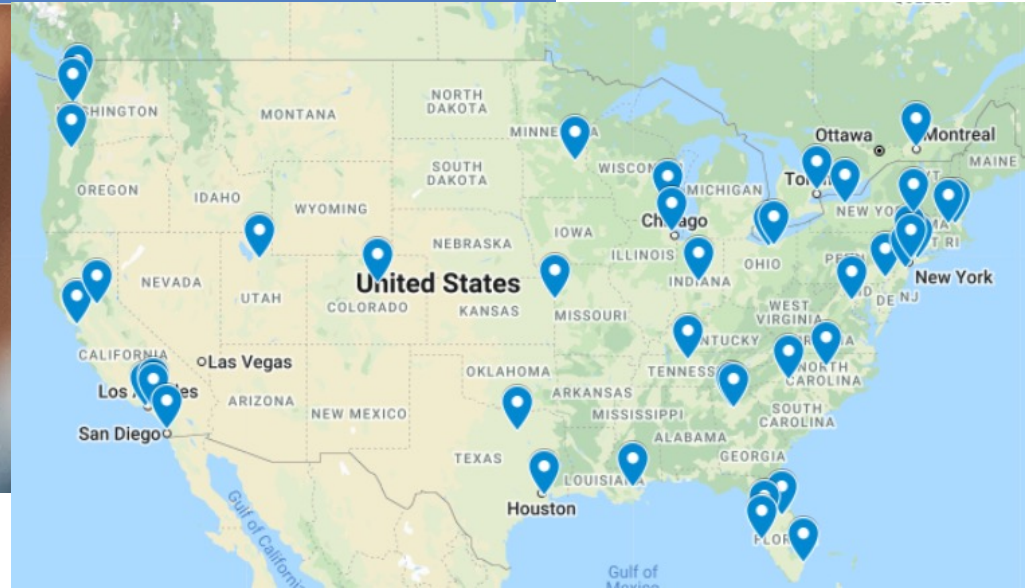
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## CLL-Specific Patient Support Groups

Over 3,000 CLL patients and caregivers are currently registered to meet monthly in our approximately 40 CLL-specific support groups across the United States and Canada under the care and guidance of CLL Society-trained facilitators who uphold standards of inclusiveness and privacy.

CLL Society's CLL-specific support groups are a place of camaraderie and strategy sharing among CLL patients and caregivers as well as a hub of learning and swift conduits for CLL breaking news and cutting-edge research-supported treatment information.

[Sign up today!](#)



<https://cillsociety.org/support-groups/>

# Stay Informed

## CLL Society *This Week*



Smart Patients Get Smart Care™

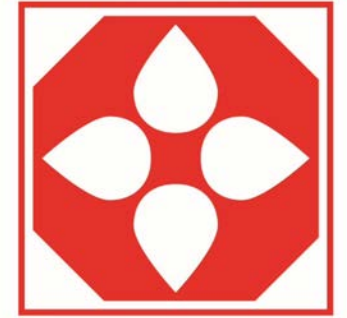
CLL SOCIETY The World's Leading Authority for Chronic Lymphocytic Leukemia Patients

✉ Newsletter Sign Up

Donate Now

Select Language ▾

How can we help you?



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<https://cllsociety.org/newsletter-sign-up/>



CLL Society

# WHAT'S NEW

March 16, 2023

Your connection to the most current news, information, and data about Chronic Lymphocytic Leukemia.

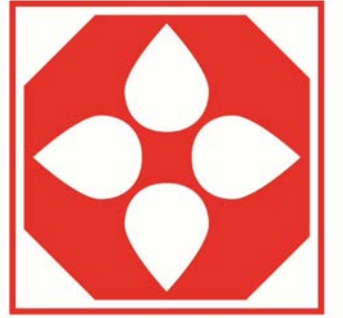
✉ Sign up for *CLL Society: This Week Email*. Look forward to Tuesday!

Click here

We suggest you BOOKMARK this page and visit it often. All content was current as of the date it was published. In science and in medicine, information is constantly changing. Published content may become out-of-date as new information and data emerge.

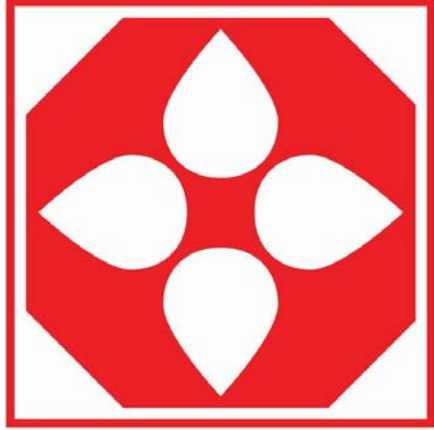
<https://cllsociety.org/whats-new-in-cll/>

# Takeaways



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- Utilize tools for education and self-advocacy
- Put together your care team
  - Include a CLL expert physician on your team
- Join a CLL-specific Support Group
- Stay informed by signing up for CLL Society's *This Week* email



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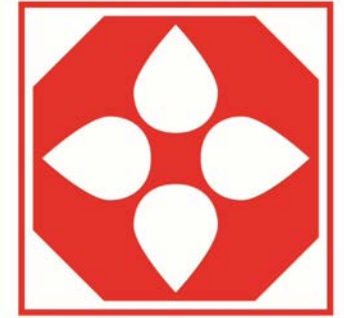
*Smart Patients Get Smart Care™*

