Webinar Transcript
Protecting Against Infections When Your Immunity Is Impaired
October 14, 2025

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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 Liza Avruch, Program Director with CLL Society.

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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 donor support and grant support from our industry partners.

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At this time, I'd like to welcome our moderator. Thank you.

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Thank you, Liza. I would like to welcome our audience to today's events. I'm Dr. Brian Koffman, Co-founder Emeritus with CLL Society.

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And we are joined by our speaker, Dr. William Werbel,..

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the Assistant Professor of Medicine in Transplant and Oncology Infectious Disease Sections of Johns Hopkins University...

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School of Medicine and the Associate Director of Epidemiology and Quantitative Sciences at Johns Hopkins Transplant Research Center.

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For your information, we will be answering audience questions at the end of this event…

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so please take advantage of this opportunity and ask your questions in the Q&A box.

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Before we begin, 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…

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differing viewpoints, especially regarding the management of CLL and its complications.

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Now it's my pleasure to welcome Dr. William Werbel.

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Great, well, thanks for the introduction. As mentioned, my name is Bill Werbel, I'm a doctor and a researcher at Johns Hopkins, where I take care of patients…

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with cancers and transplant histories, and I had the pleasure of speaking last year on some of these, uh,..

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topics related to infections in people with CLL, and I kind of wanted to…

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follow-up on a tweaked version here, focusing on protecting against infections when your immunity is impaired.

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So, as a brief outline, we're going to start with kind of a status report of infections in the community now...

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with a little bit of forecasting. Then talk about general and CLL-specific risks for infections, kind of how we can personalize risk to you, the individual.

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And to do that, we need to do a little bit of an immune system review, and think about how certain medicines we might take, or conditions we have…

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impact different parts of the immune system. Then we'll move into ways to reduce risk, both behavioral and pharmacological, like with vaccines, for example.

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And we'll close with some updates in how we can prevent viruses, and some exciting antiviral advances that are…

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moving through the trial phases and kind of ending up in some of the…

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medical literature. So first, for the status report. So, the CDC does have a number of dashboards that continue to be updated, and so this is one from the National Respiratory and Enteric Virus...

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Surveillance System, kind of a mouthful, that looks at the up and down of viruses in wastewater, like sewage, throughout the U.S.

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And I want to point out, kind of, two things. We're over here on the right to say that the COVID-19 late summer wave, which we've had for the last couple years, kind of crested and seems to be going down, still considered moderately…

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prevalent in the community, but that gray, uh, dotted line here is still pretty high, and kind of still going up, and that's actually what we would call…

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rhinoviruses or enteroviruses. Rhinoviruses are the common colds, and they're very closely related to enteroviruses, which cause, for example, stomach bugs, as well as...

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sometimes, like, flu-like symptoms, those are particularly common in the fall and sort of in the late summer, so that's something where if you have…

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cold symptoms now, or stomach upset, and you have a negative COVID test…

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that's probably what's, what's kind of going through the community.

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So that's just worth being aware of. It may not always show up on tests we do, for example.

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That said, you know, the COVID, uh, story still remains pretty dominant, particularly for people who have…

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cancers or transplants, because it can still cause problems, and it's worth just being up to speed on the variants that are circulating.

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That big purple bar in that middle box here is the CDC estimate of, um,..

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the most common variants around, and it's likely to be mostly this one called XFG.

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You don't have to remember that. The main things to highlight are that, and I'll sort of circle them on here,..

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with the arrows here are the ones that are circulating in the community, including XFG at the bottom there, and they're really children or grandchildren of…

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the vaccine strains for this season. So, they're, they're not totally new variants, they're kind of related, um, evolution of the ones that we think the current vaccines should decently cover.

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So that's good. Circled here in red are the vaccine strains that you'll see in the Pfizer vaccine, the Moderna vaccine…

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and Novavax. So, they're not too far away. Also good, and something that we will talk a little bit more about, is that, based upon just recently released information from the drug company that makes this…

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monoclonal antibody called PEMGARDA, or Pemivibart, it does seem to be active against XFG, so for people who are using this as an add-on to their COVID protection…

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it would be a reasonable choice for this fall, because it seems like it should be active. So that's good news.

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Uh, now, there are other, uh, viruses in the community that were definitely in the headlines, and they've kind of been in and out, and what I talked about last year is, was what we call bird flu, right, or H5N1, which was a big problem a year ago. What's good is in the last…

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few months, there have not been any recent human cases that have been reported, and no clear human-to-human transmission.

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So that's good. There have been ongoing outbreaks, though, in mammals and in poultry in the US, including backyard flocks.

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And actually, the Department of Agriculture keeps track of this, and…

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there are right now, for example, in the Upper Midwest,..

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uh, like in Wisconsin, Minnesota, there have been some pretty big outbreaks and flocks, several million birds affected, so clearly it's still circulating, it's something that we still…

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are going need to be keeping an eye on, because we're always worried about the potential for there to be…

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viral changes that lead to our being more susceptible to getting things like bird flu.

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So, uh, present, but not going through humans to a degree that we were worried about a year ago.

(Note to reader: video cuts out for a few seconds, no sound, speaker's slide refers to US measles outbreak)

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century, um, that's represented by these vertical blue lines at the far right of this plot here. There are over 1,500 confirmed cases, a vast majority in people who are either unvaccinated or of unknown vaccine status.

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There were, unfortunately, deaths, including in children. And probably many more cases in the community than were detected.

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Uh, what's good is it's fading, but it's not yet gone, and I actually frequently visit this Johns Hopkins resource here. It's just like a measles vaccine tracker, or sorry, measles tracker.

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And it showed that in the last couple weeks, there have been about 50, 60 cases, predominantly, uh, actually in the area of, uh, southern Utah or northern Arizona.

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There are some ongoing other outbreaks, including one in Minnesota and Wisconsin, and a pretty bad one that's ongoing still in Canada that's moved…

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further west. So, there are regions where there's likely higher circulation…

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in populations that are under-vaccinated, and these hot spots are worth being aware of if you're a person who's at, you know, higher risk for measles. Something we will chat about a little bit later.

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So, with that, we can do some, tentative forecasting. What's good is that the COVID wave, this late summer wave, is…

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fading, and likely will do so in the next 2-4 weeks, and enter a bit of a lull, and that's when we get into, kind of, the traditional respiratory season, right? So tends to begin in late October and early November, first with RSV in the community...

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which is usually circulating in children before we really kind of find out about it.

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And then they all kind of crest in late November and into December and up towards, basically, New Year's Day…

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with influenza and COVID as well. And that's due to a lot of factors, the climate and, you know, holiday mixing, and general human behavior. And we would anticipate a relatively similar…

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trend as last year which was actually a particularly bad flu season, so perhaps, or hopefully it would be a little less bad than last year, but it's hard to tell.

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Regardless, now, talking October is a great time to get vaccinated versus all these vaccine-preventable illnesses, RSV, flu, and COVID.

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It's worth noting that the greatest protection against these, particularly flu and COVID, is in the first two to three months after vaccination.

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So, thinking about the timing and getting us through that hump in late December,..

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um, is important. Interestingly, RSV vaccine protection may be more durable,..

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uh, and we're still learning about that. But it's important to know that, you know, these viruses do circulate through the winter and sometimes into the spring, particularly…

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flu, which tends to have a second sort of tail or hump…

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with influenza B in March and April, and that's something to be aware of if you're planning, you know,..

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traveling, or timing of your flu shots, etc. Alright, so that's the first bit…

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about the status report, and now we'll move into how I, and we, you know, how we assess infectious risk in people with CLL, and trying to be in a sort of tailored…

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evidence-based fashion. So, as an infectious disease doctor, what I do when I'm looking at a chart or going into a room or talking to somebody via email,..

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we really work to assess this thing we call the net state of immunosuppression. It's basically a buzzword…

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that says, like, how immunosuppressed are you? And it's really the sum of everything about you as a person,..

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the medicines you take, the conditions you have, that will determine how severe your immunosuppression is,..

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how bad your immune system is. And that has very specific, like, kind of mapping and links to, um, infection risks.

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And all these factors can contribute: importantly, your age, other medical conditions like diabetes or kidney disease, or liver disease, these are actually immunosuppressive.

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Obviously, the medicines you take, not just which, but how long you've been taking them, how are the doses,..

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and then, lab tests that you or your doctor would do, that we can look at and say, these are risk factors for, you know, you have a low blood count here, a low blood count there…

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etc. And I think I'll say the last line here is important for people with CLL, often, is the breakdown of our natural…

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barriers, so your skin, or what we call the mucosa in your mouth or in your gut.

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Uh, or, uh, those are, like, very important parts of your immune system, and obviously things like chemotherapy or things like intravenous lines, or ports…

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break into that, and that will make you, in a way, more immunosuppressed, because…

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your normal barriers are being impaired. So, these are all important factors when we sort of take a picture, a snapshot of your risk.

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What's also important is not just the now, but the past.

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So, um, and just your sort of environment and your exposures.

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Obviously, if you're a person who lives in, you know, a,in a,by yourself, in a like, in a cave or something, right? You're not going to be interacting with humans, so you're at risk for other infections from humans are lower, but…

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living in a cave has some potential risks associated with the environment, and it's not just…

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your infection in the moment, but also reactivations of old infections you might have had in the past that your body locked away before you had CLL or before you started certain medicines for CLL.

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So, there are some kind of buzzwords that I think about…

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that are important, you know, the ones that are, I think…

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probably most relevant to you all have to do with environmental exposures.

