



CLL SOCIETY

Smart Patients Get Smart Care™

FROM SERVICE TO SUPPORT: MANAGING CLL/SLL IN THE VETERAN COMMUNITY

August 28, 2025

11 AM PT, 12 PM MT

1 PM CT, 2 PM ET

**THIS PROGRAM IS MADE POSSIBLE
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SPEAKERS



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CLL SOCIETY

POLL QUESTIONS





CLL SOCIETY

Smart Patients Get Smart Care™

CLL SOCIETY RESOURCES FOR VETERANS

Dr. Edward Ratner
CLL Patient Advocate and
Support Group Facilitator

RESOURCES FOR VETERANS

EXPLORE OUR RESOURCES FOR VETERANS WITH CLL

Find information specific
to navigating care within
the VA and connect with
other Veterans



- Some US military veterans have an increased risk of developing CLL/SLL due to environmental exposures that occurred during service
- CLL Society has developed a dedicated veteran-specific webpage with many helpful resources



<https://cllsociety.org/living-with-cll-home/veterans-with-cll-sll/>

PATIENT & CARE PARTNER SUPPORT GROUPS

- Over 40 different support groups held virtually, geographically based and topic-specific, such as Watch & Wait, **Veterans with CLL/SLL**, Physicians with CLL/SLL, and CLL Patients without Care Partners
 - *The Veterans with CLL/SLL Support Group meets virtually on the 3rd Saturday of the month at 8 AM PT, 10 AM CT, and 11 AM ET*
- CLL-specific support groups are a place of camaraderie and knowledge sharing among members

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



**PATIENT &
CARE PARTNER
SUPPORT
GROUPS**



CLL SOCIETY

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



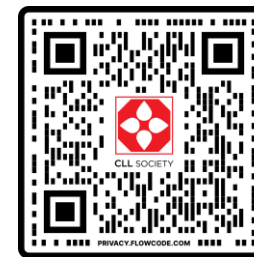
PEER SUPPORT PROGRAM

- 1-on-1 support from an individual impacted by CLL
- A Peer Support 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



AMBASSADOR PROGRAM

- 1-on-1 support from an individual impacted by CLL
- An Ambassador Volunteer can share their own experiences to help you navigate treatment questions around BCL-2 and BTK inhibitors, as well as CAR-T Therapy, and more



Get connected with a fellow Veteran with CLL by contacting:
support@cllsociety.org

CLL SOCIETY'S FREE 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/ctl-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/>



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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



CLL SOCIETY EXPERT ACCESS™ PROGRAM



**EXPERT
ACCESS™**


CLL SOCIETY

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

APPLY NOW

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

<https://cllsociety.org/eap>



ASK THE EXPERTS – EMAIL SUPPORT



- Receive email responses to your questions about CLL / SLL confidentially from an expert CLL physician, registered nurse, lab scientist, or hospice/palliative care physician
- Intended for educational purposes only and does not undertake an extensive review of medical charts or lab results



<https://cllsociety.org/resources/ask-the-experts/>



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MENTAL & PHYSICAL HEALTH RESOURCES

- Diet and Exercise
- Emotional and Spiritual
- Mindfulness and Stress Reduction
- CLL and Psychological Impact
- Combatting Isolation
- Care Partner Support



<https://cllsociety.org/living-with-cll-home/mental-and-physical-health/>



STAY INFORMED

CLL Society *This Week*



CLL SOCIETY



Type to start searching..

