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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BeiGene
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
Poll Question
CLL/SLL Patient Education Toolkit

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://cllsociety.org/toolkit
Keeping Track of Lab Results

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/
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://cllsociety.org/tb4t
Putting Together a CLL Team

My CLL Team

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

CLLS Expert Access™ Program

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

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://cllsociety.org/support-groups/
Stay Informed

CLL Society This Week

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!

https://cllsociety.org/whats-new-in-cll/
Takeaways

• 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
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

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

Median Age At Diagnosis

70

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%

- 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

BLOOD AND BONE MARROW

LYMPH NODE AND SPLEEN

WORLD HEALTH ORGANIZATION = CLL/SLL

Slide from of J. Barrientos
**CLL: Diagnosis**

- **Plus clinical**

  **CLL**
  - At least $5 \times 10^9$ monoclonal B cells/L
  - May or may not be symptomatic

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**MBL (Monoclonal B lymphocytosis)**

- Monoclonal B-cell lymphocytosis
- $< 5 \times 10^9$ B cells/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

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**SLL**

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

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Source:


Slide from A. Mato
Diagnosis of Chronic Lymphocytic Leukemia

- Median age at diagnosis: 71 years
- Male to female ratio: 2 to 1
- Diagnosis made by flow cytometry: Immunophenotype (CD5+ CD10- CD23+)
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
Tests That Will Be Performed (Blood, Lymph Node, and/or Bone Marrow)

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

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

Chromosome 17

Slide from J. Barrientos
Old Overall Survival Data by FISH When Chemotherapy Was the Only Treatment

Dohner, et al. NEJM 2000;343:1910
Immunoglobulin $V_H$ Gene Mutation: 1999 Data

- **Med OS**: >24 yrs
- **Med OS**: 9 yrs

![Graph showing survival rates for unmutated and mutated cases with median survival times highlighted.](image)

*Damia et al., Blood 94: 1846, 1999*
What are Symptoms of CLL?

- Fatigue
- Shortness of breath
- Swollen lymph nodes or spleen
- Infections
- Weight loss
- Night sweats

Many patients have no symptoms at all!
Am I Immunocompromised?

• 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

Newly diagnosed patient with CLL

- Risk Stratification and counseling
- Health Screening
- Infection Prevention/Vaccination

Adapted from Paolo Strati, and Tait D. Shanafelt Blood 2015;126:454-462
Initial Assessment and Supportive Care

Risk Stratification and Counseling

Patient Related Factors
- Age
- Sex
- Race
- Comorbidities

Adapted from Paolo Strati, and Tait D. Shanafelt Blood 2015;126:454-462
Initial Assessment and Supportive Care

Newly diagnosed patient with CLL

- Health Screening
  - Annual skin exam
  - Age Appropriate Cancer Screening (colonoscopy, PSA, mammogram, Pap smear)
  - Vitamin D deficiency

Adapted from Paolo Strati, and Tait D. Shanafelt Blood 2015;126:454-462
Initial Assessment and Supportive Care

Newly diagnosed patient with CLL

Infection Prevention/Vaccination
- Influenza
- PCV13/PCV23/PCV20
  - Tdap
  - Shingrix
- COVID19 Vaccine series with booster
  - IVIG (if IgG level <600 and recurrent infections)

Adapted from Paolo Strati, and Tait D. Shanafelt Blood 2015;126:454-462
No data to support treatment at diagnosis for asymptomatic patients.
What Does “Active Surveillance” Look Like?

• 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

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

No magic WBC threshold in the iwCLL indications!!
What Do I Do About Anxiety During Active Surveillance?

- 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
What Else Should I Be Doing For My Health?

- 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”
Summary

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
Audience Questions & Answers
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Thank You for Attending!

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

If you’re question was not answered, please feel free to email asktheexpert@cllsociety.org

Join us on May 22nd 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/