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So, there are certain links between gardening and exposure to organic, you know, matter, um, camping, etc., woodworking, that raise some risk of certain…

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infections like funguses or fungi. Obviously, travel matters, not just because you may interact with other people or be on airplanes and such, but you may interact with…

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you know, uh, ticks, mosquitoes, etc., which is less of an issue as we move out of the…

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summer for most people. And then just other, you know, factors that are listed here that,..

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that kind of end up on the list as we sort of assess...

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infection risk. So, with that information, the net state of immunosuppression...

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and life experience and exposures, we can kind of map this to people with CLL and why this, you know, matters with respect to infections. Most people with CLL are older, 60 or 70 years of age, with multiple other health issues that happen as we age.

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And CLL in particular, saps, you know, takes away the normal immune system, certain parts of it, particularly…

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cells called lymphocytes, that's the first L in CLL.

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Particularly the ones that make antibodies, so you have trouble making good antibodies.

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Then the treatments you get for CLL, like steroids or chemotherapy, transplants, will knock off other parts of the immune system, you know, as sort of almost a side effect.

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And that puts you at risk to get infections, it makes it harder to fight them off…

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and also reduces some of the protection associated with vaccines. It kind of puts a ceiling on some of that vaccine,..

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say, uh, benefits, if you will. So, I've shown this graph in a couple different settings before, this kind of picture about how you might think about yourself sitting in a chair, or on your phone listening to this.

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And how risk is on a spectrum. You know, your age is a spectrum from being, you know, a 20-year-old to being in your 70s.

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Your medical conditions can accumulate over time, those influence things like this is particularly for COVID risk but actually can be mapped to most…

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viral infections, but what we can modify are vaccines, right? So, someone who's had a recent updated booster would be at lowest risk.

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Whereas if you've never been vaccinated, you'd be at higher risk.

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And then, really relevant to this talk, is this kind of very personalized immunosuppression. People who receive, um, certain therapies to get rid of their lymphocytes, for example, are going to be at highest risk for…

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viral infections, and those therapies interfere with that ultimate benefit of vaccination. They're important, vaccines are important, but it does, like, put a bit of a ceiling on how protected you might be.

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Now, that was mostly for, sort of, regular respiratory viruses.

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But, uh things change depending on what infection we're talking about, and I just wanted to bring measles back because it's been in the news, and people have asked a lot of questions...

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about it, and I made up this basically, uh, a version of that spectrum for lower to higher risk for measles.

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That you can, again, think about your personal, you know, where you might fall on this.

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Interestingly, birth year matters a lot because people born in the ‘40s and ‘50s likely had measles when they were a kid, and that actually provides a lot of lifelong…

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beneficial immunity, despite, obviously, the dangers of getting measles as a child.

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What it also does, it creates a little bit of a soft spot, though. People born in the ‘60s and ‘70s, who are relatively older…

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may not have had measles as a kid, because the vaccines were rolled out, but they also may not have been fully vaccinated because vaccine recommendations changed over time. So, when I'm talking to people, you know, particularly in their 60s,..

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for example, you know, that actually might be a person who should be pretty concerned about measles risk if you, you know, haven't had updated vaccines later in life.

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Now we know, you know, two live attenuated MMR vaccines, which are really the cornerstone of protection, and that's…

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going to make you lower risk. If you've only had one vaccine, or you've been unvaccinated, then you're going to be at higher risk.

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We have biomarkers, like lab tests, that are, um, kind of like a surrogate for what your risk would be, and we do have a measles antibody test.

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If that's positive, you're excuse me, likely at lower risk.

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Whereas if it were negative, uh, you would potentially be at higher risk, though we don't know that precisely…

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if it's for negative despite your being vaccinated, we don't totally know what that means.

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Um, but you can look at immunosuppression, come with sort of rules of thumb…

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related to people with CLL or transplant history. If you're further than a couple years away from transplant, and this is also when people also start to get vaccinated again with, like, the MMR vaccine, that's going to be a lower risk situation versus, particularly in the first year after transplant,..

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if you're on minimal immunosuppression, you know, one or lower doses of them to prevent things like graft-versus-host disease, you know, that would be a lower risk situation versus being on multiple ones.

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If you have normal functional lymphocyte counts, ones that work, that's going to be a lower risk. Remember, those fight off viruses…

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versus having low blood counts or low immunoglobulins, which means low antibody, that you haven't been replacing with something like IVIG or injectable, um,..

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you know, uh, subcutaneous immunoglobulin, which many people maybe taking. So, this is just something to sort of like that COVID graphic to kind of be able to map yourself and then think about...

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risk for this particular virus. So, trying to empower you all there.

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To further, hopefully, empower you, I just want to talk about the immune system.

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A little bit of a primer on, you know, a little intro on what that is, and then think about it,..

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you know, uh, you as a person, what your lab test might show, and also what medicines you might take, and how that affects parts of your immune system. So, here are kind of some of the big ones that show up on your blood counts and are things that your doctors may talk to you about. They're really two to focus on. The first is neutrophils.

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Many of you are familiar with the concept of neutropenia, meaning having low blood neutrophil counts.

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Usually, it's less than 1,000 or less than 500 would be the highest risk situation for infections.

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Neutrophils eat, eat foreign invaders, right? And if you don't have them, you're at risk for particularly bacterial infections, but also…

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fungal infections, particularly if you have long neutropenia for a long time, stuff from the environment, you know, that you might breathe in or get into your, um,..

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skin. I'll kind of skip macrophages, because they're not typically focused on, but they're kind of like neutrophil cousins.

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Uh, but lymphocytes are really important, right, for people with CLL. We already talked about B cells, which tend, which make your antibodies...

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to fight off viruses or certain, um bacteria, and also T cells, which are the other part of your lymphocyte counts that can be low...

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and they're required for alarm signaling, for helping your body make response to things like vaccines. These are helper signaling CD4 cells…

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or killing and removing infected cells, and those are CD8, or often called killer cells, killer T cells.

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These are really important for viruses, but play some role for other, for other, um, type of infections.

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Uh, and then there's a whole host of medicines that people take in clinical trials and for other things that affect different parts of the immune system that are probably beyond the scope, but I'd really focus on neutrophils and lymphocytes.

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Now, speaking of which. Now, if you can look at what medicines you take, what cells they affect, and then what things we should try to do to reduce our risk of infection.

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Here's another plot that you can read across, and we'll go through some of the three biggest groups of medicines that people with CLL take. The first would be steroids, like prednisone, or dexamethasone.

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Uh, the cure and cause of all of life's problems, basically steroids, because they affect all immune cells.

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Um, and it's really impacted by the dose that you take, particularly more than, like, 20 milligrams of prednisone, and how long you take it for, you know, a few weeks or more. That really starts increasing your risk of infections.

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The most common infections people would have would be bacterial infections, for example, of the skin, or pneumonia, as well as certain viral infections, you know,

ranging from ones that you can get, like, the cold, like, common colds, as well as things like herpes viruses,..

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for shingles, which can come up and reactivate. And also, uh, you'll be noticing for each of these, I talk about hepatitis B.

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It's a relatively common virus that people get, and that can reactivate...

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uh, when you're on higher doses of immunosuppression. So for steroids,..

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each of these sort of categories in the right most column, herpes viruses, hepatitis B,..

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funguses, fungi, or this pneumonia called pneumocystis…

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can all be at high risk, and this is why you would be on, respectively, things like Valtrex or acyclovir.

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You might take a medicine like fluconazole, or something like posaconazole, these are medicines that fight fungus...

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or medicine like Bactrim, uh, which fights against pneumocystis and prevents…

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that. So, this is the sort of logic behind why your doctors may put you on these medicines or not if you're on high doses of steroids for a long period of time.

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The second category is a drug called anti-CD20 drugs, the most common drug would be something like rituximab or Rituxan.

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or obinutuzumab, which I think is called Gazyva. I don't know all the brand names here, but these are B-cell-focused medicines, and we talked about that's the kind of lymphocyte that makes antibodies.

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And the two things, if you take them away;..

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A, you can't make antibodies, so you won't actually make good responses to vaccines, and so you're at high risk for things like viral infections,..

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like we talked about, influenza, COVID, etc. Uh, as well as some other, you know…

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infections that are a little bit low risk. So, most people who get…

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things like rituximab will be on medicines like Valtrex to prevent herpes viruses. If you have a history of hepatitis B, you'll definitely be on medicine to prevent that.

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And it depends a little bit on your other medicines as to whether you'll get…

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drugs to prevent funguses and things like that. So that was anti-CD20 medicines, which many people get.

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And then the last are drugs called BTK inhibitors. So, these are ibrutinib or acalabrutinib, or zanubrutinib, they're called, like, Imbruvica or Calquence.

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Um, very common, amazing drugs for CLL. Many of you may be taking that.

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Uh, these also affect the B cells, so it's the same kind of conversation we had with rituximab.

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But they have a little bit of weird of kind of, like, side effects or off-target effects, where they actually affect some of those neutrophils I mentioned.

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And so not only are you at high risk for viral infections, but as your doctor's probably told you, you're also at higher risk for fungus...

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uh, which is a little bit different than some of this…

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rituximab-type medicines. And so, most people getting BTK inhibitors are going to be on things like Valtrex to prevent shingles,..

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um, and also medicines to prevent fungus and pneumocystis, which is this kind of fungus pneumonia.

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So those medicines, like the fluconazole medicine or, you know, the Bactrim.

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And this is the whole reason behind looking at a person,..

