



CLL SOCIETY

## Webinar Transcript

# COVID-19 in 2024: Recommendations and Strategies for Those with CLL and SLL

May 16, 2024

*In science and medicine, information is constantly changing and may become out-of-date as new data emerge.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

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

### CLL Society Comments on Masking

CLL Society is proud to be an organization driven by science. We believe we have a responsibility to inform our community of the scientific information available and make recommendations in the best interest of the safety and well-being of those living with CLL. The masking study presented in this webinar comes from a well-respected and reputable scientific source and is addressing the issue of masking's effectiveness at the community level. CLL Society continues to support the long-recognized common medical practice of masking for individual protection. We also continue to recommend [performing an individual risk assessment](#) and discussing your circumstances with your healthcare team.

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

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At CLL Society, we are dedicated to bringing incredible and up-to-date information to the CLL and SLL community because we believe smart patients get smart care.

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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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Prior to beginning, we would like to mention a few pre-event items. All attendees in this webinar are muted and the only people on camera are speakers.

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We ask you to please direct all questions to the Q&A section displayed at the bottom of the screen.

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Questions will be sent directly to our moderator, speakers, and CLL Society staff and are not visible to the audience.



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After today's event, you will receive a very brief survey that will help us plan for future events.

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We greatly appreciate your feedback. This session will be recorded and made available to everyone on our website. Close captions are available, if you want to turn them on or off go to the captions and select show captions or hide captions.

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Today we are joined by Dr. Shahzad Mustafa, who is Lead Physician of Allergy, Immunology, & Rheumatology at Rochester Regional Health as well as being a Clinical Associate Professor of Medicine, University of Rochester School of Medicine and Dentistry.

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The majority of today's event is dedicated to your questions that were either sent in advance or are being submitted through the Q&A box on Zoom Platform.

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We will try to answer as many of your questions as possible during the live Q&A. Before we welcome Dr...

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Mustafa, I want to briefly mention CLL Society's COVID-19 action plan.

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This plan is a very important resource that includes several helpful checklists to help you plan on what you're going to do should you test positive for COVID...

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19. The plan is periodically updated as information and recommendations are adapted. So, if you have not already, we highly recommend that you spend some time reading through the directions and filling in the blanks...

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as they apply to your unique situation. Then you can print out the completed checklist and keep your personal life plan in an accessible place that you can easily and quickly refer back to...

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when you need to. At this time, it is my pleasure to introduce to you Dr. Mustafa.

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Well, thanks for having me guys. My name is Shahzad Mustafa. I do allergy and clinical immunology in Rochester, New York and have a special interest in secondary amino deficiency or new defects with blood cancers,...

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including CLL certainly. And I did a lot of work with the COVID pandemic which is mostly in our review mirror but still active in certain population and that's what we're going to talk about today.



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Our learning objectives today are pretty straightforward. We will talk about current state. Why does this matter? It remains important to prevent illness rather than treat it so strategies for prevention of COVID infection, which still happens. And then if you are infected with COVID, management of infections.

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So this I think is why we should care. Obviously COVID has gone from a pandemic to an endemic and it's just another viral...

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illness in the community. Influenza, you know, other others as well. But it remains prevalent and it still is leading to hospitalizations.

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Obviously, the numbers have come down, but what you see here is the orange line is the weekly positivity rate.

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And the blue bars are actually hospitalizations, so there are still thousands of hospitalizations in America where individuals have COVID.

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I think it's important and to be upfront about how these are being diagnosed.

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Some of these are being diagnosed asymptotically as people are being admitted to the hospital. They're still often being...

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swabbed for COVID. So some of these are asymptomatic infections in hospitalized individuals.

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But certainly, some of these are active infections that led to hospitalization. So what you see is these peaks and valleys through the years.

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This data is through April the 20th and what I like to see is there's white space between...

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testing positive and the hospitalization that tells you that a lot of people are testing positive who aren't being hospitalized.

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That's a good thing compared to 2020 where actually more people were hospitalized who hadn't even tested positive and really everyone, who was a large percentage, that delta was not there.

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So, we've made progress and I think that's important. So, the numbers are going down. And then for the folks who are testing positive...



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there's a decreased percentage who are being hospitalized, which is great news. I think this is a lot of good news to share, I hope...

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right now in May 2024. This is a long list and it's purposefully got small print.

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Who is at risk for severe COVID-19. It's a lot of people. So, this isn't particularly a helpful list.

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This is taken straight from the CDC. But it includes so many people, it's really hard to discern...

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you know, who's really at risk? I mean, risk is relative, right? So, this kind of is a very broad umbrella covering...

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darn near everyone in the United States. Who's really at risk? I like this much better.

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I want you guys to know the biggest risk factor for severe illness with COVID-19 remains age.

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As we get older and as I get older my definition of older age or advanced age keeps changing. As we get older, our risk for COVID infection really, really...

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sky rockets and you see these numbers and the relative risk for severe infection over age 85 so you know, really above age 70 is where our risk goes up.

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Of course, other comorbidities and health complications, diabetes, heart disease, metabolic malignancy...

play a role but the number one risk factor is age. So kind of try to distill down that previous slide that had so many risk factors,...

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we're talking about prevention. So I do think it's important to talk about masking and this is a Cochrane review.

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Cochrane reviews are some of the biggest systematic reviews today. This one got a lot of press and took a lot of heat.

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So this was published in 2023. This was a review that looked at multiple studies about masking.



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I want to start by saying how hard it is to conduct a study about masking. This is not an experiment.

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This is not control. There's a lot of variables here. The review looked over 10 to 12 studies of masking, including upwards of hundreds of thousands of patients.

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And of course it's imperfect but this is real world data. And the study's conclusions raised a lot of eyebrows.

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These are quotes from this Cochrane review. "Wearing a mask may make little to no difference in how many people caught a flu like illness/COVID like illness."

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The word "may" is very important. The data here is really hard to interpret and these are the authors' interpretation...

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shows what they said about masks. What about N-95? Probably makes a little to no difference for influenza particularly, which is what they were studying.

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So what I would say is to take this with a grain of salt, but to be aware, that masking is not binary.

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If you are masking intermittently or taking your mask on and off, obviously that's going to be less effective than if you're masking consistently in public.

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I'm very, very, very confident that early in the pandemic where people were using masking much more consistently, it was much more effective.

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But these are hard things to prove. And again, although this Cochrane review is a population study...

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many individuals still prefer to mask and I think that is perfectly reasonable. And if you're masking consistently,

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there are studies that have shown that there are downsides. It does impact socialization. I think people who were listening to this feel that...

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it can impact communication so it's not totally benign, but it's obviously...



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a choice we make. And I think it's at this point in the pandemic if you choose to wear a mask...

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and in what circumstances, I think it's much more of a discussion between yourself and your health care provider...

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whereas before it was binary that we should all be masking in public. I think there's a little more option now.

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But I want you to be aware of this study. This is the biggest study to date on the role of masking.

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It looked at very suboptimal data. It's a hard study to do. But the reviews kind of showed insignificant impact recently.

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What's the impact of vaccination? The impact of vaccination remains significant. And one of the biggest risk factors we talked about hospitalization is age.

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But the presence of folks who are unvaccinated have a significantly higher likelihood of being hospitalized compared to individuals who have completed a vaccine series...

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or are up-to-date in a vaccine series so that bears out and this is dating back to 2023, this paper.

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So again, hospitalization and death rates. For those this is during Omicron so obviously we've a new variants but this is as a proof of concept for folks who were unvaccinated, their risk for hospitalization and death...

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was significantly higher than those who were vaccinated. So, vaccination remains a cornerstone of our prevention strategy.

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This is a complicated study that shows additional doses of vaccines confer additional benefit. You see on the left that's pre-vaccination...

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antibody titers and then after one dose and goes up, after 2 doses it goes up, it continues to creep up. So, we don't want to be over vaccinating, but additional doses of vaccination against COVID lead to increased antibodies and prolonging antibodies over time.

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And you can see that your response is going to depend on where you are in your therapy. If you're on...

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certain therapeutics that blunt your response to vaccination, it may minimize your response to vaccination, but it often doesn't...

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negate it. So even if you're on immunosuppressive agents or B cell depletion, which you folks are familiar with...

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vaccination is still beneficial although the impact may be less. So, the takeaway here is sequential doses do help.

