



CLL SOCIETY

Webinar Transcript

From Service to Support:

Managing CLL / SLL in the Veteran Community

August 28, 2025

In science and medicine, information is constantly changing and may become out-of-date as new data emerge. All articles and interviews are informational only, should never be considered medical advice, and should never be acted on without review with your healthcare team.

This text is based off a computer-generated transcript and has been compiled and edited. However, it will not accurately capture everything that was said on the webinar. The time stamp is approximately 10 minutes off due to editing. The complete recording of this webinar is available on-demand.

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Hello, and welcome to today's webinar. I am Robyn Brumble, a registered nurse and CLL Society's Director of Scientific Affairs and Research.

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At CLL Society, we are dedicated to bringing credible and up-to-date information to the CLL and SLL community...

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because we believe smart patients get smart care. As a reminder, you can rewatch all of our educational programs by going to the section of our website called Education on Demand.

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This program was made possible through support from both our donors and our industry partners.

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At this time, I would like to introduce our moderator. Thank you.

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Thank you, Robyn. I'd like to welcome our audience to today's event.

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I am Dr. Ed Ratner. I volunteer co-facilitator of three CLL support groups,...

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Veterans with CLL, a Minnesota-based group, and one for physicians with CLL and SLL.

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I'm also a faculty member at both the University of Minnesota Department of Medicine and at the Minneapolis VA Geriatric Center.

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We are joined today by our speaker, Dr. Daphne R. Friedman,...



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a staff physician at the Durham VA Health Care System, and Professor of Medicine in the Medical Oncology Department at Duke University School of Medicine.

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We will be answering audience questions at the end of this event, so please take advantage of this opportunity...

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and ask your questions in the Q&A box. I'd like to share a few important disclaimers.

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The information provided during today's webinar is for educational purposes only...

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and should not be considered medical advice. For any personal health or treatment questions,...

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please consult your healthcare team. Please note that while the CLL Society may have its own opinions and policies, our speakers may offer differing viewpoints,...

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especially regarding management of CLL and its complications. To learn a little more about our audience,...

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we have three brief poll questions you'll find on your screen.

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Please scroll down to answer all three questions. The questions are, what is your CLL/SLL treatment status?

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Where do you receive treatment for your CLL/SLL? And... and are you service-connected...

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for CLL/SLL? I'll share the results of this poll before the audience question and answer session.

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Thank you for your participation. Before Dr. Friedman's presentation,...

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I wanted to briefly share a few resources you can find on the CLL Society website.

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The CLL Society's motto is Smart Patients Get Smart Care. In this brief presentation, I'll provide resources that can help you better advocate...

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for your best possible care. The slides from today's presentation will be available for your review,...



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they contain hyperlinks to the resources that I'll be highlighting. The CLL Society has a dedicated section under Living with CLL, specifically...

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for veterans. The website includes frequently asked questions for Veterans, covering how to enroll in the VA healthcare benefits, how to access care within the VA...

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and how to include care within the community and outside the VA...

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what treatment options are available at your VA for CLL and SLL...

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and more. There is a veteran's benefit in CLL section that includes comprehensive information about applying for disability benefits for service-related CLL or SLL.

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The CLL Society is committed to supporting veterans with trusted information, resources, and access to guidance.

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Often, the best advice comes from hard-earned wisdom and emotional balance that can only be offered by fellow veterans with CLL who...

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have already experienced the challenges you are facing, or the treatment you may be considering.

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The veterans with CLL/SLL Support Group meets virtually by Zoom every third Saturday...

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at 8 a.m. Pacific Time or 11 a.m. Eastern Time. It's a great place to receive education and support.

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We hope you'll consider joining us. You can sign up for this support group on the CLL Society website.

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In addition to support groups, the CLL Society offers opportunities for one-on-one support.

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The emotional and spiritual advocate program provides one-on-one meetings with a board-certified chaplain...

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for those of all faiths or no faith background. The peer support program...



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is an opportunity to connect with another person impacted by CLL...

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who can talk with you one-on-one and help answer questions around many topics based on their own experience.

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The Ambassador Program connects you with a peer volunteer who can help answer treatment questions from commonly prescribed targeted therapies...

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and CAR-T therapy. Lastly, the CLL Society can connect you with a fellow veteran for one-on-one support if you...

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email support at cllsociety.org. The online CLL/SLL Patient Education Toolkit...

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is a great way to learn a broad spectrum of information...

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including the basic biology of the disease, treatment options and other important resources.

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This information includes preventing infections, cancer-related fatigue,...

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recognizing when it's time to treat and managing side effects, to name a few.

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Each topic is presented in patient-friendly terms. The CLL Society Medicine Cabinet...

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includes nine of the most commonly prescribed CLL medications. Each treatment page includes helpful information on dosing,...

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common side effects and how to manage those side effects, special considerations, links to financial resources from industry, and more.

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Another great resource that the CLL Society provides is the Normal Lab Values Chart...

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and the tracker. You can download and use the tracker to record your routine blood test results.

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In CLL, it's often not one lab report that tells the story but whether levels are trending up or down over time...



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that can inform your questions and decision making. It is more than likely that you will be seen by different providers, and they have...

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blood work performed at different labs. The lab tracker then, becomes an important resource...

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where you can have the history of your results entered and displayed in a single document.

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You can take this tracker with you to medical appointments if meeting with a new doctor or have better informed discussions with healthcare providers.

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It is valuable to have predictive cytogenetic testing done at the time of diagnosis.

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Importantly, it is critical to get cytogenetic predictive testing prior to the first and every subsequent treatment.

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The CLL Society Test Before Treat campaign highlights the three cytogenetic tests that are essential prior to treatment.

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These include the FISH, IgVH and TP53 tests.

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To support patients and care partners, there's a downloadable one-page sheet...

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available on our website. Is it recommended that you bring the Test Before Treat one-pager with you to your medical appointments to help inform this discussion.

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The CLL Society recommends having a CLL expert physician on your team.

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You may not see them often, but who would be available for important decisions.

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If you do not have a CLL expert physician on your team, and you have questions about symptoms, treatment, or when to treat,...

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there's a CLL Society Expert Access Program. This program provides free, second opinion consultation with the CLL expert physician.



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Afterwards, you will be provided with a written report that you can bring to your local treatment team.

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The Ask the Experts program allows you to email general questions about CLL...

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that are confidentially sent to either a CLL expert physician, registered nurse, lab scientist, or hospice palliative care physician, for a short reply.

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This resource helps you with reliable answers to simple questions.

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Please note that this service is intended for educational purposes only and does not include a full review of your medical charts or lab work.

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The best way to stay informed about breaking research, news, education, and events is through signing up for the CLL Society's This Week...

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email newsletter that is sent every Tuesday. You can find the CLL Society on Facebook,...

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X and LinkedIn. Use this time to get educated about CLL...

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and SLL and become a self-advocate in your healthcare. The CLL Society provides many tools...

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and medically curated information to support you. Join our veteran CLL/SLL support group...

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as we learn from and support each other. Stay informed with what's new through the weekly email and continue to join us for these important webinars.

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Without further adieu, we welcome Dr. Daphne Friedman.

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Hi, thank you for that kind introduction. Um, to introduce myself again, I'm Daphne Friedman, I'm a staff oncologist at the Durham VA Medical Center...

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and, uh, the VA's National TeleOncology Service. My academic affiliation is at Duke University...

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and I'm going to be speaking today about managing CLL/SLL in the veteran community.



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I have no financial disclosures, um, related to the content of this presentation...

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but I will be speaking about the unlabeled use of a treatment...

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within the context of a VA-funded research study. The information that I'm presenting today is within my capacity as a VA staff oncologist and the deputy director...

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of the VA National Oncology Program. Three learning objectives for today: number one, understanding how CLL affects veterans;..

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number two, to learn about resources in the VA and treatment considerations for veterans with CLL;..