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getting them that state of immunosuppression of this person...

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and try to prevent them from getting sick. So, it's a little technical, but I think you're hopefully up to speed here.

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You know, I was specifically asked to follow-up on one of the more complicated parts of CLL treatment these days…

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which is called bispecific antibodies, or sometimes called BiTES, and there may be some of you on the call who are taking these medicines.

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I kind of think of it as, like, a CAR-T, so like a, like a transplant in a bottle.

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Uh, these drugs, uh, have been studied very well in myeloma, multiple myeloma, but now they're useful in FOMA (follicular non-Hodgkin lymphoma) and I listed a couple here.

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These long names that end in “ab”, because they're antibodies…

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and, uh, they're specifically designed…

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to take your T cells, you know, those virus-killing cells, and then engage your…

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instead of fighting a virus, to fight your B cells and destroy them.

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So, they destroy all your B cells like a rituximab or a BTK inhibitor, but even more deeply.

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And so people get really severe long-term hypogammaglobulinemia, which means very low antibody.

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And that means you're, again, at risk for things like viral infections, or pneumonias, or recurrent sinus infections, and a lot of people end up on getting immunoglobulin replacements, like IVIG or injectable…

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once. And so, these are becoming more and more frequent, and are really very immunosuppressing.

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The other part that makes them tricky, is usually, if you receive these drugs, you're many people who receive steroids or other medicines, like this one, tocilizumab...

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to try to reduce the inflammation associated with the antibodies. Sometimes it's called CRS.

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You might have heard about this, like, cytokine release syndrome, like these bad humours that get stirred up when your B cells start getting destroyed…

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by the BiTES. And this combination, as you see, you're sort of stacking medicines that impair the immune system in different ways. Like, we talked about steroids, they all affect…

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all the immune systems, and so now, it's not just the hypogammaglobulinemia virus problem, it's bacteria problems, or fungus problems when you combine this.

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So, I do think of these bispecific antibodies as kind of like…

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rituximab are kind of like the BTK inhibitors, where these are the medicines that you get put on to prevent viral infections, like the Valtrex medicines, or…

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medicines to keep hepatitis from reactivating. But we also now likely will give people IVIG…

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because of the really long, persistent low antibody situation.

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And it really depends on what, who you are, and who your doctors are about whether you get these…

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kind of right out the bat, or when it's been shown that you're getting infections.

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Alright, so I just want to give an example now. Putting that all your that information together…

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to look at these common viruses like herpes or shingles, they're all called herpes viruses. Many people, most people have had them in their life, and they've been locked away and don't cause problems, but when you get immunosuppressed, they can come back up. So, this is a table straight from the National Cancer Center...

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guidelines, which kind of rank people at low, medium, and high risk of getting these, like, shingles problems.

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Uh, and then CLL, I'll just highlight here, or people who've had transplants, and…

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how we can pull from this now that you're all experts, into who and why should you be on medicines to prevent things like herpes or shingles…

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to sort of highlight them, it's people who have…

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neutropenia, or really low lymphocyte counts, which is very common in people with CLL, these good lymphocytes…

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pretty much all those people are recommended to be on Valtrex.

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Additionally, if we're getting, like, intense medicine to treat CLL, or after bone marrow transplant, you're going to be on a medicine like acyclovir or Valtrex…

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for a long time. And lastly, getting back to that second part, where it's not just the net state of immunosuppression, but…

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your history and your exposures, if you're someone who's had cold sores before, you've had shingles in the past.

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That's a reason, even if you're not on a lot of medicine, to be on the Valtrex to prevent the reactivation, because you're, for some reason, at higher risk for that happening.

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Just to kind of your body and your interaction with viruses.

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So this is a very practical, uh, kind of summation of what we just talked about.

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Alright, so that's the more technical, now you're an immune system expert. Now I want to talk a little bit more about just our general approaches to preventing ourselves from getting sick,

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particularly for someone with, uh, immunosuppression. So,..

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this sounds basic, but it is important. Washing your hands is really important. Hand sanitizer helps but turns out it actually doesn't work for all viruses, and I want to highlight two here.

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I'll start actually with the second one, enteroviruses, which are common right now, as I said in the community, the gray dotted thing from the first slide. For example, uh things like hand, foot, mouth, mouth, that's a kind of enterovirus that many people,..

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kids in particular, get in the late summer and fall. Also, norovirus, which you probably are familiar with as, like, the cruise ship virus, when you have hundreds of people vomiting on a cruise ship. Part of the reason it's,..

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uh, people are sick like that is because it really requires vigorous hand washing, not just hand sanitizer to you know, uh, to sort of wash off. Also, it's very contagious, and just little bits of it can make people ill, so…

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all the more reason to wash your hands before you eat,..

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after when you come back from being out in the community etc., this time of year.

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Now, as we start moving into, um, you know, flu season...

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being, I would say, cautious or just very calculated about how you interact with large groups of people.

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Uh, when there's high virus circulation, particularly in settings that are poorly ventilated, like indoor settings, like massive...

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you know, uh, you know, you might be in church, or you might be in weddings and things like that, and minimize those interactions are the safest way to keep yourself safe, but…

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otherwise, wearing a high-quality mask is going to be a good idea when you get into November or December, January.

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Uh, that's why you can protect you, yourself. Additionally, ensuring that close contacts around you are contributing to a ring of protection is really important, whether that's at work,..

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you know, at church, at school or in your home. You know, if I had mentioned, and we'll talk further about if you have CLL, you're sort of ceiling on how much you could be protected by things like vaccine is reduced. You can still get ill.

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And so having people who are healthy around you, who are...

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maximally vaccinated and boosted will protect you by association.

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Additionally, those contacts should also let you know if they're feeling ill, or even test themselves, or if you're going to be at a gathering where people aren't going to be masking, and, you know, think about that as we go towards the holidays. That is important if you're going to be with somebody who's immunocompromised.

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And that's all the, kind of, behavioral stuff, and then now we'll talk a bit about…

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immunoprophylaxis, so things that we can do with ourselves, like getting vaccines, or if we can't mount really great vaccine responses, having things like preventative antibodies on top.

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And we already kind of talked about prophylactic medicines to prevent things like, you know, shingles.

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So, the how and why of vaccines and their limits. So, why do we get vaccinated?

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You know, it's basically getting a head start on seeing some important part of an infection before it's the real game time.

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And sometimes we need to be shown those parts a couple of times. That's why sometimes vaccines are, like, you have to get two in a row...

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or even a booster, every so often to make sure that we're not, um, sort of forgetting about that,..

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that head start. Ideally, the vaccines will stimulate your B cells to make antibody and store that memory away for a rainy day, and those antibodies will bind and fight off and eat…

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invaders. But as we talked about with CLL, B cells are a significant issue, and that's why people with CLL tend to have the worst antibody production after vaccination.

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What it can also do, ideally, vaccines are supposed to build the T-cell memory, those other lymphocytes that help send alarm signals when there's an invader, also can kill infected cells, and that's actually really important…

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to prevent severe disease, like severe pneumonia from influenza, uh, things like that.

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And so that can help, that can happen even if you don't have a lot of B cells. So this is a reason why vaccines…

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are important for people with CLL, even if you're not making really high antibody levels.

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Uh, but, you know, as we discussed now a couple times, if you don't have enough of these B and T cells because of the medicines you take, or the cells are weakened,..

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because of CLL, etc., the vaccines are going to be less fully protective, so we may have to give…

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more vaccines or boosted a different kind of frequency to try to…

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get you a little bit more protected, um, when, as you enter the community.

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Now, because there is this ceiling a bit, a bit of a limit, there have been development of these passive…

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immunity prophylaxis, with which many of you, I'm sure, are familiar.

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And the two main things are either you have what they call polyclonal, like donated antibodies from some healthy blood donors, that would be, like, IVIG…

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which has been shown, and you can see in this plot here on the right, it contains antibody against things like the Omicron variant of COVID, or influenza.

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Or, you can get a high dose of a,..

(Note to reader: video cuts out for a few seconds, no sound, speaker's slide refers to high dose of a specific antibody, monoclonal antibody)

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And we get, you know, you have to repeat this, though, because it does wash out of the body if you're somebody who's persistently…

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hypogammaglobulinemic. Um, which may be as many as a third of people with CLL when they're newly diagnosed, let alone before they start taking medicines like the, um,..

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bispecific antibody or something. And if you're someone who's had recurrent sinus and lung infections, and you have low…

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antibody, IVIG is recommended. Now, that, again, this is a little contrast to monoclonal antibodies, which are for a high-risk person who has a specific thing you want to prevent.

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And right now, the main one in the community is preventing COVID, which we'll talk about.

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Uh, but there are ones in development for other viral infections…

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and the strength of these antibodies is also their weakness. As we've learned through the pandemic, for example, they're very specific to a virus at a given time point, and if the virus changes, that could escape the drug and make it no longer active. That's why I made that point…

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about that Pemgarda medicine, because it does appear active against the XFG variant, but I can't promise that three to six months from now, it'll be active against whatever variant is common, uh, present in the community. So, we always have to be aware of that…

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with monoclonals. Okay, and as we kind of wrap up, the last one of the last big things to talk about are just some related recent developments in preventing viral infections…

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in immunocompromised and immunocompromised people. And, uh, the best actually, just in the last several months, there's been quite a lot, uh, there's been quite a lot of information on RSV vaccines, particularly even in data in people with cancers and bone marrow transplants. So,..

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the main question we've, many of us have had, and I do research in this as well, is how good is the immune response to the vaccines, like the...

