



CLL SOCIETY

Smart Patients Get Smart Care™

**SHARED DECISION-
MAKING IN CLL:
PARTNERING WITH
YOUR DOCTOR TO
CHOOSE THE RIGHT
PATH**

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**THIS PROGRAM IS MADE POSSIBLE
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SPEAKERS



John Burke
MD
(SPEAKER)

Hematologist/Medical Oncologist
Rocky Mountain Cancer Centers
Aurora, CO



Christina Fisher
(SPEAKER)

CLL Patient Advocate



Stephen Feldman
(MODERATOR)

CLL Patient Advocate





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SHARED DECISION-MAKING IN CLL: PARTNERING WITH YOUR DOCTOR TO CHOOSE THE RIGHT PATH

JOHN M. BURKE, MD

Rocky Mountain Cancer Centers,
Aurora, CO

TAKE-HOME MESSAGES

- 1. Patients with CLL essentially always have choices about which treatment they wish to receive.**
- 2. “Shared decision-making” means that providers and patients work together to create a treatment plan.**
 1. The provider’s job is to educate the patient.
 2. In the era of the internet and now artificial intelligence, patients have the power to educate themselves effectively. Such education can supplement that provided by physicians.

MY PHILOSOPHY OF MEDICAL CARE

“I believe that the role of physicians is to educate patients and to help them make the best decisions possible regarding their own care. The idea that ‘physicians know best’ and should dictate treatment to patients is archaic. Instead, physicians serve as teachers by educating patients about their diseases and their treatment options and helping patients select the best treatment for their situation.”

[John M. Burke, MD | Hematologist in Aurora, Centennial, Englewood, and Littleton, CO](#)

INDICATIONS TO START THERAPY IN CLL

iwCLL Guidelines

Indication to start therapy	Comments
Hemoglobin less than 10 g/dL	
Platelets less than $100 \times 10^9/L$	
Massive or symptomatic lymphadenopathy	Size at least 10 cm, OR Size rapidly increasing, OR Physical discomfort or obstructing vital organs
Massive or symptomatic splenomegaly	Size at least 6 cm below the ribs, OR Causing pain or early satiety
Progressive lymphocytosis	Increase of at least 50% over 2 months, OR Doubling time less than 6 months
Constitutional symptoms	Weight loss > 10% within 6 months, OR Significant fatigue, OR Fever, OR Night sweats
Autoimmune complications	

OPTIONS FOR INITIAL THERAPY (FIRST-LINE) OF CLL

Drugs Involved	Duration	Comments
BCL2 inhibitor (venetoclax) + anti-CD20 antibody (obinutuzumab)	1-year, “fixed duration”	<ol style="list-style-type: none"> 1. Similar 3-year progression-free survival as continuous BTKi 2. Avoids cardiac risks of BTKi 3. Allows time off therapy 4. Can retreat at relapse
Covalent BTK inhibitor (ibrutinib, acalabrutinib, zanubrutinib) +/- anti-CD20 monoclonal antibody (obinutuzumab)	Indefinite therapy, continuous until progression or intolerance	<ol style="list-style-type: none"> 1. Long duration of follow-up in studies 2. Generally well tolerated 3. No dose ramp-up required
BCL2 inhibitor (venetoclax) + covalent BTK inhibitor +/- anti-CD20 antibody	15-month “fixed duration” OR 2-6 years MRD-driven duration	<ol style="list-style-type: none"> 1. Lower rate of uMRD at 1 year than ven-obin 2. MRD-driven achieves best outcomes reported to date

OPTIONS FOR SECOND-LINE THERAPY OF CLL

Scenario/First-Line Treatment	Options
Intolerant to covalent BTKi	<ol style="list-style-type: none">1. Alternate cBTKi2. Non-covalent BTKi (pirtobrutinib)3. Venetoclax + anti-CD20 antibody
Progression on covalent BTKi	<ol style="list-style-type: none">1. Non-covalent BTKi (pirtobrutinib)2. Venetoclax + anti-CD20 antibody
Relapse after venetoclax completion	<ol style="list-style-type: none">1. Retreat with venetoclax +/- anti-CD20 Ab2. Covalent BTKi
Relapse after cBTKi + Ven combo	<ol style="list-style-type: none">1. Retreat with same2. Covalent BTKi3. Venetoclax + anti-CD20 Ab

OPTIONS FOR THIRD-LINE (AND BEYOND) THERAPY OF CLL

- **Non-covalent BTKi (pirtobrutinib)**
- **Lisocabtagene maraleucel (CD19-targeting CAR T-cell therapy)**
- **Allogeneic hematopoietic cell transplant**
- **Less commonly used**
 - PI3K inhibitors (duvelisib, idelalisib + rituximab)
 - Chemotherapy
 - Fludarabine + cyclophosphamide + anti-CD20 antibody
 - Bendamustine + anti-CD20 antibody
 - Lenalidomide
 - Alemtuzumab