# The Importance of Front-Loading Your Knowledge During the Early Journey of CLL/SLL

Dr Joanna M. Rhodes, MD,  
MSCE

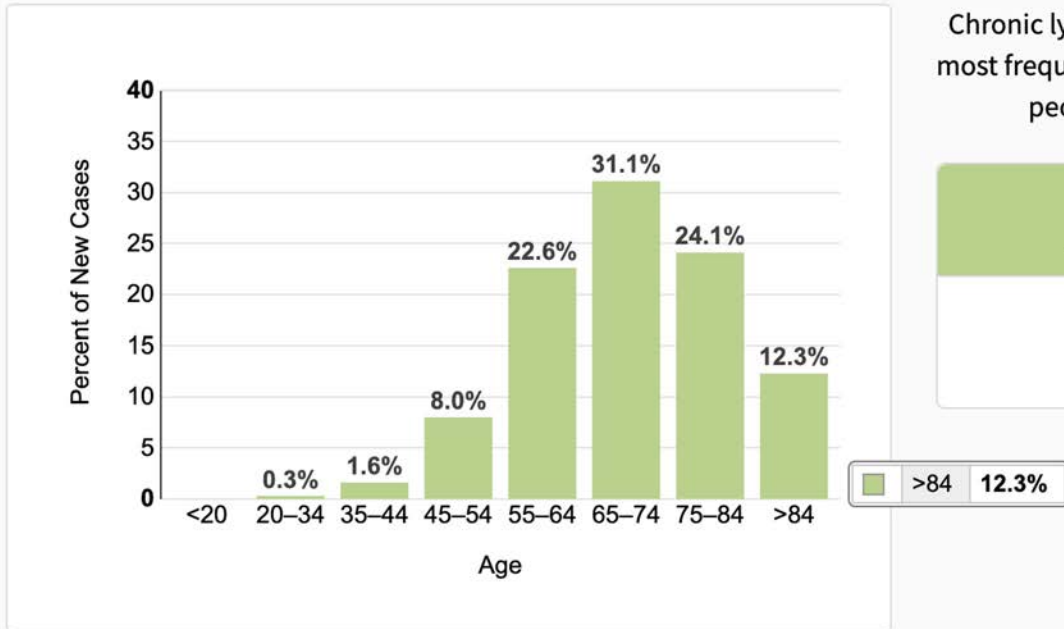
4/12/23

# Epidemiology of CLL



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Percent of New Cases by Age Group: Chronic Lymphocytic Leukemia



Chronic lymphocytic leukemia is most frequently diagnosed among people aged 65–74.

Median Age At Diagnosis  
**70**

SEER 22 2015–2019, All Races, Both Sexes

## At a Glance

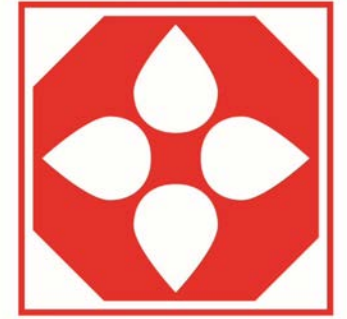
Estimated New Cases in 2022	20,160
% of All New Cancer Cases	1.1%
Estimated Deaths in 2022	4,410
% of All Cancer Deaths	0.7%

5-Year Relative Survival	<b>87.9%</b>
2012–2018	

- CLL is the most common leukemia in the Western Hemisphere countries
  - 25% of leukemia diagnoses
- More common in men
- More common in Caucasians
- ~1/3 of patients never need treatment

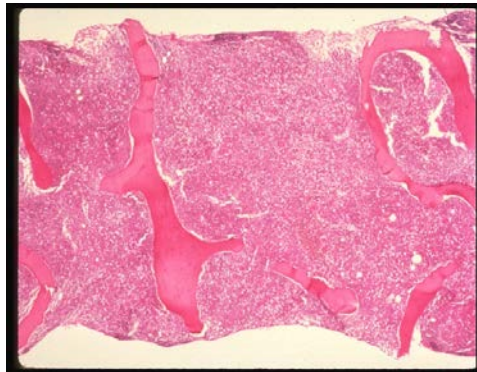
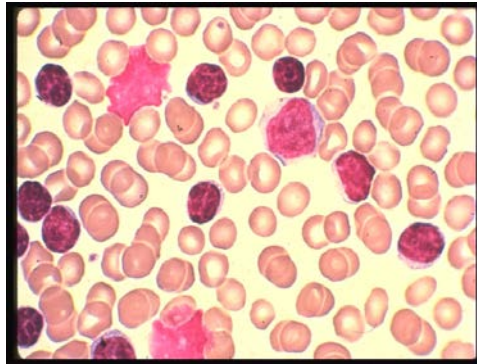


# Chronic Lymphocytic Leukemia and Small Lymphocytic Lymphoma



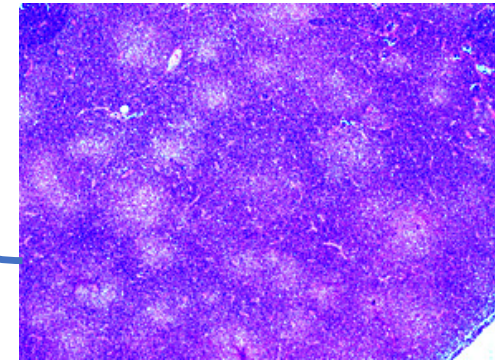
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C  
L  
L



BLOOD AND  
BONE MARROW

LYMPH NODE AND  
SPLEEN



S  
L  
L

WORLD HEALTH ORGANIZATION = CLL/SLL

# CLL: Diagnosis

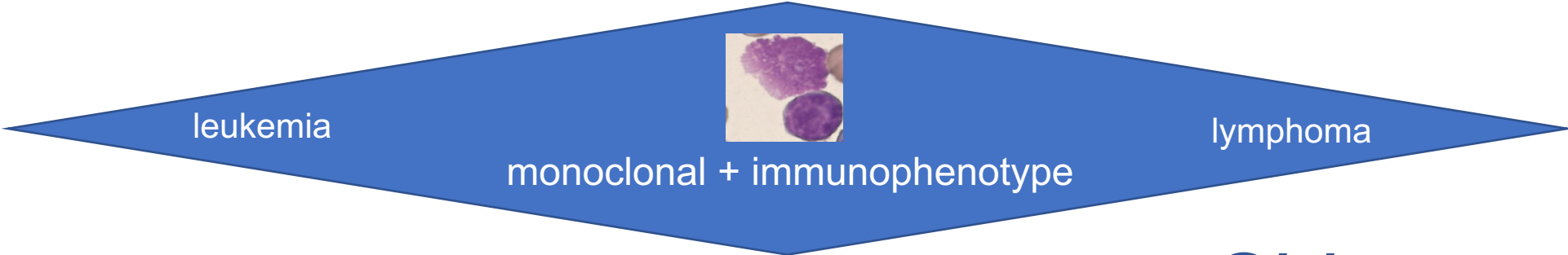
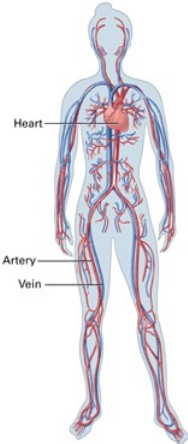