NEWSLETTER >>

DONATE NOW >>



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



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



CLL SOCIETY

TAKEAWAYS

- Utilize tools for education and self-advocacy
- Join our Veterans with CLL/SLL Support Group
- Stay informed by signing up for CLL Society's *This Week* email



CLL SOCIETY

Smart Patients Get Smart Care™

FROM SERVICE TO SUPPORT: MANAGING CLL/SLL IN THE VETERAN COMMUNITY

Daphne Friedman, MD
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VA Health Care System
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Professor, Duke University

DISCLOSURES

- I have no financial conflicts of interest related to the content of this presentation
- Unlabeled use of treatment is described within the context of a VA-funded research study
- Information is presented within my capacity as an VA Staff Oncologist and Deputy Director of the VA National Oncology Program

LEARNING OBJECTIVES

- 1. Understand how CLL affects Veterans**
- 2. Learn about resources in the VA and treatment considerations for Veterans with CLL**
- 3. Learn how CLL affects mental health and how to manage**

CLL/SLL = chronic lymphocytic leukemia/small lymphocytic lymphoma

VA = Department of Veterans Affairs

FACTS ABOUT CLL

- **CLL is the most common blood cancer**
- **It more commonly affects older, white, men (compared to younger, other racial groups, and women)**
- **Since early treatment has not been shown to help CLL patients live longer, usually there is an initial “watchful waiting” period, and ⅓ of CLL patients never need therapy**

MORE FACTS ABOUT CLL

- Often, CLL is a slow growing cancer that may never affect a patient's health
- Sometimes CLL can grow more rapidly or even change (“transform”) into an aggressive lymphoma
- Prognostic tests can be done at the time of diagnosis to predict the aggressiveness of CLL to help with planning

FACTS ABOUT VETERANS WITH CLL

- **Toxic military exposures increase the risk of developing CLL**
 - Agent Orange: Younger age at diagnosis; longer survival
 - Camp Lejeune, Burn Pits
- **Risk of other cancers (“second malignancies”)**
 - Estimated in about 16% of Veterans with CLL and is a significant cause of death
 - This excludes skin cancers such as squamous and basal cell cancer

Mescher C et al, Leuk Lymphoma, 2018.

Kyasa MJ et al, Leuk Lymphoma, 2004.

CLL: A SERVICE-CONNECTED CONDITION

- A service-connected condition includes illnesses that were caused by military service
- Service connection can provide compensation, health care benefits, and spouse survivorship benefits.
- CLL is a presumptive condition for certain exposures
 - Agent Orange
 - Camp Lejeune contaminated water
 - Burn pits and other toxic exposures

CLL: A SERVICE-CONNECTED CONDITION

- **Eligibility depends on timeframe and location of military service**
- **Veteran Service Organizations (VSOs) can assist Veterans in applying to the Veterans Benefits Administration (VBA) for service-connected benefits**

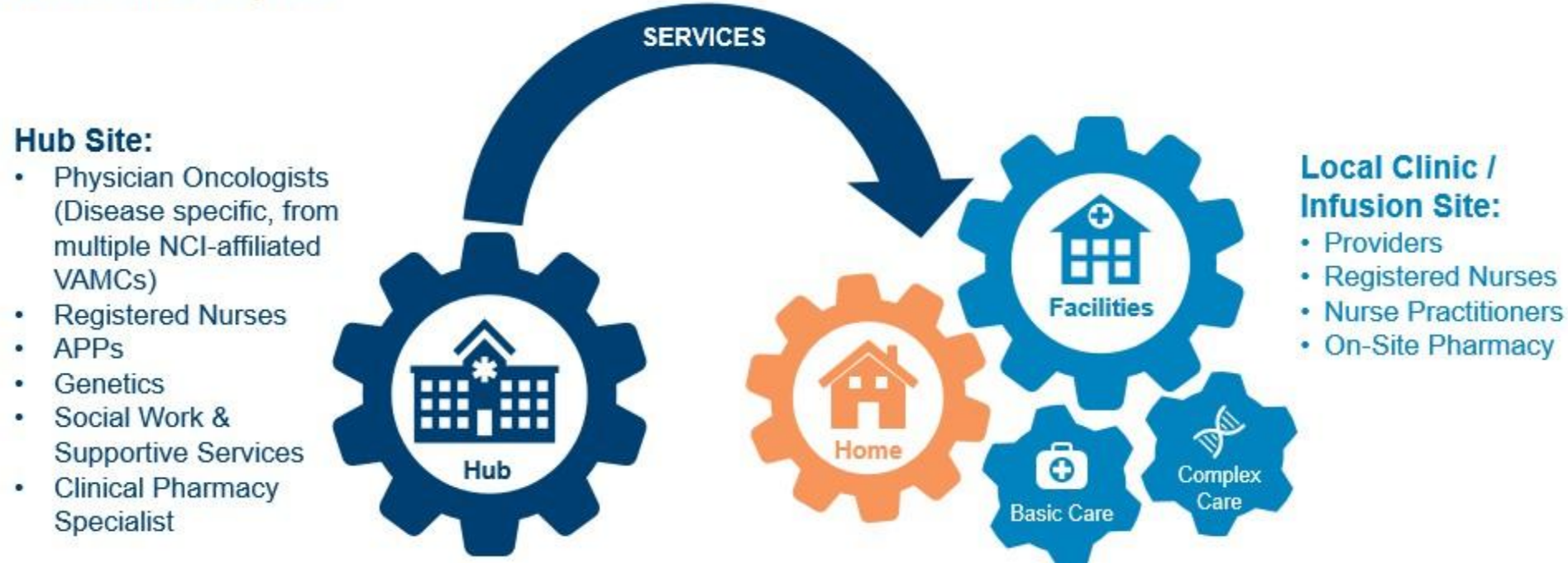
HOW DO VETERANS WITH CLL RECEIVE CARE?