COMMENT ON CLINICAL TRIALS

- **Clinical trials are options for therapy. They test new ways of treating CLL.**
- **They exist for all lines of therapy, from initial treatment to multiple prior treatments.**
- **Occasionally, clinical trials will employ placebos. When they do, patients usually get placebo in addition to a standard treatment.**
- **All trials are reviewed by independent panels to make sure the trials are ethical.**
- **Ethically, clinical trial participation should be considered an option but not a requirement.**
- **Trials are how we advance the field in CLL and in human disease in general. Without clinical trials, we cannot demonstrate improvements in outcomes with new therapies.**
- **We have all benefited from those before us who have participated in clinical trials.**
- **When I get [insert disease here], I will likely be signing up for a clinical trial. 😊 I say this because 1) I am confident that clinical trials tend to offer good treatments to patients and 2) I want to contribute to science for the benefit of those who come after me.**



QUESTIONS FOR DISCUSSION WITH YOUR DOCTOR

Question	Comments
Potential adverse effects of drugs	BTKi: atrial fibrillation, bleeding, headaches, hypertension, rash Venetoclax: low counts, immune suppression Anti-CD20: infusion reactions, immune suppression
Underlying medical problems	Consider whether these put you at higher risk for specific adverse effects
Current medications	Many have drug interactions with BTKi and venetoclax. May need adjustment.
Travel requirements	Venetoclax-obinutuzumab requires more time in clinic, more frequent lab draws
Fixed duration vs. continuous	Big difference after 1 year
Cost	Don't forget fixed duration vs. continuous
Del (17p) or TP53 aberrancy	BTKi have longer progression-free survival...but does that translate to longer overall survival?

GETTING A SECOND OPINION

Advantages

1. Additional education and information about standard treatment options
2. Additional education and information about clinical trial options
3. There is value in reinforcing information you've already learned, even if you don't learn anything new
4. The opinion you'll get is likely from someone who specializes in, and is therefore highly knowledgeable about, CLL

Disadvantages

1. It takes extra time and effort
2. Sometimes it requires travel, which can cost money
3. After all that effort, you may not learn anything new
4. The clinical trials offered may require that you live in that location, which often is unrealistic if you've traveled a long distance

EDUCATING YOURSELF – VALUABLE WEBSITES (NOT AN EXHAUSTIVE LIST)

Resource	Website	Comments
CLL Society	On Demand CLL / SLL Educational Activities - CLL Society	Large number of resources specific to CLL
Blood Cancer United (formerly Leukemia and Lymphoma Society)	Chronic lymphocytic leukemia (CLL) Blood Cancer United	Longstanding, reputable organization; lots of resources
American Cancer Society (ACS) and American Society of Clinical Oncology (ASCO)	Chronic Lymphocytic Leukemia (CLL) Resources American Cancer Society	Broken into several sections

USING ARTIFICIAL INTELLIGENCE TO EDUCATE YOURSELF (AGAIN, NOT AN EXHAUSTIVE LIST!)

Name	Website	Comments
Google Gemini	Google Gemini	Pulls from Google's search index
Chat GPT	ChatGPT	Pulls from the live web
Microsoft Copilot	Chat M365 Copilot	
Perplexity AI	Perplexity	Lists numbered citations for each claim
Open Evidence	OpenEvidence	Free for physicians, answers contain images, partners with New England Journal
Consensus	Consensus: AI for Research	Searches only published literature
Claude	Use AI	

ADVANTAGES AND DISADVANTAGES OF USING AI

Advantages

1. Quickly provides reliable information about diseases, without your having to know which websites are reliable and which are not
2. Can be used to prepare you for efficient and effective meetings with your doctor. For example, ask it, “I have a new diagnosis of CLL. What questions should I ask my doctor about CLL at our first visit?”
3. Provides a direct, conversational summary of whatever you ask it

Disadvantages

1. Can give false information. Double check what it gives you. AND, not all AI sites may be created the same. “Gemini is AI and can make mistakes.” “This is for informational purposes only. For medical advice or diagnosis, consult a professional.”
2. Cannot help in a medical emergency!
3. Not governed by medical privacy laws. Do not enter your name or personal information. White out such information on any uploaded reports, or type in the report content without uploading documents
4. “Sycophancy” refers to its tendency to tell you what it thinks you want to hear. Beware of your own biases influencing the information it gives you. How you phrase your question may impact the response you receive.