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Moderna vaccine, the GSK vaccine, the Pfizer vaccine, these are the three that are available,...

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in people with cancer and after bone marrow transplant. And kind of unfortunately, the answer is there's a huge range in how people appear to be responding. If you look at this plot on the right here, this is on the horizontal axis is time since bone marrow transplant…

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and these plots are whether people are showing good antibody or good T-cell responses to vaccination, and people very close to transplant, like three to six months, which is when many people are receiving…

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RSV vaccines. In only about one out of six people showed an antibody response.

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Only about one out of three showed a cellular response. If you get towards over a year from transplant, now you're getting up to maybe more of, like, 40% of people are getting antibody responses, and as you go further out, it's even better.

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This is because your net state of immunosuppression is higher.

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But it's a bit of a trade-off. You don't, you know, the longer you wait, the more there's a period without being vaccinated, so this is how you work with your doctor to figure out exactly...

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how and when to get vaccinated. So, across several studies, it shows that one dose of the RSV vaccines, um,..

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is very variably, uh, creates an immune response. It very depends on, much depends on the person.

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Now, the obvious follow-up is how well in the real world are these RSV vaccines preventing severe disease?

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And it looks like there's decent protection against severe disease, like getting hospitalized with RSV for a season, probably a bit worse for people who are bone marrow transplant recipients, and that's compared to about 70-80% in the,..

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you know, average healthy older population. Uh, but there's one study that followed people with transplants, um, out to a second season, and that effectiveness really dropped down to, like, basically negligible.

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And this really raises a couple questions. Do we need a booster shot?

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Uh, either in the beginning to get us up there, that prime boost, you know, how people may need two to start, or do we need another booster at a year to kind of, you know, make sure that our memory and our antibodies are as high as they can be, you know...

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after, uh, getting vaccinated. The second question is, which vaccine is the best?

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We do not know that. There's some very, I would say, preliminary data that show that adjuvanted vaccines, meaning ones that have an immune booster in it, like the GSK vaccine, may…

(Note to reader: video cuts out for a few seconds, no sound. Speaker's slide refers to the GSK vaccine but does not provide his next point)

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Also, we basically have no information on the mRNA-based RSV vaccines, so there's a lot of research that has to happen…

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pretty urgently in the next couple years, and I'm fortunate to be a part of that.

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Now, a couple exciting antiviral advances that will probably…

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trickle down into your care. The first we already talked about a couple times now, is monoclonal antibody,..

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that PEMGARDA antibody, which, you know, showed around 80% reduction in symptomatic COVID…

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by about 6 months. And that's, I think, the plot here on the right,..

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the top, uh, kind of graph are people who didn't get PEMGARDA, and the bottom one are people who did, and even when there are these virus waves, people can get infected, but it happens about 80% less likely, as long as...

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the variant that is circulating appears to be, uh,..

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um, uh susceptible to PEMGARDA, which is the case with XFG. The second that's really exciting, particularly as we just talked about RSV, is the clesrovimab...

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which is an infusion, a monoclonal antibody against RSV that we're trying to get for adults. The child, the baby version, has already been out and works really well. And so we're hoping to do...

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the adult version for adults soon. And it appears to be effective, but we don't have the final, final data yet. This is still finishing up their trials.

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So those are monoclonal antibodies. The second would be a long-acting antiviral. We talked about how antivirals are one way of preventing infections or reactivations.

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And there is one in production that's been in trials now for…

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influenza. It's basically a cousin of Tamiflu, but lasts a really long time, and it's more potent.

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And in some data that had been released by the company, back in the summer,..

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it does appear to, over about a 6-month period, reduce the risk of influenza-type illnesses…

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by about two-thirds in healthy, unvaccinated adults. How well that translates to people with CLL, people who have flu shots, we don't know. But I do know that it's something that's very, uh, felt to be an exciting development.

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The last two things, just sort of “yeah” science kind of things, are…

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this discussion about nasal sprays to prevent or prophylaxis against COVID-19. I've been asked about this over the last few years for a bunch of different products, but these are the two that actually have been in clinical trials,..

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um, that I think are reasonable. The first is a medicine called azelastine, which is like an over-the-counter hay fever...

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spray, which showed in one study that, uh, people who are less likely to get COVID, these are not people with cancer, these are just sort of all common adults,..

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um, and actually reduce the risk of some other infections, like…

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rhinovirus, a common cold, to by about half. Uh, there's a little, I wouldn't probably, uh, this is not, to my, in my opinion, something that's very strongly proven to be something that's effective, because there's some quirks about how people got the medicine. Like, they took it five times for three days if you started feeling ill, and could that interfere with,..

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you know, positive testing for certain viruses, I don't know.

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But it's a pretty benign medicine, and something that's worth, I think, continuing to follow up, particularly in people who are immunocompromised.

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The second is an interferon alpha, it's a different kind of nasal spray, and this was actually studied in people with cancer, including some people with CLL. Now, this is a very, I would say, um, uh, reasonable mechanism. Interferon is something that…

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fights off viruses, we know that. It actually has worked...

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preventing or treating COVID before. I've actually used that personally in a case of a...

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really refractory case of COVID in a person with CLL, actually.

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And so they created a nasal spray, and they compared it to placebo, just like a saline spray.

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And people were about half as likely to get COVID during follow-up, these people with cancer. So that was, I would say, uh, pretty exciting, though, uh, this is mostly early pandemic information, early pandemic data, and how well that translates to people now who might have had 3, 4, 7 vaccines,..

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we don't really know. But I'm also interested in learning more about this going forward, because it seems to be pretty safe.

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All right. And then the last development that is probably, uh, less exciting, but worth talking about as we kind of close down, are some of the challenges that you may be thinking about or facing related to these shifting policies and vaccination and medicines and…

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sort of public health stuff to prevent infections in the community. And I think it's just, we'd be remiss if we didn't talk about how,..

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you know, in the past, been really high agreement between what the US CDC or the ACIP, which is the body that helps make, um,..

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recommendations for, like, the vaccine schedule, what they say, and what major medical societies, like...

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the Infectious Disease Society or the American Cancer and Oncology Group,..

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you know, uh, but now, unfortunately, we have some conflicting recommendations, and this is, at the very least, confusing, I would say, to patients.

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So, I think it's important to get feedback on vaccination, safety, and, um, benefits from your physician team.

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If you're looking for additional outside information, I've looked at the Vaccine Integrity Project from the University of Minnesota. Link is here. Additionally, the ID Society that I'm a member of, Infectious Disease, has a nice, kind of…

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bunch of resources at this, um, web page to, for both patients and for doctors...

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if you're looking for objective, kind of, available information.

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Uh, the question about, will these changes in policy affect your access to vaccines? Some of you may be trying to get them this week.

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It is a bit of a moving target, and it seems to vary by state, pharmacy, and insurance. I think…

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if you're an adult who's on Medicare, you know, or greater than 65 years of age, or you have an immunocompromising condition like cancer, you should be able to have…

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both access to vaccines and should be covered by insurance.

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When in doubt, you can get a prescription from your doctor that may help just sort of,..

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or a note, to just sort of get over that, uh, hump, if you're in particular states that are very restrictive.

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But what's less clear are the access and coverage, particularly state by state, for healthy, close contacts, like people who are hoping to be part of your ring of protection, or healthcare workers, like myself, um, who might have to pay out of pocket,..

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Or require a prescription or a test that you have some health condition. So, this is still, like I said, a bit of a moving target. Fortunately, it does seem that certain states, many states, as well as actually a consortium of insurers...

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have committed covering COVID-19 and flu vaccines for this season, so I really think that most people should be able to get what they want to get, but…

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uh, it's a bit less certain than it had been in the past.

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I just think it's just an important perspective as you, uh, kind of try to get yourself safe for the winter.

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Alright, so with that, I just want to summarize, um,..

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number one, that respiratory season is on the horizon. We're about to enter the traditional…

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time for RSV, flu, and COVID, so this is a great time to get vaccinated.

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You know, now you're all immunology experts and CLL, you know, drug experts, so kind of understanding your risk on those,..

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you know, uh, kind of spectrums that I wrote out there, about your age and medical conditions and vaccination and the intensity of your meds you take for CLL.

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Because clearly, there's certain medicines that have certain strong links to certain infections, and that should be, that's the reason why you should…

(Note to reader: video cuts out for a few seconds, no sound. Speaker's slide refers to prophylactic drugs and then onto vaccine immunity)

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is lower in people with CLL. But still very important, even if the antibodies levels are low, there may be T-cell responses that are these things to help prevent serious disease, so

it's important to get vaccinated, but you may need add-ons, like monoclonal antibodies or IVIG…

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to kind of be on top of that, to reduce your infections at times where there's high risk in the community.

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And I do think it's encouraging, we talked about some, several interesting advances in antibodies and antivirals…

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that hopefully will be on the horizon to help keep us all, uh, safer…

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in this year and next. So with that, I want to thank you for your attention, thank my colleagues here. I work at the Johns Hopkins Transplant Research Center...

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doing research in these, uh, fields here. I also run a study called the EPOC Study,..

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Emerging Pathogens of Concern, that is, uh, studying viral infections in immunocompromised people across the U.S.

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And that's our website. Uh, and with that, I just want to say thanks again, and thanks to the CLL Society for their invitation, and looking forward to hearing your questions.

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Wow, Dr. Werbel, that was amazing. I love the way you organized it. I loved, uh, all the topics that you covered, um, and very up-to-date, and just, and there was a ton of questions, but you answered a lot of them in that, so thanks so much.