- **At a VA medical center (in-person) with a VA oncologist**
- **Using telehealth with a VA oncologist at the Veteran's medical center (video or telephone)**
- **Referral to community (non-VA care)**
- **VA National TeleOncology (NTO)**

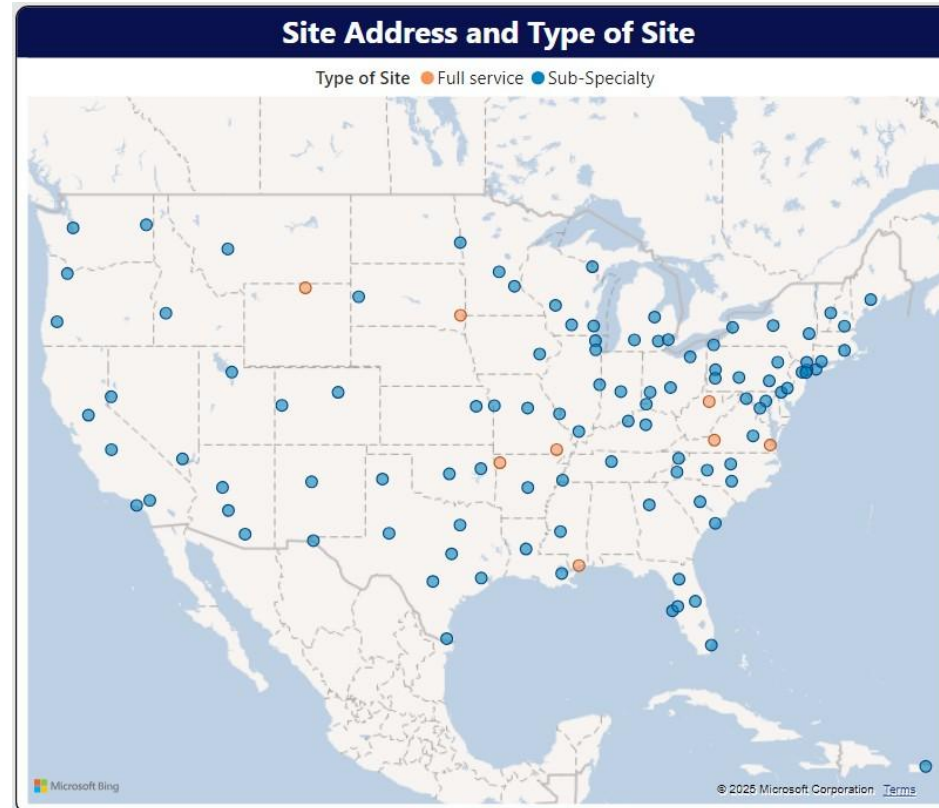
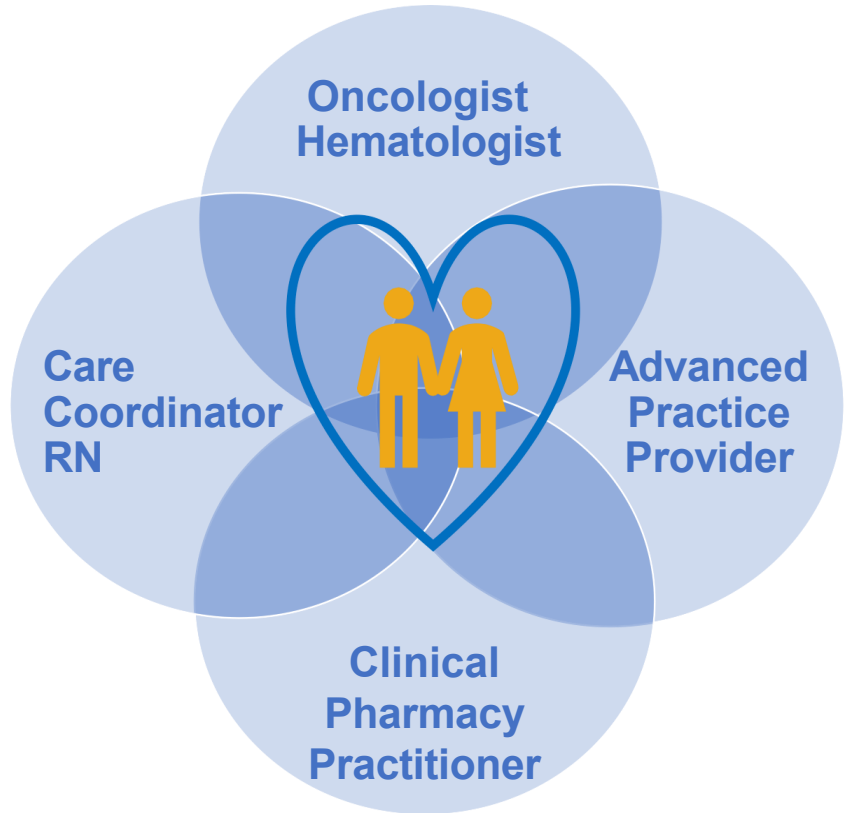
VA NATIONAL TELEONCOLOGY

Hub and Spoke TeleOncology Model

TeleOncology provides Veterans and their local VA facilities with access to the highest quality cancer care, no matter where they are.



VA NATIONAL TELEONCOLOGY



For more information: <https://www.cancer.va.gov/oncology-services-and-tools.html#nto>



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GENETIC TESTING FOR CLL IN THE VA

- **VA offers genetic testing for inherited cancer syndromes through the Comprehensive Genetics Service (CGS)**
 - CLL may run in families but there isn't one genetic cause
 - CancerGenetics@va.gov
 - Genetic/familial CLL research groups outside the VA exist, for example, Mayo Clinic, Dana Farber
- **CLL prognostic tests include testing for genetic changes and mutations in CLL cells**
 - These tests are offered as part of routine care at VA facilities
 - May be done in VA or sent out to other labs or vendors

TREATMENT FOR CLL

- **When is it needed?**
 - When CLL affects your health or how you feel
- **What is the goal of treatment?**
 - Improve health; improve how you feel; help you live longer; if possible, put CLL into remission
- **What are typical treatments?**
 - Targeted therapies: BTK and BCL2 inhibitors
 - Monoclonal antibodies
 - Traditional chemotherapy is rarely used