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and number three, to learn how CLL affects mental health and how to manage.

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And for the, um, purposes of this talk, when I say CLL, I'm talking about chronic lymphocytic leukemia...

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as well as the, um, the same disease, but in lymph nodes, small lymphocytic lymphoma.

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And when I say VA, I'm talking about the Department of Veterans Affairs.

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So, to start out with some facts about CLL. CLL is the most common blood cancer.

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It more commonly affects older white men, um, but it can affect younger people, as well as other racial groups and women.

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And early treatment has, so far, not been shown to help CLL patients live longer.

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So, usually after the time of diagnosis, there's an initial watchful waiting period.

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And interestingly, about a third of CLL patients never need any therapy for their CLL.

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They're just watched for the entire course of their disease.



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CLL is oftentimes a slow-growing cancer. It may never affect a patient's health.

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But sometimes it can grow more rapidly or even change or transform into an aggressive lymphoma.

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And prognostic tests can be done at the time of diagnosis...

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and that can help predict the aggressiveness of CLL and help with planning purposes.

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So, now to move on to some facts about CLL in veterans.

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Um, it's known that toxic military exposures increase the risk of developing CLL...

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and that includes Agent Orange, um, exposure to contaminated water at Camp Lejeune and burn pits.

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Um, and in the case of Agent Orange, there was a publication a while back...

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that demonstrated people who, veterans who developed CLL and had an exposure to Agent Orange...

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had a younger age at the time of their diagnosis with CLL...

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but had longer survival. There's also, it's also well-known that CLL can increase the risk of other cancers.

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And, um, I'll go into this a little bit more later on, but...

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in one publication of CLL patients in Arkansas, it was estimated that about 16% of the veterans that had CLL,...

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um, developed secondary malignancies or other cancers. And this excludes...

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um, the most common kinds of, um skin cancer called squamous and basal cell carcinoma...

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which are typically not a major cause of illness or death.

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Um, but what they found was also was that second malignancies cause death in 9% of CLL patients and was the cause of death...

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Um, CLL is a service-connected condition, so what does that mean? Um, a service-connected condition is...

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an illness, includes illnesses that were caused by military service and, um, Service Connection can provide compensation,...

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health care benefits and spouse survivorship benefits. CLL is a presumptive condition for certain exposures, like I mentioned before, Agent Orange,...

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Camp Lejeune contaminated water and burn pits and other toxic military exposures.

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The eligibility for Service Connection depends on the timeframe and location of military service.

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Um, a lot of this information can be found online. Um, I literally just Google for, um, Agent Orange and Service Connection when my patients have questions.

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Um, and just to give an example, um, let's say you are interested in...

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who would have a service connection for Agent Orange exposure, and so online they, um, specify that the military service...

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could be in Vietnam between January 9th, 1962, and May 7th, 1975,...

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um, or aboard a military vessel within a certain distance of Vietnam or Cambodia...

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or service in different time frames in Thailand, Laos, Cambodia, Guam,...

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American Samoa. Johnston Atoll,...



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Korean DMZ and other locations where Agent Orange was stored or transported.

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So it really gives you an idea that, or gives you a sense that the VA's very specific about...

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what situations are presumptive. Service Connect, where CLL is a presumptive service connection.

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Um, of course, if one feels that one had a military toxic, a toxic military exposure that's...

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not outlined on the Veterans Benefit Administration website, one can always apply for benefits and explain the extenuating circumstances,..

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um, and the veteran service organizations, or VSOs, can assist veterans in applying to the Veterans Benefit Administration...

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for service-connected benefits. So, how do veterans with CLL receive care?

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Um, they, a veteran can receive care for their CLL at a VA facility,..

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in person with a VA oncologist, um, they can receive care through telehealth modalities, either video or telephone...

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um, where the VA, where the veteran is at home, and the VA oncologist is at...

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the medical center, in some cases, veterans are referred to the community where the VA pays for the veteran to receive care outside of the VA,..

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and through the VA's National TeleOncology Service. So, on this third bullet point on, um, referral to the community, there are certain criteria that the VA uses...

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for establishing if somebody can be referred outside of the VA.

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And those reasons include, um, if the drive time to a VA medical center is over 60 minutes,..

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if the service is not provided at the VA facility, um, if it can't, the service can't be provided within 30 days of the clinically indicated date in the referral...



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or if it's in the best medical interest, as decided by the referring physician and the veteran.

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And, um, even if a veteran is eligible for community care,...

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they don't, it's not required that they get their care in the community. They can still decide to get their care in the VA...

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um, and in many cases, they do decide to do that...

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um, because, um, for various reasons. So, um, one reason is that VA providers can easily communicate with each other...

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and, um, wait times may be shorter in the VA than in the community.

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And also, the VA understands and can more effectively address veteran-specific comorbidities that interact with CLL, for example,...

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PTSD. Now I'm going to talk a little bit about the VA's National TeleOncology Service.

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Um, this was set up in about 2018-2019, so, um, pre-pandemic. Um, it was. it's a service that was set up with the understanding and recognition...

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that, um, the, there's variability across the VA, in terms of what different VA facilities can offer.

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So, there's some VA facilities that are larger, um, better staffed,...

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oftentimes affiliated with an academic medical center, where there's a, um,...

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higher level of care and the ability to provide more complex care...

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by specialists with special expertise in a certain disease. But then there are also VA facilities that are much smaller and not staffed as robustly, and that don't...

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offer as complex care. So we thought, understanding that there's that, um, heterogeneity across the VA with the different facilities...

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that can impact the care that a veteran receives, just depending on where they happen to live.

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So, this program was developed to, um, to connect...

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VA care providers that are in one facility that might be better staffed...

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or be able to provide them with more complex care with a VA facility and with veterans that are, um, have a lower level of staffing...

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or, um, in other situations, maybe, um, at a particular VA facility, they have some, some, um,...

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services, but not all, or maybe somebody went on extended leave and there needs to be a backup.

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There can be many reasons, but, um, these are all the kind of...

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ideas that went behind, um, establishing this service.

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So, the hub is actually the Durham VA, um, where administratively, the National TeleOncology, or NTO, is,...

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is built out of, and there are physicians, nurses, advanced practice providers, geneticists, social workers,...

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pharmacists who are all affiliated with the Durham VA even if they don't happen to live in Durham, and they, um, provide care to veterans...

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across the United States um, through video telehealth.

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Um, and they do so in collaboration with the local physicians and nurses and nurse practitioners, um, where the veteran lives.

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The picture on the left shows the collaborative, um, the collaborative work between doctors, nurses, pharmacists, and advanced practice providers,...



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um, to help the veteran who's at the center of it all.

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In the map on the right, you'll see all the different VA facilities...

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aAcross the United States that, um, that participate in the VA NTO service.

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And some of them receive what's called full service, where they're actually getting, like, all components of NTO...

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and some are subspecialty, where they might need part, you know, help with a certain type of cancer...

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or, um, or with a certain service, like genetic, cancer genetics, for example.

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Um, and I put the website tor, um, for more information on this slide as well.

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Speaking of genetic testing, um, yes, the VA does offer genetic testing,...

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um, there is a comprehensive genetics service that is part of National TeleOncology that helps...

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um, veterans who are interested in learning about inherited cancer syndromes...

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um, because there are some cancers that run it through, run in families.

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CLL does run in some families, but unlike other cancers where this happens, there isn't one genetic cause for it.

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Different families have different genes, and sometimes it's the combination of several genes that can contribute to this.

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I've put the direct website, uh, email, uh, for the, um, Comprehensive Genetic Service, um,...

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so they can be contacted. Also, for veterans who receive their care in the VA,...



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um, it's an easy referral to the service. Um, sometimes the CGS group will...

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provide information to veterans about research studies that are outside of the VA to learn more about the genetic and familial CLL, and I just...