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There's a lot of questions, and I may, we may go over to emphasize some of this stuff, and I want to remind people that the slides will be available, and this will be...

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the recorded version of this. I could, I could listen to this again to go over that. It was so crammed with information.

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Um, you, you said that CLL patients, um, respond...

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less well to vaccines, and there was a lot of questions about that.

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Um, but you still recommend we get the vaccines. Should our schedule be different? How often should we be getting a COVID vaccine?

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He kind of hinted at the RSV vaccine may not be that helpful after a year. Should we get a second dose of RSV vaccine?

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Is there a particular flu vaccine that we should get? Should we get two over the flu season?

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One beginning early in the flu, one late in the flu season.

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So, give us some practical tips in terms of how to take those vaccines.

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Yeah, thank you. Thanks again for everyone's attention. Um, these are great questions, and we don't have perfect answers to a lot of them.

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Uh, I think what is clear is that many people with CLL will have a lower, what we say, like, a peak…

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response to vaccines and early response, and as such, that does typically also mean that as it kind of normally goes down over time, the window where your risk…

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opens again, it happens a bit earlier. So, uh, there are recommendations, like the CDC recommendations for COVID vaccines for people with immunocompromised, not just CLL, or to have a booster every 6 months. That's what was recommended. That wasn't the case for…

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average people in the population, and, you know, so that's one example of a difference in recommendation that would be applicable to people with CLL.

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What's interesting about, um, the, uh, oh, sorry, I will just say a note is that...

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there's flex, there's historically flexibility for COVID in when you can get vaccines,..

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is an ability to have vaccines earlier than six months, uh,..

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if there are particular circumstances, that's usually probably something that people would want to talk about with their doctors, about whether they think they would fit for benefiting from that.

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I think, to be honest, it's been very difficult for people to get…

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you know, uh, access to and aware of one vaccine let alone two in a year, so I don't really just say people to get more than that, because if you're sticking with that schedule, I think that you would be better protected than many people. So, I'll just sort of…

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just put that there. Uh, so that was COVID for, for RSV, your question, you know, which we touched on, is that,..

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Uh, the RSV vaccines in the average older adult were billed as these vaccines that protect you for two or three years.

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And it, they were pretty good, but the very early data here show that there's probably, because of that lower…

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peak response and earlier, kind of waning down, that risk window is likely to open again for people with CLL, particularly on therapies or have had a history of stem cell transplants. There is no recommendation, though, for people to get more than one vaccine right now.

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You know, many people won't even be able to do it due to…

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insurance, or and all this other stuff. So, it's not something anybody's recommending.

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Uh, you know, people, individuals can do things as they will off-label and such, and I can't speak to that, uh, but I think hopefully in the next year or…

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two, there'll be information abou. the role in, you know, sort of niche for a second RSV vaccine for particularly higher risk people. We don't know that yet.

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And then lastly, your question for flu. I can just say quickly, is that, you know, uh,..

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in heavily immunocompromised populations, typically a high dose or an adjuvanted flu vaccine, there are many on the market for those, are the two...

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that, uh, are ones that people should be recommended to receive.

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Um, that's the case for people over 65, as it turns out.

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Rather than CLL or not, but also people who are younger who have immunocompromising conditions, those are ones that doctors would typically recommend if your insurance will cover them, they're available at your pharmacy.

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So, that was a long answer, sorry.

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And what about two flu shots, one early in because you talked about that tail. Does it make sense to get one, let's say, in October or another maybe in February or something?

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Yeah. Yeah.

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It's a good question. There have been trials of this approach...

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that do seem to reduce flu, like the late flu, because as we talked about,..

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it's really kind of like three months are your highest protection window after the traditional flu shots.

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But, um, that, I would say, that's actually been in people who have had organ transplants, like kidney transplants,..

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there was a study that showed that worked well.

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But there are always, there are these issues with, in the real world, right? Like, insurance and stuff like that, about getting two vaccines. Um, I will say that a colleague of mine did a paper in the New England Journal of Medicine about two flu shots…

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for people with cancers. that didn't show, at least in terms of the antibodies and stuff, that showed a huge difference.

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Those weren't early and late. It was, like, one and then another one, so I would say the jury's still pretty, you know, still out for people with CLL. It's not something commonly done.

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Theoretical option, if that's something your doctors would want to talk about, but it's not commonly practiced at this time.

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You've been involved with an experimental COVID vaccine that stimulates the T cells that's specific for immunocompromised, and specifically CLL patients, I think,..

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in combination with the City of Hope. Can you tell us a little bit about that?

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Uh, if patients are interested in that trial,..

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sure, and I'll say there's a woman, a colleague of mine, Veronica Dioverti, who's a doctor who specifically takes care of, mostly of people with cancer who have infections, and she's the investigator at Johns Hopkins studying this vaccine called the GeoVax vaccine.

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It is a kind of COVID vaccine that has a different technology that's really designed for people who have trouble making antibody.

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Uh, because it's mostly focused on trying to get those T-cell responses, those other parts of the immune system to help really protect you from severe disease, it's a pretty interesting…

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kind of vaccine and exciting. There's an active trial at a bunch of different centers, including Hopkins.

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Um, and theoretically, it's something for if you're a person who either has a known…

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poor response to mRNA vaccines, for example, or kind of predicted to be so, based upon how you might fall out, based on your medicines and other things. It's a pretty interesting, uh,..

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option, and something that I hope would, we get the sort of more formal information soon. The trials are still enrolling. I'm sure we can find a link…

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at some point after this, if people are interested.

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I'm not, like, uh, I'm just interested in it because I think it's a good theoretical option, but that's not something that's been proven yet. It's still in trials.

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But I like that idea of trying to get T-cell responses up when we kind of are not going to probably get antibody,..

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uh, that sort of high titer antibody, high-level antibody.

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And just a couple things I would add to that. It's certainly encouraging that when CLL patients get…

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a number of vaccines, maybe not with the first or even the second, but by the time of the third or the fourth…

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or sometimes at this point in the disease, the fifth or the sixth, you know, over all these years,..

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they're starting to show some antibody levels that, you know, look pretty good. So, I think that's encouraging.

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The other tip that I try to give people is…

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talk about getting the vaccinations before you start on therapy, because every single therapy…

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is going to make the response to the vaccine…

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worse. So, if you can do it, especially the antibody therapies, um, will make it worse.

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Yeah, good point.

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That, from what I understand, that's prolonged. It's not just, you may take rituximab or obinutuzumab for six months…

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but you don't respond for another six to 18 months afterwards, if I'm correct.

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Yeah, pretty much the case. I think that's a good way of summing it up. It can take many months, typically, at least six, to get those, like...

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good B cells back, and so getting it a couple, a couple of weeks, if not a month beforehand, if you can,...

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it is ideal.

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Um, let's talk a little bit about, um, COVID and, uh, Paxlovid.

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There's a couple questions on that. Do you think all CLL patients should take Paxlovid if they have COVID?

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And should it, and is the five days the best amount, because people, what I hear from people is they're really afraid of this rebound, um, and why can't we just take it for 10 days and avoid the rebound?

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A lot of good questions there. I think, um, the first thing is, if you recall from that graphic where it had those colored bars about, like, high risk and low risk, and where do you kind of suss out.

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If you're a person who's older, who happens to have CLL,..

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on therapy, and if you're older with multiple medical issues, you're a person for whom...

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the antiviral drugs for COVID are recommended. If you're a younger person with sort of the watch and wait CLL, let's say, in your 50s, you don't have major other medical issues, that's much more of a…

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discussion with your doctor situation. Not everybody is the same.

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Um, I think our best outpatient pill medicine you can take is Paxlovid. However, that drug is contraindicated. I mean, you cannot give it…

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with certain medicines that people with CLL take. For example, the BTK inhibitors, like ibrutinib,..

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you can't take with Paxlovid safely. At least it's not, it's not recommended…

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to be the case. I'm not a pharmacist, but that's the recommendation. Also, if we're older, you know, some people are taking drugs like statins and other things for your health.

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Some of those are, have interactions with part of the Paxlovid, so you really need to talk to the pharmacy…

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or your doctor about whether the medicine is safe for you based upon the medicines you…

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take. So it's, if you're a high-risk person with CLL who has COVID,..

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uh, it would be great to be able to use it, but you have to kind of go through your checklist about the safety.

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I think the best medicine would be remdesivir, which is an intravenous medicine...

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which you can sometimes get in outpatient infusion center.

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And it's three days or something, isn't it? Something like that?

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Uh, and it's very clean, doesn't have a lot of drug interactions, but it's, like, annoying. You can't get it at the pharmacy, right? You have to go to an infusion chair, and it's kind of, yeah, at minimum. And to your point about the length of therapy...

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Yeah.

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you know, that the trials of giving people longer Paxlovid have been kind of a mixed bag.

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Uh, and, um, I've definitely given people, including people with CLL...

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longer courses of Paxlovid, when it was safe for them to get it, up to 10 days, sometimes even combining it with other medicines like remdesivir, if they just, the person, in my mind, had just had a bone marrow transplant and was at very high risk.

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Uh, but the, the, the sort of, most people are kind of going by the label.

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Uh, and even though rebound, uh, is a possibility,..

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uh, it's typically not dangerous in the sort of average population,..

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you know, symptoms that have come back have not always been associated with, like, getting very sick from that, but you may feel…

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not great. Uh, so that's discussion, I think, up front about, is this, like, a 5-day thing, or maybe even 10 days, if that's what your doctor thinks is a good idea, but that's very person-to-person also, unfortunately.