SUGGESTIONS FOR AI USE

- Use it to get information about your disease.
- Use it to prepare for appointments with your provider – e.g. “what questions should I ask?”
- Use it as a supplement to, but not as a replacement for, information from your provider. “Gemini is AI and can make mistakes.” “This is for informational purposes only. For medical advice or diagnosis, consult a professional.”
- Double check what it tells you.
- Do not give it your personal information.
- Beware of “sycophancy.” That is, beware of your own biases influencing the information it gives you.
- Be open and honest with your provider about your usage of it.

TAKE-HOME MESSAGES

- 1. Patients with CLL essentially always have choices about which treatment they wish to receive.**
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SHARED DECISION- MAKING

Christina Fisher
CLL Patient Advocate

TREATMENT JOURNEY

- 3 + years of active surveillance
- Umbralisib – did not become FDA approved for CLL
- Combined with Obinutuzumab
- Venetoclax + Rituximab
- 4+ years undetectable measurable residual disease (uMRD)



PREPARATION

- Find a CLL specialist who communicates well with you
- Get organized with information, notes, and questions
- Connect with other people who have CLL
- Use the watch and wait period to learn and prepare



CLL SOCIETY EXPERT ACCESS™ PROGRAM



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



CLL SOCIETY

**FREE 2nd opinion
with a CLL EXPERT**

APPLY NOW

<https://cllsociety.org/eap>



CLL SOCIETY

PATIENT & CARE PARTNER SUPPORT GROUPS

- Over 40 different support groups with meetings held virtually
- Groups are geographically based and topic-specific, such as Watch & Wait, Veterans with CLL, Physicians with CLL, Young People with CLL, and CLL Patients without Care Partners
- CLL-specific support groups are a place of camaraderie and knowledge sharing among members



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



**PATIENT &
CARE PARTNER
SUPPORT
GROUPS**

1-ON-1 SUPPORT PROGRAMS

EMOTIONAL & SPIRITUAL ADVOCATE PROGRAM

- 1-on-1 support from a board-certified chaplain for people of all faiths or no faith background.
- Help with exploring coping mechanisms, spiritual/theological reflection, meaning making, goals of care conversations, grief/bereavement support, and more.

PEER SUPPORT AND THE AMBASSADOR PROGRAM

- 1-on-1 support from an individual impacted by CLL.
- A volunteer can share their own experiences to help you navigate the watch and wait period, insurance, newly diagnosed questions, making treatment decisions, managing side effects, and more.



<https://cllsociety.org/programs-and-support/cll-society-1-on-1-support-programs/>

CLL/SLL ONLINE PATIENT EDUCATION TOOLKIT

- Contains a wide variety of information including the biology of chronic lymphocytic leukemia and small lymphocytic lymphoma (CLL/SLL)
- Available treatment options, and other important CLL/SLL topics presented in a patient-friendly way