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Certainly medications, chemotherapy regimens, and immunosuppressor regimens can affect the efficacy, the effectiveness of vaccination.

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But it's not a binary thing, it's not like it works or it doesn't work.

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It's how well does it work and vaccination remains effective and our cornerstone for prevention. We're talking about prevention.

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Many of you are familiar with Evusheld, and Evusheld was authorized for prevention of COVID-19 in high-risk populations.

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Due to variants, it is no longer authorized due to lost effectiveness. Pemgarda has recently become, emergency use authorized as of March.

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It is also a human monoclonal antibody against COVID-19. It's very interesting how it got this authorization.

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There are actually no published peer-reviewed studies, that I'm aware of, that show its effectiveness.

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This was based on what you call immuno-bridging studies, kind of like empiric studies, that would suggest that this molecule is effective against COVID...

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19, although there are no real-world data. So, you need to take that with a grain of salt.

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It is felt to be safe. But there are no strong studies that show it's clinically meaningful.



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And why it is authorized right now, it does maintain presumed effectiveness against currently circulating variants.

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But in real world, it's an IV infusion. It's not a subcutaneous or intramuscular injection.

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And the logistics of an IV infusion for health systems is difficult. You're going an infusion center with, many of you know who go to infusion centers, individuals with cancer and other immunocompromising conditions.

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So the data here is minimal. It's an IV infusion which certainly raises the logistical barrier but something to be aware of...

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compared to Evusheld which was much more widely available due to delivery mechanism and data. This is not had a lot of uptake to date.

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And if I'm guessing and predicting the future, which I'm not very good at, I don't think uptake is going to be great for this...

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as we move forward.

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So there are some prevention strategies if you were to get COVID-19. What should you do?

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I think anyone who's at higher risk for COVID-19, CLL, should test for symptoms that are suggestive of an upper respiratory or viral infection.

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We have a little bit of a nasal congestion, decreased, you know, sense of smell, difficulty breathing that's unusual rather than blowing it off as just another cold.

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I would encourage testing because we do have well tolerated, well-studied interventions and the biggest one right now is oral antivirals, most notably Paxlovid.

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There's another one, that is used when Paxlovid can't be used due to drug interactions.

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The biggest side effect of outpatient Paxlovid is drug interaction. So then, that's when you go to the second line agent but Paxlovid has been shown to be highly effective in decreasing progression to moderate disability disease and decreasing hospitalizations.





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Other treat outpatient treatment options, IV antivirals like remdesivir, are not being commonly used.

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There's a lot of logistical barriers. They require its IV, obviously, multiple consecutive days of treatment.

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So really the cornerstone here is Paxlovid. There's excellent data that in individuals, who at high risk...

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for COVID, this is a highly efficacious intervention if used within 5 days of symptom onset.

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So this shows, on the left side of these dots, that favors treatment...

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and this is a group not only under 65 does it help but individuals over 65, it helps even more.

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We talked about that. Why does it help even more because the folks over 65 are at the highest risk for hospitalization...

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so they have the most to gain from this treatment. So again, if you think you have a URI (upper respiratory infection), a cold, you're around a grandchild or someone who is sick,...

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I encourage you to test. I think the intervention with this oral antiviral is highly effective and it's generally very well-tolerated as well and I think that's important, it's got a lot of talk about rebound illness.

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Now clearing COVID. It's generally well-tolerated with a very favorable safety profile,...

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certainly compared to long COVID disease, COVID conditions and this is again another Cochrane review. That shows safety and efficacy of Paxlovid.

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And again, it favors treatment versus not. So, it's strongly considered that individuals who are high risk individuals...

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test for upper respiratory symptoms and to consider treatment with an oral antiviral if you test positive for COVID.

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In medicine, sometimes we like to do something and when people get hospitalized for COVID, the treatment of choice is systemic steroids, dexamethasone.

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But using it in the outpatient setting has not been shown to be effective. In a wide group of individuals, and this is something that people often ask about, about being treated with oral steroids that have COVID in the outpatient setting.

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What I want to tell you guys is nothing is benign and if we're not using evidence-based therapies we might be doing more harm than good and for outpatient systemic steroids, if you're not having significant respiratory symptoms, your pulse oximetry, your oxygen levels are normal,...

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steroids have not been shown to help and in fact, they've been shown to hurt people.

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The number needed to harm, which is a number that if you prescribe systemic steroids..

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for individuals who don't need it, with COVID, is 27, where they actually have worse outcomes. So again, I want you to be thoughtful about what you are using for therapy, what works and not.

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Sometimes we want to do things. This is like treating viral infections with antibiotics, right?

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We want to do something. We want to feel better. But antibiotics are not effective for viral infections and in fact they may be doing more harm than good.

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And that has been shown with systemic steroids in the setting. Just as importantly, as a review I was a part of last year,...

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there's a whole long list of medications not to use for COVID. Just to know what we should do is important, but we need to know what we shouldn't do.

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We've learned a lot through the last three years and this is the list of medications we should not be using for COVID.

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Some of these we were using, some of these monoclonal antibodies we were using in the past...

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but they are no longer effective against the current variance. And on this list, there's corticosteroids for non-severe cases in the outpatient setting.

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So again, it is just as important as knowing what to do as what not to do and I want to be thoughtful about these medications that we should not take.

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I just wanted to make everyone aware for those of you who may be on immunoglobulin replacement therapy, whether it's IVIG, or subcutaneous IG, there is COVID antibody in your immunoglobulin therapy.

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So, if you're having a suboptimal vaccine response, you're getting COVID antibodies along with a myriad of other antibodies in your immunoglobulin therapy.

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The caveat here is it takes anywhere from 9 to 18 months from the time someone donates plasma to the time it gets to a commercial product to the time it gets to a patient.

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So if you're infusing yourself with an IVIG for your immune deficiency right now...

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the COVID antibodies in that product were donated upwards of more than a year ago...

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so there may be some changes and variance, obviously. But I just want you to be aware. I'm not saying anyone should be on immunoglobulin replacement to get COVID antibodies, but if you are on immunoglobulin replacement, if severe individuals with CLL often are,...

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there are COVID antibodies in that product, although they may not be fully up to date against current variants.

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So, like it's always been, this is risk mitigation against COVID with multiple strategies, common sense, social considerations.

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At times of high disease, maybe minimizing social interactions, but it's very important to use a product.

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Continue to be a part of socially appropriate and meaningful social interactions. It's the key to life, right? Happiness. We want our updated vaccines.

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We want to be thoughtful about when we're being vaccinated and stay updated on vaccination, which continues to be a cornerstone.



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There may be a role for immunoglobulin replacement for individuals who are on that. There may be , a role of protection there as well.

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And then if you get sick, oral antiviral therapy, namely Paxlovid, I'm using the brand name of this,..

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most commonly used name, is absolutely to be considered for outpatient management against COVID and having bad options.

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So COVID continues to impact high risk individuals. Hospitalizations continue to happen, vaccination, masking when appropriate, remains cornerstone of risk mitigation and really outpatient therapy is based on oral antivirals...

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particularly with Paxlovid. Trying to prevent hospitalization which has hugely decreased so that's great news. I think a lot of this is great news as the outcomes are getting better and better and the impact of this viral illness on...

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our population, including you know, compromised individuals with CLL, the impact is becoming less and less over time and hopefully that continues to be the case.

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Thanks so much.

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Thank you so much for your presentation, Dr. Mustafa. We have received a lot of audience questions today.

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We will try to get as many of these questions answered as possible, but if we are not able to answer your question, please send it to our Ask the Expert email address after this event and you will absolutely get a private reply from one of our experts.

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And also we're going to be sharing that email address just a little bit later on our closing slide.

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So, let's get started. Dr. Mustafa, here's our first question. Has there been any indication that a new vaccine will be available in the fall to deal with the known dominant variant at that time?

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It's a great question. And thanks for having me. I'm sure a lot of these are ggoing to be really great questions.

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So there is talk of new vaccination. Unfortunately, I don't have a whole lot of information on that.

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I don't think there's a lot of information in the public domain about that. There was talk last year also about potentially new vaccines, mixing it with influenza vaccine.

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So the reality is right now in May, it still remains a little bit of chatter and hearsay.

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I don't have a lot of great data. There's certainly no publications or official news releases or anything on that topic...

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that I know of.

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Thank you. Our next question is: is it possible to contract COVID through IVIg? It might be good first, ..