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And let me ask a follow-up on the, uh, COVID.

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Uh, both you and I saw a lot of…

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tragedies, mortality, uh, significant morbidity with COVID early in the pandemic. That seems to be less of an issue. Is that your impression as an infectious disease specialist?

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Yeah.

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Are CLL patients not dying like we were dying of COVID anymore, not being hospitalized?

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And why do you think that change is?

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Great, uh, important point to bring up. I think for almost every population...

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risk of things like serious death, like, or death, or being in the ICU is, like, 100, basically 100 times lower than it was in the beginning of the pandemic,..

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which is great. The relative risk, meaning the person with CLL relative to a 20-year-old with no medical problems,..

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that difference is still there, though. So instead of it being,..

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you know, I don't want to be morbid, but, like, 20% of people versus 1% in people with CLL in the first waves versus no issues,..

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a 20 times difference. That's still here, but we're talking about, like,..

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a hundredth of a percent versus two percent, or something like that, or, you know that kind of thing still remains. So, the reasons for that are pretty much three. The first is, um, people have different immunity now, right? I mean, people have had...

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a dozen vaccines, you know, half a dozen vaccines, and may have had COVID once or twice already. That's the bulk. And the second part is advances in antivirals, and our general management, I would say.

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We know what we're doing. Uh, so, those have been the main reasons why we, things, it's much less of a threat. It's still, we do still see, I mean, honestly, more of the main issue I feel like I see with people with CLL now...

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who are on ibrutinib and all these other things. Gazyva …

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Thank you, Gazyva, thank you. I use generic names, you know? So, um, people can be persistently positive for a long time.

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And that is not great, you know, because, um, there are probably two, three risks, or three associated problems. One is you can still feel kind of off. You may or are not as sick as you will, but you haven't kind of cleared the virus yet.

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The second issue is that that can tip off…

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other things, you know, people who have, like, COPD, for example, or heart failure, persistent, yeah, thank you. Persistent kind of lower level…

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Chronic obstructive pulmonary disease, yeah, yeah.

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issues like that can tick that off. Asthma attacks, heart failure, that kind of, like, more under the, sort of…

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lower level, kind of, it's not that you're having high fevers, it's that you're kind of off.

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So that can still be an issue. And the third is, you can still be contagious to other people for a long time.

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So, there's still definitely a need to optimize immunity and optimize treatment…

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even if we're fortunately out of the, like. bad days, you know.

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So, I still think it's an important priority.

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I'm going to move to another area, which is protecting ourselves, and you did touch on this and the importance of masking and hand washing.

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Talk to us in a little more gritty detail about masks, N95, N100, surgical masks.

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And is there, you know, some people wear the same mask…

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for the whole, probably the whole pandemic, you know, almost, you know, cloth masks, things like that. Give us a sense of...

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masking, and I'll push a little bit more to sort of…

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riff on this a little bit. If you go out, I mean, sometimes you have to eat, you have to drink.

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You all got to take your mask off. So, talk to us a little bit more about the masking, um,..

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and then the follow-up question I'm going to ask about this, put a lot in your head, is..

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a lot of people ask in different ways, this tightrope of, I want to protect myself…

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but I don't want to be a hermit. You know, and there's people on both extremes, people who are afraid to go out, they're missing their grandkids' birthday parties, you and I have talked about this before.

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What advice are you giving people to the risk-benefit ratios, how you play into that. So, let's start with the masks specifically, and then maybe move more generally…

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to living your life in an infectious world, yeah.

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Yeah, you're right. I mean, and these are tied. It's good that you asked them together. It's this concept of risk tolerance,..

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you know, and risk reduction. So, some of that is personal, um, I want to say attitude, you know, how your sort of priorities, right? Some of it is, I think, more biologically rooted in what your particular risk would be of getting sick, or particularly seriously ill.

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Kind of balance those together to come up with, like, a plan that works for you. Just the kind of more nuts and bolts about masks.

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The most important thing about masks is fit. That's probably the most important thing. So, masks that fit you well, that you can actually wear…

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for periods of time that are comfortable, are that's, like, most important. And then, the sort of close second is the quality thereof.

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Right? I mean, N95 masks or well-fit N95 masks are extremely effective.

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Um, surgical masks, which are, I'd say, more comfortable, cheaper, and accessible, if they're well-fit, still work pretty well.

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I mean, when I go over and see patients in the hospital,..

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apart from very specific infections, I'm wearing a surgical mask.

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And I feel comfortable with that. Uh, but N95s are generally going to be higher quality, and be more effective, you know, at the sort of at the tail, let's say, of an exposure, like, intensity of an exposure.

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So, those are really where you would want to stick. Cloth masks are really not very effective.

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Really not. Probably, uh, that wouldn't put them high up on something you should do.

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Um, but your point about the practicality is obviously notable. People need to eat, drink,..

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talk, wash your face. I mean, clearly, wearing a mask constantly is not, is not really feasible, and so that moves us more into that personalized discussion of risk tolerance and behavior. And I think, uh, it's really case-by-case, and sort of finding your comfort zone.

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It really is a tragedy to have to be a person or feel that you're a person at this...

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day and age, you can't, like, go out. Can't go for a walk, can't take a trip. I mean, that's really kind of outsized to most…

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people. Unless you're immediately post a bone marrow transplant, for example,..

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you know, or on extremely intense new therapies, that's really more of a shutdown than you would likely…

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need to do with your life. Um, you know, the only sort of caveat to that is…

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being aware of the circulation in the community is really important when we talk about exposure, so as we enter respiratory season,..

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you know, November, December, January, that's where your interactions with others are going to be by, you know, the baseline is going to be at high risk because there's just more circulating in the community. About one out of 10 people every year gets influenza.

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So, if you're in a room of 100 people,..

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there's some people, you know, the peak of flu season are going to have the flu.

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So, you just need to be aware of that.

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But if you're picking your spots with respect to both the time of year and your setting,...

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not densely crowded internal, poorly ventilated areas of people not wearing masks. Like, that's the extreme risk. Doing that in, like, super high respiratory season is probably just not a good idea for someone with CLL on therapy…

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if you can avoid it. But as you tick off those risk…

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variables, and you make it lower, it's fewer people, it's outside, or with better ventilation,..

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you're at a, you're not in the peak of respiratory season, you can get yourself down to this…

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tolerability of living your life, right? That you can do a lot of stuff…

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finding kind of those zones that fit with your personal risk and also your attitude towards,..

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you know, uh, try to avoid infections while living your life.

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Just sort of want to map out your personal risk for severity, as I showed on that plot, and then also…

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the risk, uh, intensity of risk of the environment that you're planning to, um, engage in to find that sweet spot.

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Let me, uh, one particular area that there's a few questions on was travel,..

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airplanes, airports. Um, anything that you want to add specific…

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Yeah.

01:14:31.000 --> 01:14:35.000
to those circumstances for CLL patients?

01:14:35.000 --> 01:14:49.000
Yeah, I think that, um, again, probably the two more, two most important parts of what we discussed was, one is the time of year, obviously, like, major travel and high respiratory season is going to be high risk than other times, so that's one thing.

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The second, just again, what you can modify, you can time things like vaccines before you go on a trip, usually two to four weeks before you leave,..

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If you wanted to, for example. Uh, and then your actual behavior in the airport and your plane.

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High-quality, well-fit mask, particularly actually with boarding and exiting the plane when the air is not circulating.

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Those are actually high-risk periods of the flight than in mid-flight when recycled air is, um, going around. So that's actually kind of, like,..

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sometimes not emphasized, but worth noting. Uh, and then that's sort of wiping down of your table and stuff. I know it seems intense.

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I get it, but even I do that because I have a period of time, I had, like, little kids, and plus I'm going into the hospital and seeing patients with CLL.

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I was a little, I'm a little more intense about that during high respiratory season, just because I, who wants to get sick, right? And then who wants to get other people sick?

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So, I think finding those, timing your travel and also...

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kind of being judicious about reducing your personal exposure to mostly respiratory viruses is how you can lower that risk.

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You know, on the plane, I, um, turn on the air vent above me, if there is one. I don't know if that helps or not, but I do that.

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And I'm especially cautious, like you say, to take off and landing.

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And I also worry about that ramp that you walk down, you know, when you're crowded, you know.

01:16:05.000 --> 01:16:09.000
Yeah.

01:16:09.000 --> 01:16:10.000
Yeah, the jet bridging. Yeah.

01:16:10.000 --> 01:16:19.000
Yeah, yeah, the jet bridge there. Just staying in this area, and then we'll move to some other areas.

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Um, you mentioned there wasn't a lot of data on RSV vaccines in terms of which is the best. Is there any data on which…

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Yeah.

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COVID vaccine might be best for the immunocompromised patients?

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Yeah, so, um, particularly early on…

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there was a signal in a lot of different studies that the Moderna vaccine was a, boosted more of the immune response than the Pfizer vaccine, which is probably due to two reasons. One is it has a little higher dose in it, and the other is that they were spaced a little bit apart…

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which, oddly enough, improves your boost. That difference has kind of narrowed a bit over time, as people are on their fifth, 6th vaccine, or after having had COVID.

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If I have a choice, I still end up usually doing the Moderna vaccine, just because of that historical thing, but the differences are probably not major.

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What remains a knowledge gap for us is the use of the…

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Novavax vaccine versus the mRNA vaccines. You know, just because there hasn't been that much Novavax in the community, like, we don't have a lot of big studies to compare them across a lot of people.