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put some examples of research groups outside of the VA that, um,...

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that do offer this. Now, from the perspective of...

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genetic testing on the cancer cells itself, um, that is typically within the purview of the prognostic tests, which I mentioned earlier before.

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And those tests are often done at the time of diagnosis...

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to help predict what the future will hold, and whether a person's CLL is more or less aggressive.

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And so, those genetic tests on the CLL cells themselves are offered as part of routine care...

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at the VA facilities, and, um, just depending on the VA facility, they may be done in-house or sent out...

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of the VA to another laboratory or vendor. So now, switching gears, let's talk a little bit about the treatment for CLL.

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So, I put some questions and some answers on this slide.

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So, first off, when is treatment needed? So treatment is needed for CLL when it affects your health or how you feel.

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Like I mentioned earlier on, about a third of people diagnosed with CLL will never reach a point where the CLL affects their health...

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and so they never received therapy. What is the goal of treatment? Um, it's to improve health.

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Improve how you feel, help you live longer, and if possible, to put the CLL into remission.



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But even if it's in remission, even a deep remission, oftentimes...

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um, the CLL can come back, and so, patients with CLL are always monitored, even after they complete therapy.

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And what are some typical treatments? So, um, I've put the, kind of bullet points of different types, different classes of treatment.

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There are targeted therapies such as Bruton Tyrosine Kinase, or BTK inhibitors...

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and BCL2 inhibitors. And so, the examples of BTK inhibitors are ibrutinib, acalabrutinib, zanubrutinib, and pirtobrutinib.

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And then the BCL2 inhibitor is venetoclax. And then a second type of treatment are monoclonal antibodies.

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And so, examples of monoclonal antibodies are rituximab and obinutuzumab.

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And sometimes the targeted therapies are combined with the monoclonal antibodies.

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Usually, monoclonal antibodies are not given alone but sometimes the targeted therapies are given alone.

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And then, we used to use traditional chemotherapy, like what you might think about when you think of a cancer patient getting treatment.

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But these are rarely used anymore because they've been compared to the targeted therapies and the monoclonal antibodies...

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and they don't work as well, and they have more side effects.

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So, let's talk a little bit now about treatment for CLL in the VA.

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Any FDA-approved CLL treatment can be prescribed by VA oncologists.



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In addition, non-FDA-approved treatments, which are also called off-label, can be prescribed if there's appropriate supporting data, and that would be in the form of a research study that had been published...

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or presented at a large medical conference.

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And then, similar to in the private sector, CLL treatment does require prior authorization.

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So, outside of the VA, when this happens at, um, in the private sector, at a doctor's office...

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that, um, doctor would contact the patient's insurance company...

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to get approval. In the VA, the prior authorization is done in-house.

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So, there's an oncologist who, or an oncology-trained clinical pharmacist, who reviews the patient's care and the request for the treatment...

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and make sure that it's appropriate. And then, what's really nice about having a pharmacist do this is that they can also do a review...

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for any drug interactions that might affect the dose that's needed to be used.

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Um, part of the decision-making about authorization comes down to what are called criteria for use...

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that the VA, um, creates and that's the standard for authorization.

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And in addition, the VA has clinical pathways, um, which I'll go into in a moment, and those provide the recommended treatment for veterans with different types of cancer.

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What is felt that most patients should receive and those clinical pathways are created by VA oncologists...

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and are updated every three months when there's new information or data that comes out.

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So, it's kind of a living document. I just did a screenshot here, um, to show an example of the VA's criteria for use for acalabrutinib...

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which is one of the, um, targeted therapies that is commonly used...

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for CLL, um, and it just shows, like, checkboxes, exclusion and inclusion criteria, and additional things to think about,...

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um, and so it's pretty easy for the person who's doing the review and the authorization to look through this.

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And these are also, um, publicly available, and the website is at the bottom in the red banner.

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Um, and then to give an example of a clinical pathway, this is what it looks like, um, it's kind of a flow diagram, and it leads a...

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provider through, um, what's, needed in terms of, and what's recommended in terms of treatment...

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and monitoring patients with CLL and SLL with additional notes, um,...

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in the footnote section. Um, today I'm not meaning to go through this from a medical perspective, but only to show you that...

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there's, um, there's a recommended step-by-step way of managing and monitoring patients in the VA.

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It doesn't, it's not, um, a requirement, any VA oncologist can deviate from this.

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But, as I mentioned before, when there's the variability in the VA, the heterogeneity,...

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where there's some VA facilities that have high expertise, and other ones that have...

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lower expertise in certain cancers, it's really helpful to have, like, an instruction manual that everybody can look at, and, um, there's agreement across the board on what most patients should be treated with.

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Clinical trials, so, this is really important,...

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um, I personally feel like, um, clinical trials are performed because they help us learn more...

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about, um, about cancer and diseases in general. Now, they're voluntary, you don't have to participate, but I think it's really important to consider them.

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Um, oftentimes, clinical trials involve treatment, sometimes they won't. Like, I gave the example before about...

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familial CLL, and that there are research groups that are looking at...

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what are the reasons for that? Now, that's a research study to learn more...

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but it doesn't involve treatment. But when we are thinking about treatment clinical trials,...

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there are different phases of clinical trials and if the different phases tell you information about what are they trying to,...

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to study, excuse me, so sometimes in a clinical trial,...

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um, they're, they're interested in learning what's the most appropriate dose to treat a patient with...

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or sometimes they're learning more about the side effects, um, or sometimes they're wanting to learn more about how effective the treatment is,...

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or, um, or how it compares to other treatments. So the different phases help,...

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um, you know, specify what is being, what is intended to be learned.

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Now, sometimes patients ask me when I talk with them about clinical trials, they say, is there a placebo? Is there a sugar pill?

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Um, is there a chance I'm going to get no treatment? In the case of CLL, where we do have really effective therapies,...

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CLL SOCIETY

anytime that there's a treatment being tested, they're not going to be comparing it to a placebo.

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They're going to be comparing it to the old way of treating, the standard way, and they're trying to improve beyond that.

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So whenever there's a comparison, it's always comparing it to the standard treatment.

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The times that a placebo might be used in a clinical trial is if...

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there's a combination, like, combining two medications, and they want...

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to have a situation where you don't know if the second medicine is...

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um, is real or not. Um, where, you know, if you knew it, it might change your, what side effects you might perceive, or how you experience the treatment.

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So sometimes in those cases, a placebo might be used as an add-on.

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But it would be unethical to just do a placebo by itself.

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In the VA, um, clinical trials are something that we think about., um, some VA facilities offer clinical trials,...

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sometimes the VA will refer a veteran to a non-VA facility...

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to receive care that's not available at the VA like I mentioned before, and that can include clinical trials.

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And also, the VA offers a clinical trial Nurse Navigation service, which I'll get into in a moment...

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and that's a way that veterans and their oncologists can learn about different clinical trial options when they're considering therapy.

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So, I think it's important that, um, you ask your oncologist if there are clinical trials available, because...



CLL SOCIETY

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um, sometimes the oncologist might forget to mention it, or not think about it, and,..

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um, if you, as a patient, um, advocates for yourself, advocate for yourself, then that can start a conversation that you might not otherwise have.

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I would like to, um, now speak about one clinical trial that we're just starting to enroll, uh, for in the VA.

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Um, it's called Benefit of Venetoclax Addition, or Benefit VA, um, in chronic lymphocytic leukemia, small lymphocytic lymphoma.

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And, um, the question that we're asking is whether adding CLL treatment...

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can improve response and patient experience over the long term. So, we're enrolling patients who, veterans who have CLL already,...

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then they're already on a BTK inhibitor and, um, of the patients who volunteered to participate,...

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50 veterans will continue on their treatment and 50 patients will add venetoclax to the BTK inhibitor that they're on for one year, and then they're going to discontinue both...