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I know you mentioned a little bit in your presentation, but it might be good to sort of provide a really brief explanation.

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Yeah.

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That's used for people with CLL.

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Yeah, so monoclonal antibodies that we give individuals, so a diabetic may not make insulin, so we give them insulin.

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Individuals with CLL/SLL may have decreased antibodies, putting them at increased risk for infection.

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The number of antibodies is not the most important thing. It's how do they work and are you getting sick?

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For individuals who have abnormal decreased antibodies and they're getting sick, they may benefit from immunoglobulin replacement.

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How this works is individuals go to a plasma donation center, they donate red blood cells. Kind of spin it off, the red blood cells go away and you take the plasma.



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You go through all of these ultra filtration fancy mechanisms and tease out antibodies and then that can be purified...

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and then commercialized for use. It's important And I learned that this immunoglobulin was liquid gold.

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It takes thousands of individuals to donate plasma for a single dose of a typical dose of IVIG, for example.

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That's a lot of individuals donating blood and plasma to get, you know, modest doses.

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So, we certainly don't want to be overusing this very precious resource. In my fifteen-year career,...

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there's been two nationwide shortages of plasma blood. So that's kind of a little bit of a background.

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I did mention in the presentation that immunoglobulin contains antibodies from all the donors...

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so individuals who are in therapy will have a very diverse repertoire of antibodies.

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Is it possible to get COVID infection or any infection (from immunoglobulin)? Is it possible? And if yes, how?

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I have to be careful with my words. Is it likely, very much no. This goes through incredible filtration and processing.

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The likelihood of getting an infectious complication from your immunoglobulin is almost unheard of and there have been reports in the past, decades ago, of hepatitis or other pathogens getting through.

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But I do not know of any reports of that in the last several years or even more than a decade.

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So nothing's impossible, but immunoglobulin is incredibly safe. And for someone who has any infectious complication, whether it be COVID or something else,...

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I would be hard pressed to start by blaming their immunoglobulin and on that, I would look for other reasons.



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Okay, thank you. Next question is: will getting COVID kickstart the onset of symptoms for someone in watch and wait or could my fatigue be assigned to long COVID?

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How do I know?

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Also a good question. So I think the general answer, that maybe the textbook answer, is COVID or an infection probably should not kickstart disease progression from someone in watch and wait but we have to be humble and we have to realize what we don't know and when people do transition from watch and wait to, you know, more aggressive CLL, we often don't know what actually caused the change right, so...

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there's a myriad of triggers. So generally, I don't think that's a concern that we think about or talk about, but we have to be humble about what flips someone over.

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If you have CLL, you're in watch and wait, you're on therapy, any stage of CLL and you get COVID or you get any viral illness, ...

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you're probably going to have increased fatigue, right? Viruses make you feel crummy.

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COVID, but influenza recently makes you feel crummier than COVID for some individuals right? So viral infection, including COVID, is certainly part of the explanation for fatigue.

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Now, if that fatigue doesn't resolve in a timely fashion, it certainly needs to be evaluated...

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and made sure that you don't have disease progression or any other things that have come up with your health care.

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If you've successfully ruled out CLL progression and other things that can cause fatigue, anemia, for example, then I think it's a fair thing to potentially consider that this may be a manifestation of long COVID or post-infectious complications.

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But you can only blame fatigue on something like that, once you've ruled out other things.

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And for individuals with CLL, I think it's absolutely important to touch base with your healthcare provider if you're having increased fatigue...

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CLL SOCIETY

that seems abnormal that's affecting things, absolutely reach out to get an internal evaluation and you know good doctoring rules out other things too;...

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anemia, thyroid disease. And then if everything checks off the list, and yeah, maybe it is post-infectious complication, which happens with...

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many viruses, by the way, not just COVID.

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Let me see. Okay, someone said I am on acalabrutinib for my CLL...

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I still do not produce COVID antibodies despite having 8 doses of the vaccine at this point.

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Is there a good reason why I should continue to get the updated vaccines?

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Yeah, it's a great point and we know that individuals with CLL have a decreased vaccine response and then sometimes the therapies for CLL can further inhibit vaccine response.

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I think it's important not to think of it as a binary process. Yes, no. I mean, there's degrees of vaccine response.

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We're pretty decent at checking for antibody response, B cell response and CLL is obviously a B cell cancer and B cells make antibodies.

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So, it doesn't take a huge leap of faith to appreciate that individuals with CLL may have...

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a difficult time or suboptimal antibody production. And we're good at measuring antibodies with blood work.

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We're much less skilled than medicine at measuring T cell responses. T cells are a different part of the immune system.

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So presumably, in individuals with CLL, B cells and T cells cross talk so there's a lot of cross talk so these things don't work in vacuums.

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In a simplistic way, T cells are, theoretically, not affected by CLL and there is a T cell response to vaccination as well that we are not very good at measuring.





CLL SOCIETY

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So my argument would be it's certainly disappointing that you don't have detectable antibodies with whatever measurement technique is being used.

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But you may still have some degree of vaccine efficacy through T cells and other components of the immune system that we're not checking.

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It comes down to a risk benefit discussion. What's the risk versus what's the potential benefit?

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I do think the risk of vaccination is quite low. And the benefit remains, you know, for some,...

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quite high but others modest, but still there. And once that benefit outweighs the risk, you tend to move forward with it, but yeah, it's a thoughtful discussion.

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In the middle of 2024 it's very different than what was it, early 2022?

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Thank you. On that note, if someone is on a BTK inhibitor, do you know if there are any studies that say there's value to stopping or holding the medication around the time of vaccination to elicit a better antibody response?

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It's a great question and I think I might take heed for my answer, but I'm going to say...

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there's very little data that says that. Not good science that says holding medications like a BTK inhibitor...

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or your timing of like an infusion like rituximab or B cell depletion.

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There's very little good data that says holding or adjusting your dosing affects your vaccine efficacy.

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That's the data. Now, there are clinicians who will recommend this. There are even published guidelines that will suggest vaccination after a certain amount of time after your last dose of a medication or you know...

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holding medications. Those are mostly based, those guidelines, are mostly based on low-grade expert opinion...

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CLL SOCIETY

and not great science and that's okay. We don't have science for everything and I think expert opinion matters but we have to take it with a grain of salt.

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So ,my personal opinion is these medications can have long impact on your immune system. People will make up for rituximab.

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We have good data that, you know, your immune system will recover after. Yeah, there's data that some people can have effects for two years or beyond...

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so holding it for a week or two or a month or two doesn't make a whole lot of sense.

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And the same with BTK inhibitors, these have long-lasting impact on immunity. So, holding it for some period of time doesn't make a whole lot of sense to me.

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So, my answer may be a little different than your clinician. It's a great conversation to have.

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BTK inhibitors are incredibly interesting. They can obviously kind of suppress your immunity and decrease your vaccine response, but there are papers that show that they can also help with immune reconstitution.

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It's really cool. So where they might depress B cell function, they may actually inhibit T cell function.

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So BTK inhibitors can kind of go both ways, which is kind of unique and interesting.

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But, great question. We have a lot to learn. I have to, we have to stay humble for those of you who watch Ted Lasso.

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Be curious. We have to know what we don't know and I don't think we have a great idea of what holding medications does.

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I tend not to recommend that. But you don't want to interrupt your primary cancer therapy either.

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Thank you. Alright, someone asked, I have heard anyone with CLL or SLL is immunocompromised.

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I feel fine and all my blood work is good. So how do I know exactly how I am and do you see all patients become progressively more immunocompromised with time and or treatment?



CLL SOCIETY

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Great question, complicated question. I do think everyone with CLL and SLL has some degree of immunocompromise.

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We can't look at these things as yes/no, on/off switches, it's not either you are or you aren't, it's how much I do think everyone, I mean, just by definition, this is a B cell answer and B cells make antibodies.

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So for B cells or you know, if they're cancerous, if they're malignant, if they're replicating, if they have abnormalities, obviously, I think it's makes sense that there's going to be some impairment in the ability to make antibodies.

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The question is how much? For the individual asking the question, you're healthy and feel great.

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You're probably doing pretty well. So although you may be technically immunocompromised, it seems to be a mild phenotype.

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We're talking about these things of phenotype and medicine. I can take it to some of my other areas like asthma, for example, as a disease.