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• Plus clinical

## CLL

- At least  $5 \times 10^9$  monoclonal Bcells/L
- May or may not be symptomatic



### MBL (Monoclonal B lymphocytosis)

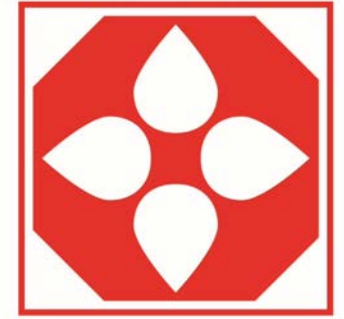
- Monoclonal B-cell lymphocytosis
- $< 5 \times 10^9$  Bcells/L
- No symptoms, low blood counts, enlarged lymph nodes, or enlarged spleen
- 1-2%/yr progress to CLL
- 2.5-5% or more of the population

## SLL

- Small lymphocytic lymphoma
- $< 5 \times 10^9$  mBcells/L
- + symptoms, low blood counts, enlarged lymph nodes, or enlarged spleen

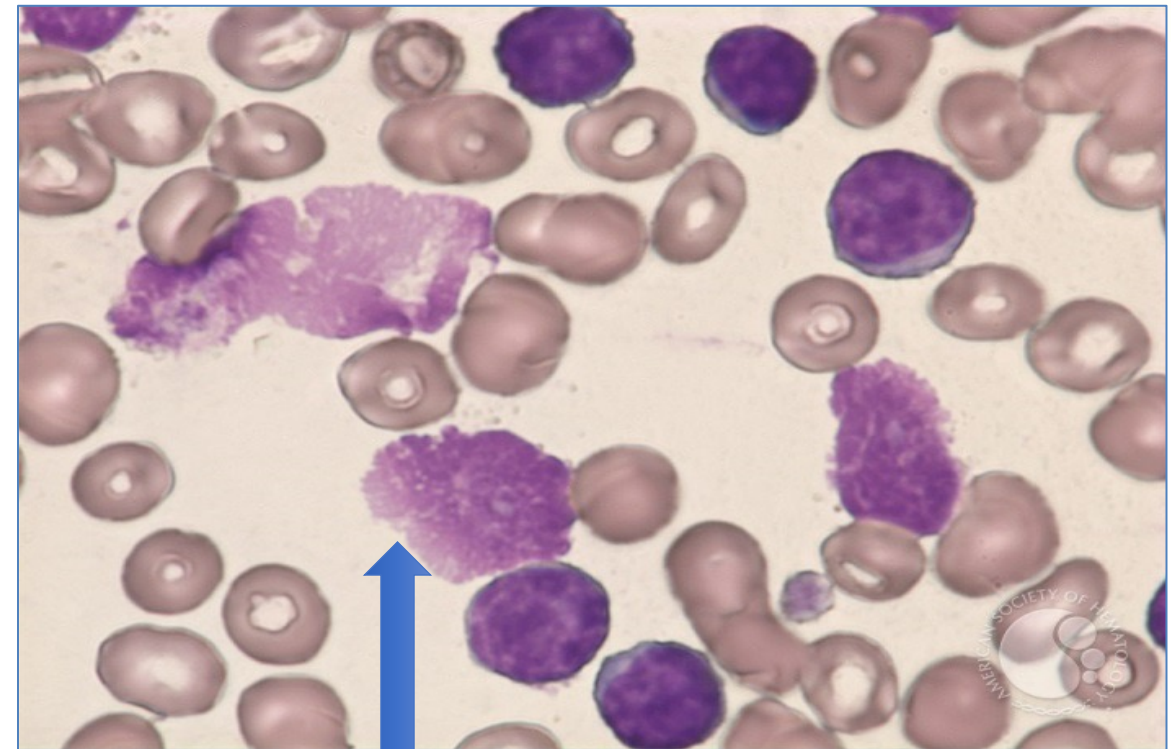
Hallek et al. Blood. 2008;111:5446.  
 Marti et al. Br J Haematol. 2005 ;130:325.  
 Shim et al. Blood. 2014;123:1319.  
 Biology:exploring life online. <http://bodell.mtchs.org>

# Diagnosis of Chronic Lymphocytic Leukemia



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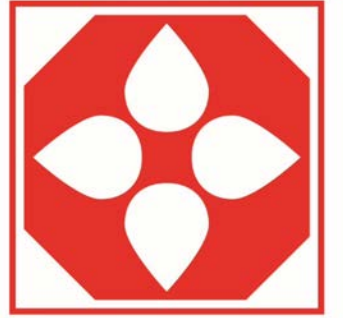
- Median age at diagnosis: 71 years
- Male to female ratio: 2 to 1
- Diagnosis made by flow cytometry: Immunophenotype (CD5+ CD10- CD23+)



Smudge Cell

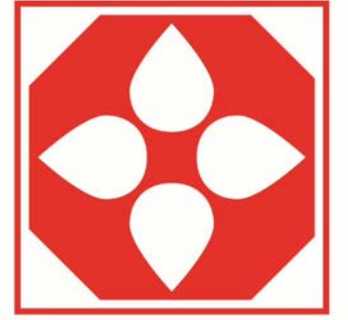
# What Tests Should My Doctor Be Doing?

- Blood cell counts and examination
  - Bone marrow examination
- Immunophenotyping (flow cytometry)
- Quantitative Immunoglobulin Test
- Fluorescence In Situ hybridization (FISH)
- Karyotyping
- DNA Sequencing
- Beta-2 Microglobulin
- Lactate Dehydrogenase (LDH)
- Hepatitis B Testing



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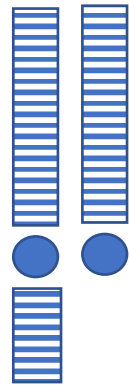
# Tests That Will Be Performed (Blood, Lymph Node, and/or Bone Marrow)



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## FISH

- Fluorescent microscope to look at whether the 17p gene is intact or not (and others!)