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The head-to-head studies have shown that they're relatively similar.

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Um, but I've not actually, I'm not aware of a head-to-head study, for example, in people with CLL, so I couldn't speak to that.

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I think there was hope that an adjuvanted vaccine,..

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which is the Novavax vaccine, meaning it has one of those immune boosters in it,..

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like the GSK RSV vaccine, would be, like a lot better in my experience and research, it hasn't been major differences, so that's why we tend to be, like, whichever one is accessible to you…

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and you're willing to get, just, I would go with that.

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There are some questions about other vaccines, like the pneumonia vaccine, and I might add to that, getting your tetanus boosters and things like that.

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Um, I know that those schedules are different in the immunocompromised, um, and…

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does it, I know that you have to get revaccinated if you've had a transplant.

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What if you've had CAR-T? What if you've had a bispecific?

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You need to get those childhood vaccines redone again. And some you can't do, like MMR, because they're live vaccines.

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Exactly right. So, you know, the immunization schedules are best established for these, like, the regular bone marrow transplants.

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Yeah.

01:18:35.000 --> 01:18:44.000
You know, getting totally revaccinated, assuming you're basically a baby again with your immune system, basically starting around a year after you can get live vaccines, things like that, the MMR.

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Um, there are less, I would say, um, well-developed um, guidance for CAR-T and for bispecific antibodies in particular, the bispecific antibodies, because they're relatively new.

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And unfortunately, it's still pretty case-by-case, or cancer center by cancer center?

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Each cancer center will have their own schedule. So, your team should be able to…

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tell you about that. But they differ, uh, by center,..

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you know, kind of more they're generally similar, but some would start vaccinating at three months, others at six months, and a lot of times there are a lot of, like, asterisks, like, you know, if you've had a bone marrow transplant before, if you were on, um,..

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GVH medicine or not. You know, it's very person-to-person, but generally speaking…

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you're not going to get live vaccines when you're on heavy immunosuppression or close to transplant. You will likely get the regular, um,..

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respiratory virus vaccines like flu and COVID and such, particularly before the respiratory season, assuming it's at least if it's been a couple of months since your transplant.

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They'll start that or CAR-T, for example.

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You know, I would add, too, having had, been a very early CAR-T adopter,..

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um, nobody talked to me about revaccination, and now everybody who's getting CAR-T has talked about…

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where you have to go through your shots again, you know, which was a very different kind of thing, so the awareness is really changing.

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Yeah.

01:20:09.000 --> 01:20:17.000
And I think that there's very little understanding with bispecifics at this point in terms of whether we really need to do that or not do that. It's evolving.

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I agree, and I guess maybe we're going to get to it, but the use of immunoglobulins is a big part of this whole thing.

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Yeah. So, before I get to that, let me ask you, because there's a lot of questions about people and watch and wait, or we like to say active surveillance or active observation.

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Um, anything specific you talked about that there may be, they, well, all CLL patients are immunocompromised, they may be a little less immunocompromised.

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Any specific advice you have for somebody in active surveillance or let's say in a deep remission between therapies, for those CLL patients?

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Yeah, you know, I can't use a broad brush for everybody.

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But understanding that you're going to be somebody who's in this sort of…

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intermediate risk, most likely, you know, for whatever problem we're talking about, you know. It's not immediately after transplant, or someone who's, you know, relapsed, or on multiple medicines.

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But you're not going to be totally normal with your expected protection from a vaccine, for example. So, uh, that factors into that whole…

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spectrum when you're talking about risk and risk behavior, understanding that you're going to be at high risk for things like sinus infections, and…

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you know, the flu and such than average, but you're not going to be in the highest risk...

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tier, so that means that you're able to adjust your behavior and your vaccine stuff kind of accordingly. Always get whatever is scheduled for the average person, but you may…

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be a person who, like I said, would want a six month COVID booster, because you're going to be in that…

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kind of at least intermediate, so to speak, middle-risk group.

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That helps.

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Specifically, question about the pneumonia vaccine. Do we need a booster every five years, or what's, what firm?

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Yeah, it unfortunately, the pneumonia vaccine is one of the most complicated schedules that we have…

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because they keep coming out with new ones, so I almost don't want to misspeak to it.

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Right.

01:22:12.000 --> 01:22:25.000
But the schedule has, like, two different, now it's two different types that you can get, and they are recommended, but the sequence actually affects how frequently it is. Generally speaking, you're likely to need a booster vaccine within five years…

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but it'll depend which one you got first, and which one you got second, and I almost kind of, like, don't want to open the can of worms. The, the CDC immunization schedule should, to my last check, be…

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pretty obvious to look at. Um, but it is actually really important to get, I wish I could speak to it really more like quickly, but it's just a little bit nuanced.

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I have to look at it all the time before I answer questions on that. They keep changing it, but it is available on the CDC website, at least last I looked. Who knows?

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Me too, me too.

01:22:57.000 --> 01:23:01.000
Today, yeah. Which lets me ask another question. You touched on this.

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Um, uh what, who are you recommending that we…

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follow guidelines right now. I mean, it's, you did touch on this a little bit,..

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but it's tough now, because there's not, there's differences between what different, you know, authorities are recommending in terms of vaccines and approaches to vaccines.

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Yes, and to sort of speak in kind of matter-of-fact neutrality, a political neutrality, it's a much more confusing environment that makes it harder for patients. I think that's...

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Both, any person would say that, I would say.

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So, um, I listed two resources that I do use…

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which are comprised of essentially, like, a lot of the prior ACIP members and members of important, um,..

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societies that had previously either weighed in or contributed to ACIP guidance. So, the first is the Vaccine Integrity Project through CIDRAP at the University of Minnesota.

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But you can just Google, Vaccine Integrity Project. They also have a YouTube channel.

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And then the second is the Infectious Disease Society of America, which I'm a member.

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Uh, that has, like, a whole bunch of resources, including for patients to kind of just at least help chunk out,..

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like, the objective info, um, I think that the CDC has an important role, which it needs to maintain, but I think perhaps in contrast to the...

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prior, we need a little bit more of an external perspective to help frame…

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CDC recommendations to make sure that there are subgroups of particularly vulnerable people, whether that's children, pregnant people, or immunocompromised people who have kind of…

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360 feedback into, you know, evidence-based recommendations. So, I do use these external resources.

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You talked very nicely about how you stratify people who are immunocompromised, and that's not just…

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blood work, but, you know, their age and their risk factors and other things like that.

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Are there blood tests that we should be getting? I think I know the answer. Is there a blood test for how immunocompromised you are?

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Things that CLL patients should be knocking on their doctor's door and say...

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“let's not just do a CBC, but let's also do these other tests to see where I'm at” that might inform…

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their risk that you would recommend as an infectious disease specialist?

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Yeah, well, I mean, I'm the person who likes information, makes my job much easier, so I wish I had everything on everybody, but it's not always cost-effective, and, you know, it's not always easy to…

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map without, like, really thinking through it. Obviously, having a CBC as you're supposed to with a differential count that tells you what kind of…

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cells you have is the most important. I think for CLL providers are very aware of immunoglobulins, antibody, and people should all basically, in my opinion, all should be screened for hypogammoglobulinemia, meaning low IgG antibody, low total antibody.

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I think those are critical start points. I had seen a question, too. There are some people, and it's definitely done a lot more after CAR-T, and some bispecifics, where you look at the breakdown of your B cells and your T cells.

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A lot of people will get that. Again, that's very, I find that very helpful for my particular job.

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But I, particularly people in maybe the watch and wait zones and such are not typically getting that in-depth…

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breakdown of their cell counts, and that's usually fine.

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Uh, but in the people with more intense therapies, I mean, that stuff is helpful. I mean, if you have basically zero B cells when they check them,..

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uh, that's helpful, right? That means you're not going to make antibody to vaccines, I can promise you that, and so you're going to need…

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IVIG, you know, or some kind of other thing to supplement that.

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Uh, similarly, if you have very low T-cell counts, which some people do,..

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that raises your risk for certain infections and is a good reason to perhaps be on certain of those prophylactic…

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preventative medicines, like the Bactrims and things like that, to prevent pneumonias.

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Let's talk about a couple specific infections that people bring up. Any with dental work, or any dental things, any specific to CLL patients that they should be doing?

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And the other one, there's a lot of questions on is sinusitis, chronic sinusitis, recurrent sinusitis.

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Seems to be a real plethora of problems for CLL patients. Any thoughts on those?

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Yes, so dental work is very interesting. There's been a big sea change in the last probably 10 to 20 years to move away from a lot of…

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preventative antibiotics for dental work. Unless you're somebody who's had recent, like, heart valves, for example,..

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uh, so, for me, uh, I'm not somebody who necessarily routinely would recommend antibiotics around dental work for every person.

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If you're someone who has, has to get the dental work done, and you have, for example, neutropenia, low...

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neutrophil count, that's a situation where antibiotics are reasonable,..

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um, and uh until your neutropenia improves, very reasonable. Uh, pretty much all the other subtypes, though, there's no, like, guidance that says, oh, you have CLL on ibrutinib, you need to get antibiotics with dental work. That's not a guideline thing.

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You did ask the question about sinusitis. That's much more, obviously, annoying, a persistent issue that tends to be related to this hypogammaglobulinemia thing I mentioned, low antibody.

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It is a reason that people should be on immunoglobulin replacement?