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It's a syndrome. It's not a disease. Exercise induced asthma is very different than asthma for someone who's been admitted to the hospital.

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Right? So CLL is the same, even though you're immune compromised. There's a wide spectrum of degree of immune compromised...

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and that can certainly change over time with disease progression. It can certainly change over time with therapies.

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How can you be evaluated? I think very simply checking immunoglobulin levels is a really, really crude and dirty way to start the evaluation.

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The problem there is that immunoglobulin levels will tell you the size of your antibody army.

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They'll tell you the number of your antibody army but they don't do a great job of telling you the function...

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CLL SOCIETY

or of your antibodies that are right so you can have normal levels of antibodies that are dysfunctional and the way to figure out function for antibodies is checking your vaccine responses.

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Immunologists do this pretty regularly. Hematology oncology docs do this less frequently.

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Where you check a level of something like antibodies against pneumonia, then you vaccinate someone for pneumonia and then a month later you check the antibodies again.

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They should go up. They should quadruple for most people, double for almost everyone. And if you don't have that response, you have glitches in your immune system, even if you're immunoglobulin levels are normal.

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So, this is a very important discussion to have with your clinicians. I do think everyone needs to be aware of the risk of being immunocompromised, everyone with CLL and SLL doesn't need to be aware of it.

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It's widely heterogeneous over a huge spectrum. Some are minimally or not very, very minimally...

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and some have serious infectious complications. So, it's a great question to ask, but how do you think about it?

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You start the conversation. You check the immunoglobulins. You consider vaccine responses. The clinical history of, you know, the person asking the questions never had an antibiotic in their life.

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They're probably doing okay. But if you've had two or three pneumonias, you've been admitted to the hospital for sepsis.

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That's a very different story. And some of this is preventable. So, I encourage you to have these conversations with your treatment team.

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Right. And on that note, I mean, I think we've talked about this in a previous...

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webinar but do you recommend having an immunologist on your treatment team just because of this, because of the immunocompromised issue?

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I defer to my hematologists to manage as quarterbacks CLL management, SLL management.

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CLL SOCIETY

But I do think in the right setting, and I mean knowledge can be a great part of the team.

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When I work with our folks locally here, the hematologist is driving, they're driving everything, but I can be a small and hopefully valuable part of the team.

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So that really comes down to where you are being seen. Is there access to immunologists? Does your hematologist, are they a world expert in this and can manage it all on their own?

00:45:08.000 --> 00:45:15.000, and CLL is a complicated health condition...

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they benefit from a multidisciplinary approach, multiple health care providers providing them care, you know.

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Two brains are better than one kind of thing, right? So, I don't think it's a carte blanche.

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I don't think everyone needs an immunologist, but I think the discussion regarding your immune system, immune impact, immune defects, risk for infection is something every patient with CLL...

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should have with their health care providers, whoever that may be.

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Alright, next question is: how have CLL patients that have contracted the most recent, less virulent strings of COVID-19 fared as a general rule?

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And does the current COVID vaccine cover the KP.2 or FLiRT variant?

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I will start by saying what I don't know. I don't know about the specific coverage of the most recently available vaccines and those exact variants.

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I'm sorry, I'm not up-to-date on the CDC on that. What I am aware of is currently available vaccines have been covering the current variance.

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I don't know about those specific ones. And obviously there is ongoing monitoring and when we lose a certain amount of coverage...

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the vaccines are pulled, right? In general, and this was a part of this, presentation,...

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individuals who are contracting COVID right now and recently, are having less severe outcomes than previously. In general,...

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this is due to a myriad of reasons, background and immunity, previous infection, the availability of oral antiviral therapies.

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So, in general, it is tending to be a less severe condition. That being said, there's obviously individuals who tend to have multiple factors: advanced age, significant immunosuppression, other comorbidities, diabetes, heart disease.

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We do still have poor outcomes from COVID and that's very unfortunate. So, the number is decreasing of those individuals, so that's great.

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But it hasn't gone down to the numbers that we want. And quite frankly,...

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bad outcomes and risk for many infections are a problem, right? Over the winter, influenza had a big role...

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in our viral illnesses and poor outcomes. So, in general these are improving and I think there's a whole host of reasons like background immunity vaccination or antivirals.

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But it's still not where we want it. We still have to be thoughtful of it.

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Next question is: how effective are home rapid antigen tests at detecting infection? Are they still worth...

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keeping around?

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Yeah, I think that's a tough question to answer because there's so many out there, but in general, I think there's a huge role for home tests.

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I think that's the easiest way to test for symptoms. I do think individuals who would benefit from an oral antiviral have any risk factor, whether it's my sister who's immunosuppressed for Crohn's disease or if it's someone with CLL.

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Anyone who would benefit from an oral antiviral when you have symptoms that are consistent with a viral infection...



CLL SOCIETY

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should test and I think the most practical way to do that would be a home antigen test. I can't speak to precise...

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test characteristics like sensitivity, specificity, positive; I can't speak to that. There are so many out there, but generally?

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They're effective and felt to be effective but they're on the market and I think these are excellent tools to be used and sequential testing is sometimes beneficial too, right?

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A negative test does not rule it out. We all know that. And you can turn positive over time.

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So, if you're still symptomatic to continue to test. Especially if you're going to intervene...

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with therapy, which would be oral antivirals right now.

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Alright, someone said: I got COVID and continued to test positive for two months afterward. Is there anything I could have done to clear the infection faster and would you recommend someone who is testing positive for so long, see an infectious disease specialist?

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Oh, complicated question. I'm going to speak in generalities. I have to wonder. I don't want to get myself in trouble with individual recommendations.

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Individuals with immunosuppression, certain conditions can have decreased clearance of the virus.

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So prolonged viral detection. That's true. Individuals with CLL, certainly qualify for that.

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If you have symptoms of active COVID and you test positive. There's not a lot of utility in continuing to test until you test negative.

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This is something we've done in the past. But there's not a lot of utility in that.

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And again, this may, you may hear disagreement on this, but I'm going to give you my opinion.

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If your symptoms clear and you continue to test positive and you're continuing to test until you test negative,..



CLL SOCIETY

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I don't think that has significant clinical impact. I don't think there is significant infectivity to others.

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I your symptoms are clear, you're clearly recovering from the infection. It's hard to interpret...

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continually positive tests over time. Obviously, if you're still symptomatic, you're not recovering, you're having respiratory symptoms.

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That is a different discussion. But as your symptoms improve and if you're continuing to test, you choose to do that and your test remains positive,...

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I'm not sure how to interpret that. And we have seen this when we have seen individuals with CLL and other immunocompromised have difficulty clearing infection.

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If the positive test is meaningful, they tend to have correlating symptoms. But if your symptoms are improving,...

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I'd almost encourage not testing. I'm not sure what you're doing with the information.

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But I don't think it has greatly and well understood clinical ramifications. I hope that makes sense.

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Okay, thank you. All right. Someone asked; can COVID cause heart damage?

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Viruses can do all sorts of bad things, as can COVID. Viruses can cause inflammatory responses that can affect any organ including your myocardium, your heart cardiac tissue.

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So can COVID cause heart damage? I think the answer would be yes. Are cardiac complications common from COVID, certainly no.

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But viruses have a whole myriad of post-infectious complications. This, you know, we have talked a lot about COVID more than about any viral infection on planet Earth in my lifetime, right?

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But all viruses can cause significant post-infectious complications. So, the short answer is yes, but unlikely.

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But certainly, if there's any symptomology to suggest that or any concerns you should definitely consult with a health care provider.





CLL SOCIETY

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Thank you. Alright. As an immunocompromised individual, I think the CDC guidance says I can get a booster dose of the vaccine every 2 months.

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But should I? And if not, how often should those with CLL and SLL get additional doses?

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Yeah, this is a great example of where there's guidelines and things being said that aren't hugely backed by science.

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There's just not a lot of great research on the utility of that. I'm going to speak to my opinion and again, please take this with a grain of salt and you may get differing opinions, I think staying up-to-date on vaccines makes a lot of sense.

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I personally think every two months, if that is what the CDC says, and I've certainly checked recently but it changes all the time,...

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I think too much is a little frequent at six vaccinations over the course of a year. That's quite a bit.

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I think every six months or so, four to six months updating vaccines when appropriate is what a lot of people suggest and probably what I suggest.

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Being very honest, there's not a great study that I can show you. We're using a little bit of clinical expertise and opinion.