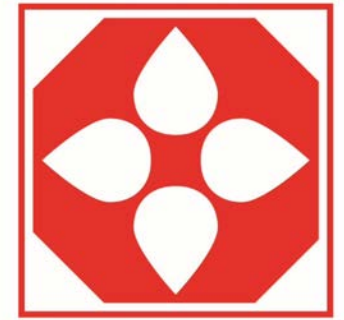


Chromosome 17

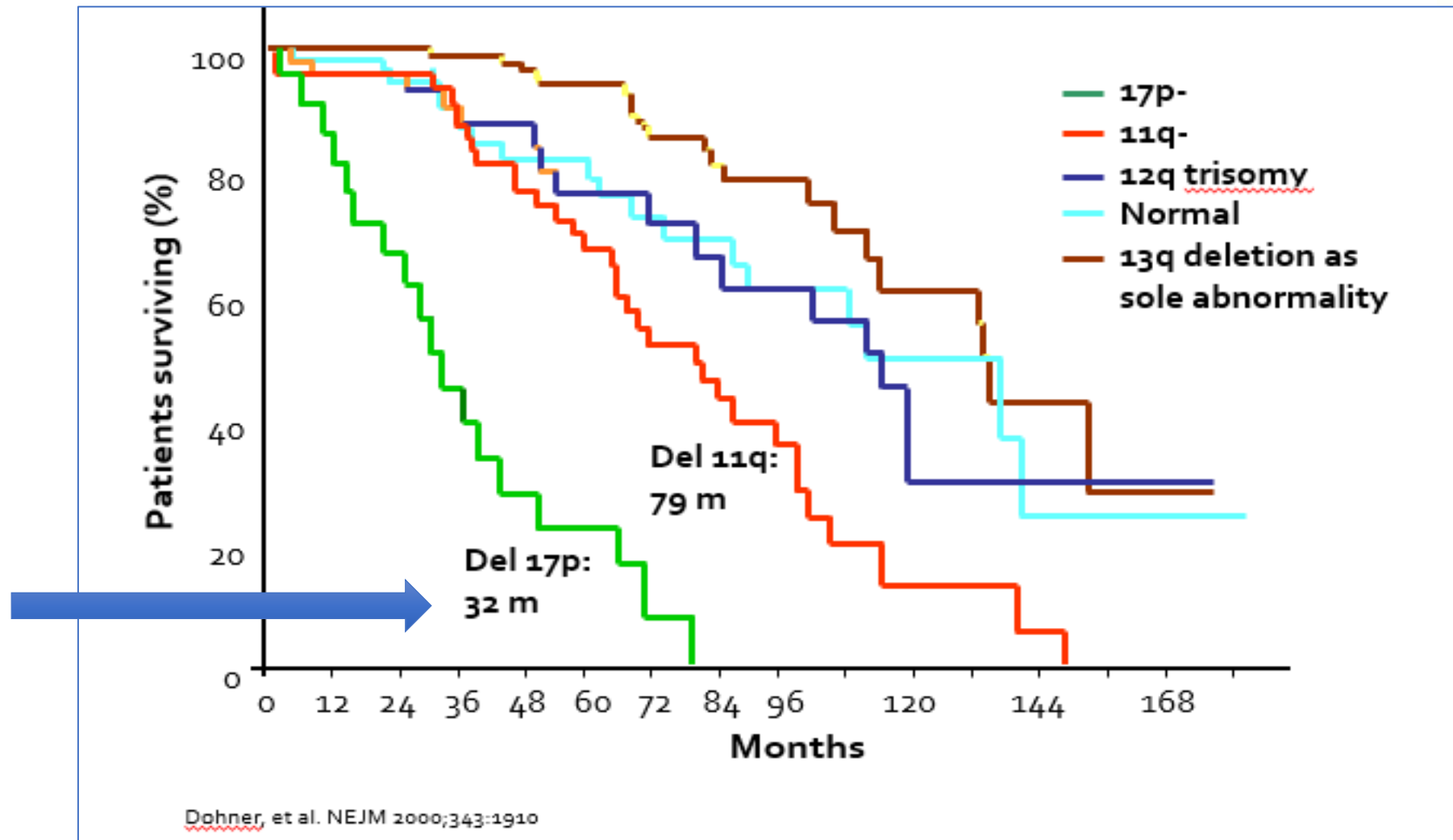
## Mutation analysis

- Gene sequencing performed in a variety of manners
- Specific mutations are known to cause loss of activity TP53
- Mutations of immunoglobulin gene

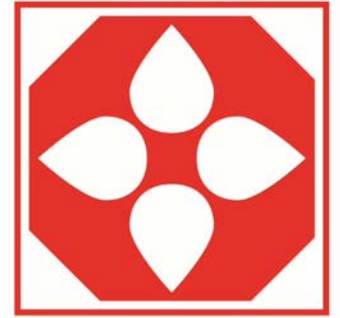
# Old Overall Survival Data by FISH When Chemotherapy Was the Only Treatment



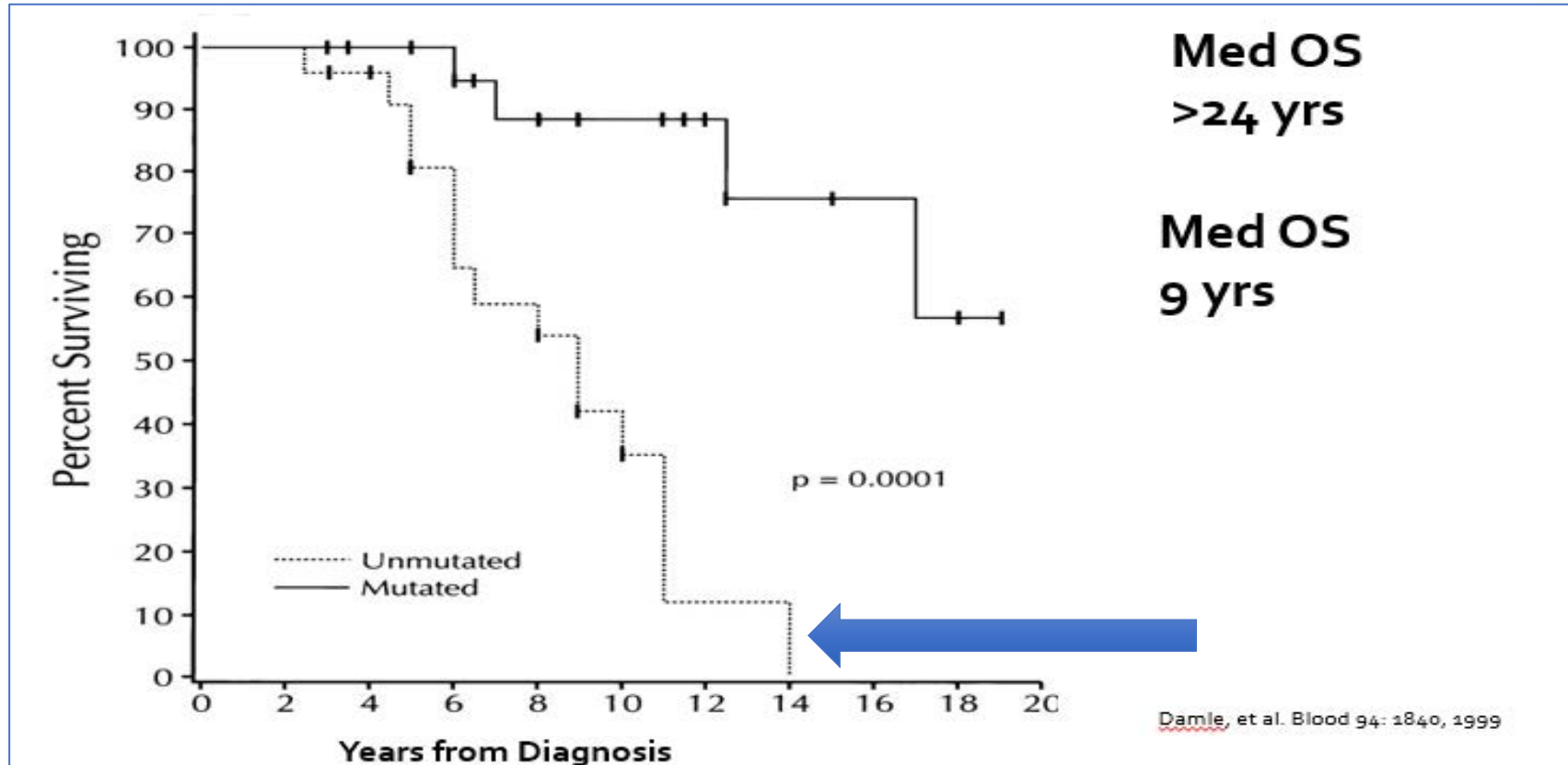
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# Immunoglobulin V<sub>H</sub> Gene Mutation: 1999 Data