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treatments and be monitored. And so, what we're trying to figure out is whether it's better to do a little bit more of an intensive treatment for a year but then get the benefit of...

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stopping treatment, and whether that does a really good job of controlling the disease...

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and helping improve quality of life and different side effects, because...

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a patient would be able to stop treatment. Or is it better to just continue on that...

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BTK inhibitor, which is an indefinite treatment, and, um, there are different VA facilities that are participating, so...

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Kansas City, Durham, Seattle, and San Francisco are offering the study...

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CLL SOCIETY

on-site, and then we're also offering it through the National TeleOncology Service, and there are 122 VA facilities...

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that are affiliated. So, almost every VA facility that gives cancer care can have their...

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patients enrolled in this study if they are interested. I mentioned that there's this clinical trials navigation service, um, and, uh, information sheet is, um, screenshotted on here.

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Um, the email address is in the bottom where it says, get in touch.

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Um, and, um, and what this service is, is if, if a veteran is interested in a clinical trial or exploring what clinical trials are out there,...

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um, they, the Nurse Navigator gives them a call, learns more about what geographic area they're interested in, or if they have certain preferences...

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with regards to types of clinical trials and then helps them by doing a search.

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Um, gives them the information, gives them information, gives their oncologist information, and that...

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is the beginning of a conversation between the doctor and the patient.

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And then, if a veteran is interested in pursuing a clinical trial, especially if it's outside of the VA,...

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the Nurse Navigator helps get all the records together, make the connection to the research team, and so forth.

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So, um, we're really happy with this, um, service, and it's for all types of cancers.

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In terms of CLL care in the VA, um, I want to make sure you all realize that we're not just talking about treatment.

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CLL patients, as I mentioned before, are at higher risk of other cancers, most commonly skin cancers.

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There's a higher risk of infections and, um, there's a need to manage other medical conditions.

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Lastly, um, people with CLL are living with a chronic condition, and that can cause worry or anxiety.

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Um, the CLL treatment itself can cause side effects that need to be managed or treated.

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So like I mentioned, there's a higher risk of other cancers, and I, um, typically refer patients to see dermatology...

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for yearly skin examinations. And then I work with primary care and recommend...

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cancer screening for other cancers, like colon cancer, prostate cancer, breast cancer,...

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lung cancer and other cancers as, um, as appropriate, given a...

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person's, sex, age, other, um, exposures and risk factors. Managing the higher risk of infections, this might include encouraging vaccination...

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so I do recommend that CLL patients get their vaccines. Um, it's kind of a catch-22. The CLL itself...

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reduces the chance that the vaccine will be as effective as it would be in someone without CLL...

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but people with CLL are at the highest need for protection...

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so, I do recommend it, um. And also, for people who get, people with CLL who get...

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recurrent infections, I'll check their immunoglobulin levels, also known as antibodies.

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And then for people who have low levels, we can consider some treatment called intravenous or subcutaneous immunoglobulins, to boost the immune system levels.

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And I do recommend to patients to consider wearing a mask...

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in high-risk situations, such as when they travel or if they're in large gatherings, or around other people who have respiratory symptoms, like a cough or runny nose,...



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sniffles. The CLL treatments themselves have side effects,...

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um, for example, a higher risk of infections. And sometimes, um, there's a need to, um, go on certain medications to prevent infections or to receive immunoglobulins.

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Um, there's a risk of bruising and bleeding with the BTK inhibitors,...

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um, and there's a risk of high blood pressure as well, and so these are things that I manage together with a primary care provider...

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and think about altering other medications or holding medicine in certain situations.

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I'd like to touch on, at the very end, um, the...

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concept of, um, well-being for, um, patients with CLL. This is a chronic disease, it can be stressful to have a chronic disease that's incurable.

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It can lead to worry, anxiety, or depression. But you're not alone. And the VA does have many different resources.

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There's a veteran's crisis line, which is private, free, and available 24-7,...

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able to call or text, or go online for a confidential chat.

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Many VA facilities have mental health providers who are embedded as part of the oncology team, and even when they're not embedded, all VAs have mental health providers.

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The VA also has a program called Whole Health. Um, Whole Health is an approach to healthcare that empowers and enables patients to take charge of their health...

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and well-being, and live life to the fullest. It's a focus on health, rather than illness.

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Um, the website to get more information is listed on the slide at the banner at the bottom.

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And there are support groups for veterans with CLL, so the VA has a Living with Cancer Skills Workshop...

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with an oncology psychologist who, um, sees patients at the Durham VA and through the National TeleOncology Service.

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An organization such as the CLL Society and Leukemia and Lymphoma Society, which is now rebranding as Blood Cancer United,...

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have different peer-to-peer support and support groups and chats available. So in conclusion,...

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CLL affects veterans and is a service-connected condition. The VA offers treatment...

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and other resources for veterans with CLL both at the local and the national levels.

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And there are many resources to manage the worry and distress that can accompany a CLL diagnosis.

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Thanks for your, um, for joining this, um, and for your attention today, and...

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now I'll open it up to any questions. Thank you!

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Thank you, Dr. Friedman. Uh, that's a really informative presentation, and I really appreciate, kind of,...

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that you, you kept it, uh, kind of non-technical, so I'm sure your patients really appreciate that you can explain things without using too much jargon. Before we go on to audience questions,...

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I want to, uh, go back and see, uh, if we can share...

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the results of the poll that'll help Dr. Friedman kind of know something about the audience, and um,...

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the, uh, first question was kind of the treatment status, and uh, about a third of people are in the untreated group, and as Dr. Friedman said, a significant number of those may never need treatment.

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Uh, about a third are getting treatment and, um, and then the remainder,...



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have either completed treatment or non-applicable. I assume those are, uh, caregivers, clinicians, or others who are attending.

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Uh, where did you receive treatment, uh, for your CLL? Um, less than a quarter are getting their care at, um,...

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at the VA facilities, uh, a couple of percent at the Department of Defense, but non-federal facilities, over half,...

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um, and it's a, and that's fairly consistent with what I've seen in, uh, the support group that I facilitate, is that...

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a lot of veterans are choosing to get their care outside the VA, and I think...

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Dr. Friedman's presentation, uh, can, uh, probably help you...

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navigate the VA better and have greater confidence that you can get the expertise that...

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uh, you may not think you're able to access, such as through the National TeleOncology Program.

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And the last question was about service connection. And, um, about a third...

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are not service-connected, uh, 18% are service-connected, rated at zero, so that represents people who've been, had exposures or some other reason that they're, uh, their connection is there, but they're in...

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uh, the, um, watch and wait, as well as not having lymph nodes, so that at stage...

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zero, um, and then, uh, about a third are rated at 100%, and for whatever reason, the VA, it's all or none...

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uh, for CLL, uh, you're either, uh, not disabled at all, but we know there's a connection, or you're 100% disabled. And that, just to appreciate...

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this all dates back to before we had such, uh, effective and tolerable treatments,...



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um, and so at some point in the future, new applications,...

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uh, might change for that, but I haven't heard of anything like that.

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So, any additional comments, Dr. Friedman, about those results? Is that consistent with what...

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you've kind of seen within your practice, and both inside and outside the VA?

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Um, yeah, thanks, that was really informative, insightful to see all of that, um,...

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those responses, um, one thing that I did want to...

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mention, which I think might address one of the questions that came in in the chat,...

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um, and I didn't mention in the talk was not every veteran is eligible to get care in the VA.

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Um, and that I'm definitely not an expert in that at all, it's kind of a little bit of a black box for me, but it does have to do with what you did in the military,...

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um, and, like, if you were combat or not, and, um, and if there was an injury, um, or any, um,...

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anything like that during the military service, and then also, like, um, income. Like, what's your current income?

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That can play a role in the decision, determination about eligibility.

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So, um, so, in the survey, um, where there was the question about where do you get your care...