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I can tell you vaccinating too frequently has a theoretical downside. I'm going to give an extreme example.

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No one would do it, but there was an article once that if someone got like 1,800 vaccines or something.

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If you were theoretically vaccinated for anything, not just COVID, but anything every day, you get this concept of immune senescence where your immune system stops responding to the vaccine like it, just like it almost gets bored from too frequent exposure.

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Is every two months too frequent? Probably not. But I just want to throw that theoretical concern of frequent vaccination leading to immune senescence out there.

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CLL SOCIETY

So, I think an interval of every four to six months makes a lot of sense but it's not backed by a lot of science.

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And you know, as we kind of back away from this pandemic into an endemic, the amount of research being done on this has gone down appropriately.

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So, we don't have specific answers, so we have to use best guidance in my opinion.

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Okay, thank you. Alright, well. We are going to, you talked a little bit about, there's a question that says: is everyone eligible for Pemgarda if they're immunocompromised?

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I was told by my health system that since I'm not currently on active treatment that I am not eligible for this. How do I navigate the situation?

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Oof, tough one. I'm going to give a very carte blanche answer that everyone with CLL should be eligible for Pemgarda and by the...

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guidelines, you are. Anyone with a hematological malignancy is. Now, I don't even know of many health systems who carry Pemgarda and I'm certainly an advocate...

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in the space and our own health system doesn't carry Pemgarda. And there are appropriate reasons for that.

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When a health system has a limited resource, they often make their own criteria. And to limit, you know, utilization of a limited, valuable resource that they don't have an abundant amount to use.

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So that may be a health system decision. You don't qualify, we're not on active therapy, but from the grand scheme of things, everyone with CLL should qualify.

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And Pemgarda has unique considerations. It's IV. It's really not that easy to administer.

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That's a big deal. We need to talk about it. There are not peer reviewed studies and that's okay.

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We don't necessarily need them, but it's something to be aware of. And what are your outcomes and how are people doing with COVID in May 2024?

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CLL SOCIETY

And those outcomes have improved. Which is fantastic. So, I mean, this is, I don't mean to sound glib, but you know, is the juice worth the squeeze?

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Do health care systems, does the benefit justify the cost, the means, the administrators thoughts on the logistics of having it available?

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It's a fair discussion. So I don't, I just checked yesterday of, you know, website.

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Back in the throws of the pandemic, there was a very nice website where I can get these therapies, right?

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You punch it in and they tell you where. I don't think that's available for Pemgarda right now that I'm aware.

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Robyn, you're agreeing. I looked, yes. I looked as well and there isn't.

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Right. I looked as well. Yeah.

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So, if you don't have it available at your health system. I don't have a great way...

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to find out where it would be available. I will say it's very limited. I don't know...

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big centers that carry it either, actually. Robyn, do you have more information on that? You might.

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Yeah.

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No, I would just say, you know, we saw this same exact issue with, where, when it came out and everyone wanted it, there was difficulty finding it.

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An, I think we're seeing that again and it's going to just unfortunately take time, which isn't a great answer, but it's going to take time for facilities to...

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you know, get it in stock. They have to request it. So that's one thing I would suggest.

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CLL SOCIETY

I've been suggesting to patients to call your pharmacy at your healthcare institution and ask, are you going to be getting this in and suggesting I would really like to receive this as an immunocompromised individual at your institution.

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It's worth trying. And I know some people have had success with that, but it is so really early.

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So, I think in summer will have a lot more available.

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It is early. And I want to say I want to be reassuring to the urgency for this,

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right now is less than it was for when it first came out. Still appropriate, still helpful potentially.

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But the urgency, the degree of urgency is not the same and I think we all feel that.

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But I think it's important to say that that's the progress we're talking about here.

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Alright, another question on Pemgarda. We got a lot. Since it has to be administered every 3 months.

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I have it available to me right now, so should I wait until the fall and COVID surge is more likely to occur or should I go ahead and get it now?

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It's a great question. I mean, the beauty of this is these are conversations and there's no right or wrong answer.

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So these are conversations that you have with your health care provider. If it's available and you can get it and...

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Is something you want to pursue, I think getting it now and then considering it again later is very reasonable. If there are considerations that you are not fond of,...

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you know, the logistics where you have to travel, where you have to go. I think the urgency to get Pemgarda is much less than when I Evusheld first came out and I think that's okay to say. So this is...

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really a choice. It's going to be a very elective decision for each individual. There's not going to be a blanket policy.



CLL SOCIETY

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I think it's a nice tool for risk mitigation. We talked about that along with others. There's no right or wrong answer should you get it, should you not and you know how often I think it depends on so many variables and it really is an individual decision and what's right for one person.

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May not be right for others and that's okay. I think we have to accept that the beauty is having some choices.

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Choices are nice. So it's a nice option. It's nice that it's available.

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But, it's not for everyone. It doesn't have to be.

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Okay. Someone asked: they said, I'm not understanding the difference between the vaccine and Pemgarda.

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Do I need to get both?

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Great question. Yeah, very simply the Pemgarda or any passive immunization does not replace vaccination.

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So vaccination is a vaccine, . exposing your body to an antigen. And then asking your body...

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to make the immune response. Antibodies, T cells,. Pemgarda, Evusheld, these are passive immunizations.

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They're not asking your body to do anything. They're actually injecting you with the antibody...

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so there's no non-responders. Everyone who gets Pemgarda or historically Evusheld is going to get what's injected into you. It's going to be there.

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Vaccination depends on the individual host to build the immune response, whereas these choices are passively giving it.

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I like it to diabetes and allergy. We all make our own insulin. But sometimes type one diabetics don't make their own insulin.

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CLL SOCIETY

We just give it to them. There's no non-responders to insulin. So that's a great question.

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I'm sorry I overlooked it. But vaccination depends on the host response. Pemgarda, Evusheld, these types are what we call passive...

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immunizations They don't depend on host response. They just supply the antibody.

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Okay, thank you for that. Next question says.

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Great question.

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COVID has taught me to perform a personal risk assessment to determine if I should participate in a given social activity. What is the best way to find out how bad COVID is in my area since the CDC is no longer requiring reporting of hospitalizations and real time case numbers?

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Still is but it's delayed now. It's not quite as updated. It's harder to get that information, but I still think the CDC is a great resource.

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The slides on their website is, I think, it's a little delayed now, but it's still there with...

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Percent testing positive and hospitalizations. You're totally right about individual risk assessment and doing, you know, socializing, things like that.

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It really comes down to what is the activity, what's your personal risk and what's your appetite for assuming some risk?

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Nothing is risk-free, driving a car is not risk-free. So it's going to really be an individual decision, but I really do think, and I say this all the time and I hope everyone's okay with me saying it, it is very important to live life and I hope everyone's okay with me saying it is very important to live life and be a part of society and family and loved ones and partaking in things that are important to...

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you. And there are thoughtful ways to do all of that, I think.

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Okay, yeah, and I would also add to that that wastewater levels are really if you can find, if your area is reporting, that's, that's kind of a good way to get a sense of how high or low numbers are.

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CLL SOCIETY

Some states have better monitoring systems than others. But, also with the wastewater levels, it's important to know that...

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if you're looking at a national average of what the COVID numbers are, area as we used to talk about...

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In the earlier days of the pandemic, there can be a state that has more of a hotspot. We used that term way back when.

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All right, next question: are the only drugs available to treat...

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COVID still Paxlovid, remdesivir, and molnupiravir?

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Yes. Two of those are directed at COVID viruses, remdesivir is a more generic anti-viral...

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which can apply to other viral illnesses as well.

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Well, obviously, other therapeutics that we use for inflammatory response for individuals who were sicker...

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like systemic steroids, other JAK inhibitors would be in an inpatient setting but in the outpatient world it's really come down to the 2 oral anti-virals.

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Yeah.

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Someone asked: this Paxlovid is still effective and does it cause rebound of COVID symptoms and as an immunocompromised individual, should I take a longer course of Paxlovid to help my body clear the infection?

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Great questions. Paxlovid is yes, still effective. There are cases of rebound but...

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they're actually quite, quite low. They've been talked about more than the numbers would suggest.

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So, the likelihood of rebound after Paxlovid is very low but not impossible. So, I think there's no data to suggest you should take more than the typical five day course.

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So absolutely, still effective. It's an antiviral.

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Okay.