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# What are Symptoms of CLL?

FATIGUE

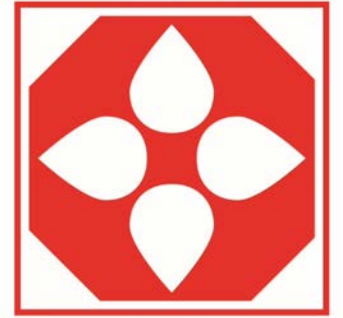
SHORTNESS OF BREATH

SWOLLEN LYMPH NODES OR SPLEEN

INFECTIONS

WEIGHT LOSS

NIGHT SWEATS

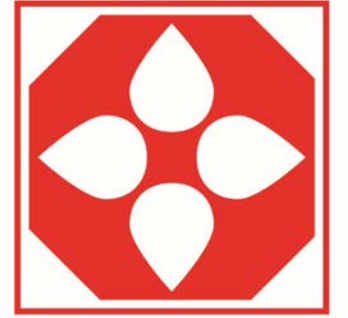


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Many patients have no symptoms at all!



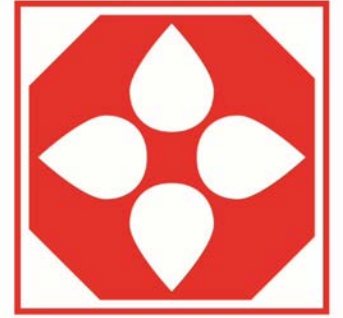
# Am I Immunocompromised?



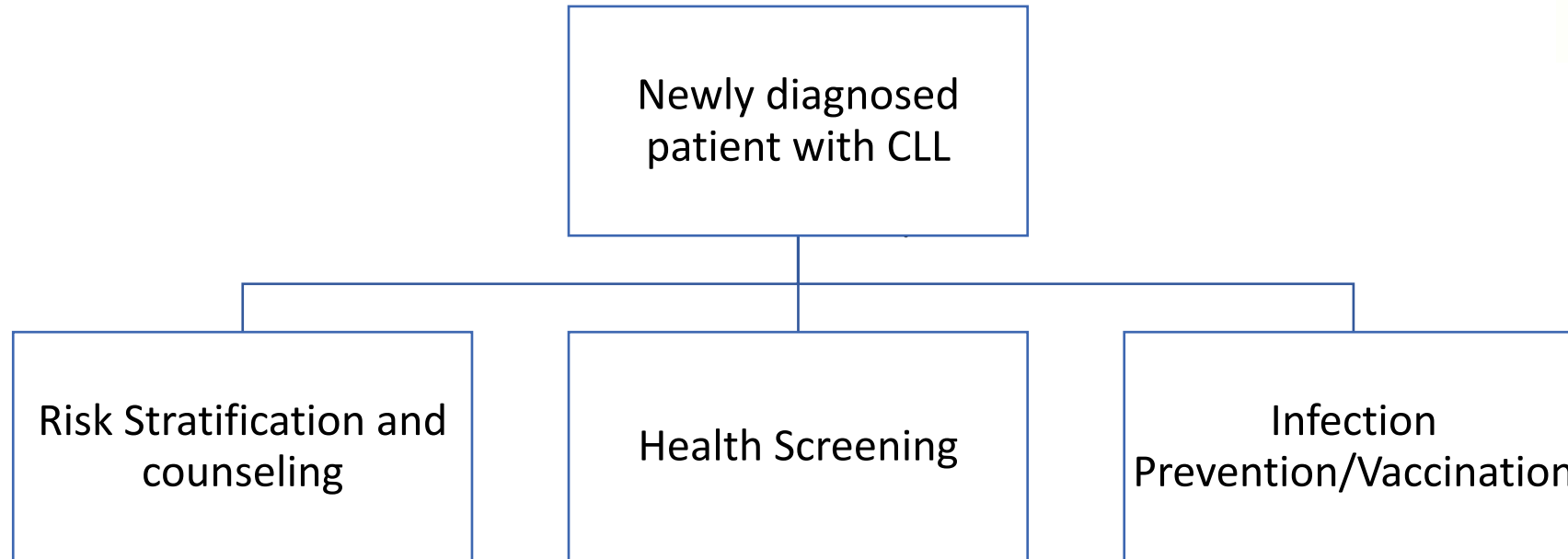
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- CLL is a cancer of the immune system (B cells) which puts patients at higher risk for infections
- CLL may make it harder for your immune system to make antibodies
- T cells are another immune cell that is affected by CLL and can make not respond to infections the same way

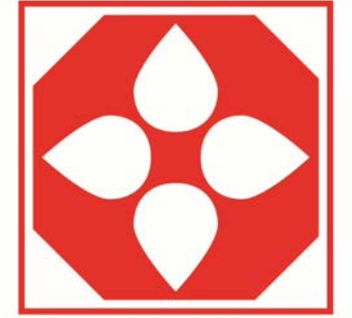
# Initial Assessment and Supportive Care