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in the VA, or out to the VA, could have, could be that some of the people who...

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got their care outside of the VA, one of the veterans who get their care outside of the VA, it's because they're just not eligible to get their care in the VA.

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CLL SOCIETY

Yeah. Okay, thank you, kind of, for that. And there's, uh, kind of a classification system, like, uh, that, that, uh, determines, and there's eight categories, and down in the eighth category. You can always go to, just so you know, you can always show up...

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at a VA ER and if, and get care, uh, if you've been in the service, they don't turn anybody away.

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But for ongoing primary care or specialty care, they have these criteria, if they're...

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healthy and have other insurance, and, or, uh, and aren't too poor,...

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uh, that then it's harder to get, uh, kind of into the system. Okay, so, uh, we have a variety of questions. We had a couple sent...

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in, uh, before the, uh, event, and so I just want to touch on one, and...

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that it, it, uh, it touches on a number of things you talked about, and...

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many veterans travel. And they live in different places, different parts of the year, uh, there's snowbirds, here in Minnesota, we have a lot of people who go south.

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But some people travel for their work, or they have children in different places.

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And so CLL is a chronic disease, both the treatment as well as the, some of the, um, ancillary...

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management issues like IVIG that you mentioned are challenging if you're not in the city...

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where you're primarily located. Can you, talk a little about how somebody could manage...

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getting, let's say, an IVIG infusion, if they're out of town.

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Yeah, that's a great question. It used to be really challenging, and then the VA did something that...

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is really cool, that solves the problem. Um, so it's this thing called Traveling Veteran Consult.

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So, basically, what I do if I have a patient who's traveling, and let's say they need labs someplace else, or a scan, or even a treatment, this happens sometimes,...

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and they're traveling, then, um, I put in the referral for that, and I say, what are the dates, and what's the location?

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And then there's a nurse who contacts the patient. And then contacts, so there's, every facility has a different traveling veteran coordinator, and then they talk to each other, and then get...

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whatever referrals placed for, to establish with an oncologist at the other VA, like for a treatment...

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or they can just directly order labs or scans, and then get the results back to, um,...

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to me, as the oncologist. So, um, it has worked really well, um, and, um,...

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and so I would, hopefully the, um, if you're getting your care in the VA, your VA oncologist knows about this, um, but if they don't, then the key word is traveling veteran consult...

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and, um, it should take it from there.

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Yeah, so it just, and that they've worked on improving this, but one of the challenges, if you don't do that kind of thing, your medical record...

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isn't necessarily accessible outside the institution that you're being seen or outside that region, and so they're trying to improve that, but that the system...

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isn't, it's a national medical record, but they don't give authority for anyone in the whole country at any VA to see a record unless you kind of are registered with that facility, so that process can work,...

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um, so that, that makes the VA, in many ways, much better than any other healthcare system,...

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uh, in that you can, there aren't other national healthcare systems that, that share that same way.

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Uh, different kind of question. You touched a little bit on the disability claims, and also said, I'm talking about CLL, but that includes SLL, so the question was somebody, and I've heard this a number of times,...



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people apply for benefits, uh, through the Veterans Benefit Administration and they have the diagnosis of SLL, and then there's some confusion, uh, in terms of the...

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questions that are asked, or how it's, uh, considered as to then they're denied...

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because they didn't, they have lymphoma rather than leukemia, and they are trying to get it for leukemia. Can you comment on...

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kind of that, how SLL and CLL are related to each other, and how somebody should manage if they're...

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denied a claim based on that kind of confusion, or any other?

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Yeah, sure. So, I just want to preface by saying I work in the Veterans Health Administration as a physician.

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And so, I don't have, I'm not part of the VBA, the benefits part, so I can't...

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really comment on exactly the inner machinations of that part of the VA.

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But I can comment as the physician taking care of patients who go through this process a lot, and so what...

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do I tell them? So, number one is, um, if the claim makes sense, and it was denied, um, you should reapply, because they make...

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mistakes sometimes, and, like, they have a lot of, they process a lot of paperwork, and...

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ao, just a one-time no is not, don't take that as a, that's the end-all and be-all. There's an opportunity to reapply.

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Um, the second thing is, like I mentioned, everything's online in terms of the presumptive diagnoses. So what do I mean by presumptive?

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The VA has a list of certain diseases where it says, like, this exposure and this disease, they're already connected.



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So, as long as you show that you are in the military...

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during that time, or had that exposure, and you show the documentation that you have that disease,...

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that's all you have to do, um, in your application. You don't have to,...

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you know, be jumping over additional, um, hurdles. It's, kind of already, some of the groundwork's already been done for that.

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So, um, like, looking on the VA's website for presumptive diagnoses for burn pit exposures, because the question...

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came in about, um, deployment to Iraq, um, it does list...

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lymphoma of any type, so, in addition to chronic lymphocytic leukemia.

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So, from that perspective, it would seem to me that if it was the disability claim was denied...

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because of SLL, then the person who's doing the reviewing didn't, didn't do it correctly, and you should just reapply.

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Um, but sometimes it can be helpful to have a letter from your oncologist,...

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um, and sometimes the oncologists, like, bristle at this or don't want to do it. It's not a requirement because they,...

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it's, they're, it's not part of their job that they have to do it, but...

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oftentimes when a patient asks me for it, I just, it's easy for me to do a letter that just explains, like...

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you're diagnosed with CLL, with SLL, SLL is the same disease as CLL.

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CLL is service-connected for this condition, presumptive service connection. And then I sign it, and then they include it in their resubmission.

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So if you can have your, if you're doctor or provider agrees to, um,...

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to prepare a letter like that, it can be really helpful.

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So let me follow up on that. There's a questionnaire for a number of the different types of...

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diseases that, uh, doctors fill out and sign, and then that goes to the Veterans Benefits Administration. It's called the...

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DBQ, and there's one specific for CLL, and, and you can use that for SLL, because they're the same disease.

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Do you fill those out or where should Veterans get those filled out?

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And, uh, and do you think that's helpful, to have that filled out in terms of doing an application?

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Um, I don't know if, it's required, helpful, or anything, except that I have filled that out for patients before.

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I don't think it needs to be filled up by a VA doctor. I mean, a lot of it's filled out by the patients themselves, but...

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there's a section for the provider. I think it can be, if you're, okay, I guess one thing to, so we're all on the same page, you can receive benefits from the VA without getting healthcare from the VA.

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So, you don't have to be seeing a VA oncologist to...

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be getting benefits from the VA, so you could have your...

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private oncologist fill out paperwork, um, and I have no idea if it's a required, if it's a required paperwork or not.

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Okay, well, good. Thank you. Um, so a question, um, about the, uh, the VA has a portal that my,...



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um, my, my veteran, I can't even remember what it's called, but the patient portal, and somebody's having difficulty,...

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uh, getting their oncology department linked into their portal. Do you have any suggestions on how, who they should contact, or how they should overcome that? Because it sounds like...

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that their oncology clinic just didn't get linked and so, then now they can't send messages to that...

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clinic.

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Yeah, so two, well, actually, so three suggestions. So, first of all, like, at least in Durham,...

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it's not called oncology, it's called hematology oncology. So sometimes you might be looking for the wrong thing.

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Okay.

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Um, second is that every VA, um, has a, um, person whose job is to help with this troubleshooting.

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Um, and, um, which, the system, My HealthyVet, but I think they changed the name recently, so I don't know what it's called now...

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but to be able to send secure messaging. So, um, if you call your VA, just ask the operator for the...

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person who's responsible for that. And the third idea is that, um, every VA has patient advocates.

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So, um, they're basically who you go to if you have a problem, like...

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any problem that you're upset with the VA, and they, they will take, connect you with the right person.

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So, um, you should be able to find who the patient advocate is, either by looking online or by calling the VA's main number.