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If you have recurrent sinus infections, or, you know, that's like a very strong, uh, reason to do that. Sometimes, even if your immunoglobulins are okay, that's where it's a little more nuanced, because…

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turns out, you can even go deeper, and there's, like, a bunch of different types of the antibodies that you can look at, and some people have a deficiency in a certain type, but maybe the donated antibody would help you with.

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And then that may, in turn, reduce. sinus infections.

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Uh, that's really a very annoying thing that's pretty complicated, because some people also have an inflammation-type aspect to their sinus infection that's not…

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from bacteria, and that's where we start working with ENTs and such to really…

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kind of narrow down on whether this is more of a…

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bacteria or virus problem, or more of an immune system…

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kind of out-of-whack problem. Then it becomes a little trickier, I would say.

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So, talking about tricky, should we have, uh, a immunologist on our team as a CLL patient.

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Um, is there things that an immunology specialist, he or she could add to the care?

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And, um, and, and then I'm going to follow up with an IVIG question and a subcutaneous gamma globulin question, yeah.

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Yeah. Yeah, I mean, the, we at Hopkins, for example, there's an immunologist for whenever we're considering…

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immunoglobulin replacement, they do it. Like, the oncologist doesn't always…

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usually do it and infectious diseases doesn't usually do it. These people who really deeply understand…

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not just what your antibody level is, but often, and maybe many of you have done this, they'll do things like check your flu antibodies and check your pneumonia antibodies…

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across all those different jillion types of pneumonia, stuff that's in the vaccine, and even sometimes do a vaccine challenge and see if you get the vaccine, do your antibodies go up…

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as a more tailored look at what, you know, what is the nature of your immunosuppression? Will IVIG fix it, or do you need…

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something else, perhaps? That's really the niche where the immunologist is really helpful. I think that's kind of beyond a lot of times, what the oncologist can do,..

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uh, and what, you know, I would be involved in.

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So that's really that, that niche is really important.

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Very specific question. If you've had an orthopedic prosthesis…

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do you need to have antibiotics before dental work?

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So, the guidelines have changed so that the answer is “no”. If you just had it,..

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usually, you're not getting dental work. That's, like, a slightly different scenario, but for people who've had a history of an old knee…

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replacement, old hip replacement, it's no longer recommended for people to have antibiotic prophylaxis per infectious disease and cardiology guidelines,..

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Heart doctor guidelines. You'll still see it happen in the community, and you still sometimes even see cancer doctors recommending it.

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So, you know, guidelines are meant to be guidelines in general.

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Individuals sometimes practice in or out of them, depending on the scenario, but that's not uh, globally, I'd say recommended at this time.

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Um, so remind us of the indications for IVIG, and it sounds like it's very personalized.

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Could you comment on home subcutaneous gamma globulin replacement?

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Sure. I mean, the two main, uh, so the clearest, um, role for IVIG or Hizentra, which is the brand name of the injectable one in your, uh, for immunoglobulin, is you have known low immunoglobulin levels, typically less than 400 or 500…

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when they test it for the IgG. And you have a history of recurrent infections that are typical,..

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um, pneumonias, sinus infections etc. That's, like, a clear reason for people to be on IVIG. When one or the other is present...

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that it's more case-by-case. If neither is present, then you're not on IVIG, but if you're a person with recurrent infections, but your immunoglobulins are normal, that's when you need to start getting those special testing with allergy.

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If you're somebody who has low immunoglobulins and you're not getting infections, that's…

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good, still makes me a little nervous, uh, so I kind of, I'm a person who tends to like supplementing immunoglobulins, if you can,..

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uh, just to get ahead of maybe some of those recurrent sinus infections and things, particularly when we get quite low, below 400,..

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I get a little bit uncomfortable with that, and I would kind of recommend it.

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I tend to recommend it when I see patients in consultation.

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I think I know how you're going to answer this. Supplements. Is there something, is vitamin D, vitamin C, B vitamins, any, and you see everything on the web, this is going to boost your immune system. Medicinal mushrooms, all of…

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I know.

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these things. Tell us, give us, tell us, Dr. Werbel, that there's this medicine that we can take.

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Oh…

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And let me ask you something that I think you may have a different response to. What about exercise? What about things like that that may…

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help with our immune system, a good night's sleep, give us, give us something that we can use here. Yeah.

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Got it. You know, I wish I would be probably much more wealthy if I knew the answer to this. Um, pretty much every study of nutritional supplementation...

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in people who are not malnourished has not really borne out. That includes even vitamin D for most things.

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Um, if you're a person who's malnourished, which can be the case if you've gone through a bone marrow transplant, right? I mean,..

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you know, mucositis for a long time, not eating and stuff, those are situations where supplements can be used,..

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usually led by a dietitian, not by going to, you know, to GNC.

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Uh, but pretty much all of the scenarios, they really have not borne out, unfortunately, whether it's a trial or whether it's, like, a big population study,..

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to really reduce the risk of, you know, serious health problems.

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Many of them are pretty benign. Uh, you know, and I don't really get in people's way about it, with two exceptions. The first is, if it's a medicine that will interact, or a supplement that will interact with your medicines in some way,..

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like, coenzyme Q and some of these other ones people might take,..

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you really want to run that by your pharmacist and cancer team, because you can have unexpected complications.

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The second would be things that are, like, live.

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Um, of which there are actually a surprising number of, like, cultured bacteria and things like that.

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I'm going to be a little bit careful. There definitely are case reports of things like even lactobacillus supplements that have people gotten ill from the bacteria in it, so that is a little bit more case by case. I don't tend to love those for people with neutropenia.

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For example, even though there's, like, some potential benefit, you're trying to get your normal bacteria back.

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You know, I still say it's okay to have things like yogurt, for the most part.

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But some of those supplements with, uh, the live bacteria and stuff are not great right after a bone marrow transplant and such.

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So, those are my thoughts.

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Quick answer, uh, there are a couple, you mentioned a couple nasal sprays that you thought there was data on.

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Oh, yeah.

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But there's also Enovid and Profi and NOWONDER, is there, you know, there's a bunch of these that a lot of us have tried. Any thoughts on those, the other nasal sprays?

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Yeah, I've read through quite a few of them, the studies. The two I presented are the ones that at least I felt a little more confident in…

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because they were done as a formal clinical trial with a relatively big number of people.

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And they were in, like, a pretty good medical journal.

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When I went down the rabbit hole for the nitric oxide one, which is, uh, Enovid…

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Right. Enovid.

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I was less, uh, impressed. That's not something I recommend for people.

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It seems relatively harmless, but I was a little less swayed by that information as compared to the two that I presented.

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Alright, so we're coming up on the end. This has been incredibly helpful. Obviously, we didn't get to all the questions, but…

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thank you so much for doing this, and you're kind of very practical and down-to-earth, but…

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deeply data-driven, evidence-based, uh, uh, responses. I loved it.

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But I'm going to ask you if there's, you know, a takeaway message, or any summaries, or anything you want to say to people…

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in the last, uh, couple minutes, yeah.

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Yeah, I think, I wanted to make sure that the message comes through that things like vaccines have an important role for people with…

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CLL and after transplants, even if they're not knocking it out of the park as compared to a person with no medical problems in terms of their protection. They still do a lot.

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They still will reduce the very serious outcomes, you know, like, ending up in an ICU, reducing that likelihood, though they may not…

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be amazing at preventing the infection at the point of infection. It's kind of like, hopefully raising the floor, so to speak.

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You know, that's important. It says one, I think, important takeaway, uh, but the second that's related is…

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and I think we've emphasized, is there's a lot of different, people are different, right? Like.

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Who you are is very individual. Uh, and I know that's difficult, but the person besides yourself, you know, is your medical team to know, where do you fall on these risk spectrums for all these different,..

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you know, infections we're talking about. You know, hopefully some of this information is empowering in the sense that, like, it's not just one size fits all.

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There are ways that you can really kind of engage with your team to reduce your personal risk, whether that's through...

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vaccines or antibodies, preventative, you know, medications, or just your risk…

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behaviors. So, I would think about that as a kind of a menu that you can select for yourself that would be well-suited.

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Well, incredible, and thank you so much for this, and again, if we didn't get to your questions, and I know we didn't get to a lot of them,..

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uh, please, um, uh, send to Ask the Experts, and we'll, um,..

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we'll try to respond there. Um, I want to thank, um, AstraZeneca for its generous, uh, support.

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And from the donors who've, uh, supported this, uh, we wouldn't be able to without you.

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Um, and thanks to all of you who joined us today, um.

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Uh, you know, big thanks to Dr. William Werbel. I mean, just, this is just great for participating in this program.

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There's going to be an event survey, and we listen to your feedback, and I think you can see how we've tweaked things and tried to change things to make it better.

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Please fill out the feedback at the end of this for future events.

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This was recorded, and I saw some questions. The slides will be available on the website…

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with a written transcript of the webinar, usually within less than a week.

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Uh, again, if your question wasn't answered, AsktheExpert@CLLSociety.org, send it off.

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And we have something coming up soon in November. It's our next virtual event, and it's an Ask Me Anything, so if your questions on CLL weren't answered here, that would be the best place…

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because you're going to have Dr. Meghan Thompson there, um, and she is…

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great at understanding and responding to your questions on anything CLL.

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And, uh, my friend and patient advocate, Michelle Nadine Baker, that'll be on November 19th. Um, the details and the timing and how to sign into that…

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will all be on the website. And, uh, please remember that the CLL Society is invested in your long life.

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You can invest in the long life of the CLL Society by supporting our work.

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So, thank you again, stay strong, we're all in this together.