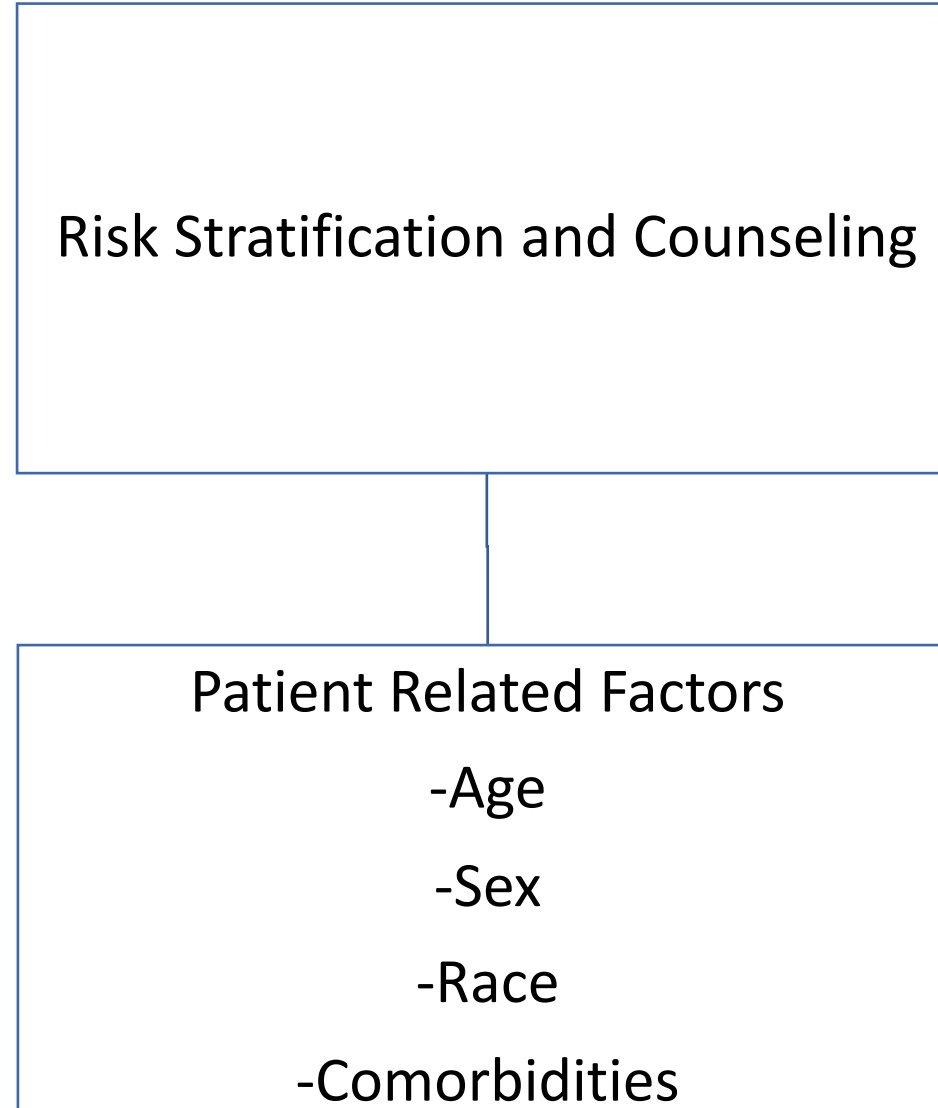
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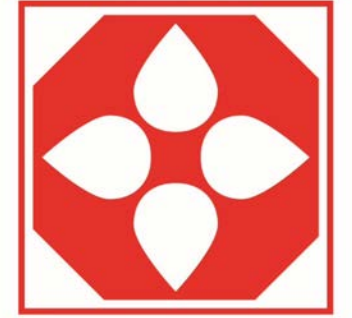
# Initial Assessment and Supportive Care



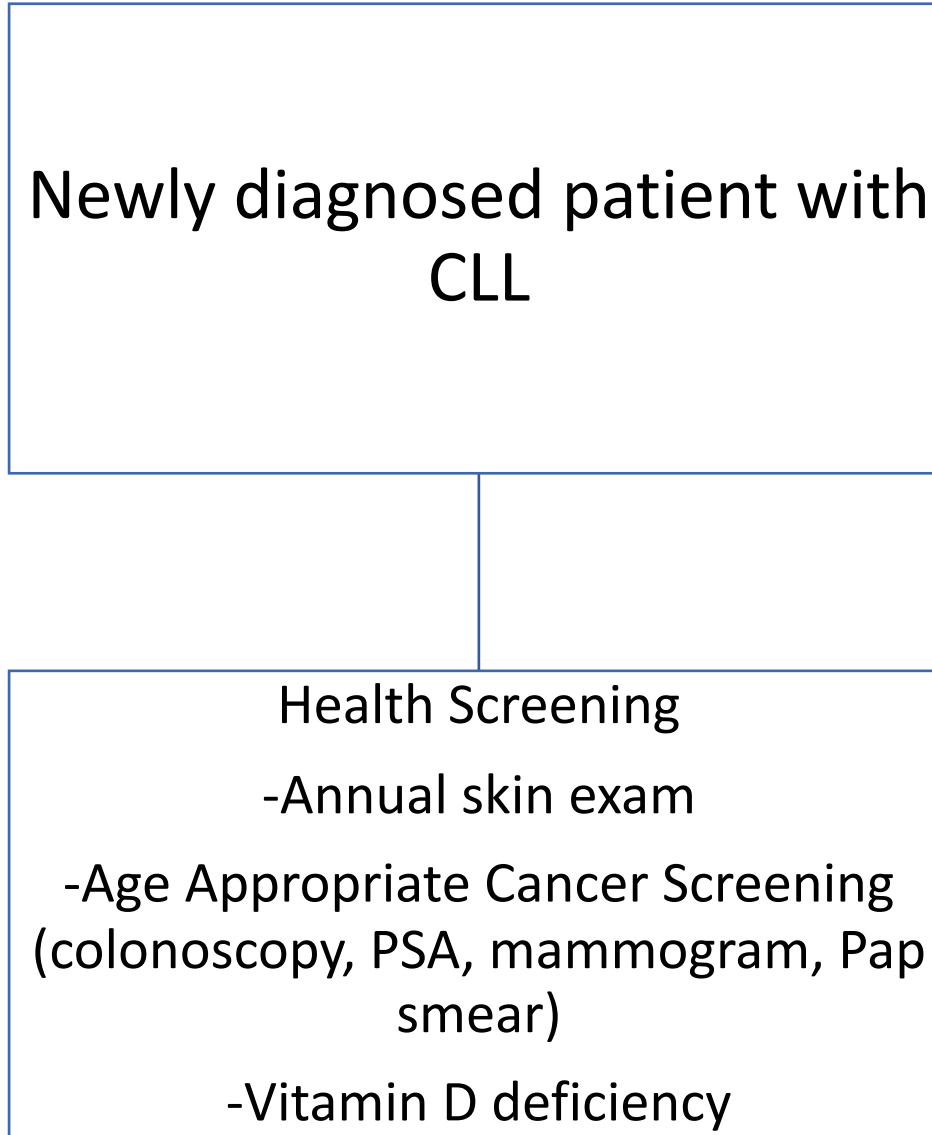
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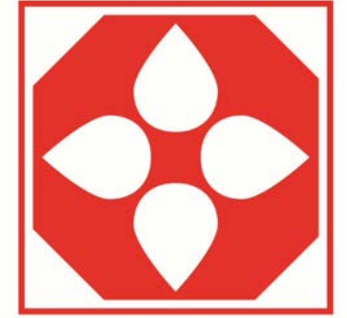
# Initial Assessment and Supportive Care