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So it has not lost efficacy with variants or anything.

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I believe I could be wrong, but I believe that, the company that makes Paxlovid, had a clinical trial going on specifically for, you know, compromised individuals where they were looking at that 10 day course to see if that made a difference.

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So we might be hearing this year sometime. So, okay. Next question. Do you have any suggestions on how to convince my family members of the benefit of COVID vaccines and boosters, especially when being around someone with CLL?

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Oh man, I wish I did. I mean, there's science and then there's ideology and we all know in 2024 vaccines have almost become a hot button ideologic topic which is really sad.

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Most public health experts would say the advent of vaccinations is probably the greatest public health advancement...

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in the history of the world. So, the fact that this has become a controversial political or ideological topic...

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is unfortunate. But it's real. So that makes it hard to have meaningful conversations with people...

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when it's potentially being driven by politics, ideology, emotion. But the concept of cocooning is age old. An individual who's immunocompromised...

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is safer when the individuals around them are vaccinated. And this is a fact on a familiar level and a society level.

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And it depends on how you look at our responsibility as a society. Herd immunity and containing is really important.

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There are individuals who truly cannot be vaccinated for certain things. And it is society's obligation, responsibility to do the right thing to provide cocooning for them.

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CLL SOCIETY

I believe so, but I don't want to get into those details, but cocooning is important.

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The folks who hang around with their vaccination status, their risk mitigation affects you. We're all in this together.

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I think that's very important. How to have those conversations in a productive way. They're tough.

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People have to be ready to hear the conversation. I, you know, it's fascinating work, the science of change.

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I've spent some time looking into it over the last year or so. There are individuals who are just not going to change and trying to change their opinion is not worth it.

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But then, there are individuals before that who are like, they're not, you know, agreeing with you, but they're willing to hear the argument.

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I would consider having the conversation with that population, that group of family members or friends. Because I think there may be an opportunity there, but there's folks who are dug in who are not going to and in fact...

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anything you bring to them, they almost want to do the opposite. So, you have to be thoughtful about how you approach that.

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Yeah, it's really tough in that.

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I do not have a great answer for you. It's tough. It's an interesting environment we're in right now.

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Right. Very tough to navigate. Alright, someone asks: do you have any data on how Evusheld one compares to Pemgarda, is it more or less effective?

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Yeah, none at all, actually. It's based on immunobridging studies, which is not a bad thing.

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Vaccines like the flu shot every year do not have big studies on efficacy. It's based on immunobridging studies.

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So I'm not saying it's wrong, I'm just saying you have to be aware of it, but there's no head-to-head studies on effectiveness.



CLL SOCIETY

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There are no studies of real world effectiveness that I know of. So it's...

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what does that term mean? And you know, if you can explain that.

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Yeah, it's trying to figure out what the molecule needs to look like in a kind of a scientific way, in a lab.

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To match the current viral variant. So there's a lot of predictive analysis that goes into it.

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And we all know since the beginning of time that, you know, you get this flu shot, this influenza vaccine, and then you hear this year's version was 40% effective or 60% effective.

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We've accepted that. That's okay. Some effectiveness is better than none if no effectiveness.

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So it was based on that type of predictive analysis, knowing about the spike protein and things in COVID.

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But real world effectiveness and decreasing symptomatic co-infection, we actually have no idea.

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We don't have a great sense of that. For Evusheld either, so we certainly don't have that information and certainly don't have the head-to-head in.

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It is felt, again, very important to be safe. So if you have access to the medicine and the logistics are not a barrier,...

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it should be well-tolerated from what we understand. There should not be significant side effects. So the risk is hopefully here.

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Where is the benefit? I don't know, but the risk is really low.

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Okay, along those lines, I know I've had a couple of questions about the small percentage with the risk of anaphylaxis and with individuals who have more autoimmune issues, is there more risk there and so is that something to consider when you're trying to figure out if you should get Pemgarda or the...

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CLL SOCIETY

the new Evusheld 2.0 (sipavibart), is easier to say that name. But what do you think about that?

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Yeah, so the newer version of Evusheld (sipavibart) is not available right now for you, for clinical use.

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So that's important. There is risk for allergic reaction anaphylaxis to any medication or really anything you put in your body.

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The risk is exceedingly low. I don't think that's a real, clinically meaningful consideration that should stop anyone from getting that therapy, if they so choose.

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Could it happen? Yeah, it could. But the likelihood is low. I mean, with...

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Pemgarda, if it's an IV infusion, you're going to be getting it at an infusion center that's infusing a lot of medications where people might be having allergic reactions so you're certainly in a setting...

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equipped to handle it but I think the likelihood of that is extraordinarily low.

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Thank you. Well, you did. I know you talked a little bit about masking in your presentation.

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Someone asked: as an immunocompromised individual should I continue to wear an N95 mask all the time and is it really necessary for all patients to wear a mask and social distance even outdoors?

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I think we're in a world where words like "never" are unnecessary. I think we should get away from those. I think outdoor transmission of COVID has always been relatively low.

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So, I think that's a much safer environment than indoor transmission. The utility of masking in an outdoor setting or social distancing is far less than an indoor setting or a crowded indoor setting.

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Masking is it necessary? I'm going to say it's not necessary. Is it desirable, potentially depending on your situation?

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And I really think this comes out to individual preference. I see lots of immunocompromised individuals who continue to mask because they wish to.

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And it's probably providing some protection even if I can't show you a great study that says that.

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CLL SOCIETY

And there are other, I mean, compromised individuals that I see that are not masking. There is no study that says your likelihood of...

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you know, getting COVID or being hospitalized from COVID is less if you mask. There just isn't.

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But if you're masking consistently, it should decrease viral illness.

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And not just COVID, other viral illnesses as well, especially during the wintertime. So I do think there's utility in masking, but I do think masking has impacts.

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It has impacts on socialization. It sets people aside in a group setting.

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I'm not saying these are reasons to do it or not, but there are impacts. So you have to weigh again, keep saying is the juice worth the squeeze?

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Is it worth it to you? And I think it's an individual discussion. I mean, we obviously think it matters on even where you live and who you're socializing with...

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and how it will be received. So, it's very nuanced, it's very individual. The utility of masking today versus March 2020 is different.

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I think that's okay. I think that's great. But there's still a role for it.

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Especially for individuals who are immunocompromised and especially in certain situations or in certain times of the year like the middle of the respiratory viral season.

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I think May and June, July is much less impactful to masks, especially outdoors. Then these cold winter months when we're all huddled inside or in much, much of the country at least.

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So it's really a nuanced discussion. I think anyone who tells you, you should, you have to, or you shouldn't.

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You shouldn't. Never should. I don't think that's it. That's a genuine approach.

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I think it's much more nuanced than that.

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CLL SOCIETY

Yes, and you're right. And it's also dependent on how much risk an individual is willing to take because everybody's risk level that they're willing to accept is a little bit different.

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That's why this question is hard to answer, but again, looking at those numbers to see what are the numbers in your area, how crowded is it going to be?

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Is it indoors or out or there's all those variables to consider, on an individual level?

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So that's a hard one. It's a really hard. Someone asked: what are the recommendations for travel for CLL and SLL patients?

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Is it safe to sleep in a hotel, travel by train, bus or plane?

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I don't know if there's specific recommendations. I think of my own approach, I think it's important to travel and you should travel with appropriate...

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thoughtfulness and risk mitigation. Is it safe to sleep at a hotel? Yeah, I think the answer to that is yes.

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Is it safe to travel in public transportation? I think the answer is yes. Is it more likely to get a viral infection, COVID if you're traveling...

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in public transportation setting? More likely, yes. How likely? Still unlikely, but like, you know, likelihood in medicine is very different than likelihood in Las Vegas.

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If your risk goes up from 1% to 10%, that's 10 times more likely, which is a lot more likely.

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But it's still 90% chance of not having something happen, right? So, I think it's important to travel if you wish to travel.

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If you're traveling and it makes you so nervous that the experience is undesirable, then you probably shouldn't be traveling.

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And again, I think this really comes down to individuals and their own appetite for some degree of risk.

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And is it worth it to them or not? You know, is it your child's wedding?



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Might be worth it to most individuals. Versus, you know, a random acquaintance's retirement party which may not be as important.

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You're not making these things up but it's very hard to say that, but I do think it's safe.

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I think it comes with some risk that I think can be adequately managed. The hotel situation, I think, is...