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Great, thank you. So, question about, uh, there's a lot of different kinds of...



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cancers, and most, uh, VA hematologists, oncologists, are fairly generalist. Uh, so a question that someone asked was, how do VA oncologists keep up...

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on CLL, given that things have changed so quickly over the last 5-10 years?

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Um, and if, if they, kind of aren't confident that their doctor is...

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knowledgeable about CLL, um, kind of what should they do?

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Those are great questions. Um, so, um, for the, uh, for the first one, how do people keep up to date? Um, so just in general, um, oncologists keep up to date with...

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the newest, um, breakthroughs through, there's professional societies that send emails, and there's annual meetings.

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Um, and, um, different, um, journals have, um, summaries of the...

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most up to date, um, and the breakthroughs that come out, so, uh, that is, one, um, one way that we keep up to date.

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Um, of course, it's a lot harder if you're treating patients in every type of cancer. You have more to keep up to date with than...

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uh, if you have a focus in one area. So, um, so I definitely recognize that...

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and that was part of the, um, part of the, um, reason for developing those, um,...

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those pathways and keep, and updating them every three months is for a recognition that, um, that there may be oncologists in the VA...

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that, um, that aren't, keeping as up to date...

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or maybe they kind of know that things are changing, or there's new medications coming out, but they don't have the...



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same depth in knowledge about using those treatments and what to watch out for, side effects, and...

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how to preemptively, um, like, make sure they don't happen, um, or manage them when they're not very severe.

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So, that's also kind of baked into those pathways as well.

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Um, and, and so, um, a lot of oncologists have given feedback that they really, um, find a lot of usefulness in those...

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documents. So, um, so that would be another way.

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So those guidelines, would they typically match the NCCN?

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Um, the VAs basically tracking that, and as long as there's something...

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that's a little too off the wall, that that's where that comes from?

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Um, so, um, the pathways are developed by VA oncologists with special expertise in the different diseases.

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Um, they do differ from the NCCN guidelines, which are basically, like, give you every option.

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So, it doesn't tell you, like, which to pick, it just says, here are all the options. And sometimes there might be, like...

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six or seven options for some cancers. Um, in, for the path, VA pathways, it's selecting, um,...

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what is the preferred option. The oncologist can always pick something that's not preferred.

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But it's just helps if you have no idea, or if, all things being equal, like, three things are equal, so what are you going to pick? Instead of flipping a coin, there's...

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CLL SOCIETY

a preference, um, and there's different criteria that are used to make that. So, they definitely mirror NCCN, but they're not,...

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um, they're not a copy of that. It kind of, it's a different goal.

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Um, and then the second question, the second part of the question was, um, if you don't trust your oncologist, what do you do? Okay, that's a big problem, because I'm a firm believer that...

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patient and provider, like, need to see a lot, be aligned and trust each other, and have a good relationship.

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Um, personally, as somebody who's been, not only, who's a doctor, but also as a patient at times,...

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um, I have switched doctors when I feel, felt like I didn't have that connection. So, like, you just have to advocate for yourself, and...

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um, and find a good connection, but how do you do that? Of course, listen, number one, like,...

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you don't want to hurt somebody's feelings. It's okay, hurt my feelings, it's more important for you to have a doctor that you connect with.

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I will get over it. I'm busy, I have a lot of patients, so that's fine. Don't worry about it.

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Um, I guess it's kind of like your hairdresser, like, you don't want to hurt your hairdresser's feelings by going to get a new hairdresser. It's fine, we're all adults.

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Um, so then, but how do you find somebody else? So, number one is, um,...

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a lot of VAs do have more than one oncologist, but not all of them.

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So, um, so sometimes you don't have the luxury of that. You can request,...

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as I mentioned, um, community being referred to the community to have a different oncologist.

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There has to be a reason for that. There are different reasons that I mentioned before, so as long as...



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that gets approved, that would be another way. Um, and then the National TeleOncology Service does have second opinion consults.

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So, um, that goes, referred to another oncologist in the VA.

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And, um, because almost all VAs are affiliated with National TeleOncology that pretty much opens it up that wherever you're getting your care, you're likely to be able to...

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get the second opinion, and even request maybe some ongoing, um, like, check-ins with another oncologist at a different VA, and those oncologists all are...

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specialists in blood cancers, like CLL. So that way, that could be, uh, if you don't have the luxury of changing...

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but to have somebody that's helping follow along with that expertise.

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Okay, and what I'd kind of add to that a little bit is, as a physician and a CLL patient, I, and working in the VA, I can say it's highly unlikely that you'd go to a hematology and oncology clinic, and they'd be doing something wrong.

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The bigger problem is probably they didn't explain their work adequately...

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in a way that the patient understands. And so, sometimes these kind of what's called second opinion, or getting...

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another view of this is just somebody else to explain it, um,...

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and possibly simplify it in some way that, uh, that there's greater confidence. So it's not, kind of doing something wrong, because they're actually, it's hard to do...

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a really wrong thing in CLL. There's a couple options, and, uh, but they're, they're all good.

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Um, okay, so, um, uh, did that, the, the, uh, question, related question is, somebody's...

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transitioning from care in the community to a VA oncologist and now they want to say, how do I know,...

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how do I judge or evaluate the oncologist? How do I tell? And I would add to that,...

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how should this audience communicate what they want or need to their oncologist up front, so the oncologist is,...

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isn't, uh, kind of explaining it in a way that isn't helpful?

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Yeah, that's, um, that's a, those are, these are great questions.

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I guess I would suggest, um, just being upfront with the, um, doctor who's going to be taking care of you to say, like, just ask them.

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Whatever questions you have, I mean, I've had patients ask me, how long have you been doing this for? You look really young. And I'm like, well, they're surprised when I've been doing it for...

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you know, I'm like, well, I started doing oncology 20 years ago, and they're like...

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wow, you don't look that old. But that's, um, but, you know, they say, oh, well, do you have expertise, special expertise in CLL?

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Um, or, you know, how long have you been doing this for? Where did you train? Like, whatever questions you have. I mean, some stuff can be found online, but,...

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Um, but if you have specific needs or preferences, that's really important for the doctor to know.

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um, so, um, and so just make whatever, whatever questions you have, you should feel free to ask them.

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Um, and, um, and I guess I don't really have any other suggestions, because I don't, I don't really know in general how people determine, evaluate their doctors in general outside of the VA. I think it's, like,...

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yeah,...



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question across the board.

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So, to follow up on that, and to remind everybody that a doctor with...

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20 or 30 years experience in CLL, the first 15 of those...

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were kind of irrelevant, because the disease is totally different now. How we, kind of, uh, do tests to assess prognosis have changed, and the treatments have changed. And so, the younger doctors, somebody just out of training,...

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uh, is going to have, uh, , considerable experience with the newer drugs,...

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uh, and the doctor, who's kind of at the tail end of their career, uh, may, have a similar amount of experience, because these newer treatments have only been around for a few years. So, I wouldn't worry so much about the years of experience in this particular thing, unlike...

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let's say a surgeon is how many times have you done this surgery? They can just get better at it with more,...

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More treatment. So that, that should reassure some people. Okay, um, uh, a veteran describes that they don't have access because of means testing,...

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um, and the CLL hasn't been determined to be service-connected. Since he, uh, never, uh, served outside the U.S.,...

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um, and so the question is, is there a way that he can access CLL care...

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through the VA if he isn't poor and, uh, isn't...

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significantly disabled, because that's one of the other ways, if you're, if you kind of need help getting around or getting dressed,...

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uh, that gets you into the VA, if you're at that point. Do you have any suggestions, um,...

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and, uh, kind of one is kind of going to what types of veterans who served in the U.S. might still be eligible for service connection...



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kind of exposures.

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Yeah, um, I mean, again, I'm, because I'm not, super familiar with, like, all the criteria for the different categories and the means testing and all of this.