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# Initial Assessment and Supportive Care



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Newly diagnosed patient with CLL

Infection Prevention/Vaccination

-Influenza

-PCV13/PCV23/PCV20

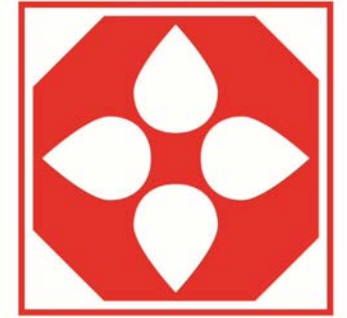
-Tdap

-Shingrx

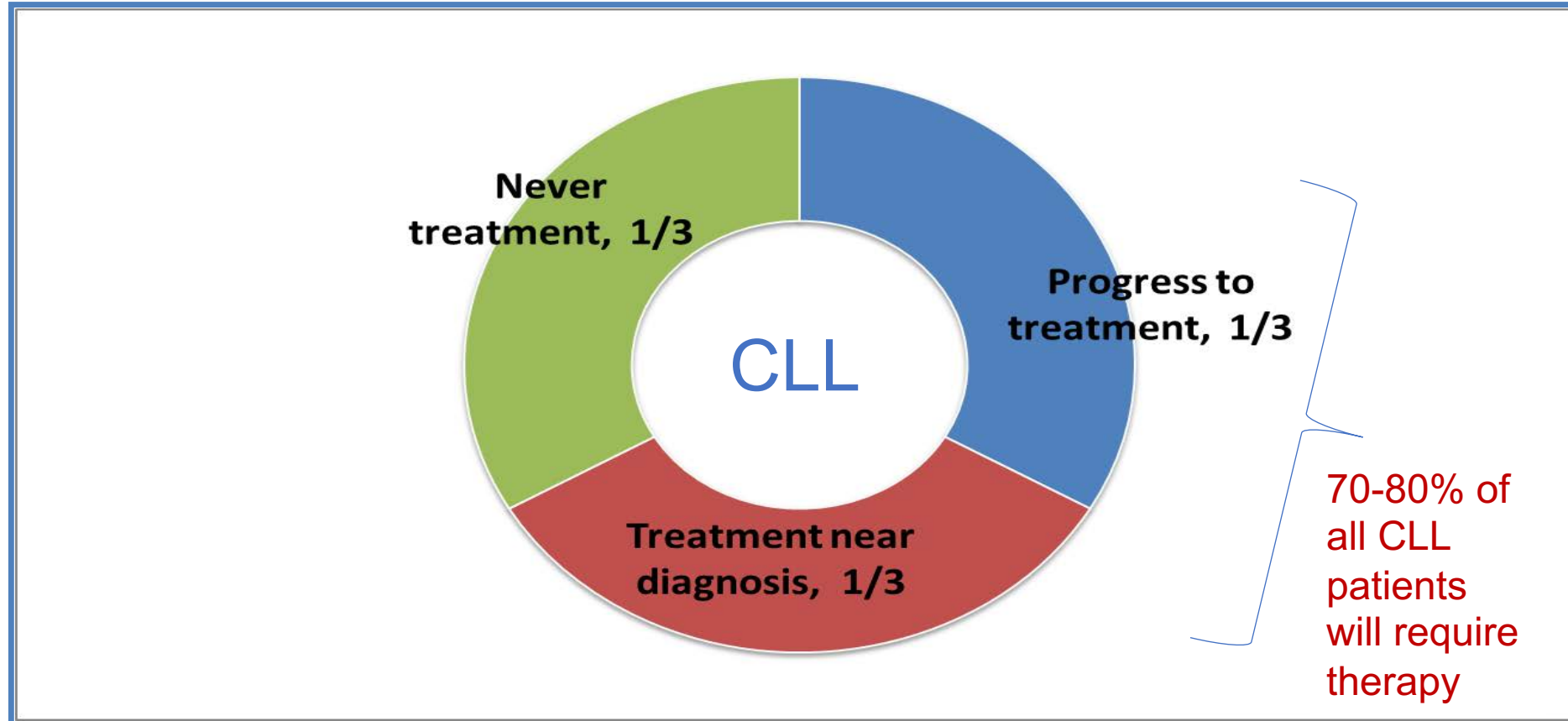
-COVID19 Vaccine series with booster

-IVIG (if IgG level <600 and recurrent infections)

# CLL: Dynamic Monitoring vs Therapy

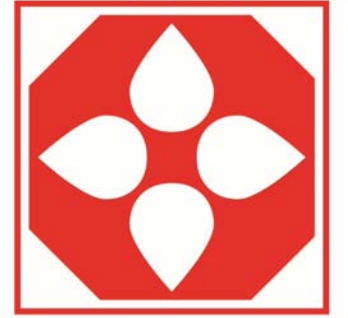


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- No data to support treatment at diagnosis for asymptomatic patients

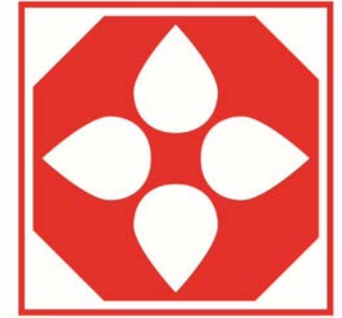
# What Does “Active Surveillance” Look Like?