TREATMENT FOR CLL IN THE VA

- **All FDA approved CLL treatments can be prescribed by VA oncologists**
- **Non-FDA approved treatments (“off label”) can be prescribed if there is appropriate supporting data**
- **Similar to the private sector, CLL treatment requires prior authorization**
 - In the VA, prior authorization is done by an oncologist or oncology trained clinical pharmacist (not an external insurance company)
 - The VA has “criteria for use” that are standards for authorization
 - The VA has clinical pathways that provide the recommended treatment for Veterans with cancer, that most patients should receive



VA CRITERIA USE FOR ACALABRUTINIB

Acalabrutinib tablet (CALQUENCE)

Criteria for Use

December 2024

VA Pharmacy Benefits Management Services, Medical Advisory Panel, and VISN Pharmacist Executives

The following recommendations are based on medical evidence, clinician input, and expert opinion. The content of the document is dynamic and will be revised as new information becomes available. The purpose of this document is to assist practitioners in clinical decision-making, to standardize and improve the quality of patient care, and to promote cost-effective drug prescribing. THE CLINICIAN SHOULD USE THIS GUIDANCE AND INTERPRET IT IN THE CLINICAL CONTEXT OF THE INDIVIDUAL PATIENT. INDIVIDUAL CASES THAT ARE EXCEPTIONS TO THE EXCLUSION AND INCLUSION CRITERIA SHOULD BE ADJUDICATED AT THE LOCAL FACILITY ACCORDING TO THE POLICY AND PROCEDURES OF ITS P&T COMMITTEE AND PHARMACY SERVICES.

The Product Information should be consulted for detailed prescribing information.

See the VA National PBM-MAP-VPE Monograph on this drug at the [PBM INTERNET](#) or [PBM INTRANET](#) site for further information.

Exclusion Criteria

If the answer to ANY item below is met, then the patient should NOT receive acalabrutinib.

- ☐ Patient has not been screened for Hepatitis B Virus (HBV).
- ☐ Unmanageable drug-drug interaction identified
- ☐ History of stroke or intracranial hemorrhage in prior 6 months
- ☐ Clinically significant cardiovascular disease such as uncontrolled or symptomatic arrhythmias, congestive heart failure (NYHA Class 3 or 4), or myocardial infarction in prior 6 months
- ☐ Active or uncontrolled infection
- ☐ Severe hepatic impairment (Child-Pugh C), as drug has not been evaluated in this population
- ☐ Known pregnancy
- ☐ Lactating

Inclusion Criteria

One of the following criteria must be met:

- ☐ Mantle Cell Lymphoma (MCL) and progressive disease or intolerance to at least one prior therapy
- ☐ Chronic Lymphocytic Leukemia (CLL) or Small Lymphocytic Lymphoma (SLL)

Note: Acalabrutinib is not effective in the setting of the BTK ^{C481S} mutation that confers resistance to ibrutinib

Additional Inclusion Criteria

All of the following must be fulfilled in order to meet criteria:

- ☐ Care provided by a VA/VA Community Care hematology/oncology provider
- ☐ Goals of care and role of Palliative Care consult have been discussed and documented.
- ☐ Eastern Cooperative Oncology Group Performance Status 0-2

Additional Inclusion Criteria *Select if applicable:*

- ☐ For females who can become pregnant: Counseling on potential risks vs. benefits of treatment and the use of effective contraception during therapy and for at least one week after the last dose
- ☐ Advise females not to breastfeed during treatment and for at least 2 weeks after the last dose

Other Justification

☐

Prepared: February 2019; updated August 2020, September 2022, Dec 2024. Contact person: Berni Heron, Pharm.D., BCOP, National Clinical Pharmacy Program Manager, VA Pharmacy Benefits Management Services