cllsociety.org/cll-sll-patient-education-toolkit

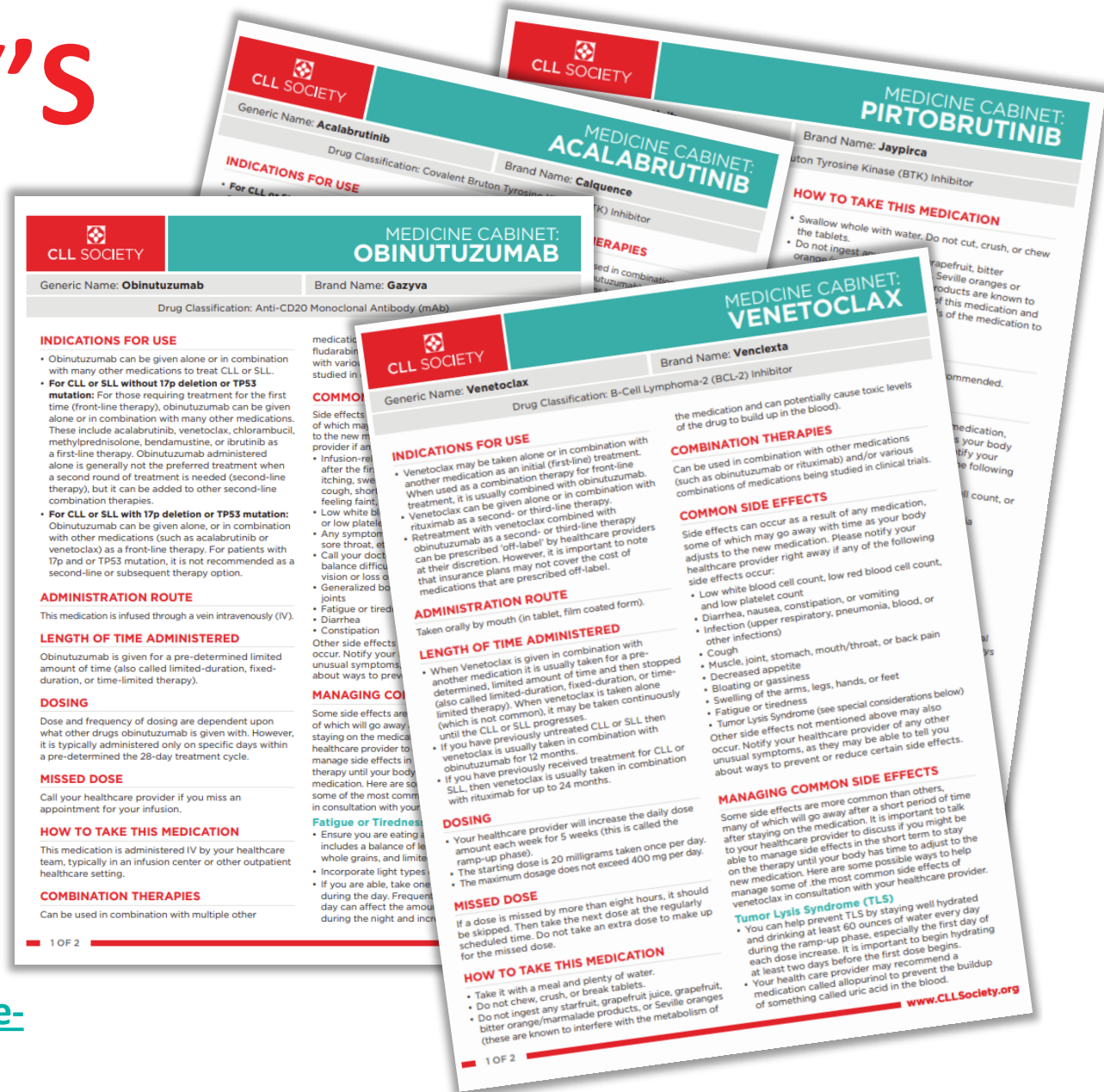


CLL SOCIETY'S MEDICINE CABINET

- Includes nine of the most common CLL medications
- Non-branded, patient-friendly handouts that can be printed on demand



<https://www.cllsociety.org/ll-medicine-cabinet/>




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

 Keeping Track of Lab Results

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



CLL SOCIETY'S TEST BEFORE TREAT CAMPAIGN

Provides guidance on biomarker testing recommendations and their implications for prognosis and treatment decisions



TEST BEFORE TREAT

Critical testing should be performed as follows:

- FISH, TP53, and IgVH at diagnosis or before the first treatment is started
- FISH and TP53 should be tested again each and every time a new treatment is started

CHEMOIMMUNOTHERAPY SHOULD NOT BE CONSIDERED

for those who are:

- Deletion 17p
- TP53 mutated
- IgVH unmutated



<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

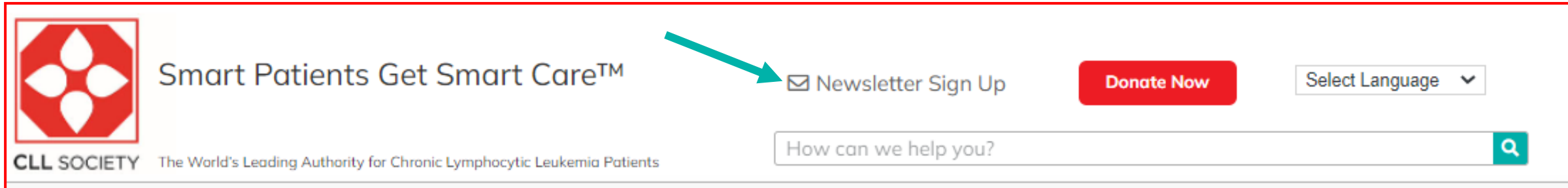


<https://cillsociety.org/cll-sll-patient-education-toolkit/putting-together-a-cll-team/>



STAY INFORMED

CLL Society *This Week*



The screenshot shows the top navigation bar of the CLL Society website. On the left is the CLL Society logo, a red square with a white stylized flower-like shape. To its right is the tagline "Smart Patients Get Smart Care™" and the text "CLL SOCIETY The World's Leading Authority for Chronic Lymphocytic Leukemia Patients". A teal arrow points from the tagline area to a "Newsletter Sign Up" button, which features an envelope icon. To the right of this button is a red "Donate Now" button and a "Select Language" dropdown menu. Below these elements is a search bar with the placeholder text "How can we help you?" and a magnifying glass icon on the right.

Stay informed about the latest CLL / SLL research, upcoming events, on-demand education, free programs, resources, and more



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



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**

AUDIENCE Q&A



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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 your question was not answered,
please feel free to email: trustedcare@cllsociety.org

Join us for our next virtual event,
ASK ME ANYTHING – FEATURING DR. JOANNA M. RHODES AND JEFF FOLLODER
JULY 15

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/