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very safe, but travel and being around others comes with some risk but appropriate...

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someone mentioned an 11 day cruise. Would you go on an 11 day cruise?

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Sure, if you like 11 day cruises is there a risk? Yeah, I think cruises, and there's data on this, have a higher risk for viral infections than other types of vacations.

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That's true and it makes sense. You have, you know, thousands of people in a generally small environment,...

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eating and drinking. So the risk is higher than getting on an airplane for three hours.

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I'm certain sleeping in a hotel room. But should that risk stop someone? I can't say it should.

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It might stop one person and another person. I know many people, see a lot, take cruises, including family members.

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But I know many people, see a lot, who would never set foot on it first. I know many people who, so again, these are individual discussions, but I do think if we're being honest and there is science to this that, the likelihood of infectious complications are higher on a cruise vacation than other vacations.

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I think that's true.

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Okay. Okay, next question: are there any other drugs that are in the pipeline that might help prevent COVID for the immunocompromised?

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CLL SOCIETY

Prevention would come down to vaccination or passive immunization, things like Pemgarda or Evusheld.

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I do not know of any others. And quite frankly, I'm not sure if there's a need to invest the resources to develop any others.

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If we have these, hopefully we can focus more on improving access and utilization rather than making more...

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in my opinion. So, I think between vaccination and potentially passive immunization that will move a long ways, that ...

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prevention depends not on a medication, but often on antibodies, right? And you're not going to be able to get those in an oral form.

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That's not how antibodies work. So, you know, trying to come up with something...

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oral prevention that's going to be very unlikely. So, I don't think of any, I don't know of any. Robyn you might know of anything in the pipeline.

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But I think we have the tools that we need. We have to get maybe better at using them and implementing them.

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I don't know of any as well. If they are, they're very early in development.

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So, let's see here. Do you feel someone who is vaccinated...

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can travel safely to Europe and receive treatment while there if needed, if I become infected? Do you know if the drugs for treatment for COVID are the same in Europe?

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Oral antivirals are available in Europe. I don't know all the access points though to be honest with you and it's so different depending on where you are.

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I do think it's appropriate to take a European vacation if you have CLL and I have many patients who have done that.

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CLL SOCIETY

I'm going to just give you again my own personal approach. Your clinician may disagree with me and there's certainly no like, there's no right or wrong here, but I'm also comfortable...

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providing a prescription for oral antiviral to patients who are traveling abroad. Whether that's technically the right thing to do or not, I mean, I trust individuals to not use it...

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necessarily but having something in your back pocket if you need that. It's not inappropriate in my opinion.

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This is just me speaking for me. Not on behalf of anyone else for the sake of society. So, I do tell people if you're going to travel, which is great,...

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I encourage you to travel, maybe take a couple of home tests with you. And I would be happy to provide,...

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you know, a prescription for an oral antiviral to take if you so choose. Certainly, there's therapeutics and health care in Europe that's excellent for this stuff.

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Just depends on where you are and where you're going and access.

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Okay. Someone asked and I know we get this question quite a bit: do you have any updates on nasal vaccines for COVID?

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And do you think they will ever get FDA authorization? And then along with that, I saw a question regarding...

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are these live vaccines because some nasal vaccines are live, which would make people with CLL ineligible for that?

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Yeah.

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I have no knowledge, man. You guys stumped me every time with this group. I have no knowledge of any R&D on nasal COVID vaccines.

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Robyn, do you?

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I know there's some in clinical trials that Dr....





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Koffman and I were just talking about this recently. We haven't heard any readouts or anything on them.

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Yeah.

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If we do, we will definitely put it on our website.

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For sure. So, I don't think there's anything close to clinical use. Yeah, live vaccines, they're not always an absolute contraindication, but there are, you know, very, there's significant considerations of using live vaccines in immunocompromised individuals.

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Data from influenza vaccines has kind of gone back and forth depending on the population of what's more effective,...

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nasal versus intramuscular. So lots of considerations, but I don't think we really are going to be faced with that decision anytime soon.

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Let's see. This is a good one: when it comes to COVID influenza and RSV,...

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which one is more dangerous to those with CLL and SLL?

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I wish we were so good at predicting the future. These are all meaningful viruses that can have meaningful health impacts.

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It depends on a lot of things, background, immunity, time of year, current strain. They can, all 3 can, lead to very mild...

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asymptomatic disease. You don't even know you have it.

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To mild illness, to very severe illness, morbidity. And frankly mortality. There's no, there's no order of one is more serious than the other.

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These are all things to be aware of. Encourage vaccination against all of them. They are available.

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And then appropriate treatment, but there there's not a carte blanche statement I think that I should make that one is more dangerous than the other.

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So lots of questions just on RSV. Is there any data to say that those should receive the RSV vaccine?

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And since we are out of the winter surge, if I have not got it yet, should I wait till the fall to get it?

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So I do think folks with CLL should be updated on their vaccine schedules and RSV is an appropriate vaccine.

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Consider well-tolerated with good efficacy data. Timing. Don't think you necessarily need to wait for the fall.

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I'm this I should know and I don't. What is that interval of dosing, Robyn, you know for RSV vaccine?

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I do not know it off the top of my head.

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Actually, I actually do not know that either. I should know that. But you know...

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since it was just approved last fall, we might get some updated guidance on that in this all.

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Yeah, but I don't think you need to wait. Vaccines tend to have, you know, pretty sustained immune responses.

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They're not on the order of weeks to months often. But again, your response may be suboptimal.

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That's a tough question for me to answer. But I do think people should stay up-to-date on the vaccines that are available to them...

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because these are all very meaningful infectious complications.

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Sorry for my little bit of a wishy-washy answer.

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Okay. Along those same lines with RSV, someone asked: whyd o clinical trials typically not include, you know, compromised individuals when looking at vaccines?



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Yeah, because they want it to work. And they definitely, always exclude special populations. So that is always a secondary.

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It's hard to study everyone because it's a you can't compare apples to oranges kind of thing.

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So they try to keep the populations narrow, whether it's age or certain health conditions. So they try to make it a population that they can make a generalized statement about like such as in individuals over the age of 18, this vaccine tends to work.

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Excluding individuals who are on certain therapies with certain health conditions is commonplace because they want to be able to assess...

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effectiveness of vaccines in a population that should be able to respond to vaccines the best, right?

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So that makes a little bit of sense. But again, I don't want to think about vaccine responses as binary as you either respond or don't.

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There's degrees of response. So I do think everyone probably benefits. It's just how much do they benefit?

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Someone asked: how long do antibodies last after a COVID vaccine in a healthy person on average and are there any data on how they how long they last in someone who is not?

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Yeah, I mean, very simple. Cheap answer is they last longer and individuals who are, and you know, immunocompetent than immunocompromised.

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They can last for years. We have a lot of immune memory. And that's why certain vaccines are only recommended every 10 years or so like a pneumonia vaccine.

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Individuals in immunocompromised CLL tend to have decreased memory, so they tend to lose their vaccine sooner, but it's very hard to say how long.

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Whether it's, you know, some weeks months or years it's hard to say but it's shorter than typical of course, which is intuitive but we all make, we have immune memory.

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Our immune systems can remember for a very long time. So it's very hard to say how often.



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So we come up with vaccine schedules on our best guesses. How often do we think we would need to be back?

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It's not like we're measuring your vaccine level before we vaccinate everyone. So, it's just based on predictive modeling again.

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Alright, every COVID webinar we get lots of questions on the nasal spray. That is not FDA approved in the US, however it is in Europe.

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Do you have any comments about it?

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I have to, I have to search for it.

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Yeah, we have.

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Okay, I think you know, well, I think we've talked about it before. I think it's approved in maybe Israel and India and a couple of other places.

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But you know what, Dr. Koffman, I know I said before is that, there's no studies to say that it hurts anything, but there's also no like real strong studies either that says that it prevents COVID.

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Yeah, I don't know a lot about it. Yeah. Deals with the inflammatory response.

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So, no data. It's not yeah, yeah.

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So, it's not specific to just the COVID antibody but by all inflammation.

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I just don't have a lot of data either way on what it does.

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Someone asked: are there any drugs available or anything that I can do to rebuild or boost my immune system to help me from getting sick?

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If you have meaningful antibody deficiency, one can consider immunoglobulin replacement. That is for a relatively small percentage of individuals.