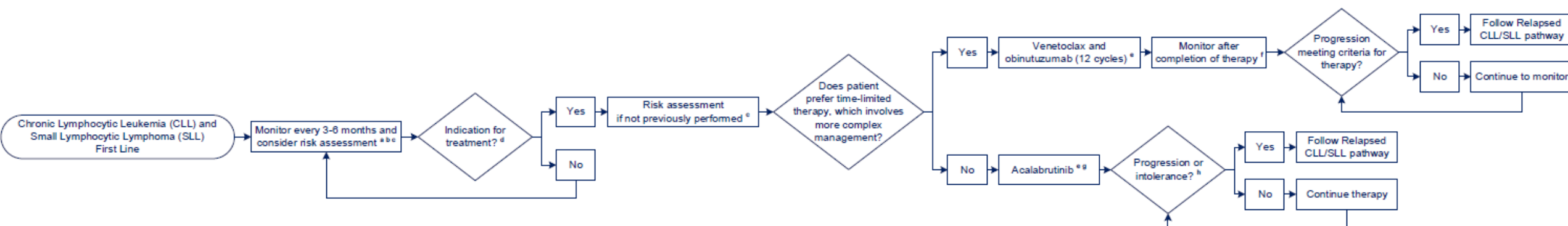


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https://www.va.gov/formularyadvisor/DOC_PDF/CFU_Acalabrutinib_CALQUENCE_Criteria_Rev_Dec_2024a.pdf

CLL CLINICAL PATHWAY

CLL and SLL – First Line



Clinical trial(s) always considered on pathway. For assistance finding a clinical trial, email CancerClinicalTrialsNavigation@va.gov

^a **General Supportive Care for CLL/SLL** includes IVIG for hypogammaglobulinemia and frequent infections, vaccinations (e.g. COVID, influenza, pneumococcus, and varicella-zoster virus); do not administer live attenuated vaccines; screen for secondary malignancies, particularly non-melanoma skin cancers

^b **Monitor** consider hepatitis B and C and HIV testing at baseline; monitoring frequency dependent on current symptoms, patient preference, absolute lymphocyte doubling time

^c **Risk Assessment** using CLL/SLL IPI score which includes CLL/SLL FISH panel, TP53 mutation status, serum beta-2-microglobulin, IGHV mutation status, Rai or Binet staging, and age; also consider checking FISH t(11;14) to rule out mantle cell lymphoma, and CpG-stimulated karyotype; CLL FISH panel should include probes for: 13q, 17p, 11q, and 12

^d **Indications for Treatment** include anemia (Hgb <10 g/dL) hemoglobin < 10 g/dL, platelets < 100,000/mm³, thrombocytopenia/anemia must be non-immune and not related to alternate causes, B-symptoms, and symptomatic adenopathy; consider cross-sectional imaging prior to initiation of therapy

^e **Supportive Care and Pre-Treatment Evaluation During Therapy** Includes: 1) Hepatitis B serologies if not already checked, particularly with anti-CD20 antibodies (rituximab, obinutuzumab, ofatumumab), 2) TLS risk stratification prior to Venetoclax initiation, with prevention strategies as recommended by manufacturer, 3) provide COVID prophylaxis dependent on availability, and 4) consider HSV/VZV prophylaxis

^f **Monitor** after completion of therapy for indication for therapy (footnote d); undetectable MRD by flow cytometry or targeted sequencing assay following venetoclax + obinutuzumab is associated with favorable prognosis

^g **BTK Inhibitor** avoid BTKi in severe hepatic impairment

^h **Progression** BTK or PLC-gamma-2 mutation testing can identify causes for progression on BTKi therapy but is not recommended

BTKi Bruton Tyrosine Kinase Inhibitor



CLL SOCIETY

<https://www.cancer.va.gov/clinical-pathways.html>

CLINICAL TRIALS

- **Clinical trials (CTs) are performed to learn more as part of research. They are voluntary.**
- **CTs can involve treatment (but not always)**
- **There are different phases of treatment CTs**
 - Phase I: testing different doses of a new treatment
 - Single arm Phase II: everyone is treated with a new treatment or regimen to learn about effectiveness and side effects
 - Randomized Phase II or Phase III: patients are assigned to different treatments to compare how well they work and side effects