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- Reporting new symptoms to your doctor
- Medical Examinations to monitor lymph nodes and spleen size
- Periodic blood counts to monitor:
  - Lymphocyte count
  - Anemia (hemoglobin)
  - Thrombocytopenia (platelets)

# CLL/SLL: Indications For Treatment



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No magic  
WBC threshold  
in the iwCLL  
indications!!

## Disease Symptoms

- Fatigue
- Night Sweats
- Weight Loss
- + Affecting quality of life

## Low Blood Counts

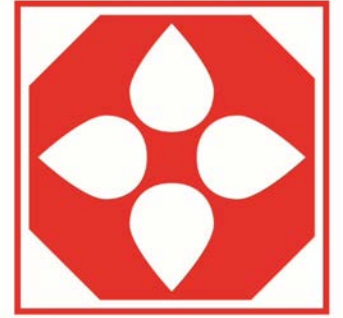
- Platelets <100
- Hgb <11
- Ref autoimmune complications

## Bulky Disease

- Enlarged Lymph Nodes
  - symptomatic
  - >9-10cm
- Enlarged Spleen
  - symptomatic
  - 6cm+ on exam
- Rapid WBC increase\*
  - Doubling (over 30K) <6mo



# What Do I Do About Anxiety During Active Surveillance?



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SUPPORT GROUPS

VACCINATIONS AND ROUTINE HEALTHCARE  
MAINTENANCE

PATIENT EDUCATION

For more information on anxiety: CLL Society Webinar - A Psychological Perspective: Dealing with the CLL Emotional Roller Coaster found on [Education On-Demand](#)

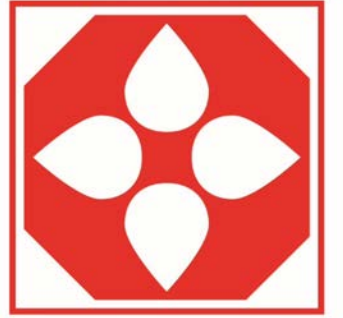
# What are the Benefits of Active Surveillance?

MAINTAINING QUALITY OF LIFE

AVOIDING TREATMENT SIDE EFFECTS AND  
COMPLICATIONS

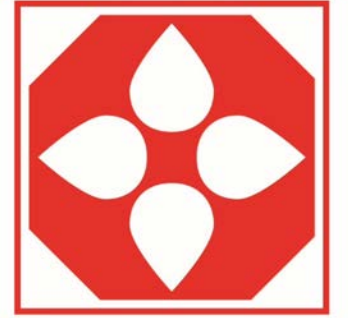
“BETTING ON THE FUTURE”

BUILDING A CARE TEAM



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# What Else Should I Be Doing For My Health?



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ROUTINE HEALTH CARE MAINTENANCE

ELIMINATE TOBACCO

MAINTAIN A HEALTHY DIET

INCORPORATE PHYSICAL ACTIVITY INTO ROUTINE

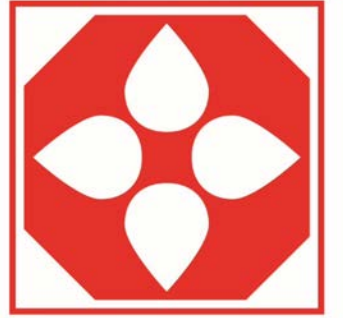
MANAGE STRESS

PRIORITIZE SLEEP

For more information: CLL Society webinar - Health and Wellness: Beyond the Medicine Cabinet from CLL Society found on [Education On-Demand](#)

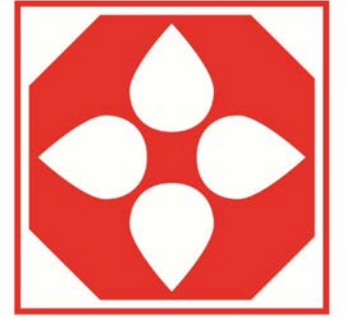
# What Should I Expect When I Need Treatment?

- Repeat testing
  - FISH/Karyotype
  - Next Generation Sequencing
- Clinical Trial vs. Standard of Care
  - Risks/benefits of treatment options
  - Time-limited therapies vs. “treat to progression”



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# Summary

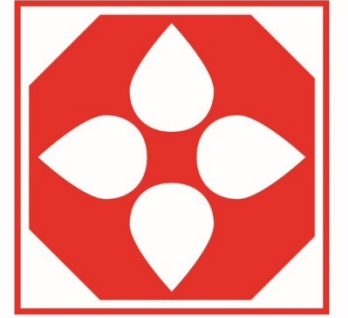


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Because CLL/SLL is often slow moving and treatment is not needed for most at time of diagnosis, it gives time to:

- Gain the knowledge
- Gather the resources
- Plan your journey
- Build your team for a healthy long life

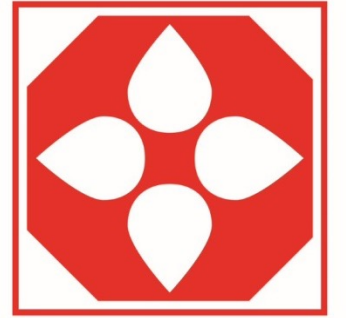
**Smart Patients Get Smart Care**



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# Audience Questions & Answers

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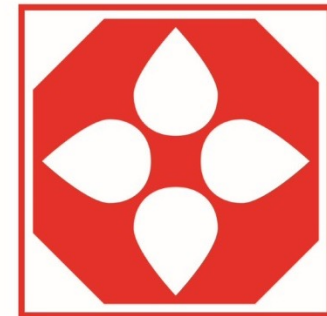


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# Thank You for Attending!

Please take a moment to complete our **post-event survey**, your feedback is important to us



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If your question was not answered, please feel free to email [asktheexpert@cllsociety.org](mailto:asktheexpert@cllsociety.org)

Join us on May 22<sup>nd</sup> for our next webinar on understanding how biomarkers help guide treatment decisions

CLL Society is invested in your long life. Please invest in the long life of the CLL Society by supporting our work

**[cllsociety.org/donate-to-cll-society/](https://cllsociety.org/donate-to-cll-society/)**