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Um, it's all, it, I can't, you know, give, like, explicit advice.

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Um, I will say that there's some, uUm, some programs that are available regardless, like I mentioned about the...

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clinical trial navigation, like, we just have a functional email that any veteran, you don't even have to be getting your care in the VA, can access that.

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So, um, so there are certain things that are available regardless.

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Um, but for the most part, that's not the case. Um, and, um, and then sometimes, um, for the, there's sometimes the people who serve in the U.S. do have certain expo, military exposures that do make them eligible, like, if you were,...

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I've had patients, like, be like, oh, I was handling jet fuel, and I got sprayed all over me, and, like, there are...

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Coast Guard had, like, fire retardants sprayed all over me, or there's certain situations like that, too...

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that they just take a little bit more work to, um, put in the paperwork for.

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Um, but, um, but otherwise, if you don't qualify, you're...

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kind of out of luck for getting care in the VA until things change and you do qualify.

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Yeah. And one of those things that can change, if you get really sick, uh, and disabled, you have a stroke and things like that, um,...

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the, uh, the VA has really good long-term care benefits, and so I do kind of, uh, kind of keep it in your back pocket, uh, as an additional...



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kind of a separate set of benefits if you develop a...

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severe disability, because that, that gets you into the VA, even if you have financial means.

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Um, okay, so we talked a little about, uh, switching oncologists, but a fair number of people, and we didn't ask in the survey about people getting dual care or co-managed care.

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But, uh, in our support groups, we have a fair number of people who go...

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to a VA and a private oncologist. And do you have thoughts about...

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is that good, bad, uh, and what are the pros and cons?

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Yeah, so, um, a lot of veterans do this, like, you have your private insurance, you like your oncologist of the VA, you want to continue with them...

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but the cost of this oral medication with the co-pays and...

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whatnot is, ends up, you know, being thousands and thousands of dollar per, dollars per year.

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And, um, and so that, like, can the VA help out? And so that's often the situation where we have this dual care...

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where the veteran is continuing to see their non-VA oncologist for...

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appointments and physical exams and blood tests but when it comes to the oral therapy, they're wanting the VA to prescribe it.

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And that's fine, and we have a system for that. It's, like, basically, like,...

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I, if I'm in the VA, it's like, I might, I'll prescribe it, you still have to talk with me, we could do phone visits,...

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um, every couple months, just to make sure the medication's going okay. I review blood tests that are obtained outside of the VA to make sure that everything's okay.



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Since I'm the prescribing physician, I need, I'm responsible, so, um, so we do do that, um, that's pretty common.

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Um, pluses and minuses, pluses to the patient, you get to keep your oncologist and have the VA pay for the medication, which is pricey.

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Otherwise, um, and, um, and then cons, um, is that sometimes there can be challenges with communication, just because...

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um, it's like, well, you know, do we send emails? Do we, we're not in the same system, like...

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if we're all in the same system, we kind of have...

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internal communication methods. Um, whereas outside,...

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between, like, it's just very fractured. The medical system is very fractured when it comes to...

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communication, um, so that can be a challenge, and be potentially a detriment to a patient who, especially if there's...

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very complex, um, the patient has a lot of complex issues, or, um,...

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or illnesses that, you know, where doctors talking is a good thing. Um, so, um...

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and then, one thing I wanted to mention in terms of co-pays, again, this depends on your level of service connection and all of this,...

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but, um, either the cost of an oral medication is...

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\$0 per month, depending on your level, or service-connectedness, um, or...

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a maximum of, there's, like, graded co-pays, but I think that...

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CLL SOCIETY

highest one is, like, \$12 a month, something like that. So, it takes something that oftentimes people are paying a couple hundred dollars a month...

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to, you know, less than \$20 a month, it makes it much more, um, affordable, which is a major reason to do this.

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So, and just kind of to expand on that, I recently kind of put into ChatGPT what...

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does it cost out-of-pocket for a non-service-connected veteran to get a year of obinatumab...

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and venetoclax, which is one of the common combination therapies, and the out-of-pocket cost was, uh, somewhere...

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about \$750, according to the ChatGPT, and that's probably as good as you could get an answer...

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anywhere in the VA, if you ask somebody, but uh, so it just gives you some idea, and in contrast...

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if you're having Medicare pay, uh, at th, uh, just the drug costs...

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are typically \$2,000, which is the cap now. It's a lot better than a few years ago. So, um, so related question.

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Is somebody wants to, their CLL service-connected,...

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um, but they want to get their VA to pay for their care outside the VA, so that's called community care,...

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um, do you have, uh, advice about how to request that, or how to manage that?

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Yeah, so you need to have somebody in the VA put in a community care oncology consult.

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Um, it doesn't have to be an oncologist who does that, it can be primary care...

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but it has, somebody from in the VA has to put in the referral to send you out of the VA, and they're, I mentioned at the beg, er, in the...



CLL SOCIETY

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recorded part, um, earlier, where I was talking about, um, all these different things, was that,...

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um, there are different criteria, so, um, so, like, drive time,...

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um, is the service not provided in the VA? Um, is it, can they not see you in a certain, like, within 30 days,...

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um, because they're too busy, and then the last one is the best medical interest, which is, um,...

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more qualitative, you know, it's just whether, in the opinion of the referring physician and the patient, it's in the best medical interest...

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to continue, or to see a non-VA doctor. So, um, that is what I'd recommend that you do, is get...

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talk to somebody and get a referral put in.

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Yeah, and that, and that can be in primary care. In fact, the best interest, the last I saw was that that was supposed to be primary care...

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provider has the authority to say that. Um, so that's, that...

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surprises, and if you were to not go out base, you live too close, they did loosen up the criteria and added this best interests of the veteran. But you have to come with a pretty good story,...

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uh, as to why it's better for you, rather than just, I like that. And this co-managed care is an obvious, kind of compromise to say, yeah, I want to...

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let's see this oncologist outside, but the VA, you know, I don't object to the VA...

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arranging for and paying for my drugs, uh, because that'll work out, uh, kind of okay for me anyways.

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Um, the, uh, question about testing, uh, there's a variety of tests...

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that, uh, the CLL site has been a strong advocate of performing before you start treatment, like the FISH and the TP53,...



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IGVH. Uh, somebody said that their oncologist didn't want to do them, and I've heard that before, is that at the time of diagnosis, they say, well, we don't need to do that now, we'll do that later.

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Uh, what do you, uh, think of that, and what approach do you take? Do you do things both at time of diagnosis and...

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before treatment, or put it off?

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Um, I typically do it right off the bat, um, just so then I can have a conversation...

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with the patient, I kind of take all that information, I plug it into this calculator called the CLL...

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International Prognostic Index, and it gives predictions about what...

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like, what, how aggressive the CLL is going to be, and what that translates to in terms of...

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survival at five years and at 10 years. So, that is, like, really, that's...

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good starting place from, uh, to have that conversation with the patient, so I kind of just do it at the beginning so we can have that conversation.

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Um, will it change anything? Like, let's say you're in the aggressive group...

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or the higher risk group, um, should you get treatment sooner? No, we don't have any data that would support doing that.

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Um, but you might be monitored more closely, or maybe it's just something you want to know, the patient wants to know, so that they can...

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kind of discuss it with their family or make certain life plans or go on a big vacation, or whatever.

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Um, or maybe consider a clinical trial that looks at whether using, doing...

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CLL SOCIETY

early therapy with some of the newer medicines is, you know, is the way to go, since all the data we have about early treatment is with older medications, so...

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there are always research studies looking at these questions, and maybe looking at, you know, non-treatment but nutritional ways of optimizing things. There's all sorts of questions and people interested, so...

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I definitely say, I like to do it from the get-go, that's just my preference.

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Um, but the people who wouldn't do it from the get-go might be people who say, well, I'm going to just monitor you anyway, so what's the, what's the point?