CLINICAL TRIALS FOR VETERANS WITH CLL

- **VA facilities offer clinical trials**
- **VA can refer Veterans to non-VA facilities to receive care that is not available at a VA, including clinical trials**
- **VA offers a clinical trial nurse navigation service**

CLINICAL TRIALS FOR VETERANS WITH CLL

Benefit of Venetoclax Addition ("Benefit VA") in Chronic Lymphocytic Leukemia/Small Lymphocytic Lymphoma (CLL/SLL)

- Can adding CLL treatment improve response and patient experience over the long term?
- Veterans with CLL already on BTKi therapy
- 50 Veterans will continue BTKi therapy
- 50 Veterans will add venetoclax to BTKi for one year and then stop both
- Locations: Kansas City, Durham, Seattle, San Francisco, any VA affiliated with National TeleOncology (122 VA facilities)

VA CLINICAL TRIAL NAVIGATION

VA Clinical Trials Navigation

What is a Cancer Clinical Trial?

Cancer clinical trials are research and rely on people volunteering to take part in them. Clinical trials help doctors learn about ways to find, prevent, and treat cancer. They also help doctors learn the best ways to improve the quality of life of people who have or had cancer.

You might not know much about clinical trials and have questions or want to learn more about them. You may know about clinical trials but want to find out if there is a specific clinical trial that is right for you. Maybe you have questions about how being part of a clinical trial would affect your VA care, benefits, and the time it would take to participate.

How we can help



Answer questions about clinical trials as a treatment option.

Address any concerns about participation, cost, safety, time commitment, and travel.



Connect you with trials that make sense for you.

Help in finding clinical trials that are open for enrollment and fit for your needs.



Assist you and your doctors navigate the clinical trial journey.

Work with you and your doctors to connect, share records, and communicate with the clinical trials team.



A clinical trial might be right for you. In fact, access to clinical trials is considered standard of care for most cancers and is essential in broadening treatment options.

Get In Touch

Email the VA cancer clinical trials nurse navigator for assistance!
Cancerclinicaltrialsnavigation@va.gov



If you have questions about cancer care or screening options available at VA, visit cancer.va.gov



Choose VA



U.S. Department
of Veterans Affairs



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CLL CARE IN THE VA

- **CLL care isn't just treatment**
- **CLL patients:**
 - Are at higher risk of other cancers, most commonly skin
 - Are at higher risk of infections
 - Often need to manage other medical conditions
 - Are living with a chronic condition that can cause worry or anxiety
- **CLL treatment can cause side effects that need to be managed or treated**

MANAGING HIGH RISK OF CANCER

- **Referral to dermatology for yearly skin examinations**
- **Recommend and work with primary care provider on appropriate cancer screening**
 - Colonoscopy, stool testing
 - Prostate exam, PSA
 - Breast exam, mammography
 - Low dose lung CT

MANAGING HIGH RISK OF INFECTIONS

- **Encourage vaccination**

- Yearly influenza and COVID-19 (or more frequent)
- Pneumococcal (pneumonia) every 5-10 years
- Shingles (Shingrix)
- Respiratory syncytial virus (RSV)

- **Check immunoglobulin (antibody levels)**

- If low, and there are recurrent infections, consider intravenous or subcutaneous immunoglobulins

- **Consider wearing a mask in high-risk situations**

- Travel
- In larger gatherings
- Around others who have respiratory symptoms

MANAGING SIDE EFFECTS OF CLL THERAPY

- **Risk of infections (any therapy)**
 - Preventative anti-infective medications, such as acyclovir
 - Intravenous or subcutaneous immunoglobulins
- **Bruising or bleeding (BTK inhibitor)**
 - Limit or reduce use of other medications that can cause easy bruising or bleeding
 - Hold therapy before and after procedures or surgery
- **High blood pressure/hypertension (BTK inhibitor)**
 - Dietary changes, such as low sodium
 - Adjust dose or start high blood pressure medication

MENTAL HEALTH AND WELLBEING

- Living with a chronic disease like CLL can be stressful and can lead to worry, anxiety, or depression
- Remember:

YOU ARE NOT ALONE

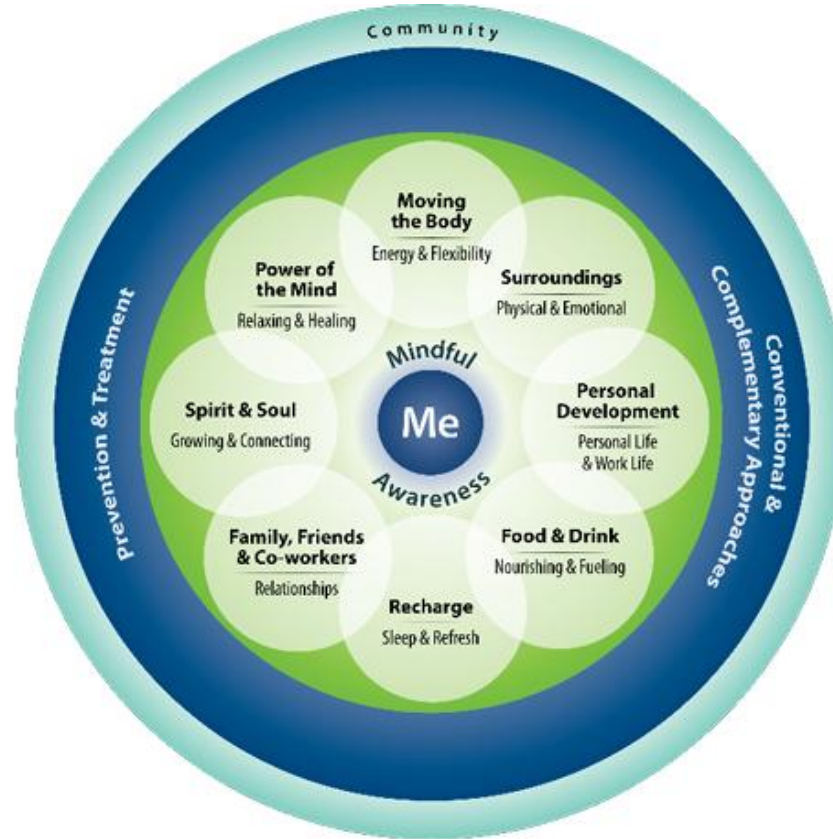
MENTAL HEALTH AND WELLBEING: RESOURCES

- **Contact the Veterans Crisis Line, which is private, free, and available 24/7**
 - Call 988 and select 1
 - Text 838255
 - Go online to start a confidential chat
- **Let your oncologist or primary care provider know**

All VA facilities have mental health providers, and some have psychologists as part of the oncology team

WHOLE HEALTH AT THE VA

“Whole Health is an approach to health care that empowers and enables YOU to take charge of your health and well-being and live your life to the fullest.”



SUPPORT GROUPS FOR VETERANS WITH CLL

- **VA “Living with Cancer: Skills Workshop”**
 - Available through VA NTO, Dr. Graham Ford, Oncology Psychologist
- **CLL Society**
 - Veterans with CLL Support Group and peer-to-peer support
<https://cllsociety.org/venue/veterans-with-cll-support-group/>
- **Leukemia & Lymphoma Society**
 - Peer-to-peer support and weekly online chats
<https://www.lls.org/support-resources/online-chats>

CONCLUSIONS

- 1. CLL affects Veterans and is a service-connected condition**
- 2. The VA offers treatment and other resources for Veterans with CLL, at local and national levels**
- 3. There are many resources to manage the worry and distress that can accompany a CLL diagnosis**

**THANK YOU FOR JOINING!
QUESTIONS?**



AUDIENCE Q&A



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AstraZeneca 

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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: asktheexpert@cllsociety.org

Join us for our next virtual event,
UNDERSTANDING MEDICARE AND CLL: WHAT PATIENTS NEED TO KNOW
September 18th

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/



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