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But that's something to discuss. Getting sick could mean frequent colds. Getting sick could mean sepsis in the ICU 4 times a year.

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Those are very different, right? So, if folks who are getting meaningful infections, requiring antibiotics were being hospitalized,...

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certainly warrant a thorough immune evaluation and consideration for immunoglobulin replacement. Viral infections are...

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much harder to prevent. And I'll be honest, there's a very large industry...

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in America about immune boosting and as an immunologist. Over the counter remedies and things you see being sold.

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They have no responsibility to provide well done scientific research for their claims. So unfortunately, we do not know of any real ways to "boost your immune system".

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And there have been real studies on vitamin D antioxidants prebiotics and we just don't know enough.

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So, you know, speaking in a very holistic, very wishy washy way, boost your immune system by staying active, exercising, these things have real impact on human health actually.

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Broad diet, healthy diet activity. The usual stuff, but I don't know of any specific therapies.

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Of course if you're having meaningful infections, you have meaningful antibody deficiency, immunoglobulin replacement can replace what you're not making.

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But that's a pretty small percentage of individuals.

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There's a question about reinfection. Someone asked now that people are getting COVID infections multiple times, is there any data to say...

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the damage that can be done to the body is cumulative?

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I don't believe there is data to suggest there's cumulative damage from recurrent infection.



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I actually don't think so. I might be wrong, but I don't think so.

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And I don't believe from an immunologic standpoint that recurrent infection of the virus would lead to cumulative damage.

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Tend to be independent events. They obviously can have post-infection complications. But I don't think there's any concern for cumulative damage,...

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from what I know.

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Kind of along that note, someone said: I had my second COVID infection in December. Am I safe to no longer take precautions?

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I haven't been wearing a mask since I thought I would have antibodies.

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I don't think the...

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episode of infection in December prevents reinfection. So that's not the reason not to take precautions.

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Yeah, if you don't wish to take precautions for other reasons, I think that's...

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your prerogative and that may be appropriate but I don't think the presence of infection in December...

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prevents recurring infection. So how long the antibodies last we don't know but I certainly know people including immunocompetent individuals who've been reinfected within six months.

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So I don't think the reasoning there is sound. The desire or the need to take precautions is perfectly appropriate.

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Everyone doesn't want to take precautions and that's okay, but I don't think the infection in December...

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meaningfully decreases your risk for infection right now.



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Okay. Couple of comments, in, regarding, we have very smart patients.

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Which we love. Someone said that the RSV vaccine recommendation is actually 2 years, which I do remember that now.

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And regarding being able to access the preventative monoclonal antibody.

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As someone said they are currently working on developing a Pengarda locator tool and this person is actually helping to work on that.

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So that's really great. And we would love to, you know, share that tool with our audience once that locator comes out.

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Someone asked a question about getting norovirus. Can you kind of share a quick look at what norovirus is for those that don't know and they said it that it took me three days longer to recover than my healthy husband.

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Is that because of CLL?

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Noroviruses are more of a gastrointestinal virus. Hard to say why it took one person longer to recover than another.

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It's a myriad of factors, but I see it in immunocompromised and other health conditions...

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can certainly play a role. But everyone recovers at their own pace for a myriad of reasons,...

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including their own immune system, but CLL can certainly impact that for sure.

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Someone also asked about the SUPERNOVA trial (sipavibart), which the SUPERNOVA trial is for lack of better terms...

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This is not what it's being called, but Evusheld 2.0 (sipavibart), the new name we've already discussed is a little difficult to...

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pronounce but someone actually stated that there was an update that came out today on that monoclonal antibody.

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So, did you read anything on that? Anything on the update?

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Yeah, I love coming to this group. They teach me more than I teach them. I'm sure of it.

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There was an update today on the SUPERNOVA trial, which was essentially about the new molecule for a long-acting antibody and it was great.

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It showed that it hit their topline. Impact. Top line results where individuals who are treated with Evusheld 2.0 (sipavibart) versus placebo...

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had decreased symptomatic COVID infections. That's awesome. That's a really hard study to do.

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And there's a lot of factors that go into it and it works. So that's fantastic.

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That doesn't mean it's clinically available and so hopefully that may mean down the line...

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it will be. But that was just released from AstraZeneca, which is the company.

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We did the study, you can Google it. But that update on topline results, you know, very initial...

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analysis of the outcomes was just published today so you guys are all over it. So very reassuring.

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I think beyond COVID, by the way, I think it's really important as I said, it served as a proof of concept.

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There are therapeutics that can prevent infection in an immunocompromised population because they may not respond optimally to a vaccine.

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This is a proof of concept and this can be used potentially or other infectious entities. I think it's very important, exciting work being done.

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And I credit the folks who've done the work on this because viruses are hard to crack. Viruses have gotten us since the beginning of time, right?





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They're mutating, they're changing. But these studies serve as a proof of concept.

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Okay. Someone asked: should I still try to find some place to get a PCR test instead of the rapid antigen test?

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To know that I am positive earlier on in my infection so I can start Paxlovid a little bit earlier?

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Depending on your home antigen test, the PCR maybe more sensitive and pick-up- early infection, but it's hard to know.

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But it comes out to practicality realistically, where are you going to get that and how quickly will you get the results?

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I think it's something to consider, but I do think in general if I'm being very global, these home antigen tests are pretty good and I think using it, checking it more than once makes a lot of sense.

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Looks like we have time probably for one maybe two more questions. Someone asked: I had significant lymph node enlargement after taking every dose of an mRNA vaccine.

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Should I take note of that and would I have a similar reaction from the protein-based vaccine?

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Very hard to know. Vaccination can certainly lead to large lymph nodes, that's your immune response.

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Okay. Is the likelihood of that more with an mRNA versus a protein-based vaccine? I actually don't think we have reason to say that.

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It's hard to say how you react to different vaccine formats, the vaccine platforms.

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So, hard to predict that. I think these are generally well-tolerated side effects like that and now they are effective for sure.

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Okay. It looks like also someone asked a question about the PCR test. Those are still available.

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You can order them online and they do, I think, they had one over the winter that they had combined influenza and COVID and you can still access those and are still approved by the FDA.

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So just back to that PCR question. If you want to get some of those and keep them at home then you wouldn't have to search for a location to get a PCR test.

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During the pandemic, you could get a PCR at anyplace, in a parking lot, right? So, they're a little bit harder to come by now, but you can.

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And get the home Lucira (PCR test) I think that's the name of the test.

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So, okay, well, we are going to wrap things up here. I wanted to ask you if you have any closing thoughts today.

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I wanted to ask you if you have any closing thoughts today, Dr.

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Yeah, no, Robyn, thank you. I want to thank the CLL Society for hosting this.

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I want to thank the group of attendees. I hope you found this worthwhile. COVID and infections remain something on our forebrain for everyone but especially for individuals who are immunocompromised.

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But it's promising. We've made great strides in the last three and a half years and I think we should be very, very proud of what we've learned and the ways we have to prevent and treat infections now.

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So I think it's very promising. I hope it leads to impact on how every one of you is living, enjoying quality of life...

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and your health. And you know we have wonderful resources like the CLL Society and yourself, you guys are the best advocates...

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for the entire group. So I want to thank you guys. I think it's an exciting time.

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I think we're moving in the right direction and we'll continue to learn.

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Great. Well, we would like to thank our generous donors. For making this event possible today through their support.



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And on behalf of CLL Society, I would like to thank each of you for joining us today.

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And a huge thank you to Dr. Mustafa, your presentation and your thoughtful responses to our audience questions. If you can, please complete our event survey and provide your feedback to help us plan for future events.

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We really do take your comments into consideration. So, if you could take a moment to fill out the survey that would be great.

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The virtual event has been recorded and will be available along with the slides on our website in about a week.

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So if you miss the first portion, you can go back and watch it there on demand. And if your question was not answered today because we did get a lot, you can please send those to our email address called Ask the Expert.

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So that email address is asked the expert@cllsociety.org and that is a service that we offer that you can send any of your questions to, not just COVID.

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19 questions. And you will get a response from an expert. If you will, please consider joining us for our next webinar on June 3rd, It's going to be...

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called treatment for CLL. When is the right time to start? And we will have that with our nurse practitioner.

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Laura Zitella. So please remember that CLL Society is invested in your long life and you can invest in the long life of CLL society by supporting our work.

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Thank you.