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Um, so I can see where that's coming from, but I usually ask the patient, and most times patients say, yeah, I'd like to have that done so we can have the conversation about prognosis.

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Um, so if your oncologist is saying no, they don't want to order it?

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Then, um, I'd suggest two different things. One thing is you can request a second opinion, like I mentioned before, through National TeleOncology.

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Um, so that's one thing we're getting another doctor with special expertise...

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um, to kind of weigh in on it. Um, the other thing is, on our CLL pathway, we do include that as part, those tests as part of the initial evaluation.

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So, um, and that pathway is publicly available on, um. Cancer.va.gov. so, um, you could always go to that website,...

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print out that thing, highlight it, and take it to your doctor, and you say, um, the VA National Oncology Program...

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Pathway has, recommends this as best practice for the VA, and,...

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um, hopefully it doesn't tick them off, but, um, but who cares if you tick them off? You're advocating for yourself, and that is the most important thing.

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CLL SOCIETY

Okay, okay. Um, different kind of question, uh, about, uh, what causes CLL? And the specific question is radiation.

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And, uh, can you comment on, uh, kind of your understanding of the research on...

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the relationship between radiation exposure and CLL. It's just kind of up front to, it's not a presumptive cause...

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but it, is it a potential cause that somebody could, uh, still seek benefit with a nexus letter, getting some, somebody to write a letter saying that this, that their exposure...

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is, is more than likely to have been contributed to their CLL.

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Yeah, um, I am not aware of radiation being a risk factor for CLL. It is for some other cancers.

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Um, whenever somebody comes to me with these questions where it's not, like, off the bat that I'm like, yeah, that's a definite,...

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I'll just do a medical literature search to see if there are any publications. A lot of times, there...

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are publications that are helpful, like, people who were survivors of atomic bombs, people who worked...

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at, um, who were near testing sites, people who were, like, there are all sorts of, um, what are called epidemiologic studies that...

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aren't specifically about veterans, but are about people who had certain exposures, and so...

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that can be helpful. Um, the main things that I think about are exposure to herbicides, so people who work on farms,...

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um, or grew up on a farm, um, of course, Agent Orange being a herbicide.

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Um, and, um, then, again, the familial, that is some, it runs in some families, together with some other, um, with other blood cancers, so sometimes...

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CLL SOCIETY

one person might have lymphoma, and one person might have CLL, and another person has multiple myeloma.

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So, other blood cancers, it can all run in the same family.

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Um, so that's another, uh, risk factor as well, but I don't know offhand about radiation, but it's something that could easily be...

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reviewed.

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Okay, some questions about, uh, research, and you mentioned the VA benefit, uh, program. Uh, is, is that, uh,...

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does that project require some assistance from the CLL Society in terms of recruitment?

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Should we send out things to our mailing list of veterans,...

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uh, telling them about that, and if they're already on a BTK inhibitor...

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they should ask their oncologist about enrolling?

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Um, sure, like, help, always happy to have, um, direct referrals, um, there might be a couple little extra hoops to jump through...

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because of making sure that the patients at a facility where,...

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uh, we already have an agreement to go ahead to enroll patients at a facility, and if there isn't, then we just have to make that agreement to happen.

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Um, and then, you know, evaluating the, um, the eligibility to make sure that the patient is eligible for the study.

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Um, but, um, our main, our main method of identifying veterans who might be eligible are to use...

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pharmacy dashboards that tell us who's taking which medications, and then reaching out to their oncologists...



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to ask the oncologist to, ask the patient if they're potentially interested in learning more.

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Yeah.

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But we're always happy to, um, do, think about direct, um, referrals and, um, and that email that I put in the talk with the...

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Nurse Navigator, that could be a good way of just, direct way of feeding that information in, um,...

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and connecting, that person can connect the veteran with the research team.

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Okay, um, there's a question about, uh, concerns about reduction in research, and, I think anyone who's followed the news about, uh, the National Institute of Health has seen that things have been canceled.

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Have you seen, uh, research within the VA or CLL-related research,...

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uh, being reduced, uh, in the last couple years, or the last six months?

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Um, so I haven't seen any particular research that's been canceled. I think the main challenge to...

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performing research in the VA has been challenges with staffing,...

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um, because there has been a, um, there's, there's, the secretary of the VAs sought to reduce the workforce in the VA,...

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um, and most of that's been done with people retiring early, um,...

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and, or taking, um, voluntary, voluntary separation, um, and so that has affected some research groups, um, because their staff have left, but then it...

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is difficult to replace them just because of the caps on hiring.

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Um, so that kind of becomes a problem. We're like, okay, we have the research study, but...



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we have trouble enrolling patients because we don't have the staff at this time.

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Um, I think there are things that are, um, we're kind of climbing out of that hole. Um, there's a lot of interest, congressional interest, like, so your representatives are all very interested in supporting...

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research to help veterans, so, um, so that is really great when we have...

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Congress coming to the VA and saying to us, we think that cancer research is important, keep on doing it.

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Then, um, that we actually get, we have to do that, because that's, we're directed by the federal government. We have to do what they say.

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Um, and so you, as patients, you're all, um, 2ell, we're all federal employees, we're working for you, really, right? So, you have to make your, what you feel known to your representatives.

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So, if you feel like research for cancer for veterans is important, please let your representatives know, and then...

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that kind of gets funneled back to us, and um, and so, it's, it's not the same as what's happening in NIH, which I think is, uh,...

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um, kind of affecting, um, a lot, and the funding is going down dramatically.

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Um, for us, it's more of a staffing issue.

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Okay. And some of the staffing issue, and knowing how things are working, is the HR department took a very big hit, uh, very early retirements and things...

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and so it's hard for the VA, even when they want to hire new people,...

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uh, to get them on board as quickly as possible. Um, other research-related question,

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they're in a research trial outside the VA and it's not a fully covered, uh, trial.



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Can the VA, um, kind of approve payment for drugs for non-VA-based trials?

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So, um, maybe? So, the way that, so they can't do anything retroactive, so it can't go back.

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But can they do it going forward? So in order to make that happen,..

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um, you would need somebody to put a referral in the VA, to put a referral...

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for community care, outside of the VA, and um, and then, it gets to that facility where you're getting the medical care, where you're part of the clinical trial.

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And there's a directive, or there's a guidance document that is, um,..

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explaining more information from a VA directive about community care for oncology that...

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states that it can, the oncology care that's approved through Community Care can include care on a clinical trial.

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So, um, so once that gets approved, then the, parts of that clinical trial, which are considered standard of care,..

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um, like, if there's a treatment that is.

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Okay. I'm going to cut you off there, uh, because we're just about out of time, and I just want to give you, there were a number of questions that we didn't get to, uh, some of them were very specific to, here are my lab tests, and...

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what should I do, kind of thing. Uh, we will, uh, make an effort to try to respond to those, or you can send those...

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to the Ask the Expert on the CLL website. I want to give Dr. Friedman a chance to kind of wrap things up and see if you have any closing comments.

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Thanks. This has been a lot of fun, and um, and I really appreciate all the questions and the interest, um,..



CLL SOCIETY

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and hopefully I've given you a snapshot of a lot of the different efforts that...

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have been undertaken in the VA, um, to address the care of veterans with CLL and other cancers as well.

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So, I hope that, um, you all do well in your journey with CLL.

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And I hope to connect with you all again later. Thank you.

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Thank you very much.

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So, thank you for attending. Uh, there's a post-event survey. Your feedback is very important to us, help us plan future events. Uh, and our next event is Understanding Medicare...

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In CLL, What Patients Need to Know, and that'll be on September 18th.

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If you could also kind of consider in your annual giving, and this year, uh, even if you're not taking,...

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If you're not itemizing deductions, you can deduct up to \$1.

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Please consider CLL Society as one of your sources of charitable giving.